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'I'm a rambler, I'm a gambler, I'm a long way from home': exploring participation through music and digital design in dementia care

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Submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

National University of Ireland, Cork

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January 2017

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Declaration

I declare that the work presented in this thesis is, to the best of my knowledge and belief, original and my own work, except as otherwise acknowledged in the text. The material has not been submitted, either in whole or part, for a degree at this or any other university.

Kellie Morrissey

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Papers from this thesis

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Morrissey, K. (2015). Community in dementia care and the role of familiar technology. In Gabriela Avram, Fiorella de Cindio, Volkmar Pipek (Eds.), International Reports on Socio-Informatics (IRSI), Proceedings of the Work-In-Progress Track of the 7th International ACM SIGCHI Conference on Communities and Technologies, 12 (1), 33-42.

Morrissey, K., Wood, G., Green, D., Pantidi, N., & McCarthy, J. (2016). 'I'm a rambler, I'm a gambler, I'm a long way from home': The Place of Props, Music, and Design in Dementia Care. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems* (pp. 1008-1020). ACM.

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Morrissey, K., McCarthy, J., & Pantidi, N. (2017). The contribution of experience-centred design in dementia care contexts. To appear in Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '17). *(accepted and awaiting publication)*

Chapter 1: Introduction

"I lay in bed the night before the fishing trip and thought it over, about my being deaf, about the years of not letting on I heard what was said, and I wonder if I can ever act any other way again. But I remembered one thing: it wasn't me that started acting deaf; it was people that first started acting like I was too dumb to hear or see or say anything at all."

— Ken Kesey, **One Flew Over the Cuckoo's Nest**

Introduction

People with dementia (PWD) living in care are a population commonly termed as 'vulnerable', and whose challenging life situations are often described in the academic literature as being a part of a 'burden', both on the part of their loved ones and larger society (Duncan & Hodge, 1984; Etters, Goodall & Harrisson, 2008). The difficult circumstances faced by PWD are often compounded by moving into nursing homes (or other care facilities) late in life; a move which, along with the progression of their dementia, can lead to a lack of meaningful social experiences and a sense of dislocation and disconnection.

With many millions of people living with the condition worldwide (Langa, 2015), as well as a lack of available and effective pharmaceutical treatment for dementia (McKhann et al, 2011), there have been increasing calls for the 'problem' of dementia to be addressed through psycho-social pathways, with technological design implicated as one of these. To date, the vast majority of extant design research in dementia has focused on alleviating the cognitive issues that come with the condition – problems with short-term memory, issues with executive function such as planning (Walker et al, 2000; Pollack, 2005; Lopresti, Mihailidis, & Kirsch, 2004) – and has largely lacked focus on issues also identified in the care literature as 'problematic'. These issues include aggressive or agitated behaviour, repetitious speech, or lack of cooperation in carrying out activities of daily living (ADLs).

In the last twenty years or so, practice-based research by people such as Tom Kitwood (1992) and Dawn Brooker (2003) has resulted in the promotion of 'person-centred care' in care institutions for people with dementia. Starting from the position that every person with

dementia is an individual and not just a diagnosis, person-centred care holds that ascription of deficit to the person with dementia rather than to the situation itself is heavily influenced by the biomedical model of dementia. In this way, behaviour commonly labelled as hostile, aggressive or disordered (for example, a nursing home resident refusing to take a bath when told) may be mislabelled by not considering a broader social and environmental context (the resident is unaccustomed to, and insulted by, a stranger demanding he or she bathe). In this context, the resident's behaviour may be less a marker of hostility than an indicator of relative well-being (Kitwood & Bredin, 1992) as it shows how the resident asserting both desire and self-respect.

Person-centred care is often held up as the ideal model of care for most care institutions working with people with dementia – however, in reality, it is difficult to ensure that those who work with people with dementia uphold the humanizing tenets of the ideology. In reality, working with people with dementia can be difficult, and issues such as understaffing and staff rotation can often mean that people with dementia who are living in care can be characterized as 'objects of work' rather than as complete, whole persons with potential in creative and communicative interactions. In institutions where care is considered as task-oriented, the practicalities of ensuring physical safety and wellbeing are prioritized. In a qualitative study of carers' understanding and applications of person-centred care, the importance of carers' own lived experience and the task-oriented nature of their work are placed in contrast (Colomer & de Vries, 2014):

> *''To me good care, as I said previously, means you ensure that they are happy, they're as healthy as you can make them, that they have adequate food, adequate fluids, that they are warm'' (p. 112)*

> *"'A lot of my training has come from the floor. And our senior carers and our management are fantastic, and they guide you. You're learning all the time, and it doesn't matter what courses you do, what you learn from a book, experience on the floor is priority.'' (p. 114)*

Although the carers in the above study were striving to provide adequate care, they did not seem to connect their own experiential way of understanding their work to the more practical, task-oriented way in which they were dealing with the residents under their care. This tension between ensuring *physical* safety (and relative comfort and wellbeing) and trying to understand what it means for people with dementia to continue to live a *meaningful* life is one which spans not only the care literature, but which continues into the design literature as well. It is disingenuous to frame this tension as 'those who wish to design for safety' vs. 'those who wish to design for meaningful experiences' – the two are inextricably connected – nor is it right to frame it as a problem of focusing on cognition vs. focusing on social experience/environment. This thesis attempts to unpack the complexities of what it means to work with design and technological futures within this area, and how we can understand these design challenges and opportunities in the context of what it means to provide good care in the overall setting of a meaningful life.

In his popular book 'Being Mortal', surgeon Atul Gawande places his medical knowledge and expertise in dialogue with the experiences of older people (including people with dementia and people with other terminal illnesses), their families, and carers, in seeking a meaningful conclusion to their lives. In unravelling the wishes, hopes and disappointments of these people, he first considers autonomy as the important agent in building a meaningful end of life. Discounting its importance if sought to the exclusion of anything else, he frames the ability to make narrative sense of this life as crucial:

> *Our lives are inherently dependent on others and subject to forces and circumstances well beyond our control. Having more freedom seems better than having less. But to what end? The amount of freedom you have in your life is not the measure of the worth of your life. Just as safety is an empty and even self-defeating goal to live for, so ultimately is autonomy. […]* ***All we ask is to be allowed to remain the writers of our own story.*** *That story is ever changing. Over the course of our lives, we may encounter unimaginable difficulties. Our concerns and desires may shift. But whatever happens, we want to retain the freedom to shape our lives in ways consistent with our character and loyalties. (*p. 85)

What is particularly notable about Gawande's insistence that remaining the writers of our own stories is important as we face challenging circumstances and perhaps confront the end of these stories, is that he does not exclude people with dementia from claiming some form of authorship. He presents the stories of people who are facing diagnoses of dementia and despite their progressive decline, he strives (along with their families and caregivers) to consider what is meaningful for them when it comes to decisions such as surgery, medication, and entering care. He does this with the input of the person as they are now, rather than the person that they are seen to have become through their diagnosis, though he acknowledges the difficulties that progressive dementias can bring to communicating this participation.

Where Gawande's research sets down, the experiential and practitioner research of Claire Craig and John Killick picks up. Their 2013 book, 'Creativity and Communication in People with Dementia', provides a carefully-considered, respectful and practice-based approach to working with people with dementia in creative ways to express feeling-states and communicate (often non-verbally) in ways which make sense and are fulfilling to them. Craig and Killick advocate an arts-based approach to communication in dementia, via methods such as painting, drawing, reciting and creating poetry, and music and dance. Their main stance is that communication *changes* in dementia, and if we wish to work with that communication, if

we want to hear those voices, as designers (and practitioners) it is our obligation to relearn how to hear them, rather than trying to fit the voices of people with dementia to our tried and trusted methods of research and design.

At this point, it is worth considering why I chose to work with ideas of interaction design and human-computer interaction when working with people with dementia. One is circumstantial and personal – I was interested in the potential for technologies to be sensitively designed so that people with dementia could engage in them in ways which made the technologies invisible, rather than the technologies themselves being incongruous in the care environment, becoming unused and unusable at best, and barriers to care and narrative fluidity at the worst. As will become evident in chapter four, I entered into my first dementia care setting fairly sceptical as to what these technologies might eventually be or become – in fact, I was ready to discover that there was no need or meaningful opportunity for technological interventions in this dementia care setting.

The second reason I carried out the work in this thesis with an eye to design and human-computer interaction is the potential that holding a 'making' mind-set gives to the researcher when they are involved in a design environment. Much like the nurses in the study earlier in the chapter who emphasis 'experience on the floor', I was interested in embodied ways of learning, and learning by doing. Having come from an undergraduate degree and final year research project which emphasized the importance of quantifiable, positivistic and scientifically-produced knowledge, I had been somewhat disillusioned at the limitations of the knowledge I had produced. I was ready for the challenge of becoming an 'active and kinaesthetically engaged researcher' (Charmaz, 2001) in a project that was not *just* qualitative, but *ethnographic*. For me, a new qualitative researcher, getting to grips with the work and the setting meant that thinking about making and doing alongside my participants (whether it be painting, baking, or later actually designing technologies) let me learn things I

wouldn't had I not had this sort of bodily engagement in the research setting. Ingold (2013) refers to this as the art of inquiry – where participation is not enough, and the conduct of thought goes along with, and answers to, the fluxes and flows of the materials with which we work.

Overall, this thesis presents the findings and insights from a three year long project carried out in three dementia care settings in the south of Ireland that – in the end - *explored how people with dementia can participate within creative (music) sessions*, and how this participation can be included in an ongoing design process to result in a multi-authored account of experience, as well as in meaningful design processes and objects.

The above-mentioned unfolding learning process allowed insights into the potential of embodied communication in dementia care and design. As we progress through the thesis, I will position embodied communication as a way to access and understand the lived experience of participants whose verbal abilities may have waned, but whose ability for communication and expression is still present in alternative ways (such as eye contact, touch, movement, vocalisation, informal chat, gesture, song, and dance). I evidence this with data from my fieldwork, which was primarily in the form of field notes, but also includes some video, artwork and interviews and conversational data. The thesis includes an account of the development and introduction of a design object (*SwaytheBand*, introduced in chapters 5 and 6), the creative (and embodied) use of which helps to make visible certain social and communicative processes by participants, and which itself leads to a novel account of creative, spontaneous participation in dementia.

Ultimately, the thesis provides an analytic account of ways in which people with dementia can communicate and participate within design processes in ways that have not yet been articulated in the design literature. Positioning itself within the larger literature, surrounding

dementia and design, the thesis indicates a number of ways in which a body of research concerned with the experience and participation of people with dementia might proceed.

Participation and community

Although I spent some time reading the literature on dementia as well as available technological interventions and designs for this population, I entered the field in 2013 with very fresh eyes. I had not worked with people with dementia before. I was in the first year of my PhD and supplementing my studentship stipend with weekend work in a pharmacy where I had worked for five years. Starting on the counter, I had progressed to a point where I worked solely in the dispensary, putting together blister-packed medications for older people and for local care homes. I was interested in the drugs I was packing, but more generally I was interested in the people who took them: heart medication, warfarin, paracetamol – and then there was the psychoactive drugs, anti-depressants, anti-anxiety medication, sedatives, anti-psychotics, and drugs to slow the progression of dementia. I read the information on the packs and wondered what these people might be feeling, what their lives might be. My first interest in dementia was through this sideways-glimpse of the experience – delivering medication to the care home where I would later carry out my ethnography, holding a 'relax and rejuvenate' event for carers – ostensibly to promote our skincare and beauty regimes, really because I was interested in the chat that would come along with the tea and the cakes – but it was just one tiny sliver of the picture.

I grew up in the town where I carried out that first piece of ethnographic research, where the most recent generations of my family are from. My paternal grandfather, Ned, died quite young, when I was three, but until fairly recently all of my grandparents were alive and well. In 2013, my paternal grandmother, Lily, died of a fast-spreading infection following a surgical procedure, and in 2014, my mother's father, Noel, died of a variety of causes, one of which was his progressing dementia. My grandmother, Teresa, is still alive today, and is

probably the grandparent with whom I have spent the most time and been closest with. Growing up, I would spend time with all of these grandparents, sleeping in the same bed as grandma Mona as a six or seven year old girl, staying with Noel and Teresa when my parents were away. What is most evocative, what stands out to me now is their houses, the spaces I explored and carved out in these houses as a child, and the way in which I experience them now. Gaston Bachelard, in his 1958 *Poetics of Space*, describes the ways in which we relive past homes as 'daydreams' where 'these dwelling-places of the past remain in us for all time' (p. 6). For me, retaining objects from these homes which I remember then and experience now as so different – a box of recipe cards, one with a hedgehog cake which captured my imagination like nothing else, a scarf I still wear, a fireman's helmet which was Ned's, long ago. I also remember spending afternoons after school as a young teenager with my grandmother Teresa, reminiscing and chatting about classic films – a favourite subject of mine at that age, partly because of the ways in which it could knit me closer to her.

For my grandmothers, I don't remember them as being old, or as being sick, though I do remember their gradual ageing, their growing thinner as they became ill, remember the way their hearing seemed to slip away bit by bit. I remember how with every year I wanted to embrace them a little more, a bit longer during our goodbyes as the shyness of youth fell away from me. They were never alone – their families loved them. As they aged, grew ill, died, they always had a son, a daughter who would stay with them for the night – both had had medium to large-sized families, all of whom were devoted to their parents (and in more fractured and shifting ways, to one another). They were well-known in the community – going back, even now, hairdressers, doctors, dentists will remark to me about how much of a 'gentleman' my grandfather was, and father is; they will ask for my grandmother, and tell me about how their own mothers and aunts still call on her every week. When Teresa's husband

Noel died in 2014, the house was full of people, of trays of sandwiches and cake, frozen meals enough to last for weeks.

My grandfather Noel died in 2014 after a lengthy illness, in the local hospital (though not in the same wing) where I carried out the first ethnographic study described in this thesis. He had been ill for years – almost a decade – and died at 84. His entrance into the hospital was precipitated by a series of falls and infections at home that Teresa could not deal with alone, and in the end he was in the hospital for almost five years. Like my grandmothers, once he was there, he was never alone – Teresa was there every day for hours, as were various family members. I would return from college on the weekends to a mother who was gone for five or six hours of the day, and who, when home, clung onto her fathers' words as tightly as though he was always about to go at any moment, cycling them around in her head and under her breath as she worked in the kitchen or in the garden. When I visited him, he knew me sometimes – my mother would try to stir his memory by calling me 'the college girl' (though it's changed since, at that time I was the only one of my family to have been to university). As the illness bore on, and as his cognitive facilities waned, he knew only his wife. Though his family sat by his bed every day, keeping a vigil that stretched on for years, the last few months of his life were difficult, and recounting them now – the pain he was in, the confusion, the lack of engagement, inflected by the occasional glimmer of recognition, a humorous comment – brings pain to my mother and my grandmother. Interviewing my mother about this experience, she describes her regret over her father having spent so much of his life in care:

L She [*Teresa*] wanted to bring him home one time out there, she was adamant, adamant he was coming home, and all the nurses and sisters asked us to bring mammy in, to explain to mammy how she wouldn't be able for him at home.

K And what are you saying, you don't think that was right?

L I'm just so sorry he ended up out there. Really am. I never say that to mammy, so how does she feel?

[…]

K You see the reason I talk about it the way I talk about it is, I honestly think ye did such a good job.

L I keep thinking we could have done more.

Though I had spent much of my childhood in my grandparents' house, Noel was somewhat of a stranger to me – he wasn't as engaged as my grandmother was in helping to bring us up, in chatting to us at the table. As a child I was somewhat afraid of him – he was part of that generation of Irish men and women who spoke so fast and yet still mumbled, so much so that I rarely remember having long conversations with him, or of embracing him. I remember the sitting room in the house in which he most frequently sat – looking out onto Tobermore Bay. When we sat there for the hours after his funeral, without him, it felt somehow wrong.

These contested memories were what I brought to my research – a (then) dying grandfather, but one who had once existed in a house full of people, full of love and the scents of cooking, a large stretch of grass outside and then the sea and sky. My other grandparents had died quickly, and their stays in hospital were painful but brief. They never needed professional care – they had families, friends, community members who thought so highly of them that, twenty years after their death, they spoke to their grandchildren about them. So when I entered St Eithne's Unit, and found that *these* older people, *these* people with dementia, had very little sense of connection, very little sense of visible community, I was surprised and a little bit sad. It became the lens through which I viewed many of their experiences, actions and responses: that of being in community.

In chapter four, I articulate participants' being in community as being in-between; in long-term, residential care, people with dementia come to constitute a community that is always in transition and whose members may not particularly engage as community members would.

However, they wake together, dress together, eat and spend the day together, all in spaces far removed from the spaces they may have lived their lives in. In St Eithne's, I thought about the smells and tastes of my grandmother's cooking (bacon and cabbage, floury potatoes, roast chicken), the big bed which I crept into as she sat, leafing through magazines. I thought about the sunlight which drifted through the windows, about the friends whose visits I dreaded as a shy child.

Although it is easy to think of how carers of people with dementia can come to form communities, sometimes the thought of people with dementia in community can seem difficult. This is partly because a significant problem in dementia is that of changes to social cognition. Researchers studying people with dementia write that they show a reduced ability to understand sarcastic statements and negative emotions such as anger, disgust, fear and sadness (Rascovsky et al, 2011). A significant amount of research has emerged in recent years which suggests that isolation in older age can be problematic and potentially contribute to, and worsen, diagnoses in dementia. However, in a paper exploring the possibilities of friendship in dementia, Sabat & Lee (2012) suggest that this decline in social cognition need not be considered to be a direct result of the brain damage and cognitive deficits characteristic of the disease. Instead, they write, losses in social functioning could instead be explained by the way in which the person with dementia is positioned by carers and medical professions.

In Sabat and Lee's ethnographic study, people with dementia living in care invited others to join them in activities (e.g., prayer ceremonies), were selective about whom they chose to socialize, engaged in social activities, displayed humour, empathy and searched for common ground. More recent observational research by Sandhu et al (2013) suggests that relationships often form between residents who consider or find themselves 'functionally similar'. The authors describe how residents in an assisted living scenario experience 'coming together and

pulling apart' over various aspects of function – for instance, someone who suffers from visual impairment may either be helped by another resident by having the newspaper read aloud, or indeed may also experience scorn from other residents when they take time to navigate hallways or spill a drink at the table. Instances of 'pulling apart' may lead to feelings of shame in the person who is less 'functional' and could lead to greater instances of social isolation.

A particularly illuminating ethnographic study of 'Deer View Grange' in Scotland, UK, by Gillian McColgan in 2010, illustrated complex ways of being together in care by signposting previous research investigating different forms of community:

> *Like prisoners who feigned compliance (Fox 2001), residents feigned sleep, and like schoolgirls who resisted invasion of privacy (Okely 1978), they chose to gain some control over privacy. Just as Paterniti (2003) found, residents wished to make their own identity claims by presentations different from those suggested by staff labels. Residents often longed for home, a safe maternal place as suggested by Bachelard (1994), and searched for familiarity. Rebecca* [participant] *did this on her walks around Deer View Grange, and others did it from their seats by creating defensible space like other older people in care (Willcocks, Peace, and Kellaher 1998). At other times, such as when tea drinking, residents were prepared to engage in "incipient talk" (Schegloff and Sacks 1973) with others in Lavender Wing lounge to recreate familiarity and reconstruct something resembling home.* (p. 430 – 431).

I was interested in chasing down these two elusive things in my research with people with dementia – *participation* and *community*. I learned that, for people with dementia living in care, the two aren't entirely separate. I knew, from my engagement with healthy and sick older adults, in the community and care, that these things weren't outside the realm of people

with dementia living in care – but neither did I know how the two would link together so tightly in my research. What emerges from the thesis is not a totally congruent picture of how participants co-existed together in a participative community, because that was not what happened in the care homes I visited. Like McColgan, what I report here are the complexities of being together in an erstwhile community, which as Sandhu describes, comes together and pulls apart in moments of ebb and flow, participation and passivity.

Research through design and knowledge creation

Before I detail the structure of the thesis, it is worthwhile to spend a moment talking about the sort of research I carried out as part of this thesis and the kind of knowledge created from the work. From the beginning, as described above, I was interested in an active ethnography which saw me as a participant-observer (Jorgensen, 1989) whose status shifted and changed as the research continued and relationships developed. Moreover, as detailed in the final chapters of the thesis, as I moved to other research settings, my methods became informed by Participatory Action Research (Whyte, 1991): this shift from observation to action happened naturally as I matured as a researcher and as circumstances shifted to allow a more active kind of research formed in solidarity with the engagement of carers and management.

Beyond this, the work functions as a piece of research through design (Zimmerman, 2007; Gaver, 2012). As detailed in the final chapters, the design process which we carried out inevitably helped me to learn more about what it meant for people with dementia to participate in communities, both through the design of the object itself, the experiences leading to it, and the ways in which the technology was deployed in care homes. Design, encompassed in active ethnography and PAR methods, was as much a method for the creation of knowledge in this project as observation and field notes.

In his 2012 paper, Gaver asks what we can expect from research through design, pointing to then-recent criticisms of the field as unscientific. He spends time going through a number of

important characteristics of scientific research, indicating by way of comparison that instead of being scientific research, which is backward looking (also noted by McCarthy & Wright [2004]), research through design is invested in creating future-oriented knowledge: *"... the reason that research through design is not convergent is that it is a generative discipline, able to create multiple new worlds rather than describing a single existing one"* (p. 943).

The research presented as part of this thesis is deeply qualitative, and draws from numerous epistemological backgrounds – social constructionism and phenomenology in particular. The thesis is heavily informed by experience-centred design practices (McCarthy & Wright, 2004), and as a part of this I draw upon the pragmatist philosophy of action of John Dewey, as well as the writings of Mikhail Bakhtin on dialogue and novelistic discourse. At many points in my research process I describe coming up against nurses, healthcare professionals, and other researchers who assume I am a cognitive or clinical psychologist, or who are uneasy or dismissive of my research due to its disinterest in detached scientific observation and experimentation. It is a strange intersection to find yourself within – dementia and technology design – two fields which, although replete with opportunities for qualitative investigation, in many people's minds, are still strongly scientific fields. I mentioned above how I came to this project as an ex-quantitative research psychologist – and so, for me, this thesis functions as an act of learning, and an act of slowly becoming a part of a larger community of care and of research.

The kind of knowledge created within this thesis is primarily *experiential knowledge*, which has come about by dialogical processes of listening, acting, performing, making and doing within different communities of care. It is important to note that the data I collected was submitted to analysis (e.g., Grounded Theory); however, the kind of reality I describe within the thesis is one which is informed by ethnographic practice and co-created by the people with whom I worked and who populated the care homes. This co-constructed reality is

complicated by the involvement of people with dementia as participants; there are times at which a number of different realities intersect, and at those points it is crucial to acknowledge my own position within the research. At no point do I claim that the research is scientific, or that I am a detached observer; in fact, my own participation and own place in the research has to be acknowledged in order for the work to be understood as a whole. This is emphasised in chapters three and four.

The emphasis in this thesis on my own point of view and personal experience as a 'knower' in an overall discourse or experience is inflected by the writings of Belenky, McVicker Clinchy, Goldberger & Tarule (1986) on separate vs. connected knowing. The authors characterize separate knowing as a form of knowing which attempts to depersonalize the knower from the experience itself – they give the example of a young student who struggled to erase her own personal hatred for the character of Heathcliff in Wuthering Heights from a critical analysis of the character as well-formed or not. Connected knowing, in contrast, acknowledges the inextricability of the knower from the experience itself, gives primacy to experience, multivocality and conversations, dialogue and the longitudinal nature of many experiences and discourses. The authors contrast the sceptical 'doubting game' which many separate knowers play in order to make more visible the cracks in knowledge, to the 'believing game':

> *"Connected knowers know that they can only approximate other people's experiences and so gain only limited access to their knowledge. But insofar as possible, they must act as connected rather than separate selves, seeing the other not in their own terms but in the other's terms. Elbow (1973) calls this the believing game, and he says it is very hard to play […] And, while women frequently do experience doubting as a game, believing feels real to them, perhaps because it is founded upon genuine care*

> *and because it promises to reveal the kind of truth they value – truth that is personal, particular, and grounded in first-hand experience."* (p. 113).

The authors' account of a community of separate knowers who come to the doubting game because of a generation of educators (mostly college lecturers) who instilled into their minds that *only* this form of knowledge is worthwhile, resonated with me and my background. For me, the process of coming to value connected knowing again was frequently frightening for me as I came to trust myself and my own perceptions in a way which I had not for some years. However, it was also a process that was necessary in order to engage with my participants on emotional and experiential domains and not to abstract them as 'population' or 'groups', and instead to work with them as whole people.

Research aims and questions

The research is motivated by two main aims:

- To identify ways in which people with dementia living in care can participate in group activities and in community settings, with a view to understanding how this participation can become a part of meaningful communication and involvement in research;

- To explore ways of being together and community for people with dementia living in care, with particular attention paid to the ways in which technologies can/could mediate this being together.

In meeting these aims I ask the following questions:

- What is it like to participate in a group activity when you have a diagnosis of dementia?

- To what degree can this participation be considered as co-authorship (of research, of

designed technologies, of the experience that the person might be living)?

- How can embodiment, making processes, and doing together be configured in dementia to facilitate communication between participants with dementia and researchers?

- How can any prototypes developed be used and evaluated to support community practices within groups of people with dementia living in care?

Thesis structure

Chronologically, this research project spans my entry into St Eithne's ward in Tobermore Community Hospital in May of 2013, encompasses my almost two years there of off-on engagement, before moving to encompass design processes carried out between St Eithne's and a number of other community groups, resulting in the development of a prototype system, SwaytheBand, which is then trialled in two locations – Rosebank Nursing Home and Clermont Place – from September 2015 to May 2016.

Chapter 2 is a literature review of extant literature surrounding the design and deployment of technologies for and with people with dementia, and focuses particularly on research published in the ACM Digital Library. However, some relevant literature from gerontological journals has also been included. The literature review is articulated through the following 'themes':

<u>Connecting and being present (relational approaches)</u>

A considerable body of work acknowledges a potential loss of contact with others in dementia as (firstly) physically dangerous and (secondly) a risk to (psychosocial) quality of life.

<u>Compensating and automating (compensational approaches)</u>

These papers provide a contrast to those of the above, and detail the development of technologies which automate aspects of caring for/interacting with people with dementia. Such technologies include conversational agents (Sakai et al) and robots for caring for/interacting with PWD suffering from isolation or loneliness, or computer programs which automatises the process of reminiscence therapy (Bermingham, 2013), or provide music therapy via video link (Kosugi, 2014).

Working with (lived) experience (experiential approaches)

A smaller but fairly substantial subset of these papers turn to the lived experience of PWD in order to ascertain possible design spaces in dementia. They are more disparate than the above in their subject matters – embodied communication (Schelle, 2015); musical creativity (Favilla and Pedell, 2013); selfhood and the importance of objects (Wallace, 2013); virtual reality (Siriaraya, 2014) – and some focus entirely on considering ways in which designers might best work with people with dementia (Lindsay et al, 2012; Holbø, 2013). However, in each of these papers the authors attempt to engage with the experience and meaningful participation of participants with dementia in order to design technologies for and with these people which have the potential to enrich their lived experience.

At the end of chapter 2, I identify a number of key differences between the former approaches and the experiential perspective, and outline a number of challenges (to which this thesis responds) in the development of design and services for people with dementia which prioritise meaningful lived experience.

Chapter 3 outlines my methodology and describes in depth the approach to a) ethnographic research and, later, b) PAR that I took in the project. I also discuss the ways in which I use experience-centred design approaches as a scaffold for making processes that value the phenomenological (sensual) experiences of participants with dementia. Beyond this, I also

discuss the ethics of working with my participants, the tensions I felt between institutional ethical ways of configuring consent and my own personal feeling of assurance that participants *participated* in their involvement in the project.

Chapter 4 is a long chapter which details my ethnographic engagement with a community hospital in Tobermore, Co. Waterford, and in particular my involvement as an ethnographer in St Eithne's Ward, a long-stay ward in the community hospital that was publicly funded and housed 10-12 residents. I describe the residents and carers who lived and worked there during my stay of about two years, the space itself and its routines, before moving onto an account of my Grounded Theory analysis concerning the creative activities I was a part of during my time there. The analysis primarily concerns the value of musical experiences for engagement in community 'moments' for participants who spent much of their time together yet who did not necessarily engage in social interaction. This chapter ends with the development of three main themes describing this participation – *performing and spectating, connecting with another,* and *belonging in community* – and describes aspects of these musical experiences which are brought through into the next chapter.

Chapter 5 builds on the previous chapter by imagining the space in St Eithne's Ward as a design space in which it is possible to imagine how familiar technologies can be co-opted to enrich community and musical experiences. The chapter also details a change in management in St Eithne's which necessitated the end of my involvement there, and describes how I spent the intervening months before re-entering the field by visiting with community groups in Ireland and on research trips abroad (to Aarhus, Denmark), before engaging in earnest with interaction design researchers in Newcastle-Upon-Tyne, UK, in order to produce a prototype which responds to the questions, opportunities and challenges raised by engagement in these diverse communities – SwaytheBand. SwaytheBand are a set of interactive batons which facilitate people with dementia to engage in creative and communicative ways in musical

sessions, which add a dimension of participation to these music sessions that is not present without interactive props, and which help to make visible certain social and community interactions. These prototypes were trialled in two care settings – Rosebank Nursing Home and Clermont Place – where they formed a piece of PAR which involved residents/clients with dementia as well as care staff in designing and developing a series of music sessions which ran from September 2015 – May 2016.

Chapter 6 details in more depth the development of the SwaytheBand prototypes as well as their use ('enfolding') in Rosebank Nursing Home and Clermont Place. The findings extend current understandings of participation to reveal that a more nuanced view of participation is required when designing in the dementia context. This chapter suggests that participation in music sessions for people with dementia is about touch and intimacy, connection via movement, shifting roles, materiality and using props to disengage. I discuss these themes, and their implications for Experience-centred Design. Intermittently throughout this chapter, I include excerpts from evaluative interviews undertaken with care staff from the later research settings as well as with the head nurse, Eleanor, from St Eithne's. I also engaged at this point with musicians and research assistants who had come to join the project at a later date, and interviews with these co-researchers illuminate the process of coming to be a part of a caring community.

In Chapter 7, I reflect on the process of carrying out the PhD work, at first revisiting the challenges I set myself at the outset which were first encountered at the end of chapter two. I describe how the work has built on current conceptualisations of experience-centred design and notions of what it means for people with dementia to participate meaningfully in research. I consider the value of working with a 'design-mindset' and later, design(ed) objects when trying to engage participants, and apply a critical lens to the notion of working with technology in dementia care contexts, including my own devices. I also critically

examine the dialogues created by engaging within communities, and note the value of staying open and reflexive when working with institutions and with participants with dementia.

Contributions

The thesis contributes to current interaction design knowledge and practices, particularly focused on experience-centred theory and practice, in designing for expressive technologies within contexts of community and care. The thesis makes this contribution in three distinct ways:

First, the thesis extends experience-centred design approaches by using them as a methodology for inquiry into the lived experience of people with dementia living in care. This application of experience-centred design has produced an understanding of life in "communities" of care which is brought to a head by sensual and bodily engagement in musical experiences. The thesis contributes to an understanding of the practice of dialogical aesthetics to inform the building of relationships within communities of care where the tensions of protection and safety for its clients are balanced with the need to provide fulfilling and meaningful engagement. This is achieved through an in-depth long-term study with three care settings in the south of Ireland.

Secondly, the thesis further contributes to understandings of how participation via creative, expressive embodiment can help to drive forward a design process. The thesis uses data collected through these ethnographies to question the meaning of participation for people with dementia in the context of challenges set by experience-centred design approaches. This is achieved through the design and deployment of the SwaytheBand prototypes within two care centres.

Thirdly, the thesis contributes to interdisciplinary approaches that seek to use participatory approaches in the design and evaluation of technical devices within care contexts for and with

people with dementia. This is achieved through the utilisation of evaluatory methods within the design project which are responsive to the ways of communicating of individuals with dementia within the project, rather than applying an evaluation method that is not specific to them and their needs.

Chapter 2: Literature review

Introduction

At the moment, there is little in the way of treatment for the various types of dementia, and there is no cure, though headlines flashing through tabloids and internet advertisements may suggest it is so. Proliferations of this sort of headline – *'Marry an intelligent woman to defeat dementia, men told', 'Jab 'can reverse Alzheimer's in only one week''* (Daily Mail); *'The £3.45 'Alzheimer's drink' that stops brain from shrinking'* (The Telegraph) – indicates a growing public interest (and fear) in dementia and in ways of preventing or reversing its effects. This interest has been mirrored by a growth in the design literature surrounding dementia, which tends to find a focus not in reversing or preventing dementia, but in helping people to live with dementia in ways which are more independent or more meaningful to them. Beyond this, within the HCI and design community, designing for and with people with dementia has represented interesting and possibly fruitful opportunities for designing new technologies which can tell us more about the experience of dementia.

This chapter represents a critical review of many full and work-in-progress papers published in ACM SIGCHI conferences and journals over the past 15 years, which take for their subject matter the design of technologies for and with people with dementia and their carers. Beyond this, as the chapter narrows to a conclusion, I include evidence from anthropologists and writers in the HCI/design field in order to highlight some of the most pressing issues indicated by this review. The chapter aims to answer two broad research questions: 1) what are the most common approaches taken when designing for and with people with dementia in the HCI literature?, and 2) what directions are indicated by the extant literature on the topic of designing for and with people with dementia?

Although this chapter is not meant to function as a systematic review of the literature, there are several inclusion criteria that reduced the scope of this chapter's review:

1. Papers were chosen which focused primarily on living with dementia as a person with a diagnosis of dementia; therefore, papers which were interested mainly in the experiences of carers were not included.
2. Papers were chosen which focused on the social contexts of living with dementia; therefore, papers which focused on diagnosing dementia were not included.
3. Papers which focused on rehabilitation, 'brain training', GPS tracking or ambient-assisted living were usually not included as they tended to lack indications into the larger context of these technologies within people's lives.

Keywords used to search the ACM Digital Library were 'dementia', 'Alzheimer', 'Alzheimer's' 'Lewy Body', 'vascular dementia', 'cognitive impairment', 'MCI' and 'mild cognitive impairment'. Searches were performed intermittently between January 2016 and August 2016.

In ACM forums, dementia has reoccurred as a subject of interest for some years, in conferences as disparate as ACM Big Data & Social Informatics, UbiComp, Creativity and Cognition, CSCW, Groupwork, Designing Interactive Systems, and CHI. Within these conferences, the papers exploring dementia as a topic are presented under similarly disparate headings, but typically reoccur under session headings that pertain to care, wellbeing and health. The spread of approaches and topics indicated by conferences rings true in the papers themselves – it seems that there is little agreement as to where the place of designing for dementia is within HCI.

"Unmet needs": configuring dementia as a series of problems

This is not a drawback of the efforts to design within this space – rather, it reflects the complexity of dementia and the difficulty of understanding the condition and its experience sufficiently enough in order to design within that context. A significant amount of (both HCI and non-HCI) literature has aimed to delineate the 'needs' of people living with dementia in a

way which sets them up for future work – for instance, research by Lauriks et al (2007) with carers of people with dementia indicated the following 'unmet needs':

- Need for general and personalised information pertaining to dementia
- Need for support for carers with regard to the symptoms of dementia
- Need for social contact and company
- Need for health monitoring and perceived safety

Most design research has focused on addressing these issues by way of designing assistive technologies – technologies which assist people to carry out tasks which they ordinarily would have been able to carry out alone, but which sickness or disability now makes difficult or impossible. For people with dementia (and older people in general), assistive technologies (such as mobile phones which are specially designed to be simple and have large text, watches with large numbers, and wearable alarms which sound or alert remote services when they detect a fall) are now commonplace and can be purchased via catalogues or even in pharmacies. These technologies may offer people living with dementia as well as their carers some peace of mind – particularly in the early stages of dementia, where symptoms are limited to relatively mild cognitive impairment and where independent living is still possible. However, as the condition progresses, symptoms such as impairment of short term memory and other cognitive processes can worsen and be compounded by issues such as changes in communication styles (often moving to non-verbal forms of communication [Kopelman, 1991]), and feelings of frustration, anger and uselessness as independence is curtailed or precipitated by a move into living in care.

Before I progress, it is worth taking a moment to consider the context of this literature review within the overall flow of this thesis – as described in the previous chapter, early ethnographic work in care homes saw me narrowing my focus to care settings in particular –

in this thesis, several settings are visited, but they are all *institutions*. I do not visit with people still living independently; although I do visit day care settings, I restrict my research activities to the boundaries of those day centres. Most of the technologies that are described in this chapter are 'meant' for a general user base of people with dementia (thought may or may not be given to the context and place of their use); however, some work solely and explicitly *in the homes* of people living with dementia. I include these papers still, as they often tell us interesting things about the ways in which designers configure dementia – but it is important to bear in mind that this thesis will eventually come to rest on themes of *community* and *participation* ***in*** *dementia care contexts* – in institutions.

Whatever the context of the design, much design research sees deficits in cognition as gaps which can be overcome successfully by design intervention; addressing the (highly individual) *experience* of dementia via design methods is attempted less frequently. Although each person will experience the condition differently, an illuminating paper by Ryan, Bannister & Anas (2006) which examines the experience of people with dementia via personal writing emphasises several themes which concern a sense of a changing self – see table 1, below.

Theme	**Example quotation**
A loss of status as a competent social partner	'*I have become keenly aware of a patterned response from some individuals as soon as they find out I have Alzheimer's disease. They switch their eye contact and attention to whomever I am with. It is as if knowledge of the disease immediately cloaks me in invisibility*'
A loss of social and familial roles	'*During this illness our roles have changed. Suddenly she is not only the wife I have loved, but now she is also my caregiver. She has to guide me through daily living, as I have become a care-receiver*'
Difficult feelings in social situations	'*Unhappiness shows itself often, especially when there is a group in the house. Amid chatter, I am silent. I sit with my elbows on my knees and stare straight ahead. My mind is nearly empty in these moments*'

Table 1: findings from Ryan, Bannister & Anas (2006) concerning personal feelings of those having received a diagnosis of dementia

These are overwhelmingly negative emotions and experiences – however, we will see later in this thesis (chapter 7) that people can often reach a stage of dementia where they are content, either through acceptance of their 'memory problems', through placement in a loving, fulfilling environment, or through disassociation connected with the progression of dementia. The picture of the aggressive, agitated 'demented person' is rarely true – Twigg (2000), describing an investigation into the changing functions of old age, writes the following:

> *The changes imposed by the loss of function in old age are massive. When people speak of the rigidity of people in old age or their reluctance to accept change, they fail to grasp the magnitude of this. Most people in [*study*] dealt with such change in a stoical way. Raging against its realities was seen as a route to pain and unhappiness, and the dominant approach was one of acceptance and of taking each day as it came.* (p. 48)

It's clear that dementia is complex – even the term 'dementia' itself used as a catch-all belies the fact that there are over 100 different types and aetiologies of dementia (Meulen et al, 2004) – and the cognitive and the social, emotional aspects of the condition cannot be considered as separate from one another. Rather, researchers should work to emphasise the interconnectedness of the two. When we work with people with dementia – in particular when we configure them as participants, co-researchers, or even simply users in a study – we need to consider the way in which we *position* them:

> *The response of the family caregiver and other meaningful people to the patient's illness or disability, to his communications of distress, and to his inability to perform the usual social roles may spell the difference between optimal recovery or psychological invalidism.* (Lipowski, 1969, p. 1200)

Configuring the person with dementia as fundamentally disabled is not only disruptive to their sense of self ("psychological invalidism"); it can contribute to faster decline in cases of

excess disability – disability beyond that which can be usually expected as part of the already-existing condition (Rogers et al, 2000). Given the effects of the condition, it can be difficult to remind ourselves against positioning people with dementia as somehow 'lesser' but it is a reflex that we need to fight against, particularly as researchers and designers whose decisions impact upon the public configuration of people with dementia as well as potentially upon their lives. Unlike family, unlike carers, unlike medical staff, whose time and emotional wellbeing can be easily compromised, designers have nothing to lose from working with a view of the person with dementia as fundamentally capable. The following review will investigate this configuration of the person with dementia in more detail.

Compensation, connection and working with experience: themes in designing for and with people with dementia

I have divided the papers reviewed as part of this chapter into three different themes – compensation, connection, and working with experience. This is a division that overlaps significantly (particularly between the second and last categories), and is shot through with considerations of the thesis' two main themes – those of community and participation – and how those themes are treated in both the topics and the methodologies of these papers. The role that both of these themes play in the papers reviewed is investigated in a final section that identifies the design approach that I will take throughout the remainder of this thesis.

It is worthwhile to note that the following literature review is not intended to be entirely systematic and is not inclusive of every paper that was delivered in ACM forums concerning dementia. The reasoning of this scoping is described above. Beyond this, although I have divided these papers into categories, it should also be noted these approaches overlap significantly and cannot be considered as entirely discrete categories – instead, they serve a purpose within the context of this thesis to illustrate important differences in design methods while carrying out what may seem to be similar work within the context of dementia.

Compensation: replacing lost cognitive skills and automating personal interaction

A main focus for much technological research and design in dementia has been the desire to enhance or replace cognitive skills that have been seen to have been lost in the progress of a person's dementia. Dementia is characterised most strongly by deficits in short-term memory, but as dementia progresses, long-term memory is also affected. Episodic memory is particularly affected, which can have serious consequences for day-to-day life. However, people with dementia also often experience a decline in the ability to successfully perform executive functions; as the disease progresses, persons with dementia tend to lose the ability to organise information and thus show deficits in attention, planning and problem-solving (Hornberger, Piguet, Kipps, and Hodges, 2008; Tse et al, 2010; Harciarek & Cosentino, 2013).

These deficits have for many years represented seemingly 'fixable' challenges for many designers, even when applied to real-life situations – for example, the problem of wandering is often 'fixed' by a GPS sensor, or issues concerning remembering faces can be solved with prospective memory aids employed in wearables such as Google Glass (Michael, 2013). This sort of design conceptualizes each deficit as a gap that can be bridged with the right design. For instance, the COGKNOW DayNavigator (Mulvenna et al, 2010) is one such example of a technology that aims to displace some of the issues caused by memory loss in dementia. It consists of a touchscreen device with computer-mediated controls as well as a mobile device to bring along when going out for the day, with an aim of reminding its users of particular tasks in their day-to-day lives.

Many of these technologies are undoubtedly useful for people with dementia as well as their carers – participants in Mulvenna's study, above, attest to this – yet there is a dearth in empirical evidence concerning the take-up and sustained use of such technologies. Although such assistive technology is ostensibly useful for people living with dementia (Gibson et al,

2014), there is increasing evidence that (even when the technology is offered for free) many people with dementia and carers are reluctant to use it (Lazar, Koehler, Tanenbaum, & Nguyen, 2015). This paradox constitutes a large gap in our understanding of the deployment, implementation and use of these technologies for the benefit of people with dementia and their carers in these processes. In the absence of results of long-term trials on the effectiveness of assistive technology in dementia care (currently being undertaken via the UK's Department of Health ATTILA trials), evidence about adoption and use of assistive technology in Ireland comes from the evaluation report of the first year of the Genio Dementia programme, which funded four site-based programmes to develop and test new service models to improve the range and quality of community-based supports for people with dementia and carers (O'Shea & Murphy, 2014). Although each of the four sites included assistive technology as an integral part of their service models, the evaluation indicates that adoption of new technologies was slow. At the time of the evaluation, emergency response telecare had been installed with four families in Stillorgan/Blackrock and Ambient Assisted Living (AAL) systems had been placed in three homes in Kinsale, despite attempts to place such technological systems with many more. Indications are that technology adoption did not improve greatly later in the projects.

It is possible that focusing solely on the cognitive 'gaps' to be filled in dementia is not as effective as we might hope. By positioning our potential user as a set of deficits rather than a holistic person, we seem to be missing out on something important. If we must 'compensate' in designing for people with dementia, a move away from a more computational theory of mind may be necessitated. This necessitates a turn to working with experience, and for some researchers, embodiment as espoused by phenomenological writers such as Heidegger, Schutz, and Merleau-Ponty:

In psychology, these tendencies (culminating in the computational theory of mind and

> *the equation of nature with bits of information about the measurable properties of matter) treat subjects as fully determinant objects that then act upon the things around them. In contrast, the phenomenological tradition and Merleau-Ponty in particular discover subjects to be an opening onto, and an engagement with, their surroundings: "consciousness is always consciousness of something." All attempts, therefore, to isolate and examine subjects initially apart from this engagement, however useful otherwise, are a distortion, a crucial misunderstanding, of these subjects.* (Evans & Lawlor, 2000, p. 14)

Looking at participants engaging within an environment, Monk & Wherton (2005) and Olivier et al (2006) 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. Although the system still poses several issues for people living with dementia (will disembodied voices unnerve people who may be prone to hallucinations? Can the system protect against injury during cooking processes?) it represents a different approach to designing in dementia – one which makes use of the skills still present in the person themselves.

To follow on from this more embodied approach, if we are to compensate for problems such as forgetting in dementia, we must pay attention to the way in which we configure memory, and in particular, how memory can be both transformed and remain the same in dementia. Our memories are constructive – memory is something we do, something that we work at (Schacter & Addis, 2007), which is why the image of an erosion of a fixed 'memory bank' in dementia is somewhat misleading. John Sutton describes remembering as 'a dynamic

singularity rather than the reproduction of fixed contents'; using his philosophy to decode the autobiographical storytelling inherent to everyday life in a community of aboriginal people in Alpurrurulam, Monchamp writes that "… *while it may be conceptually useful to define memory as something people have and remembering as something people do, as Sutton states, '**neither the past nor the mind sits waiting**'*" (p. 17). We need to move past the instrumental vision of people with dementia as full of holes, ready to be filled or fixed, if we want to design for the dynamism and the 'life' that still remains.

Compensatory approaches are further 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*" (Hodges, 1998, as cited in McCarthy & Wright, 2015). Like the word 'community', the word 'care' is one which is phenomenologically 'warm' – it feels nice to care and be cared for; ideally, we would all exist in a state in which we are cared for. What is often ignored in community practices of care is the inherent imbalance of power between the carer and the cared-for; for older people who have lost some function, or people with dementia, Twigg invokes Foucault's notion of power as imbuing everyday mundanity; care, she writes, is a 'site of conflict':

> *Care is a site of conflict in which two social groups, both of whom suffer from a wider social diminishment, struggle to establish autonomy and personal esteem. Clients struggle to resist the domination of workers and to maintain a fragile sense of self in the face of the erosions of disability and age. Workers strive to establish control over their work and to extract from it sources of esteem and status.* (Twigg, 2000, pg. 179)

Although Twigg describes the tensions inherent to receiving/providing domiciliary care, the workers she refers to can be substituted by any number of others – medical staff, family caregivers, even designers. To return again to positioning, it is important to reflect on one's

own position when designing for people with dementia – what power do I hold? What power is the participant denied? This will be explored in more detail in the next chapter (which deals with reflexive ethnography) – but for now, let us try to understand the experience of power imbalance as it relates to compensatory approaches to designing in dementia.

A large number of design studies have attempted to solve or ameliorate problems such as wandering in people living with dementia. Wandering is a common symptom of dementia and manifests in different ways – people with dementia who wander may do so either 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 eventually forgotten (Klein et al, 1999). The dangers of wandering are perhaps heightened for people with dementia who live at home – a well-publicised case in Ireland was that of Peggy Mangan, who, in 2013, set out seemingly to walk her dog, became lost and was found by a search team several days later, having died of exposure in an isolated seaside area, far from her home.

Because of these dangers, many design studies incorporate GPS technologies to help to position people with dementia, whether in their home environment or in their locality. Although these designs can be potentially life-saving, ethical questions have been raised concerning the constant tracking of a person who may not be able to consent to having their positions tracked (Landau et al, 2012). Because of this, the use of GPS technologies with people with dementia is often initiated by family members or appointed caregivers. Tracking has also been used in different ways to monitor the physical status of people with dementia in their homes – for instance, Biswas et al (2009) describe the use of an agitation monitoring system, and Lotfi, Langensiepen, Mahmoud & Akhlaghinia (2009) describe the use of a tracking system which successfully monitored the night-time movements of a resident with dementia – which revealed that the resident was waking in the night and spending long periods of time alone in a sitting room, relatively immobile. This led to a change in

medication and a normalization of her night-time schedule. Still others embed GPS technologies into everyday objects such as rosary beads (Ou, Kuan, Wang, Tsai, & Chen, 2015) and canes (Wan, Müller, Wulf & Randall, 2014).

Though potentially enriching to the lives of people with dementia, many of these designs can tend to place the 'problem' of dementia first and foremost, and therefore lead with a picture of their users as somehow already diminished or incapable (Vines et al, 2015). What is more, some of this design work can increase the visibility of dementia – for instance, needing to inform casual visitors of cameras placed around a home necessitates disclosure of a condition which still carries stigma (Hopper et al, 2015), as does the wearing of an alarm or a camera around the neck for life-logging purposes (Zheng et al, 2010). Dementia is a condition that is still stigmatised around the world - the World Alzheimer's Report (2012) found that 75% of survey respondents with dementia and 68% of carers felt negative associations (i.e. stigma) about people with dementia in their own country. In Ireland, a 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' (Nolan, McCarron, McCallion & Murphy-Lawless, 2006), while research by Hopper, Piasek & Irving (2015) indicated that users of assistive technologies for dementia had concerns surrounding their implementation – such technologies may help manage the symptoms of dementia, but their obtrusiveness in living environments and on the person (i.e., wearable alarms/sensors) tends to make an already stigmatized condition even more visible. Again, if we seek to compensate for deficits caused by the progression of dementia, the experience of the person we design for needs to be front and centre.

If we don't take into account the positioning as well as the lived experience of people with dementia, those of us who do not have the condition can often fail to see aspects of these 'deficits' which affect people's lives in ways we may not anticipate. For instance, a common

variation on wandering in care homes is ‘exit-seeking’ – where residents (often those new to the care setting) will wander the care home, trying doors and windows in an attempt to escape (Lucero, 1993). This not only poses (small) escape risks – it is a distressing scenario for both the person with dementia as well as the care staff who have limited recourse and often can do little more than redirect or even ignore the residents. A care home in Germany found a novel way to deal with this problem by creating a ‘fake’ bus stop outside of the care home itself where carers can bring residents to sit and await a bus which will ostensibly bring them home (de Quetteville, 2008). This is often enough to satisfy residents who – at the very least – are not getting ignored, and who can be more easily coaxed inside again once they see this is the case.

Although not technological in nature, this simple design feature of the care centre demonstrates a way in which researchers, designers and carers can help to keep people with dementia safe, can make their experience of a difficult time a little better, and in general demonstrates a way of design thinking that equalizes the communication space between designers, carers, and people with dementia (though it does use a small amount of deception). Although other studies may use alarms and sensors to provide a solution to a problem such as this, this simple interaction demonstrates a way of working with the experience of people with dementia. More than this, it is one which attends not only to the past and the present experience of the person with dementia, but which is open to an (literally) imagined future. We will return to the notion of future-facing design later in this chapter, but for now, this section will rest on the thoughts of two central philosophers of experience – Dilthey and Dewey – on what it means to articulate an account of experience that is future-facing. For Dilthey, life is a temporal flow, which each event occupying a spot in time. Writing on Dilthey, Bruner (1986) describes how his account of experience saw *“... meaning [..] in the present; the past was a memory, a reproduction; and the future was always open, linked by*

expectation and potentiality. However, present experience always takes account of the past and anticipates the future." Deeply connected to Dilthey is John Dewey's account of experience as active; again, McCarthy and Wright (2004)'s experience-centred design is predicated strongly on this view of action "retain[ing] its eventness by always being open to the future" (p. 84). For Dewey, and for McCarthy & Wright, there is an interplay between past, present and future, which continually shape and renew each other.

The dynamism of these future-oriented philosophies is ultimately denied by most of the approaches which seek to compensate for the losses that occur in the cognition of people with dementia. Although it can be said that they are anticipatory technologies, that which they anticipate is predicated by the past and is blind to the openness and potential of the future as enacted by people with dementia. In chapter 4, I will describe how people with dementia subverted my own expectations through displaying strong improvisational and performance skills within impromptu 'music sessions' in a care home; however, it is enough for now to note the humanity of people with dementia:

> *... 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.* (Sabat, 2005, pg. 295)

Although some may see them as emancipatory, another view of these technologies is that they propagate a power imbalance and position their user as somewhat lesser and the technology (and implicitly those who design and deploy the technology) as more intelligent,

capable or powerful. Although the intentions are good here – they want to improve the lives of people with dementia – they miss out on something that is deeply connected to the humanity of the person with dementia.

Connection: networking, socialization and keeping in touch

Social and relational aspects of dementia (the idea that certain aspects of the condition may be worsened by positioning or certain social constructions) can impact upon the person as much as the cognitive issues which come with it. In the above-cited paper by Nolan, McCarron, McCallion & Murphy-Lawless (2006), participants who had recently received a diagnosis state that people tend to '*stand back from dementia, because it's too heavy*' (p. 33); they also describe how people who had been diagnosed with the disease were often considered to be less valuable or invisible in society, that family and relatives had begun to talk about them as though they were not there (*"ah he won't know me after another time"*) and that interactions with medical professionals were dehumanising and disrespectful. Compounding this were their own perceptions of the disease as constituting a mental disability, insanity or something that provokes violence and lashing out against loved ones. Despite this, it seems that an active social life in later life can delay or prevent the development of dementia, and may also slow the progression of the disease: Wang, Karp, Winblad & Fratiglioni (2008) suggest that the effect may be seen via psychosocial pathways, wherein participation in meaningful activities lends the person with dementia a heightened sense of self-esteem and usefulness.

There are several concurrent issues here, but all of them have to do with a growing sense of disconnection when real connection is needed – this connection may be found in community, in family life, or in intimate encounters with loved ones and friends. Given the disparate nature of what it means to 'connect' or to socialise, HCI studies have approached this problem from several different standpoints. Alm et al (2007) focus on the design of a

touchscreen system designed for the express use of people with dementia, which they suggest 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 media basis the idea of reminiscence for people with dementia as being potentially useful, with three main reminiscence themes – 'Dundee Life' (the locality), 'Entertainment' and 'Recreation'. The evaluation notes that the system allows its users to interact with it on a 'more or less equal basis', but this is not explained further. It is interesting to think of a system which can mediate between people to change conversations, and the interest here lies in the emphasis for a disconnect between these sets of people on a difference of *communication* rather than a deficit in *cognition*.

Other studies in HCI have used the idea of reminiscence and reminiscence therapy as a way to encourage conversation in people with dementia – (Sarne-Fleischmann, Tractinsky, and Dwolatzky, 2009; Lazar, 2014) who create web-based applications and interactive systems to deliver these services. The Sarne-Fleischmann, Tractinsky & Dwolatzky study details the development of a system that delivers 'personalised' reminiscence therapy via a web-based platform. The design is innovative and allows for some individualisation, but the use of the term 'therapy' is unclear – the system is not indicated for use in particular by therapists, but rather carers or (ostensibly) people with dementia on their own. This theme continues in a paper by Kosugi et al (2013), which provides a proof-of-concept of a music therapy system but which does not include participants with dementia as users in its evaluation and which also does not allow for the music therapist to view the participant with dementia on the other 'end'.

There are some problems apparent with these studies. One is the rush to describe a design as delivering 'therapy' rather than being potentially useful in therapeutic situations. There is nothing about these interfaces that is potentially therapeutic *without the input of another*

person – which leads to the second problem. If these studies can understand the (truly therapeutic) value of the co-presence of another individual, why then are they so quick to automatise and erase the need for that person to be there? In describing the spectrum of care experiences, Twigg writes the following:

> *Even if not involving positive cruelty, we can imagine rough handling, denigrating language, sneering or nasty words, a silent refusal to recognise the person, the demeaning exposure of the body, cold indifference to embarrassment or anxiety. At the other end, we can imagine the very best sort of care, where the careworker brings a sense of life and fun into the house, where the older or disabled person is encouraged and sustained, where what is particular about them is endorsed and valued, where care is structured around their preferences, and where lapses of the body are smoothed over.* (Twigg, 2000, p. 2)

I am not claiming that the above technologies are anything like the former example; I am suggesting that we should be aiming for the latter. Many of these qualities – a sense of life and fun, encouraging, sustaining the older person, endorsing and valuing them – these are (still) uniquely human capabilities. Sakai et al (2012) describe the development of a 'listener agent' for people with dementia, which they say may be useful for the users 'if they can accept the agent as a companion' – itself probably a larger hurdle for the design than its sophisticated speech recognition abilities.

Listening, conversation, creative forms of therapeutic engagement are all likely to be important in designing for and with people with dementia, and in this way studies such as these are providing interesting and new contributions to knowledge. However, one of the largest stumbling blocks is the complexity of the effects that are desired – ameliorating conversation, achieving therapeutic effects or (as described later) cognitive rehabilitation.

Some studies simply attempt to keep participants with dementia ‘in touch’ with larger social networks of friends, family and caregivers.

A paper by Martins et al (2014) describes a social network design which attempts to ‘friendsource’ unmet needs of people with dementia, firstly by automatically capturing data from the PwD’s smartphone to track their whereabouts and activities, and secondly, by providing a private social network group used to ‘validate’ events in the PwD’s life. The paper begins by identifying memory support and social contact as concurrent issues which occur in dementia and posits the friendsourcing system as a potential way to ameliorate both situations at once, listing three potential uses of the system as ‘reminiscence therapy tool’, ‘in-situ communication aid’, and ‘daily routines and reminders’. The system is 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.

This paper makes an important contribution by engaging in a more elaborated and more meaningful way with stakeholders – staff who work with people with dementia. Although many of the studies described above hinge on the inclusion of, and participation of, people with dementia as a desired outcome of their designs, few of these designs a) engage people with dementia in the design process, or b) elaborate on the evaluation of designed technologies or systems with people with dementia. Indeed, some work only as ideas – a listener agent which people with dementia might be able to see as a companion, a remote music therapy system with which people with dementia may not have too much trouble – however, the studied **participation** of people with dementia is mostly lacking throughout these papers so far. All of these designs require the participation of the person with dementia, at least on some level, but what shape this participation took or even might take is not described. Without this, there is little to be learnt about the experience of dementia.

As I note above, what is also paradoxically lacking in many of these projects is *actual* connection and presence between two or more people – instead, several of these papers intend to automate processes such as choosing material for reminiscence sessions or even conversations (such as the listener agent). This process of automation of (all or part of) social processes is an objective in these studies despite the acknowledgement that socialization itself is important for people with dementia – if being with others is so important, the technologies we design should work to ameliorate and enrich this co-presence rather than provide a facsimile of it. The following section will further describe this automation process.

Working with experience: designing for and with felt life histories

The final theme explored here is entitled 'working with experience'. This collection of studies does not have as tight a topic focus as the other themes, but retains a strong methodological focus that is interested not in 'solving' issues such as a lack of socialization and conversation or problems with memory, but instead seeks to explore these issues in ways which might enrich or change something about the life of people with dementia (for the better), but is also focused on learning something from the process of design, co-research and making.

The papers described in this section are typically *participative* and *creative*. They seek to enlist the participation of people with dementia in creative ways. In order to understand this approach to experience, it is first worth exploring the value of creativity in working with people with dementia. For people with dementia, engaging in creative or arts-based practices such as painting, making music, dancing or writing poetry can offer a way to express themselves. For Claire Craig and John Killick, dementia is too often configured as a problem of cognition, when in fact many issues that arise as part of dementia can be socially constructed (Harding & Palfrey, 1997). Although the underlying problem is that of damage to the brain, issues such as agitation, depression, etc, can arise more often due to gulfs of

communication. For people with dementia, creative practice places emphasis on multimodal forms of communication and expression (Algase et al, 1997) – for example, the tactile feeling of working with clay or paint or materials, and the physical exertion and closeness to another experienced during dancing can provide opportunities to connect and express emotions and thoughts that are difficult to express in verbal conversation (Rylatt, 2012). It is always the process that is emphasised during these acts of making – never the end product. There is a sense of embarking upon something rather than solving a problem – although creative methods are often employed in expression, the expression itself is not a solution. It is rarely even an object of analysis, and this is mirrored by Dewey's theory of art, which states that:

> "*A rigid predetermination of an end-product ... leads to the turning out of a mechanical or academic product ... the unexpected turn, something which the artist himself does not definitely foresee, is a condition of the felicitous quality of a work of art; it saves it from being mechanical*" (Dewey, 1934, p. 139).

Dewey also reflected upon the communicative nature of art, writing that "… each art speaks an idiom that conveys what cannot be said in another language and yet remains the same" (1934, p. 106) and that "because objects of art are expressive, they are a language. Rather, they are many languages" (p. 106). Later in this thesis, I will describe how I used musical approaches to engage people with dementia in group activities and in more intimate moments of connection. The cultural weight of music and performing music can be likened to that of any other play or ritual; in writing about a series of parades and other public displays enacted by a community of ageing Jewish people in Venice Beach, California, Myerhoff foregrounds their displays with the following:

> *One of the most persistent but elusive ways that people make sense of themselves is to show themselves to themselves, through multiple forms: by telling themselves stories;*

> *by dramatizing claims in rituals and other collective enactments; by rendering visible actual and desired truths about themselves and the significance of their existence in imaginative and performative productions.* (in Bruner & Turner, Eds., *Actual Minds, Possible Worlds, 1986)*

Chapter 4 will unpack the sense-making processes of people with dementia performing in musical sessions; for now, it is worthwhile discussing what it means for someone with dementia to participate in a research project. In many of the projects explored in earlier themes, people with dementia are rarely consulted during the design process, and in some cases, are not involved even in the evaluation of the design itself. This is somewhat concerning, especially when the technology is claimed to have some therapeutic benefit. It is simply not enough to believe that, because researchers have a fair understanding of what the deficits concomitant with dementia are, researchers can then design effectively for a group without consulting them prior to this.

This is a theme that is brought up by Stephen Lindsay et al's work (2012) on using participatory design techniques to design with groups of people in the earliest stages of dementia. Their approach to these workshops echoes Craig & Killick's notion of 'deficits' in dementia being attributable to communication rather than cognition; they invoke the need for an empathic relationship between researcher and participant; one which bridges the 'gulf between life experiences' (p. 521). The concept of empathy is important when designing for and with people with dementia using participatory methods, Lindsay writes, because caregivers cannot be a stand-in for people with dementia and because of this, close contact between designers, researchers and participants is required.

Lindsay et al appropriate traditional Scandinavian methods of participatory design in workshops surrounding devices to help keep people with dementia 'in touch' and safe when

outside of the home. Participatory design, they write, democratizes the design space and may be particularly suitable for people with dementia given their characterization as 'vulnerable' and often voiceless people. Beyond this, Lindsay's exploration of these workshops included a focus on relational approaches to design fostered by caregivers' involvement as well as by an initial focus on empathy. They highlight the complexities of designing within not only the context of dementia, but also taking into mind the participation of family, friends, and professional care and medical staff, all of whom may have different ideas surrounding the need for and use of technologies within everyday life for the person with dementia.

These methodological complexities are again highlighted by a paper by Holbø et al (2013) which – similarly to Lindsay – focuses on participatory approaches to designing safe walking technologies for people with dementia – but which devotes a significant amount of space to discussing methods used. Reflecting on a multi-method study consisting of interviews, informal meetings and workshops with people with dementia as well as their caregivers, Holbø et al describe several methodological and ethical concerns with carrying out this sort of research – i.e., distinguishing views of PWD from those of their carers, a focus on strengths retained rather than abilities lost, a desire for control, experience of symptoms, routines and skills, empathy for caregivers, and supportive and unsupportive characteristics of the local environment.

Themes recur between these two studies – the importance of everyday experience, empathy as a useful interpersonal lens and tool in design, and the separation of views of PWD from those of their caregivers/allowing space for PWD to be critical of designs and design ideas. This final theme is an important one, as it speaks to the inherent tensions within participatory projects – that of authorship. The hallmark of most participatory design research has been the idea that stakeholders/eventual users are involved in the design process from the ground-up – and so, can be said to be co-authors or co-designers of any eventual design (Asaro, 2000).

The presence and contribution of caregivers and the provision of ideas/designs from designers or researchers have to be carefully managed in order to not dilute the contributions of PWD themselves. Participation itself does not further progression, Beck (2002) writes, as some forms of participation play into instituting dominance – if we are to espouse notions of participation in our design, we need to be more critical about how we configure the participation of some over others. He counters that this 'new' form of participatory design may necessitate a new language:

> *Terms are needed for discussing combinations of head, heart, and hands; of insights and courage; of compassion and scientific curiosities; of sensitivity and methods development; of the building of theory that helps trace 'disappearing' voices. How to specify all this in a name?* (pg. 34)

The workshop-type approach adopted by Lindsay and Holbø bears much in common with workshop approaches taken by conventional participatory design research (Spinuzzi, 2005) – however, there is a question surrounding its suitability for people with dementia. It has already been established that communication is something that is very often changed in dementia, and there is often a shift towards non-verbal communication that prizes attributes such as tactility, familiarity, touch and movement (Caris-Verhallen, Kerkstra & Bensing, 1999). Given these changing forms of communication, is a highly-verbal workshop which works with high-level abstractions such as prototypes entirely appropriate here? Beyond this, although these approaches were useful and led to insightful observations, they were also carried out with a select group of people – those in the early stages of a diagnosis of dementia. What about those in the mid-to-end stages of dementia? What about those who live in or attend care settings, where people with earlier stages of the condition may live alongside those in the middle-to-end stages? This is not to indicate that there is something wrong with the existing research – just that more studies are needed.

Dementia is a complex condition that cannot be reduced even to a given set of cognitive, social and emotional issues – in many cases, more holistic approaches are necessitated in order to understand the experience of participants and how to keep that experience *alive* in design processes and in any resulting design objects.

Keeping experience alive – experience-centred design and dementia

The danger with working with concepts such as 'empathy' or even 'creativity' is that, if they are treated as concrete, they can become reified in design processes, so much so that they are not questioned. To a certain extent, this is what has been seen in earlier studies such as those in the *Connection* category, above, which work towards a goal of 'conversation' or 'therapeutic effects' or even 'user satisfaction' without really critically questioning what that might mean in practice – and particularly in practice for people with dementia.

It has long since been recognized that paying attention to experience in designing technologies is a useful approach (Ljungblad, 2009; Elsden, 2014; Leong, Wright, Vetere, & Howard, 2010) – experience in design is something larger than usability, and instead concerns the emotional and sensual, social and interpersonal aspects of what it means to use technology. More than this, however, the notion of experience can be critical in design. In particular, in research that concerns issues of vulnerability, emotion and wellbeing, a turn to experience can be both ethical and critical. In terms of the ethics of experience, such design research projects should be characterized by dialogue between researcher and participant and thus be necessarily dialogical. Bakhtin's notion of responsivity to an other in felt life has been influential in projects such as these (1985): as people come together in experiential moment, each reflects particularistic value centers. If they are answerable to each other, the experience between them is enriched. This answerability, or responsivity, is a felt, valuational and strong relation to the other, and is never instrumental. Moreover, it is crucial to the other in terms of how that other views his or herself, as it is in dialogue with another person that the self is

authored – in writing about dialogical ways of viewing relationships, Hicks (2000) gives an example of a child moving from a loving home to a destructive school environment, and how interactions therein can change the way that child views his or herself. Responsivity entails being heard; for people who are facing difficult life circumstances, being heard is often being validated.

In terms of the critical potential of experience, it is here helpful to turn to further conceptual work by McCarthy & Wright (2006) which positions the turn to experience as necessarily critical due to the ambiguities and attention to lived experience and felt life within these projects: within this uncertainty, experience finds its critical edge. Immersed in our everyday, prosaic experiences as we build relationships, engage ourselves in design, and make an impact upon the world around us, reified and unworkable concepts fall away in the face of what we know, in our own experience, to be true for us. Thus, paying attention to the experience of the researcher and the researched in design research is likely to yield both ethical and critical results.

Beyond experience lending a critical perspective to design work, there are several participatory projects in HCI that mostly ran concurrently as part of research in Newcastle University's Open Lab. As Lindsay notes above, they necessitate the development of a relationship between researcher and participant, but because of their interest in the lived experiences of vulnerable people, they also complicate any application of a static notion of 'experience'. These projects are by authors such as Wallace et al (2013), Thieme et al (2015) and Clarke et al (2013), and are participatory projects focusing on the felt life of people facing challenges in their lives: people with dementia, women living in institutions, and migrant women who have suffered domestic violence. While each of these projects saw the researchers within navigating designerly skills (such as selecting participants, doing creative work), the vulnerability of these participants, the sensitivity of the research setting, and the

longitudinal nature of the study meant that, in each, the research process took on a dialogue-like quality as the relationship between researcher and participants developed and deepened.

It's important to pause for a moment and think about the ways in which these projects configure relationships and participation by the participants as well as by the research. This research is typically energised by a sense of responsivity. In talking about responsivity in design, I turn to a quote from McCarthy & Wright (2015), which emphasises the dialogue-like nature of processes as partly constitutive of participation (in the second instance, on the behalf of people living in nursing homes):

> *Having a say* […] *enables people in community to express themselves and reproduces meanings and feelings that existed independently of community interaction. Having a voice goes beyond having a say by creating new understandings that were not available prior to the encounter … A dialogic approach, which treats the voices of diverse participants as constitutive, has the potential to render community collaboration radical and generative. Seeing communities as constituted by the voices of those participating in them is a theoretically significant shift from the nostalgic yearning for stable, cohesive community that could be a significant design aspiration for community-centred projects.* […] *From a dialogical perspective, people know that they have a voice, not when they express themselves, but when others respond to them. If they are ignored or treated superficially, they know that their contribution—and in community that means themselves—is not valued. They know that they are not expected to participate. The response that recognizes the worth of another starts with active listening: listening to the other person, to the situation from which their contributions come, and to their otherness and distinctiveness.*

McCarthy & Wright articulate a dialogical ethics which is predicated on aesthetic experience or 'richly seeing' (Hicks, 2000), which is integral to keeping the experiences of participants alive. This approach is typified by research by Jayne Wallace which sought to explore the design possibilities surrounding the support of personhood within a married couple's relationship, where the wife had recently received a diagnosis of dementia. Wallace's project made use of a set of designed probes to which the couple were asked to respond. This approach – mediated through objects – helped Jayne 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. Her designs – a series of digital objects intended to be worn and used as jewellery – reflect intensely personal aspects of Gillian's personhood. For example, a series of brooches were created out of pieces of material from Gillian's older dresses, with an ornate music box built to pair these brooches. When placed on a particular patch of the music box, RFID tags in the brooches would interact with mini-speakers placed in the device in order to play music that Gillian and John associated with that dress, and therefore with that time in their lives and the associated activities.

Design research

The title of Wallace's paper – 'A design-led inquiry into personhood in dementia' – positions *personhood in dementia* as the object of interest. Research through design has a strong history in HCI, and was perhaps most famously illustrated by Frayling's 1993 paper that criticizes an approach to creating art and design work that prioritises the resulting objects rather than the knowledge and understanding gained from creating that work. In 2012, Gaver warned the design community against seeking standardization in their work, and instead "*take pride in its aptitude for exploring and speculating, particularising and diversifying, and - especially - its ability to manifest the results in the form of new, conceptually rich artefacts.*" (pg. 937)

The sorts of scientific theories produced by design research are not of interest in the kind of generative, future-oriented research that is described in this section. This is in part due to the ways in which the production of scientific knowledge involves separate knowing; a distanced stance, playing the 'doubting game' (Elbow, 1973) as described in the introductory chapter of the thesis. Involving 'making' processes in research has a long history (Liamputtong, 2008), and these making processes rarely have 'finished' objects at the end. Although complete 'designs' have the potential to change lives for the better, designing *with* our participants helps to understand not only what might change experiences, but also what challenges and opportunities our participants may face in doing this along with researchers and designers. In part, this means the taking up of a 'making mindset' as described in the previous chapter; Ingold (2014) describes this as a method that seeks not to describe the world, or to represent it, but to open up our perception to what is going on there so that we, in turn, can respond to it**.** In this way, the sort of knowledge that is sought (and ultimately generated) by this project is experiential knowledge; a knowing from the inside.

Knowing from the inside – ethnographic and phenomenological approaches to dementia

Workshop- or lab-based research methods are probably the prevailing way of designing within dementia contexts to date – however, ethnographic or field research approaches to working with this population may be more advantageous in a) understanding the person on their own terms, in their own context and b) allowing opportunities for the 'voice' of the participant to be heard in the research and in any resulting design.

Although ethnographic research with people with dementia is rare in the HCI field, it has a long history in social sciences research. In particular, Erving Goffman's studies of institutionalization (captured in 1966's *Asylums*) presents people living in nursing homes as institutionalized persons, in particular investigating the effects of institutionalization on social relationships, attachment to place and medical perspectives of those overseeing the

institutionalization of others. Often mentioned in tandem with Goffman when discussing nursing home ethnography is Jacob Gubrium's 1970s ethnography of a many-floored nursing home in *Living and Dying in Murray Manor*, which focused in particular on the way work is managed within these organisations, from higher-level management to 'bed and body work' carried out by carers. The ethnography also explored the intersection of people living together at different stages of dementia, and the challenges that this posed in particular to those who were at earlier stages of the condition.

Recent years have seen a continuance of this research, most often within single-paper research studies such as McColgan's 2010 study *'A Place to Sit'*, which investigated creative resistance strategies employed by residents of a Scottish nursing home in order to claim space and express their wishes to participate and not participate in daily activities. Reed-Danahay's 2011 'This is your home now!' investigated the previously-mentioned symptom of dementia in care – exit-seeking – from the point of view of care staff who must deal with the difficult situation and with residents' sense of 'location and dislocation' within the care unit. Sabat & Lee's 2013 paper utilized an observational approach to explore social cognition in dementia care by exploring the kinds of friendships made by people with dementia living in care together, whereas Sandhu et al (2013)'s observational research examined the social structure of care settings, finding that people whose dementia was at about the same stage ('functional similarity') would tend to 'group' together – which meant that those who were less 'able' were often excluded from larger group activities.

Kontos' large body of ethnographic work in dementia care is particularly interesting in terms of design for its focus on bodily experience and phenomenology. As described earlier, as dementia progresses, expression and communication can become non-verbal. Kontos describes much of the life of nursing homes in terms of their embodied potential – for instance, choosing to dress in certain ways, participating in the sleep-wake cycle of nursing

homes, the attempts of care workers to transform (via various methods) residents into 'docile, dementing bodies' (echoed also by Reed-Danahay, 2005). However, through embodied actions, residents can retain and communicate a strong sense of selfhood. She gives an example from one of her own ethnographies during which a resident's dignity is being compromised during her being fed by a care assistant:

> *The Health Care Aide tried to give Molly another spoonful of cereal but Molly pushed her hand away as she established eye contact with each of the others at the table to acknowledge their presence. Then reaching her wavering hand to the back of her neck, she struggled to pull something from underneath her bib. Extending her arm appeared to cause her pain and discomfort and yet she persisted. Molly eventually revealed a string of pearls she was wearing that had been covered by her bib. She allowed the pearls to pass through her long slender perfectly manicured fingers placing them ever so delicately atop her bib. With this simple gesture, Molly emerged from her world of decrepitude, incontinence, dementia and helplessness as a woman of grace and style. Now ready to eat her breakfast, Molly accepted the spoonful of cereal the Health Care Aide again tried to feed her.* (Kontos & Naglie, 2006, pg. 311)

Progressing from Merleau-Ponty, Kontos positions the body as a site for knowing the world – which can help to explain some of the challenges in living with dementia. Merleau-Ponty suggests that, in illness, our notions of ourselves and our life-world (long since sedimented in our body), break down, meaning that any attempt to try to rebuild this world via our senses can be problematic – particularly when placed into unfamiliar places such as care homes.

<u>GPS rosary beads, wearable lullabies – 'lost opportunities'</u>

Research by Wallace, as well as some of the ethnographic research described here, indicates another aspect of design that is too often neglected – meaningfulness. In writing about how

alternative ways of living for people with dementia can make their lives meaningful again, Gawande (2015) invokes Royce (1908):

> *It does not necessarily produce happiness, and can even be painful, but we all require devotion to something more than ourselves for our lives to be endurable. Without it, we have only our desires to guide us, and they are fleeting, capricious, and insatiable. They provide, ultimately, only torment. "By nature, I am a sort of meeting place of countless streams of ancestral tendency. From moment to moment… I am a collection of impulses," Royce observed. "We cannot see the inner light. Let us try the outer one."* (p. 148 – 149)

For Wallace, her creative probe approach to designing within the dementia context meant that the process and the resulting designs were intensely personal and meaningful to Gillian and John; similarly, Kontos' ethnographic approach which prioritized communication via bodily means indicates that Molly found both her appearance, the way she presented to others in public spaces, as well as the pearls, meaningful. Interestingly, both sets of studies focus on exploring and honouring the *personhood* of their participants, and through this approach, bring about significant contributions to knowledge of what it is like to experience dementia. What they also invoke is the 'ancestral tendency' described by Royce, above, which echoes Bruner's statement that "i*t can never be the case that there is a "self" independent of one's cultural-historical existence*" (p. 129).

Within this context, it is useful to discuss two promising studies which seek to ameliorate the lives of people with dementia but which have some shortcomings in doing so: Ou, Kuan, Wang, Tsai & Chen's GPS prayer beads (2015) and Ehleringer & Kim's 'wearable lullaby' (2013). Ou et al's paper details the process undertaken to create a prototype of a set of prayer beads which are embedded with a GPS tracking device intended to track the daily movements

of elderly people, particularly people with dementia, whereas Ehleringer & Kim describe small-scale field studies testing the feasibility of a motion-sensor-triggered 'wearable simulated presence therapy system' intended to soothe back to sleep people with dementia who awaken in the night (who may be confused as to where they are or where others are and become agitated). When the motion sensor is triggered, the following response plays:

> *"Go back to sleep. It is night time. Mom is asleep. (Wally) is asleep. They do not want to wake up. The urinals are by the bed. You can urinate lying down. It is very important to be quiet. Put your head on the pillow and go back to sleep. We will see you in the morning, and we will have coffee for you."* (p. 412)

The authors report positive results from limited field trials using this device with a family, one of whom had dementia – however, the participant with dementia's response to the device was limited to a sentence describing his compliance with the audio-recorded response.

There are some problems inherent to both studies if viewed through an experience-centred design lens. Both are deployed during sensitive moments where what we can imagine as really being needed in the situation is a response that is akin to being soothed or experiencing calm. Ou et al note that prayer beads are usually used in religious practice during moments of prayer or meditation, while waking in the night in a strange place (particularly if it is a care home with a communal bedroom) can be terrifying for people with dementia. At both of these critical points, designers take the opportunity to a) embed tracking devices in religious paraphernalia and b) design for quiet, simulated 'presence' rather than soothing, meaningful and real 'presence'. The approach taken here is not necessarily exploitative, and again aims to improve the experience of users, but at the very least it does not honour the personhood and the lived experience of their participants.

How could these be better? Both have identified important, experientially rich opportunities in the lives of people with dementia – religious or meditative significance and rest, sleep and the possibility of feeling frightened and anxious. With the rosary beads, could their meditative significance be enhanced by a different digital design? For instance, Thieme's (mentioned above) spheres of wellbeing incorporated digital elements and co-making processes with vulnerable participants to provide soothing potential during difficult moments. The wearable lullaby, with its evocative name, could be a much more simple wearable object – a bed jacket or a soft bracelet embedded with music or sounds which are soothing for participants and meaningful in the context of their everyday life or life history. It could incorporate tactile or sensory significance and be made out of familiar materials or scented with a favourite perfume or essential oil.

I do not wish to draw particular attention to 'flaws' in designs – rather, what is important at this point is to demonstrate that taking a meaningful object or an emotional experience and reducing the rich potential inherent to it to GPS tracking or pre-recorded messages **does not honour or reflect the lived experience of the person with dementia**. It is a wasted opportunity, and reduces a moment that could have been participative and creative to something which objectifies our participant as something to be tracked or someone to be quieted. Although both wandering and night-time shouting/vocalizing can be difficult times in the lives of people with dementia and their carers, and certainly deserve to be designed for, there is hopefully a way in which this can be done that does not begin with, or lead to, an impoverishing of our view of the person.

What is different between these approaches (compensation, connection vs ECD-type approaches)?

I have already stated that this thesis uses an approach that is primarily concerned with experience in investigating the ways in which people with dementia participate and belong in

communities. I have spent some time discussing what I mean by paying attention to experience – drawing from McCarthy & Wright, as well as from phenomenological philosophy, an experience-oriented approach means being open to potential, being oriented to possible futures; by a sense of placement that is grounded in our phenomenological understanding of our selves, our bodies, and in our own particularistic social and cultural histories; by an attenuation towards dialogue and response.

This section delineates in practical terms what differentiates the experience-centred approach from some of the studies discussed in the sections pertaining to connecting people within networks and compensating for abilities that seem to have been lost. This will be followed with a discussion of the 'gaps' that exist currently within the dementia care and HCI literature, and point to what it is hoped the design community can deliver in the future, and what this thesis aims to deliver as well.

Putting experience into action: differences in approaches

1. Solutionist thinking vs. explorative thinking

The critique of solutionism within HCI has risen within recent years; it pertains to a growing insistence upon the natural endpoint of research studies being the solution of a 'problem', usually via the creation of some kind of technology, and has been sometimes characterised as "*solving problems that don't exist or proposing technological quick fixes for complex social, political and environmental problems*" (Blythe, Steane, Roe & Oliver, 2015). When we deal with experience, we do not look for solutions for problems we might face within that experience – in fact, experience-centred design is not really interested in 'problems' at all. If it is, it is more interested in problem-*finding* rather than problem-*solving*. To borrow an explanation from the arts:

> *[C]onsider a traditional theatre performance, perhaps a play by Shakespeare, where the actors start with a script, with memories of past performances by other companies—the long tradition of Shakespearean theatre. This type of performance is at the problem-solving end of the spectrum, because the "problem" is well-specified: to create a successful performance of the script. In contrast, in improvisation the actors have to create everything; the dramatic elements emerge from the dialogue, in a problem-finding process that is collaborative and emergent.* (Sawyer, 2003, p. 105)

Experience-centred design projects seek to explore certain situations that are not very well understood in terms of experience – for instance, how it feels to withdraw from social situations following a diagnosis of dementia – and in this, we can use making and otherwise creative processes to learn from these situations. In this way, working with experience in design situations is almost always research through design. It may be employed as a part of an action research methodology which seeks to achieve mutual change and benefit within a situation, but the primary goal is exploration and the achievement of a negotiated understanding, thereby contributing to knowledge of the situation and experience itself.

2. Working within 'cuttings out of time and space'

Although experience-centred design is interested in achieving a holistic, qualitative view of the participants involved, it is also aware of its methodological limitations – which in fact function as strengths. Experience-centred design is almost always situation-specific design, which seeks to understand a person or people in context in their surroundings. In this way, ethnographic or participatory action research is often employed. McCarthy & Wright (2015) describe this as working within 'cuttings out of time and space' (a phrase borrowed from Rancière), where working within these boundaries helps to keep experience alive within the design process and design interactions. These processes typically result in technologies that are aesthetically meaningful to participants but which may be used only within certain

situations or reflect emotional rather than solely practical uses. Beyond this, to work with experience within these 'cuttings out' means a recognition of the place of the ethnographer within the project and within the interpretation of that knowledge. Ethnography has long been used in HCI, but some still struggle with the sort of knowledge it produces. In a 2006 paper, Dourish notes that growing 'marginalisation of theory' within HCI work (specifically that work published in ACM forums) means that ethnographic studies in HCI can find themselves in a double-bind:

> *That ethnographic studies have something to say to HCI designers is broadly recognized; I have argued, however, that a focus on implications for design reads ethnographic inquiry too narrowly, constraining ethnographic studies in ways that fail to do justice to the kinds of insights that they can provide. As a spin-off benefit, perhaps this might also help to transform our evaluative criteria for ethnographic papers. Frankly, I doubt that this is the last CHI paper on ethnographic work that will find itself forced to end with "implications for design"... but it is certainly nice to think that this is a possibility.* (p. 9)

To work with experience is to acknowledge both the limitations and opportunities offered by taking an experiential approach, particularly an ethnographic approach; ethnography means writing others' sense-making in a language that we can understand, but in a way which is never finalised, write McCarthy & Wright (2004). For them, it is a "turn away from the possibility of neutral description". This turn will be described in the next chapter in more detail.

3. <u>A strong focus on methodology and documentation</u>

It may seem strange to emphasise the importance of methodology in experience-centred projects, given the relative fluidity and particularistic nature of these methods; however, those

studies in HCI which describe experience-centred design as an influence almost inevitably document and reproduce, in their final text, accounts of these methodologies. This is something which is regrettably omitted in many HCI projects, which purport to do qualitative analysis or field studies without naming the processes involved and analytic methods undertaken. ECD projects also typically acknowledge the design researcher's reflexive experience within these processes. These are typically qualitative methods - often ethnographic, interview or action research/participatory action research approaches which aim to gain as full a picture as possible of the person in context (whether that context be in work, in public or in private spaces). Workshops can be used, but are often more flexible and reflexive than (for instance) typical participatory design workshops, and usually are accompanied by at least some field research. The methodology used is always well-documented, with thoughtful evaluation that is suited to the design method used as well. Speaking to the previously-mentioned critical edge that experience brings to research, experience-centred design will not pursue a reified notion of 'user satisfaction', and will question what this means in a) different contexts such as when working within dementia care, and b) what satisfaction might mean to individuals in the context of their felt life histories.

4. Working together to imagine futures

Experience-centred design is necessarily 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 eked out with design materials). Although ECD is a process which results in the co-creation of new knowledge, it is not focused on the past (i.e.,

much scientific thinking/research) but is instead oriented always towards possible futures that are made possible by working together; McCarthy & Wright (2004) explain that, in ECD approaches, persons and things are always in a dynamic process of becoming, and are always open to the future. In this way, experience-centred design processes are dialogues between two or more parties, with any eventual design object representing a co-created response to this conversation. In reflecting on an experiential, ethnographic approach undertaken in a design research study in a nursing home, Blythe et al (2010) describe this approach:

> *If we have succeeded at all in enhancing our participants' experience of ageing through technological interventions, it is not by observing users, identifying needs, goals and activities, then specifying the requirements of design solutions. It is by spending time, living with them a little, and by letting our relationship grow to a point where we could respond empathically with something. The form of response was less of a solution to a problem and more like a gift.* (Blythe et al, 2010, p. 169)

In the context of the outstanding literature on dementia care and HCI, it is these four facets of experience-centred approaches that differentiate these projects from those of our first two categories. With these differences in mind, and with a small yet growing interest in working with experience when designing for people with dementia, let us now turn our attention to current gaps in the dementia care and HCI literature to begin to imagine how these may be filled.

Defining the place of experience-centred design in dementia contexts	
What differentiates experience-centred design methodologies from other approaches to design?	**What are the future challenges for experience-centred design approaches in dementia contexts?**
1 Solutionist thinking vs. explorative thinking	1 *The place of design in dementia*: there is a need for an in-depth account of life in care for people with dementia, which indicates possible spaces for design.

2	Working within 'cuttings out of time and space'	2	*The nature of designed objects and systems in dementia*: there is a need for systems and devices which are simple but yet hold the potential to a) help us learn more about the experience of dementia and b) ameliorate or enrich the experience of the user(s).
3	A strong focus on methodology and documentation	3	*The (relatively) unexplored potential of creativity:* Researchers need to engage not only with the output of these sessions but in learning about some of the ways in which people with dementia engage to give us an idea of the sorts of design spaces needed to build in order to make room for new and (to us) unfamiliar forms of communication.
4	Working together to imagine futures	4	*The meaning of participation for people with dementia:* there is a need to reconfigure what we consider as communicative in order to open up our notions of participation and authorship in dementia.

Table 2: conclusive points of chapter two

What are the outstanding issues in the dementia-HCI literature as it stands?

It's clear from the extant work in design and dementia that has been reviewed in this thesis so far that there are multiple ways of working in this area, and there are certainly many ongoing projects which use different approaches to design for and with this population. This thesis intends to extend the experience-centred design approach described in the previous section to address the following gaps in the literature, identified through the review of papers above:

1. The place of design in dementia

Given the small but substantial amount of ethnographic work carried out in dementia care contexts, it is perhaps surprising that there is a lack of an elaborated account of the place of design/technological interventions for people with dementia. It is perhaps because of this that there is a lack of meaningful exploration of many of the terms involved in the above research (e.g., therapy, conversation, user satisfaction). Most papers in the ACM digital library which pertain to designing within dementia are short papers – three pages or less – and a large number of them concern only technical feasibility of systems which could imaginably help people with dementia at some point in the future (e.g., a conversational agent, a remote music

therapy video link system). There is little discussion as to the temporal or physical place for these systems in people's lives. Systems such as the COGKNOW DayNavigator are slightly better in that they include greater detail on possible uses of the system; however, overall **there is a need for an in-depth account of life in care for people with dementia, which indicates possible spaces for design.**

2. The nature of designed objects and systems in dementia

Although this thesis has emphasized that the process of design itself is often fruitful in terms of the ways in which it can connect communities and people as well as its use in generating knowledge, it is perhaps unavoidable that the vast majority of design is undertaken in order to produce objects or systems which effect positive change upon the lives of people with dementia and their carers. However, in much of the research cited in this paper, designed objects are typically either very complex (e.g., Lazar's ambulatory system which features screens for not only cognitive training but also social interaction), or require prior ownership and/or mastery over relatively sophisticated technological devices (i.e., smartphones, touchscreens). Although it is probably right that researchers should not 'dumb down' technologies for people with cognitive problems (not only because it is unethical; because challenging people to use skills is important in retaining those skills), creating technologies that are unfamiliar to people with dementia requires learning which they may not be able or inclined to work to achieve. Beyond this, there is the emotional facet of being presented with a system that is difficult to understand or use and the feelings of 'uselessness' and disability (already present in many whose cognitive skills are declining) that this may provoke. The aesthetic experience of using or experiencing the technology also needs to be explored in more detail, and so overall **there is a need for systems and devices which are simple but yet hold the potential to a) help us learn more about the experience of dementia and b) ameliorate or enrich the experience of the user(s).**

3. The (relatively) unexplored potential of creativity

As mentioned previously, adopting a creative approach to working with people with dementia can be advantageous in terms of allowing space for different modes of expression (Phillips, Reid-Arndt, & Pak, 2010). The role of creativity in caring for people with dementia has a rich history in practice – from art, drama, comedy and music (Basting, 2006) – however, this has rarely been explored as a possibility for design; instead, researchers and designers typically focus on workshop-type approaches and in using the caregiver as a proxy for the person with dementia. Extant ECD approaches position artistic or creative design processes in the context of participants' life histories in order to imbue the process with meaning for participants. If designers and researchers can live with the ambiguity of working within a deeply qualitative and experiential space, we can certainly learn to work with and value the process of creativity with our participants, and the documentation of this process via field notes and conversational data (and other methods) is likely to be illuminating. For people with dementia, not only the output of these sessions but learning about some of the ways in which they engage with these sessions may give us an idea of the sorts of design spaces needed to build in order to make room for new and (to us) unfamiliar forms of communication. **Researchers need to engage not only with the output of these sessions but in learning about some of the ways in which people with dementia engage to give us an idea of the sorts of design spaces needed to build in order to make room for new and (to us) unfamiliar forms of communication.**

4. The meaning of participation for people with dementia

To follow on from the previous point – it is important to deeply explore ways in which people with dementia might be able to participate in research and design processes before dismissing out of hand the very possibility. Institutional ethics often preclude the involvement of people with dementia in research on the basis of an incapacity to consent, or

else they hand off this consent entirely to appointed caregivers – although there are problems with consent in dementia, it is also true that the voices of people with dementia need to be heard in design which affects their own futures. It is possible that creative approaches to expression and communication in dementia may herald a way forward in involving people with dementia (in all stages – Lindsay's workshops with those in early-stage dementia proved to be successful) in design activities in a way which may be considered participative and facilitating to processes of co-authoring. As an example to how this may be achieved, an example may be found in conventional Scandinavian participatory methods employed in research such as Ole Iversen's work with school-aged children (Iversen & Nielsen, 2003; Iversen, Kortbek, Nielsen & Aagaard, 2007). Iversen's approach is highly creative and gives a large amount of creative space over to his participants – he sets them loose in museums with cameras, for instance – and then uses this creative material in order to create technologies and systems which attempt to respond to participants' experiences. This work reflects the label of 'participatory' in almost all forums in which it is published and presented – yet it is little different to the sort of work that might be carried out with people with dementia. Why, then, are people with dementia denied the opportunity to be said to be participating? Just because someone does not answer us in the language we speak to them does not mean that their input cannot be valued and incorporated. A common language must be forged, and **there is a need to reconfigure what we consider as communicative in order to open up our notions of participation and authorship in dementia.**

Summary

This chapter has detailed three common approaches undertaken when designing for and with people with dementia – *connection*, *compensation*, and *working with experience*. These categories are not discrete – it is impossible to discount the importance of, for instance, safety when ensuring meaningful experiences for people with dementia – however, the remainder of

this thesis will primarily build on research encountered within the final category – working with experience – as well as making reference to research which pertains to the importance of connection for people with dementia. In the next chapter, I expand on the methodologies undertaken as part of this research which place a primacy on experience – ethnography and participatory action research in particular – in order to understand the dialogical nature of relationship creation within caring communities for people with dementia.

Chapter 3: Methodology

YOUNG BOY
And there's someone in a tree —
OLD MAN
— Or the day is incomplete.
BOTH
Without someone in a tree,
Nothing happened here.
OLD MAN
I am hiding in a tree.
YOUNG BOY
I'm a fragment of the day.
BOTH
If I weren't, who's to say
Things would happen here the way
That they happened here?

OLD MAN
I was there then.
YOUNG BOY
I am here still.
It's the fragment, not the day.
OLD MAN
It's the pebble, not the stream.
BOTH
It's the ripple, not the sea.
Not the building but the beam,
Not the garden but the stone,
Not the treaty house,
Someone in a tree.

(from 'Someone in a Tree' from Pacific Overtures by Stephen Sondheim & John Weidman)

Introduction

In the previous chapter, interaction design approaches taken up in HCI research for and with people with dementia were discussed. I divided these approaches into broadly three themes – 1) approaches which prioritise the issues with cognition caused by dementia by designing systems which 'fill in' or circumvent these gaps, 2) approaches which attempt to answer problems of socialisation in dementia by designing systems which promote socialisation, and 3) approaches which work with people with dementia in order to gain an idea of their experience and position design as a response. I identified the final approach – and its focus on working with experience – as the approach that will be taken in this thesis. The previous chapter also ended with a set of challenges that should be addressed in future work in designing for and with people with dementia. These challenges were **1)** to produce research which is deeply considered concerning, and reflective of, its place in the ecology of dementia, **2)** to produce design objects which are more reflective of the experience of people living with dementia rather than objects which answer only the deficits in their cognition, **3)** to explore the potential of creative methodologies when working with people with dementia, and **4)** to explore what it means for people with dementia to participate meaningfully in activities and in design which may play an integral part in their futures.

This chapter directly responds to three of these four challenges – 1, 3 and 4. It outlines my epistemological position that describes an interdisciplinary approach (psychology [inflected

with anthropology and sociocultural approaches], HCI and creative arts) that was developed to engage with a series of care settings and communities within the project as it unfolded.

At this point, it is useful to return to the research aims and questions laid out at the beginning of the thesis. To a certain degree these aims and questions were shaped by my longitudinal engagement within the care communities during this research project; however, the initial focus was on *participation through creative methods*. This thread, along with the emergent theme of *community*, runs through the aims and questions of this thesis.

The research is motivated by two main aims:

- To identify ways in which people with dementia living in care can participate in group activities and in community settings, with a view to understanding how this participation can become a part of meaningful communication and involvement in research;

- To explore ways of being together and community for people with dementia living in care, with particular attention paid to the ways in which technologies can/could mediate this being together.

In meeting these aims I ask the following questions:

- What does it mean to participate in a group activity when you have a diagnosis of dementia?

- To what degree can this participation be considered as co-authorship (of research, of designed technologies, of the experience that the person might be living)?

- How can embodiment, making processes, and doing together be configured in dementia to

facilitate communication between participants with dementia and researchers?

- How can any prototypes developed be used and evaluated to support community practices within groups of people with dementia living in care?

The methodology used was rooted in ethnography and (as the project unfolded and relationships changed) participatory action research. The project began with the intention to explore the potential of creative approaches with participants with dementia living in care via an ethnographic approach which also compiled a large amount of contextual data; however, as the research progressed, complementary approaches (e.g., interaction design, focused creative workshops, and participatory action research) were included as relationships deepened and developed. In this way, the process was highly contingent and responsive to participants' (and institutions') wishes throughout the process. This focus on creative and 'making' processes was twinned with an approach to knowledge creation and communication that was focused on the 'feltness' of life, and which quickly became one which was open to communication via non-verbal and bodily means, which itself was underpinned by an ethnographic sensibility. The following section will discuss the epistemological background of this ethnographic approach.

Ethnography, participatory action research and their role in HCI

Emotional ethnography

In the previous chapter, I briefly detailed a series of well-recognised ethnographies in the mid-20th century which were carried out in the context of institutions and nursing homes – prime among these are Erving Goffman's studies published as *Asylums* and Gubrium's ethnography of Murray Manor. These texts were seminal when published and are still referenced today, and are very much in the earlier style of ethnography which has the researcher immersing his or herself within a context that is largely seen to be 'alien' or

‘other’ to them. As a type of observational research, ethnography has its roots in anthropological research carried out in the early 20th century and is characterised by a rejection of neutrality and objectivity in research and, instead, a recognition that all research is affected by the researchers’ own values (Hammersley & Atkinson, 2004). Such early research saw ethnographic researchers investigating cultures which, at the time, were anthropologically ‘strange’ to them. In time, this ‘format’ of research garnered criticism of uncritical approaches to the power structure inherent within – or rather, the prefigured relational space within the ethnography as one participant (the researcher) as ‘the listener’ with the others (participants) as informants (Gonzalez, 2003). The role of experience in ethnography is important, and ethnographic approaches to data collection can help to keep the experiences of our participants ‘alive’; Bruner (1986) notes, despite the deconstructive nature of analysis and representation:

> *Most good ethnographers, interestingly enough, reintroduce vitality in their descriptive accounts by including illustrative snatches of personal narrative, bits of biography, or vivid passages from their field notes (Peacock 1984). In effect, the experiential component returns to the account as a by-product rather than as an explicit object of research. We systematically remove the personal and the experiential in accordance with our anthropological paradigms; then we reintroduce them so as to make our ethnographies more real, more alive. […] Meaning is always in the present, in the here-and-now, not in such past manifestations as historical origins or the author's intentions. Nor are there silent texts because once we attend to the text, giving voice or expression to it, it becomes a performed text, active and alive. It is what Victor Turner called "putting experience into circulation.”* (p. 9)

Making our ethnographies real and alive involves storytelling and representation. In writing about the anthropology of experience, Bruner notes also the 'double consciousness' inherent to all ethnographers – "*there are always at least two double experiences to be dealt with: on the one hand, our experiences of ourselves in the field, as well as our understanding of our objects; and on the other hand, our objects' experiences of themselves and their experience of us*" (p. 14). This double consciousness emphasises the plurality of being an embodied agent in a dynamic field, as well as points to the constructive nature of ethnographic research. He describes how this pluralistic, intersubjective process unfolds as a series of three 'tellings':

> *"First we tell the people why we are there, what information we are seeking, and how we intend to use the data. We do this directly, by explaining our project and by our behaviour, by the questions we ask and the activities we attend. ... In the second telling we take this verbal and visual information and process it, committing it to writing in our field diaries. This transcription is not easy. Every ethnographer is painfully aware of the discrepancy between the richness of the lived field experience and the paucity of the language used to characterize it. There is necessarily a dramatic reduction, condensation, and fragmentation of data. In the third telling the audience consists of our colleagues, who provide feedback as we prepare our materials for publication, and here the story becomes even more prominent.* […] *Retellings never cease; there is an infinite reflexivity as we go from experience to discourse to history. Eventually, all experience is filtered out and we end where we began - with the story."*

Ethnographic research is an active process, in which researchers produce accounts of the context of interest through this observation and interpretation of what is seen and experienced. Bruner emphasises the narrative aspect of the tellings, but (following from Dewey and Dilthey) does not dictate their chronological order; rather, just the temporal

unfolding of experience. These tellings are negotiated with those in the field, but it must be remembered that the researcher in ethnography *is* the research instrument, and thus vitally a part of the research. Active engagement in an alive field involves a learning process on behalf of the ethnographer which is often more of an assimilation process, an intoning of a 'way of being' which can affect the researcher, as well as the researched (Davies, 2008). The research process itself contradicts this somewhat – research projects bounded by funding, time and resources may mean that relationships developed in the field are inevitably, and artificially, cut short (Murphy & Dingwall, 2007). In the following chapters, I will describe the artificial 'ending' of some of my relationships with care institutions, as well as the cultivation of relationships anticipated to extend beyond the thesis.

The emotional tensions inherent to doing ethnography in dementia care are worth describing. Ethnographers face a number of issues when carrying out what Wacquant (2005) 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*" (Wacquant, 2005), 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. This embracing of the intersubjectivity between researcher and researched is characteristic of a new form of ethnography, which emerged from feminist perspectives in the late 1990s and belongs to an approach called 'the intimate stance' (Lerum, 2001; Irwin, 2006).

Several researchers have attempted to produce accounts of this empathic approach to navigating and configuring relationships 'in the field'. Wang (2012) details her reactions to the formation of relationships during her ethnographic work in an international school in mainland China. Here, her participants are both students and faculty, and she finds herself feeling in-between the two. 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?* (Wang, 2012, pp. 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. In my own research, I straddled a different line between falsehood and reality – suffering from dementia as they did, my participants often believed that I was someone who I was 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 I chosen reality over falsehood. I will discuss my experiences in navigating this schism responsively and responsibly later in this chapter.

Ethnography faced criticism in the early 1980s that accused the method itself of being colonialist and exploitative (Naples, 2003; Cole, 2001). Key to changing this, writes Katherine Irwin (2006), is to craft a new narrative style. She proposes that the development of, and participation in, intimate field relationships can 'keep alive' the experience of what it is like to be in the community of interest in the first place, but that we must be mindful of issues of structure which might affect the ways in which we work with and represent our participants. Writing of her deep involvement in her own ethnographic research – she dated,

married, and divorced the key informant of the ethnography which served as her own doctoral thesis – she considers discourse from feminist writers who hold that a deeply empathic, intimate stance in ethnography is less exploitative than an objectifying stance (Oakley, 1981); moreover, she writes, adopting this stance may challenge colonializing tendencies inherent to the research process itself by situating the researcher, and the researched, in a historical context sensitive to the particularities of experience. However, researchers should not accept 'the intimate stance' as an inherently equalising way of enacting ethnographies; differences (sometimes inequalities) can remain:

> *If researchers and research participants enact inequalities when they are intimate, intimacy can be even more damaging and problematic than objectivity. If there is any distinction between real and false intimacy, my relationship with my key informant and other study members was as true, real, and genuine as any in my life. Being genuine, committed, and forging special bonds were not the problem. The problem was the structures between my study population and me. In the end, the bonds we formed were not strong enough to overcome multiple inequalities. (p. 170)*

On reflecting on my research, I realise there were many points where I faced difficulties in separating my life outside of the care homes from my life in the care homes. For a long time, the tensions between 'real and false' intimacies troubled me as my relationships developed with care staff and with participants who would seem to forget me from one week to the next. Dickson-Swift et al (2007) investigate struggles facing researchers who carry out primarily qualitative research, and find that most of the issues concern the formation and navigation of relationships with their research participants. Prime among these concerns is the issue of entering the lives of others and the inability of a consent form to truly represent the forthcoming engagement with the researcher and the 'signing over' of the permission to 'analyse' their lives. This is even more complicated when we work with people with

dementia who are facing changes in behaviour due to disinhibition – Hannah, a research assistant who joined this project in its later stages, describes a sense of guilt that dogged her through her engagement in care settings:

Hannah […] I've found that I've felt more guilty more times than sad. You know the guy, the guy in Clermont Place who always spoke of his daughter…

Kellie Greg.

Hannah Like when I was dancing with him and he would just tell me all of these personal issues that he had and I'd like, feel bad even listening. I didn't ask about them obviously, I'd ask something about the song and he'd just bring that up. I felt guilty even hearing, like he didn't really know he was telling this to a complete stranger. Like I didn't do anything with it – I didn't put it in my FYP *(final year project)* – but still he wasn't aware of… like, I'd never do that. So I kind of felt guilty even hearing those stories even though I hadn't asked for them.

The issue of reciprocity as necessary in empathic relationships with participants is also discussed by informants in the Dickson-Swift et al study, and it echoes across most writings about ethnography – ethnography, these researchers hold, should run on a principle of 'fair exchange', whereby the researched is not the only person sharing their stories, but the researcher also engages in sharing their own lives and experiences. This co-collaborative process leads to a more completed, arguably more ethical piece of research which is more intimate, but which may (as Wang also notes above) transgress professional and personal boundaries:

> *I'm not gonna hold back and not offer myself to them as a source of support just, just to make sure that my research is within the confines of what a textbook says – like this is a real experience for them, they are letting me into their lives, they're – you know – privileging me so I actually need to give them something back.* (Dickson-Swift et al, 2007, pp. 334)

Prefigured roles in ethnography and qualitative research often position the researcher as 'the investigator', the 'one who asks questions' – however, in real world research, dealing with

people who are allowing you into their lives to record and even analyse their words and actions deserve reciprocity. These issues, inherent to the formation and maintenance of relationships between researcher and participant in ethnographies, are highlighted further when the ethnographer is working with people who are facing challenging circumstances, or when we are employing aspects of participatory action research (Kindon, Pain, & Kesby, 2008) in order to bring about a change in the community. Within this domain, the issue of researcher responsibility is inevitably raised: have participants benefited from the researchers' involvement in this setting? Will this benefit be erased by the researcher's departure from the setting? If the research has brought about social change in the community, can this be maintained given the absence of the researcher going forward? What does the researcher leave behind?

The ethnographic approach undertaken in this thesis helps to answer the two main research aims of this thesis – 1) it serves to identify ways in which people with dementia living in care can participate in group activities and in community settings, and 2) through ethnographic engagement in these communities, I explored ways of being together and community for people with dementia living in care. The ethnographic approach employed here is not just another ethnography of dementia care – it is novel in its context (Irish dementia care in 2013 – 2016 across a number of different care settings), and in its contingencies (attention paid to design potential as well as existing and imaginative technologies). I document ways of being for people with dementia living together (or attending) dementia care, and in this I try to unpack larger questions surrounding the possibility of participation.

Co-creation: participatory action research

Many of these questions feed into a larger discussion surrounding participatory action research (PAR). Although I did not start out working with PAR as a method, elements of this approach entered my research process in later studies and so it deserves some attention here.

PAR is a collaborative approach to research that involves all possible stakeholders (users, partners, participants) in the process of research. It is a process of systematic enquiry, undertaken with the collaboration of those who may be affected by the issue being studied, and typically involves a process that creates some kind of change on the situation itself – whether it is through education or intervention. In this, it is a step beyond ethnography, which does not intervene beyond acknowledging the presence of the researcher in the context. Participatory action research attempts to present participants embedded within these situations as co-researchers themselves 'in pursuit of answers to the questions of their daily struggle and survival' (Tandon, 1988), and 'attempts to break down the distinction between the researchers and the researched, the subjects and objects of knowledge production by the participation of the people-for-themselves in the process of gaining and creating knowledge' (Gaventa, 1988). In this way, PAR is a method which is frequently engaged with political issues, and although it does not have to be employed in settings where there is a 'struggle', it frequently *is* – for example, Reese et al (1999) use the method in trying to ameliorate hospice care for African-Americans, Wang (2009) employs the method in trying to reach larger communities and policymakers with issues of women's health, and Ariyadasa and McIntyre-Mills (2015) address issues of human rights of children facing difficult life circumstances in Sri Lanka using a PAR lens. PAR's usefulness in contentious or politically difficult situations is in its tendency to reduce the ways in which the investigator is treated as the primary actor within the situation, and instead focuses on how a group of people (often a community at the outset, or who become a community through the process) co-create knowledge to solve problems or make life better for themselves and others facing the same situations.

Methodologically, PAR is cyclical and iterative, where action is taken on an issue following initial co-planning, any resulting change is observed, reflected upon, and action is taken again. This iterative cycle continues until the issue is resolved, improved upon, or until

agreement is reached by all parties. The benefits of this approach are numerous – participants have the opportunity to increase their knowledge as well as retain a sense of authorship over their own lives, it is (at least in theory) a research arrangement that allows for a greater sense of trust and reciprocity between all parties than most others (even in ethnography, which is generally non-interventional, there are issues, as Wang [above] indicates), and it is an approach that involves all stakeholders from the ground up, and thus any solution is likely to be one which speaks to their experiences and fits into their lives.

The 'P' in PAR is what differentiates it from many other types of research – however, it is somewhat problematic when it concerns participating with certain people. Can we carry out PAR with children, with people who have problems with their mental health, with people with mid-stage dementia? Of course, this final population is what this thesis is most interested in. The type of participation necessitated by PAR – planning, reflecting, observing – is often made difficult to nearly-impossible when you have dementia. Does this mean that this is a population that we should not include in PAR studies? Dementia and dementia care is a setting which seems ripe for PAR-type research – however, if we look at the literature we see that any such research that has been undertaken here has been undertaken primarily with caregivers and nursing staff (Holter & Schwartz-Barcott; 1993, Chenoweth & Kilstoff, 1998; Heslop & Parker, 2003).

If PAR should include all possible stakeholders, it should involve those with dementia as well. To do this requires being open to the types of participation that different types of people may use. In later chapters I describe making a move towards a form of observational research that is influenced and changed by the wishes of participants and the care settings I worked within. At times I describe this as PAR, or influenced by PAR methodologies – this is a retrospective label applied to the work and describes how the method unfolded rather than how it was planned. It should be noted that it is not conventional PAR, but instead aspires

towards a future way of doing research with people with dementia that may be considered truly participatory.

PAR and participatory approaches in HCI

In terms of the notion of participation in HCI, the Scandinavian participatory design (PD) approach has of course been influential. Writing about PD in the late 1990s, Asaro suggested that PD can be a model for the critical practice of designing new technologies rather than merely the insertion of public dialogue into technology design, and that comparing different design approaches which involve the user in design *'... invite[s] contrasts: in who the "user" is, in what part of "design" the user becomes involved in, in what goal "participation" is hoped to achieve, and in what the crucial aspects of that participation are.*'

PD is inherently political, and has been from its roots in the 1960s and 1970s which consisted of studies in workplaces where workers were becoming disenfranchised through the use of new technologies. The first PD study – 1981's UTOPIA project – was formulated to oppose the '*technological dehumanization of work through deskilling ... [which] was an inevitable result of the introduction of new technologies which necessarily served the interests of management and owners'* (Haslam, 2006, p. 3). One of the major contributions of UTOPIA was its work in breaking down the barriers in communication between different 'experts' who shared in these design processes.

How do PD researchers configure participation? Clement & Van den Besselar (1993) review PD literature up to that point, and pinpoint 5 requirements for participation: 1) access to relevant information, 2) the possibility for taking an independent position on the problems, 3) participation in decision-making, 4) the availability of appropriate PD methods and 5) room for alternative technical or organisational arrangements. In 2015, Halskov and Hansen review the history of the Participatory Design Conference from 2002 through 2012, and indicate that participation is either undefined in these studies, or else configured as a general concern with

users' points of view, an engaging within an opportunity space, or else a process of mutual learning. In a paper exploring the methodological underpinnings of PD and how accountability and rigour function within these projects, Frauenberger, Good, Fitzpatrick & Iversen write that "*instead of seeing the practitioner as an objective observer who inquires about an absolute reality and the best possible solution, PD sees knowledge generation as a dialogic process that is mediated by values and strongly situated*" (p. 94). Scandinavian participatory design, relying as it does on the dialogic engagement of researcher and participant in a shared process of knowledge creation, can be 'messy' but is rarely applied in emotionally-compromised situations where power imbalances are due to, for instance, physical or mental disability or ill-health, or due to participants' experiences of domestic violence and a need to hide (e.g., Clarke et al, 2013). These 'carnal' situations (Wacquant, 2005) are rarely addressed by participatory design.

In Halskov's & Hansen's articulation of the field, one of their stated contributions is a description of "how PD unfolds through a series of design events, strung together by decisions, interpretation, and planning" (p. 87). It is clear, the authors note, that there is considerable diversity in how participation is configured within these studies. For them, PD is about 1) **politics** ("people who are affected by a decision should have an opportunity to influence it", 2) **people** ("people play critical roles in design by being experts in their own lives"), 3) **context** ("the use situation is the fundamental starting point for the design process", 4) **methods** ("methods are means for users to gain influence in design processes", and 5) **product** "the goal of participation is to design alternatives, improving quality of life").

Experience-centred design

Is this complex but occasionally instrumental approach to design – focused on timelines, design events, and products – appropriate for working with people with dementia? While some of the fundamental tenets of participatory design are important in dementia contexts –

people should have the opportunity to influence the technologies which affect their lives; people are experts in their own experience – some of the others are both less interesting and potentially less fruitful for people with dementia. Despite its stated focus on people, PD seems to be much more about the process. Is there room for relationships, emotions, and experience in PD?

Experience-centred design (ECD - McCarthy & Wright, 2004, 2015; Wright & McCarthy, 2010) posits that interpreting the relationships between people and technology in terms felt life and emotional quality of action and interaction is a potentially rich way to understand the socially embedded nature of design processes and objects. The approach proceeds from social-practice accounts of interactive technologies that can understate the felt life in their accounts of experience (Suchman, 1987; Lave & Wenger, 1991). Instead, the approach is pragmatic and sees knowledge as participative. Any knowledge we have, the authors write (2004) is dependent on the technologies, circumstances, situations and actions from which it was originally constructed. It is this strong approach to experience and the participative nature of knowledge construction that makes the approach a highly suitable one to pair with approaches such as ethnography and PAR.

ECD is particularly influenced by the philosophy of John Dewey and Mikhail Bakhtin. For Dewey, experience is constituted by the relationship between self and object, where the self is already always engaged and contextualized; this is echoed by Bakhtin, who holds that the unity of felt experience and the meaning we make of it is accomplished dialogically in a tension between self and other. Dewey holds that action is situated and creative, and that in this action there are no separation of means and ends – rather, people create goals and the means to achieve these goals in the midst of their engagement with the world. Bakhtin emphasizes the emotional-volitional quality of this experience, and highlights the particularity of this experience.

ECD is future-oriented, and suggests that pragmatism is particularly valuable for understanding technology and design. For Dewey, scientific thinking is backward looking, and he sought to *change* rather than *represent*. Adopting a pragmatic viewpoint means asking, what can we offer toward enriching experiences? This is carried out even to the point of imagining what a rich experience of technology could be. This future-orientation of design is something which is agreed-upon by Gaver (2012) who argues against a positioning of the sorts of knowledge which come about through design projects as scientific knowledge and instead emphasizes the generative quality of this sort of work. The forward-motion of pragmatism and ECD is echoed in the seeking to create knowledge and effect mutual change within PAR-type research projects.

Aesthetic experience is an integral part of ECD, which sees activity as "*simultaneously sensual, emotional and intellectual*". Aesthetic experience is held up by the authors as paradigmatic of the potential richness of all experience because it integrates all the elements of ordinary experience in a zestful and holistic way. In aesthetic experiences, meaning and movement, and the integration of means and ends, is emotionally satisfying and fulfilling for those experiencing it. For Dewey, who drew comparisons between different kinds of aesthetic experiences with artwork, the aesthetic qualities of loving relationships (part of everyday experience) in which one person values the other as a separate centre of value is also a form of aesthetic experience. These are all moments and activities in which we are fully immersed and engaged in the present experience, and are activities filled with meaning and value - that are also often primarily sensuous.

McCarthy & Wright (2004) give an account of attending a jazz concert "full of sensual and emotional complexity" to illustrate an aesthetic experience – however, for the purposes of this chapter, I present an example from my own research memos. This experience took place

late in the research process, during a music session in a daycare setting for older adults and people with dementia:

> "*By now, dancing in these circles was so familiar. It was so easy for me to stand up and cross that wide circle and invite someone to dance. […] I was starting to feel free. It was actually more awkward to sit there and not ask someone to dance than it was to just get up and extend a hand. A few people would refuse, but that's OK. Someone would always say yes. Once we were all moving together, Nano the carer across from me, Barry, Joan, Gerry, Imelda and Breda, in a circle dancing to 'Rock Around the Clock', I felt myself letting go and drifting away. Usually I am looking around to see is Maud OK, is Barry having fun, do the RAs need anything from me, is the musician signalling for a glass of water, etc – but really I just felt like dancing and just wanted to dance. I was dancing like I would dance with my friends at a concert, in fact I thought back to dancing with Linda, James and Freida at the Pixies/Arcade Fire concert, head down, then up, catching friends' eyes, then down, feet shuffling, swaying, hand in hand and arm in arm. So far, this dancing has often been fun but it's never been this free.*"

For me, this moment was an important one – a realization that I was not only a researcher dancing as part of a research process, but instead a person who had made friends dancing with a group of others. I felt 'free'. Navigating the ethical responsibilities inherent to working with people with dementia and working hard to gain and maintain the trust of these people, their families, carers and care staff surrounding them – this all had been a difficult process, and there were many times where I entered care settings feeling nervous and worried and unable to let go *enough* to have this aesthetic experience. For me, this dancing was an aesthetic experience that was full of meaning – I was here, with others whom I knew and liked very much, who knew and liked me, and we trusted each other enough to get up and

hold hands and dance. Twigg configures touch similarly to the ways in which Dewey configures art as a language (as discussed in the previous chapter): "*touch has profound emotional significance. Preceding speech as a form of communication, it takes us back to our earliest experiences."* Looking back to those notes, it was a highly emotional moment, though I had been part of many sessions like this before and would be again. Again, Dewey notes that "*moments of fulfilment punctuate experience*"; my engagement and sense of 'losing myself' in this moment is described by McCarthy & Wright (2004) as "*absorption [being] a pivotal characteristic of an aesthetic experience – a breaking down of barriers between self and object, an outpouring of self into object.*" Experience-centred design gives us a language for these fulfilling moments as they stand both apart from, and as a part of, the temporal flow of our everyday experience. For me, this moment proved to be a benchmark as I engaged with residents and carers similarly engaging in aesthetic activities throughout the research process.

Seeing, self and sensuality

Mikhail Bakhtin's dialogical aesthetics focuses on the struggle to achieve the sense of fulfilment that can be seen as characterising Dewey's account of aesthetic experience. For Bakhtin, understanding or making sense of an experience occurs in the tension between self and other, and within this we only make sense of our selves in terms of history of selves and how we have related to others. People perceive from their own uniquely situated place and thus have a certain uniqueness of vision. In relational terms, this is called an excess of seeing, defined by the ability each of us has to see things that others don't.

Within Bakhtin's account of dialogicality are considerations on how these self-other experiences are very sensual in nature:

> *"As soon as the human being begins to experience himself from within, he at once meets with acts of recognition and love that come to him from outside. The child*

> *receives all initial determinations of himself and of his body from his mother's lips and from the lips of those who are close to him. It is from their lips, in the emotional-volitional nature tones of their love, that the child hears and begins to acknowledge his own proper name and the names of all the features pertaining to his body and to his inner states and experiences. The words of a loving human are the first and most authoritative words about him: they are the words that for the first time determine his personality from outside, the words that come to meet his indistinct inner sensation of himself, giving it a form and a name which, for the first time, he finds himself and becomes aware of himself as a something."* (Bakhtin, 1990, pp. 49-50).

This sensuality is highlighted by McCarthy & Wright as one of the threads of experience (along with emotional, compositional and spatio-temporal threads), and connects as well with phenomenological accounts of self as extending into the environment. For instance, Merleau-Ponty's account of embodiment includes an emphasis on the primacy of perception, and of *'a body that can be itself only by going beyond itself',* that is not just *'a unified group of organs that then confront the things around them … [but rather] an integral part of the subject-object dialogue'* (p. 4). The work of Pia Kontos uses the sensuality of Merleau-Ponty's embodiment to describe the phenomenological construction and performance of self by people living with dementia in care settings. The embodied communication of her participants echoes Bakhtin's descriptions of knowing and expressing oneself in the context of others, and although Bakhtin speaks of words (his work is most usually invoked to discuss novelistic discourse), for Kontos, this knowing does not have to come about verbally – it can come about through bodies:

> *When observing the residents of Chai Village – such as when Dora held Bertha's hand and sang her a lullaby to comfort her, when Florence would peel for herself a boiled egg at breakfast, when Molly would reach behind her neck to pull from*

> *beneath her bib a string of pearls she wore so that they could be seen, or when Sam clapped his hands and tapped his feet in excitement as music would play – they would intend a certain outcome by their actions and the enabling actions were spontaneously distributed amongst the appropriate parts of their bodies. 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.* (Kontos, 2005, p. 261.)

In interpreting Bakhtin, McCarthy & Wright write that self is constituted not only in words but in tones, lips, and responsivity. They emphasise Bakhtin's attention to embodiment (i.e., lips) and the 'enfleshment of experience', where the physicality of bodies in a space sees dialogue occurring between bounded entities.

The value of creativity in designing with people with dementia

McCarthy and Wright proceed from Dewey, and position creative action as always embedded in human-situated freedom, where we "*make something out of what is given, construe and respond to the situations that one inevitably meets*" (p. 68). They give the example of children playing, where there are no means and ends, and problems are overcome by imagination. In describing how action is both the means and the ends within creative situations, they describe what it is like to experience paint (as a material), which can be both useful and enjoyable. These two are experienced together in qualitative immediacy.

In the previous chapter, I discussed how working with creative methods for people with dementia can be fruitful in allowing expression and communication. This is a position (and a body of research) also espoused by Claire Craig and John Killick, whom we also visited briefly in the previous chapter. The value of creative methods for people with dementia, they write, is multiple. They offer thoughts on what it means to be creative in a dementia context:

creative activities must give pleasure; must be pursued and enjoyed for their own sake, and involve a making process. It may be an appropriation of raw materials – paper and paint into a portrait, flour and eggs into a loaf of bread – but the process must be pursued for its own end but also result in a something. Another vital characteristic of creativity in dementia is that it is expressive. This is something that has been acknowledged by academic research in dementia across the board – in a 2012 systematic review, Palmiero, Di Giacomo & Passafiume conclude that creativity allows persons with dementia to express emotions and wellbeing, and state '*in the setting of dementia, creativity can be seen as an outing of the most internal states that cannot be differently expressed*.' Beyond this, creative activities are often sublimated into therapies that have been indicated to reduce stress and agitation in dementia (Mimica & Kalini, 2011).

Even as dementia progresses and the ability to recognise familiar objects and faces is reduced, engaging in familiar activities and hobbies may help both improve the quality of life for persons with dementia and help to remind and bring to the surfaces skills (such as needlepoint) which have a strong physical and repetitive basis. These activities may orient the person with dementia to space and time (Yatczak, 2011), as well as provide a sense of meaning in life and an increased sense of usefulness (Wang, Karp, Winblad & Fratiglioni, 2002).

In the next chapter, concepts of group and emergent creativity will be brought to bear on an analytic ethnographic account of life in a dementia care unit; as a prelude to that, it is useful to review some of Sawyer's characterisations of creativity as emerging from group improvisation. Like Killick & Craig, he emphasises creativity as constituting the process rather than any final object – he points to intersections of the work of Dewey and Collingwood, whom he quotes:

> *"The painted picture is not the work of art ... [however,] its production is somehow necessarily connected with the aesthetic activity, that is, with the creation of the imaginative experience which is the work of art" (Collingwood, 1938, p. 305).*

As we describe before, this aesthetic inquiry is connected as well to *problem-finding* rather than *problem-solving*, and Sawyer acknowledges the likening of creativity to everyday language use (though this language is not necessarily verbal). He also emphasises the role of the audience in collaboration, and in discussing the 'role of ready-mades', he writes that '*most jazz musicians can't imagine the possibility of never playing a phrase or motif that had ever been played before—that's not the way jazz works. Jazz is heavily motif-based, but that does not diminish the creativity of the performers*' (p. 116) and that '*even the most overused verbal clichés can require creativity in use*' (p. 117). We will return to the 'role of ready-mades' in the next few chapters, which describe people with dementia as performing familiar songs – although not penned by them, their 'creativity in use' bears some exploration.

In the previous chapter, we briefly discussed some studies that necessitated or encouraged the creative participation of people with dementia. These are studies such as Favilla & Pedella's (2013) and Alm et al's (2002) which have mainly focused on the designing of touchscreen systems for people with dementia to create, and participate in the creation of, music. These studies are few and far between, given the potential that technology can offers for engagement in meaningful experiences. Returning to McCarthy & Wright (2004), when we design for and with people with dementia, we should try to see potential in everything – which probably means spending time with people with dementia in order to gauge the communicative potential in different modes of creative participation which our participants may use.

Revisiting research questions

Before I describe in a more applied way the ways in which I applied ethnographic and participatory action research methodologies to experience-centred design research, it is worthwhile to revisit some of my research questions to query in what ways I expect them to be answered by the chosen methodologies.

Revisiting research questions and planning methodological approaches

Research aims	**Methodological approach**
To identify ways in which people with dementia living in care can participate in group activities and in community settings, with a view to understanding how this participation can become a part of meaningful communication and involvement in research.	Ethnographic exploration of the experiences of living with dementia in a long-stay dementia care unit with particular reference to group activities and experiences with creative processes.
To explore ways of being together and community for people with dementia living in care, with particular attention paid to the ways in which technologies can/could mediate this being together.	Targeted inquiry following the consolidation of above research aim regarding the place of everyday technologies in the care unit; exploration of small-scale design experiments and making/crafting workshops.
Research questions	**Methodological approach**
What does it mean to participate in a group activity when you have a diagnosis of dementia?	Adoption of participant-observer stance within above-mentioned group activities *with* residents with a diagnosis of dementia; data collection: informal conversational data and targeted field notes.
To what degree can this participation be considered as co-authorship (of research, of designed technologies, of the experience that the person might be living)?	Critical analysis of above data with reference to a) critical perspectives on experience [McCarthy & Wright] and b) extant design perspectives [e.g., Scandinavian PD approaches]
How can embodiment, making processes, and 'doing together' be configured in dementia to facilitate communication between participants with dementia and researchers?	Collection of reflexive data concerning my own phenomenological engagement within the care unit – within everyday life as well as in creative sessions; close observation of participants with dementia with regard to their bodily experiences and expressions
How can any prototypes developed be used and evaluated to support community practices within groups of people with dementia living in care?	Deployment of low-tech prototypes within care unit; careful qualitative evaluation analysed in reference to extant accounts of community participation; post-study interviews with care professionals and co-

	researchers

Table 3: research questions and planned methodological approaches

Much of the knowledge generated by the thesis is emergent through my own engagement with different communities of care in the south of Ireland; in this way, we will revisit these research questions throughout the thesis. In the next section, I will describe in practical terms my approach to ethics, data collection, and data analysis.

Method

Ethics, informed consent and the practicalities of involving people with dementia in qualitative research

Most research in the social sciences pertaining to people with dementia tends to be quantitative and interventional. Within these studies, it is typically the behaviour of people with dementia that is measured in order to see if there is a reduction or other change in the symptoms of the condition. When this behaviour is measured, it is typically measured by proxies (Albert et al, 1996; Hoe, Hancock, Livingston, & Orrell 2006) - family carers are interviewed or nursing staff are asked to retrospectively report on their perceptions of patients' moods and activities. This is something that is necessitated by research that is carried out within positivist paradigms and which necessitate clear and reliably-given responses to closed-question instruments – however, when it comes to carrying out creative and design work with people with dementia, closeness to the people who are actually experiencing dementia and a level of interpretation is needed that calls for qualitative approaches. This can be problematic, given that the sort of ethical approval that social scientists seek when working within medical and care domains can be scrutinised with the same eyes that judge the ethical value of RCTs and interventionist studies which seek to change something physical or pharmacological about the person themselves (Bell & Elliot, 2014).

We need to include people with dementia in qualitative research if we want to improve care and design from the ground-up. However, the process of including people with dementia in qualitative research is not signposted clearly in extant literature. Dewing (2009) criticises the lack of discussion on how to include people with dementia in qualitative research in a way which is meaningful for them, which does not exclude them on the basis of a diagnosis of dementia (or on the basis of their stage of dementia) but that is also mindful of their values, the sorts of futures that they might want, and is sensitive to how this may change during the course of the research project. She points to the 'exclusionary ethics' of working solely with proxies during the consent-seeking process: *"little attention is given to the subjective and experiential realities of persons with dementia in the here and now. Consequently, the person with dementia is both invisible and lacking a here-and-now voice within consent"* (p. 157).

Dewing suggests an approach to seeking and maintaining consent in working with people with dementia that is relational – where we work out issues of consent within relationships by engaging with people at communication levels at which they are comfortable. What Dewing is proposing here is a dialogical ethics; an ethics that is based on inclusion means developing an ethics of personhood in dialogue with caring others. Dewing emphasises the importance of looking for bodily cues when seeking consent from people with dementia, and gives the following excerpt from fieldwork as an example of how this process might look:

> *Researcher: May I talk with you please?*
>
> *Participant: Talk to me! . . . [turns towards R and looks to empty seat next to her, smiles, body language looks relaxed] what about?*
>
> *R: I am working on research about this place [pause for assimilation to assess reception] and what people like yourself feel about it. [pause] [P nods and smiles slightly] I feel you could help me with this – if you would choose to.*
>
> *P: I am sure I could – do you think I can't? [R still standing beside P]*
>
> *R: I feel you* ***could*** *help me with this . . . may I sit down with you?*
>
> *P: Sit down here [indicates chair next to her, leans over]. I will tell you anything you want to know – but it will be the truth. Only the truth! Mind you it will be the truth. I won't mean to*

> *hurt you but only the truth from me is what you'll get. [leans closer, covers my hand with hers and squeezes tightly]* (p. 166-167)

McKeown, Clarke, Ingleton & Ripper (2010) discuss the benefit of utilising a process consent framework for working with people with dementia, and cite the Mental Capacity Act (MCA; 2005) as a basis for establishing capacity for consent, rather than simply excluding people with dementia from the consent process based on their diagnosis of dementia. They argue that a once-off gaining of consent is not adequate when working with people with dementia, and instead argue that when we work with these populations, a continuous process of 'checking in' and actively monitoring consent is necessitated, which echoes Dewing's call for a relational approach to working with people with dementia in qualitative research. Moreover, this relational approach is extended to considerations of what researchers should do when these research relationships come to an end – especially given that the relationship may have been enjoyable or personally significant for the person with dementia. They authors advocate sincerity and honesty on the behalf of the researcher, with the suggestion also that the 'end' of the research relationship be marked with a celebratory event to clearly mark the 'lines'. They also suggest that participants be given a clear way to contact the researcher in a way which makes sense to them – i.e., being provided with a stamped and addressed envelope, or a landline number – if questions do arise after the process.

Beyond all of this are larger questions which govern the disciplines we work within. My research was carried out in an Applied Psychology department, and thus I was governed by the Psychological Society of Ireland's guidelines given seeking proxy consent for anyone whose capacity was deemed to be under threat. In this way, I provided the care settings in which I worked with a) consent forms to be used with participants, b) proxy consent forms to be sent to families and appointed caregivers, and c) information packs aimed both at participants with dementia and families who had larger questions surrounding what it meant to be involved in the research process – examples of these are available in the appendices of

this thesis. I began almost every session in each care setting with an announcement regarding the purposes of our visit to the setting, and 'visited' one-on-one with participants to ensure they understood the reasons for our being in the care setting. For most of my consent-monitoring process, my conversations regarding this with participants looked very much like the one cited from Dewing, above. I also checked in with nursing, care and managerial staff repeatedly in order to ensure they understood our purposes of being within the care setting as well as understood the research process more generally.

Data collection and data analysis

These studies compiled as part of this thesis first utilized an ethnographic approach in order to gain an 'insider's view' into life in care for people with dementia. In two of the care settings later visited, this ethnographic approach naturally progressed into a PAR-type approach as members of staff and participants themselves came forward with research questions and challenges they face that they thought may be interesting or fruitful to explore together.

As each ethnographic field study progressed, we commenced carrying out a number of music workshops alongside observation of daily life in the unit (described in more detail in the next two chapters). For a number of these workshops, I was accompanied between 2-4 research assistants – all of whom were junior researchers working on their own projects within the setting as part of final year research projects or first year data collection. My primary data collection method consisted of field notes, which I took briefly on-site before writing these up as field texts during the evening following. The below examples show the progression from quick field notes (taken after a conversation with a client of a daycare for older adults who was physically disabled but had no cognitive problems) to a field text:

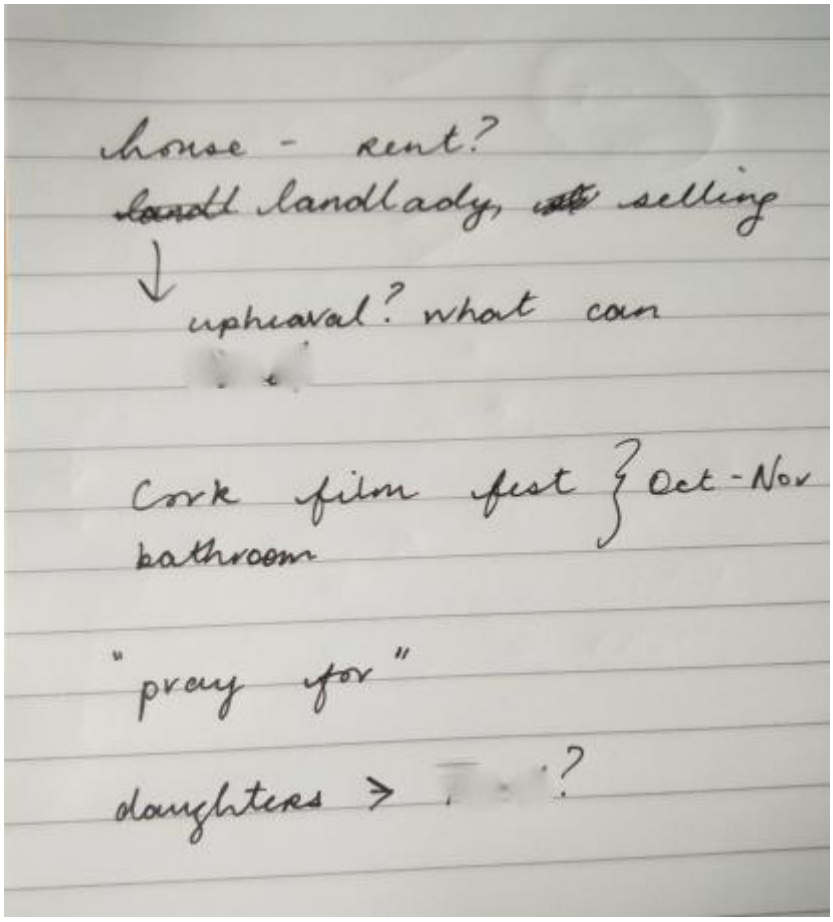
house - rent?
~~landl~~ landlady, ~~at~~ selling
↓
upheaval? what can
Cork film fest } Oct - Nov
bathroom
"pray for"
daughters >

Image 1: field notes taken briefly on-site

[Micheál] described a life of terrible loneliness. His grand house was rented out for €850 a month, which provided him with enough money to rent out a wheelchair accessible apartment near the university, but his landlady has spoken recently about selling the apartment. He is very anxious about this – it would mean a great deal of upheaval for him. Something which I did know about him before this conversation was his love of film, seeing as he was always interrupting music sessions which featured songs from cinema with anecdotes about the films themselves – for instance, Moon River, Audrey Hepburn and Mancini – but now he cannot go to cinemas anymore as the Gate Cinema requires him to have a chaperone to bring him to the bathroom. He told me about a friend of his – Perchik – an Eastern-European man whom he'd met on a bus trip, who spends about a day a week with him and occasionally brings him to the cinema. This relationship with Perchik and his relationship with his two daughters seemed to bring some solace to him, but as we ended the conversation he reached out suddenly to embrace me against him. When he withdrew I saw that tears were falling down his face.

'Pray for me, Kellie,' he said. 'I do want to walk again.'

Although the primary data analysed in this thesis were these field texts, in addition to these, conversational data was recorded via note-taking on-site, and interviews were carried out with musicians, research assistants and care staff in order to gain a multi-vocal account of the process. The data collection was restricted to observations and field notes given the sensitive nature of the contexts – in general, photography by us was not allowed (though many pictures were taken of us as ways for the care setting to document activities and community – see below image), video recording was not allowed, and audio recording was restricted to gaining verbal consent from participants to engage in the research process.

Image 2: some of the research team in a photo taken and later shared on social media by carers at Clermont Place

Reflexivity in data collection

Given my embeddedness in the ethnographic context, reflexivity was highly important for me from the beginning of the research process. Given that the data within this thesis was analysed using a Grounded Theory method after Charmaz, her description of research reflexivity is important here – for her, reflexivity elucidates "*the researchers' experience, decisions and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researchers' interests, positions and assumptions influenced inquiry*" (2006, p. 188–189). My personal reaction to my participants' situations and the interactions and relationships we slowly came to share together are an important part

of the field notes which make up the texts themselves (for instance, the notes above which reflect how dancing with participants became an aesthetic and emotional experience for me); however, I have tried to temper this by keeping a reflective journal throughout the research process as well as adhering to Charmaz's recommendations re: memoing in the coding and analysis process. These memos are most usually about the process of coding itself, but occasionally hinge on my own reflexive processes in making sense of my own experience.

The research process has occasionally been a very emotional one – beyond the stresses of carrying out a PhD, to carry it out with people who are facing intense challenges and often struggle to comprehend these challenges at the end of their lives, in strange places and surrounded by strangers has been at times very difficult. At many points I have been confronted by the deaths of participants, or the sudden moves into a different care facility – at this point, having tracked their contingencies throughout our building relationship, participants can simply disappear from my field notes. Although it has been difficult to confront the death of participants, witnessing the decline of one participant – Charlie, whose story is detailed in depth in the following chapters – as well as the moments where his life is enriched by music and company, has been intensely emotional. As I moved on in my research process, Micheál (whose story is told in part above) has affected me in similar ways. The following is an excerpt from my reflective journal:

> "*I have not stopped thinking about Micheál since earlier this week. I love films too – and going to film festivals – could I bring him? Could I be his chaperone? But I can't bring him to the bathroom. And do I have the time? Would I be able to make this commitment or would I be just another disappointment in his life? I want to help him, seeing as what he seems to really want is company and maybe an outlet for his frustrations and maybe someone who shares some of his interests. But is it within my ethics? He doesn't have a diagnosis of dementia – but you can't say that our relationship is exactly power-balanced either. It is just*

> *like Charlie all over again. I used to think about Charlie all day once I left St. Eithne's. That night I thought of Micheál getting into bed alone, unable to get past the long-term fact of his disability, "leaving the door open" to what was obviously a mutually unsatisfactory relationship* [his relationship with his apparently abusive ex-wife]."

Although these reflective texts were not expressly analysed in the same way that the field texts were, they are occasionally included within write-ups of the analysis in the thesis as we go through in order to acknowledge the specificity of my own perspective as well as how these emotional experiences and often-difficult relationships coloured my ethnographic process as well as my analysis of many of the interactions featured within.

Grounded Theory analysis

As mentioned above, field texts were organized and analysed using Grounded Theory (GT; Charmaz, 2014). Grounded theory is a systematic method of analysing and collecting data which begins with inductive inquiry (though Charmaz characterises the method as 'abductive inquiry' as a whole). GT 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. The emphasis in grounded theory is on analysis of data; however, early data analysis informs data collection, and in this way, my workshops and design were driven by successive field texts' analysis from week-to-week.

Grounded Theory is often characterised as a method for studying processes (Charmaz, 2009), making it a sensible choice for my 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. My 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, I 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 my 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 these primary stages, Grounded Theory allowed us to expand my analytic focus beyond the singly-authored (but multivocal) field texts by promoting the asking of analytic questions from the beginning. Charmaz suggests that such questioning involves asking the following: What is this data a study of?; what do the data suggest? Pronounce? Assume?; from whose point of view?; and when, how, and with what consequences are participants acting?.

Finally, as I drew near to the end of the research, my categories were finalised with the help of theoretical sampling. Theoretical sampling is a method which involves the gathering of data to fill out the properties of a tentative category. The researcher is instructed to keep gathering data until no new properties of this category emerges (Thornberg & Charmaz, 2011), which ensures saturation of the properties of categories themselves, rather than the data itself. Although I, like most qualitative researchers who use GT as a method, did not use the method to construct a theory, my analysis resulted in a set of robust categories which helped to provide rich answers to our research objectives at each point of the process.

It is worth noting that Grounded Theory was used as an analytic method throughout the thesis, in both major field studies – although the results of the analysis are presented at length in chapters 4 and 6, I will not revisit Grounded Theory as a method during these chapters – however, I have included extra information concerning using NVivo to carry out GT in my appendices.

Settings

Three care settings were visited during the course of this thesis, and each one will be described in more detail during the chapters which deal with the research within – however, below is a brief description of each setting. At this point, it is important to note that all settings and all participants have been anonymised in line with the School of Applied Psychology's ethical guidelines. This is the case for the entirety of the thesis, from beginning to end.

Image 3: St Eithne's, Rosebank Nursing Home and Clermont Place

St Eithne's

St Eithne's is a publicly-funded long-stay care unit in a rural town in the south of Ireland. Music sessions in this unit were carried out on an opportunistic basis depending on the wishes of residents during particular days, and involved all of the ten residents (all of whom had a diagnosis of dementia) as well as up to three day-care residents, at any time. Fieldwork in St Eithne's was carried out for 18 months, with weekly to biweekly visits. St Eithne's is the first setting visited in the thesis.

Rosebank Nursing Home (RNH)

RNH (engagement with RNH begins in chapter 5) is a private nursing home in a suburb of a small city in the south of Ireland. It is large, with four floors and 100+ residents. Music sessions within RNH were carried out on a bimonthly basis for four months, and involved residents on three floors (approximately 70 in all; about 30 residents would engage from

session to session). Participants were chosen based on their professed interest in joining the sessions, or on care staff's/family's knowledge of their interest in music. Not all residents have received a diagnosis of dementia: those who have were identified prior to the sessions by care staff so that field notes could focus on interactions with these participants. Sessions in Rosebank Nursing Home were carried out for four months.

Clermont Place (CP)

CP (engagement with CP begins in chapter 5) is an assisted living facility which also has an expansive day care facility. Both people who have gotten a diagnosis of dementia and those who have not attend CP, and again clients with a diagnosis were identified by care staff prior to sessions beginning in the care home. Music sessions were carried out on a bimonthly basis in CP and involved anywhere between 20-33 clients. Sessions in CP were carried out over a period of nine months.

Negotiating access and deciding on research questions together: the move to PAR

Gaining access to care institutions can be difficult, and can require significant negotiation on the part of the researcher. In each of the above settings, I approached people in managerial or Head Nurse positions in order to inquire about the possibility of carrying out observational research and creative sessions with people with dementia in each place.

For the first setting, St Eithne's, this negotiation was made a little easier by having a family member know Eleanor, the head nurse on the unit. My aunt knew Eleanor as a customer in her shop, and, knowing I was looking for somewhere to conduct some research/observations, asked her if I could call her. When I called her a day or two earlier she'd been very accommodating, though she quizzed me a little bit on the phone. Eventually, she asked me to call in that Friday to St. Eithne's, which, she explained, was home to ten residents aged from their late 60s to their 80s (with two early onset cases at 43 and 52). Most of the residents were long-term care residents, though some residents joined the unit just for some day care.

Eleanor talked a lot through this meeting, describing the various types of dementias, occasionally pausing to check that I had some grounding in the medical aspects of dementia. She asked me what the ultimate aims of the research was about but we didn't spend much time talking about it. When Cathy (vice administrator of the hospital) came along to meet me and check out my documentation, she told her that my work is about 'making gadgets' for people with dementia. We decided on my coming in two days a week, 10-4 for 10 weeks or so to begin and Eleanor invited me to have a look around the ward before I left.

In Rosebank and Clermont Place, negotiation was carried out at the highest levels initially – I contacted the directors of both nursing homes to inquire about the possibility of carrying out research there. At this point, I had spent quite a long time in St Eithne's and was more sure about what my own research was about as well as the complexities of navigating life in care homes as a researcher. As the focus was now more explicitly on creative activities – particularly music – I worked with the Activities Team in both care centres. For Clermont Place, I was invited to call in prior to the workshops beginning to talk through the research so far as well as the aims for the future, and gave this presentation to the CEO, the nursing and care staff as well as the activities team. Early on in this process I was honest with the team as to the interest I had in carrying out research which was not only interesting and useful for me, but which could deliver something tangible for them as well. We settled on my giving presentations to the staff at regular intervals, updating them on the research as it went along, as well as delivering a set of collected materials and guides to running music sessions by the end of my time there.

The team at Clermont Place were particularly engaged in developing and improving their care practice, and were also heavily involved in the actual running of the music sessions I came to carry out in the centre. We came to value each other as experts in our respective

domains, and the relationship I carved out with Glenda – the head of the activities team at CP – stands out for me as an incredibly valuable professional relationship:

> *For the first time I feel I have such an open and equal relationship with a care staff member, and it's with Glenda […] Glenda and I truly talk like we are collaborating on something – not like she's just "letting me loose" on a group of clients. She really wants this relationship to continue – and I'm not naïve, I know that at least part of it is because I provide a free hour of activities – but we are learning things together. Things are coming out of this. It really does feel like a process of making.* (from field notes, March 2016)

Our time, spent together with participants in these music sessions, inevitably led to questions. These questions could be as simple as 'what if we tried a more fast-paced song now?' or 'let's try to bring in a new piece of fabric next week' to questions of how do we form connections with non-verbal or physically disabled participants who cannot rise from their chairs to dance. In this way, the iterative cycle of PAR became a reality from week to week for me in CP – every set of field notes ended with a new question, crafted with Glenda or with participants themselves – and a process of learning. This process is described in more detail in chapters 5 and 6.

Summary

This chapter has described the methodological underpinnings of this thesis, ranging from ethnography to participatory action research; both inflected with an experience-centred design approach that draws from Bakhtin and Dewey. I have also briefly described the ways in which I approached creativity as a method of communication for participants with dementia within this study. This chapter has also described the complexities of working with people with dementia in qualitative research and the ways in which we can ensure consent in a way which reflects respect in their own personhood. Finally, I have described the methods

undertaken with respect to this project – from negotiating access to the settings, data collection, and analysis. In the next chapter, I describe my first ethnographic engagement in care settings – St Eithne's.

The next chapter describes the ethnographic work undertaken in St Eithne's. In particular, it highlights the creative potential inherent in the everyday experiences of people with dementia living in care and (in tandem with the following chapter), describes how these experiences may begin to constitute a design space.

Chapter 4: Ethnography

'Every institution captures something of the time and interest of its members and provides something of a world for them; in brief, every institution has encompassing tendencies.' **Erving Goffman, Asylums**

Introduction

The main building of Tobermore Hospital dates back to the 1840s and the Irish Famine, where it was a workhouse for families who could not pay their rent; a long corridor inside the main building traces its history in Ogham-stone like etchings along the walls, marking out notable points in its almost 200-year history in the area. The hospital is governed by the Health Service Executive (HSE). The total capacity of the hospital is for 132 residents, and the hospital itself provides a variety of care services, mostly to elderly patients in the area – long-term care, rehabilitation, respite, convalescence, palliative and dementia-specific services. All services are provided via six different ground-floor units, their names reflecting the religious background of the hospital and most of its residents: Assiscus' Unit, Brendan's Unit, Holy Trinity Unit, Mochta's Unit, and, the setting of this ethnography, Eithne's Unit.

Only Eithne's Unit is a dementia-specific long-stay unit. Across Ireland, a large proportion of people with dementia live in these long-stay units (Cahill, O'Shea & Pierce, 2012):

> *There are currently about 14,000 people with dementia living in residential long-stay settings across Ireland, a figure which is considerably larger than the figure of 5,880 estimated using official government long-stay activity statistics. This means that about two-thirds of all people in long-stay care have a dementia. Our research suggests that most of these people are living in generic settings, sharing accommodation with other residents who do not have dementia.* (p. 124)

St Eithne's occupied an in-between space – a ward in a community hospital, the unit was segregated from the other units but open selectively to group activities involving other wards, and upon occasion, residents participated in games sessions with local groups catering to

young adults with intellectual disabilities and mental health issues. Though the unit was small, catering only to 10 people at a time, its situation in a hospital and its multi-bed dormitories meant that a sense of the space as institutional permeated certain times and activities. It is important to spend some time describing the unit itself, as well as the phenomenological sense of the space – this next section will expand on both.

Navigating Eithne's Unit

Eithne's unit is located at the very back of the grounds of Tobermore Community Hospital, and is accessed by a set of double doors locked with a keypad code. Once inside the doors (see image 4, below), a long corridor links to the now-defunct Brigid's Unit (occasionally utilised now for art sessions and games) and on the other side, to Eithne's Unit. On the way to Eithne's Unit, rooms to the right include a canteen for staff, a kitchen used for staff and residents' food, and a central closet unit with residents' clothes stored together, all accessible only by care staff.

Image 4: entering Eithne's Unit via the main entrance to the wing

The day room is the first room to be entered upon arrival, where dark-wood cabinets line the walls; their drawers are stuffed full with magazines and occasionally some of the residents' personal possessions. Religious artwork and sculptures hang on the walls and are displayed in

the cabinets. Hanging next to the window is a large whiteboard on which is written messages like the following:

TODAY IS WEDNESDAY

6TH JAN

IT IS A CLEAR, COLD DAY

Followed by:

TODAY FOR BREAKFAST PORRIDGE, TOAST AND ORANGE

LUNCH FISH FINGERS CHIPS AND MUSHY PEAS

DINNER CORNED BEEF CABBAGE BOILED POTATOES

These boards ostensibly help to orient residents to time and place, as well as giving a sense of their day to come, and are filled in by carers every morning. This was a low-tech solution for this problem of disorientation in the ward – many programmable orientation boards also exist, for use both in residents' homes and in institutions such as St Eithne's.

Towards the back of the day room is an entrance to the dormitories – three beds for men, and in an adjoining room, six beds for the women, plus an extra bed for respite residents. Each bed is a single bed, ringed around with a curtain rail. Dormitories open onto the central corridor of Eithne's Unit, a square corridor, with floor-to-ceiling plate glass windows, encircling an open space in its middle. The main garden, on the other side of the corridor, allowed residents to see the paediatric unit of Tobermore Community Hospital running along the back of the grounds – a low, long red-brick building – and in the farther distance, Springfield, a housing estate. In the garden, low work benches hold some small plants in terracotta pots.

On the other side of the corridor is the Sensory Room and the Nurses' Station on the way. These three rooms are nestled in a nook, with two comfortable armchairs placed between the bathroom and the Nurses' Station. A pinboard above these chairs displays artwork from residents made during creative sessions as well as a printed timetable of the activities the unit advertised for its residents. An art therapist is scheduled to call once a week, as are a pair of therapy dogs, but these schedules are not always reliable. The Sensory or Snoezelan Room is intended for light and sound therapy, and is fitted with a comfortable bed as well as a machine that made lights and waves dance on the walls of the darkened room. During my time in Eithne's Unit I only see the Snoezelan Room utilised for residents who are severely ill or dying – during this difficult time, when many residents become agitated and experience pain, the room gives residents and their family privacy that is lacking in the multi-bed dormitories.

The parlour is the largest room in Eithne's Unit, and is the space in which residents spend most of their time. Along one side of the wall, below the nurses' station, is a small, two-seater brown leather couch with a coffee table stationed just in front. Along the longest wall of the room, are an array of cushioned chairs with slightly sloping backs and wooden arm rests. These seats are desirable because of the view they offer of the television – a flat screen, mounted against the opposite wall above an electric mantelpiece. Running along the farthest wall is another long, low leather couch. Directly opposite is a small bookcase, typically full of books and magazines with full-colour pictures of laughing babies and fashion and celebrity magazines such as *OK!* and *Hello!*. There were also some books on types of horses and dogs – one resident in particular, Ros, had brought these along with her on her arrival into the unit, and these books bore her name on the inside pages. At the far end of the parlour was 'the nook', a small, enclosed area with large glass windows looking out onto the parlour and onto the lawn outside Eithne's Unit. This nook was intended for residents who wanted some

private time, and the nook was stocked with some books and DVDs/VHS tapes, though the only TV was in the parlour and the DVD player was inaccessible to residents. There was no VHS player.

These spaces were shared by nine residents each day, with three day residents calling during the hours of 10am and 6pm, and one respite resident whose stay lasted one to two weeks at a time and often acted as a prelude to their living in the unit full-time. In terms of staff in the unit, there was always a qualified nurse on duty in the unit, to whom the carers (of which there were usually 2-4) would report. In the evening, the staff would reduce to just two – an issue frequently brought up in HIQA (Health Information and Quality Authority) reports on the unit, and one which meant that residents could sometimes not get to the bathroom on time or were waiting for food in the evening.

In the following section, I will describe a typical day in the life of the unit through a composite of my field notes.

A day in the life of Eithne's Unit

Residents are roused each morning by carers at about 8am. They are helped to dress, carers drawing the floral curtains around their bed, helping them to stand up to pull on jumpers, dresses, stockings, trousers – all residents' own clothes taken from the communal closet in the corridor. The effect of this small wardrobe is that each resident has a 'uniform' of sorts – Aideen often wears a red jumper, Ros a certain pair of grey plaid trousers, Moa long, checked skirt – though they do not seem to choose or ask for particular clothes themselves. Jewellery and accessories are rare in the unit, though Mo often has a hairband pushed through her hair, and Aideen carries about with her a small, black leather handbag, which she fusses over. Bathing occurs throughout the day, as carers selectively approach and cajole residents to take a bath or a shower, with which they assist – this morning, Aideen is adamant that she will not be bathed. It is too much for her, and she dashes from the grasp of the carers and makes her

way out of the dorm. She is offended at their insistence that she bathe, but carers wince, saying to me, 'she hates bathing, but today she really needs to. It's been a week – she smells.'

Residents are dressed each morning by carers and throughout the week, they are bathed – at this, they suffer some embarrassment and can put up a fight, as Aideen does this morning. In her work on bodywork and bathing in particular, Twigg (2000) observes:

> *You may have meals made for you, clothes ironed and laid out, domestic life smoothed by wives or servants, but even the richest bath themselves and wipe their own bottoms. Only the very young or people who cannot manage are helped in these ways; and this is a powerful source of the infantilising tendency in carework. This social symbolism is difficult to resist; it is hard to maintain adulthood or dignity in the face of being fed with a spoon, having your pads changed or your face and body washed. The loss of bodily control whether over limbs or bowels threaten the return to a pre-adult status.* (p. 45)

For at least some of these residents, much older than the carers themselves, having to face this 'social nakedness' in the morning must be difficult and feel very much like a 'return to a pre-adult status.' For carers, it is part of a job and not much more than that – particularly in the busy morning, where after dressing, residents are led to the day room for breakfast. Micheál and the two Bens sit at the table by the window. Mo and Aideen, fast friends, sit beside one another. 'It's too early for breakfast,' scowls Aideen, still annoyed, eyeing the chrome trolley which is being wheeled into the unit by carers Deirdre and Georgina, who in doing so have to navigate the heavy door into the unit and the keypad which beeps loudly if the door is left open for too long. This trolley is shadowed by a second – a white plastic trolley on which is carried the medication for residents.

During breakfast, most of the noise and chatter in the room comes from the carers who dole out the breakfast – porridge, orange squash, and toast and tea – to each resident in turn. Some stare at the food for a while, seemingly lost in thought; others, like Aideen, complain about its taste or the speediness with which it is served. With some encouragement from the carers, however, everyone begins to eat, though today Micheál does not eat much of his porridge. This is noted in his care schedule by Billie, who looks worried for a moment before she begins to wheel around the medicine cart. Once Billie reaches each resident, she places their medication down and asks them to take it, which they do without question or without fuss.

Once people have finished, carers Georgina and Deirdre pile the plates back onto the chrome trolley and wheel it out once more, navigating the difficult door as they do so. Fionnuala, a large woman with short, curled white hair and large, thick-rimmed glasses, gets up from her chair and walks slowly and carefully, her hands on her hips to support her back, to the door to watch the two carers wheel the trolley away through the glass of its window. She reaches for the handle and begins to pull at it, banging the door against its frame as she does so. Other residents stare at her. As Cahill, O'Shea & Pierce (2012) note above, levels of dementia vary in long-stay settings, and for St Eithne's, this means people in the mid-stages of the condition live with those who are coming to the end. As residents come to the end, their behaviour can seem erratic, and trouble other residents. Veronica, a resident in for respite, scowls at Fionnuala and shouts 'shut up!'. Lizzie, the third carer on for the day, walks back into the room and sees Fionnuala's efforts at the door. She is at her side immediately.

'Come on now,' she says, steering Fionnuala away from the door. 'It's almost time for mass.'

Lizzie guides the residents along the brightly-painted corridor in through to the parlour, where the residents will spend much of their day. Some residents sit together – Aideen and Mo will never be more than a chair's distance apart from one another – while some have

chairs or spaces which they habitually inhabit; Veronica will always take one of the chairs directly in front of the television.

Mass is 'piped in' from a chapel on the grounds of the hospital, and it has started by the time we all sit down. Micheál takes a seat on the leather couch, his arm on the armrest, long legs folded in front of him. Most residents are looking at the television but no-one seems to be truly watching the mass unfold. The television is large, but the picture on the screen is fuzzy – the camera looks down at an angle at the priest at his altar. As the mass draws on, some residents echo the responses – 'thanks be to God,' 'praise to you Lord Jesus Christ,' and others make the sign of the cross at the appropriate time. The mass brings residents together in an activity, and although the responses they observe can seem learned by rote, coupled with the religious artefacts on the walls, seem to be part of an effort on the behalf of the staff to make St Eithne's a meaningful place to be:

> *Where memory is problematic, not least for guaranteeing continuity, being remembered by God (Goldsmith, 1999, p. 131) 'in the land of forgetfulness' (Psalm 88:12) is a statement not only of faith, but also one which opens up the possibilities for the location of memory. Rather than limited by definition, as a function of the individual, it is seen as that which resides in community, tradition, and place and so is not entirely dependent on any one individual's level of cognitive function.* (Woodward, 2006, p. 217)

This focus on religion is inextricably bound up in the culture of the town – a small, rural Irish town in the south of the country – and the social and cultural history of its residents, who grew up in parishes, attended mass multiple times a week, and attended schools which were ruled over by the Catholic Church. The hold of the church in Ireland is one that only recently began to lose its sway.

At just past 10am, some of the day residents arrive into the unit. About three of these people visit every day, and they are typically in earlier stages of dementia, living with family 'on the outside'. Ben, who is 49 and suffering from early-onset Alzheimer's, has taken a seat next to the dozing Betty. He sits up straight and seems to watch the mass – he gives the right responses, and when the responsorial psalm is sung, he sings along, quietly. There is a commotion in the hall that draws some of the residents' attention. Another day resident, Claire, has arrived into the unit, and is shrugging off the arm of her son-in-law.

'No,' she shouts. 'I'm not staying here!'

Nurse Billie approaches her, and tries to soothe her. After a minute or two, she has persuaded her to take off her coat, and Claire stalks into the parlour, where she sits down next to me and folds herself up, clearly unhappy. Billie walks across the room and holds out her hands to Claire. She gestures to me.

'Claire, this is Kellie. She's a research student who's here to meet you all today.'

I've met Claire before, but she doesn't remember. We say hello and she retreats back into herself. I pass some remarks for the duration of the mass, but she clearly doesn't want to engage in conversation, so I stop. Once or twice, she hums along with Ben who is still singing some of the hymns under his breath.

Once mass ends, there is a lull in which the television goes black. On a walk through the unit, Deirdre spies the blank screen and switches the channel to RTE 1, where a popular morning talk show is playing. She leaves and after a beat, Una, the resident who was difficult to rouse this morning, gets up to fiddle with the buttons on the television to turn it down.

'What are you doing?' hisses Aideen, before raising her voice and saying to no-one in particular, 'Tell her to stop!'

‘It’s too loud,’ Una protests, but she is abashed by Aideen’s outburst, and takes her seat again. There is another sound from the hall – a soft tinkling of bells; another visitor. This time, it is a woman from the chapel who is taking communion bread to the residents who do not visit the chapel in person. She is joined by Nurse Billie, and the two work their way along the row of chairs, Claire indicating who takes communion.

I get up to change the channel at Aideen’s behest. Billie comes over to talk to me. She asks me about my degree in psychology and as we chat, her eyes move to Micheál, just across from us, who has taken his communion wafer out of his mouth and placed it down on the arm of his chair. ‘Micheál!’ she admonishes. ‘You can’t do that! That’s holy!’ She picks the wafer up with a piece of tissue, frowning. Micheál looks suitably scolded.

Halfway through the morning, residents receive a cup of tea and are handed a biscuit. By now, even the sleepiest residents have begun to awaken. Beside me, Claire nibbles gingerly at her biscuit. She is a bit more amenable to conversation now, and will respond to my comments with interest but not with responses that tell me much about her. Later, one of the carers will tell me that Claire not only has poor short-term memory but also has little memory for her life in general. She knows she used to be a nurse, and that she used to live in Dublin. Beyond this, she cannot tell any more and her family is not very forthcoming. Carers tell me that her family will not even tell Claire about parts of her life of which they did not approve. I wonder what that must be like – to have your past guarded so closely that in effect it is not yours anymore.

Residents are watching a DVD now – Daniel O’Donnell. Most of the ladies in the unit are fans of the singer, and sit watching the show quite happily. The media in the unit is somewhat lacking – there are a few Daniel O’Donnell DVDS, some DVDs of traditional Irish music, some of musicals but that is that – about ten in all. We watch Daniel almost every day. I have

started to bring in DVDs of old musicals to help the collection each time I visit. Aideen now eschews the television entirely to read the latest edition of the local paper, which carer Lizzie has today brought in for her. She holds the paper open wide, frowning down at its headlines, before shifting in her seat slightly to allow Mo a better look in at the paper. Mo's eyesight is poor, however, and she cannot see the small type, so Aideen reads aloud to her.

Some residents begin to doze once more or else stare blankly at the television, but others engage fully. One of these residents is Fionnuala, and today she is in full swing. Recognised by carers as a resident who 'comes alive to music', she is seated in a chair that has been pulled close to the television, and is interacting with the wall-hung television as though she were at the concert itself. She sings along to Daniel's songs, waves at him as he winks into the camera, blows kisses, and applauds wildly at the end of every song. I sit next to her.

'He was at my house last year,' Fionnuala tells me.

'Really?' I ask.

'Yes, him and his wife,' she answers. 'She is lovely.'

She continues, telling me all about their relationship as though the three were old friends. Fionnuala's type of dementia was Korsakoff-type dementia, which is characterised by excessive confabulations – people with the dementia tend to 'lie' to cover up gaps in their memory or to retroactively explain experiences or feelings to themselves. She turned to me once more.

'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?'

Fionnuala already had an idea of our relationship in our head – one that I was not privy to. She believed she had told the doctor about my problem. If I answered 'incorrectly' here, it might throw our whole conversation off-kilter.

'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. It made me think about the ways in which my responses to her helped her to preserve a continuous sense of herself. I wondered who I was to her in those moments; how she was positioning me. We know that positioning the person with dementia as sharing 'a common humanity' (Sabat, 2006) with us is a more ethical and responsive way to work with the population, and Oppenheimer writes that:

> *Old age psychiatrists daily see patients who experience some threat to their autonomy, and a minority of our patients, at some point in their lives, can scarcely be said to make autonomous decisions at all. Yet we see that these patients, for all their impaired autonomy, play an immensely significant part in the lives of the people who are connected to them. They are participants in relationships that can be joyful and rewarding; or troublesome, full of pain and guilt; relationships deeply rooted in the past, or fresh encounters between a new carer and the person needing care. 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.* (Oppenheimer, 1999, p. 321)

This ability of the personhood of the person with dementia to persevere in social relationships is something which this chapter will detail more later; for now, however, it is worth reflecting

on my responses to Fionnuala as a ‘narrow escape’ – what if I had not been paying attention and replied incorrectly? What if I had ignored her comments altogether? Practice guidelines for care centres for people with dementia emphasise the importance of the environment allowing a ‘continuity of self’, but what happens when this continuity is broken?

It was almost one by the time that Lizzie called everyone in the day room for lunch. Aideen and Mo sit next to each other again, while Máire slides in next to them. Ros sits at a table with the two Toms and Micheál, while Mell, a late-arriving day resident, sits next to Charlie, who is having a little bit of trouble in his move into the unit, and for whom the company is welcome. Residents sometimes chat quietly during lunch, and today, Mell helps Charlie reach items on the table that are out of his grasp.

After lunch, residents are settled once more back into the day room. Daniel has been replaced by the Clancy Brothers. Music, I noted early on in my time in St Eithne’s, is important in the unit, as is familiarity of the music – residents don’t know as much Clancy Brothers as they do Daniel and thus the toe-tapping subsides a little. I sit down next to Marie, a well-coiffed lady, well-dressed and elegant. We have gotten on well during our time in Eithne’s Unit – she is a warm person, and greets me often with a hug, a kiss, and we spend time sitting together. Some of the things that she says to me indicates that she thinks I might be a family member. My answers to these statements are soothing but non-committal; like Fionnuala, our relationship runs along different but parallel tracks in both of our minds, and I don’t want to upset that, but neither can I fully immerse myself into this role of her daughter or sister.

After about ten minutes, the DVD ends, and I get up to switch it; passing by, Ros, the resident who seems to believes she is a carer herself, slaps the hand that I have reached out to open up the cabinet wherein the DVD player is housed. 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. Behind me, I hear the other residents sit up in their chairs and call for the nurse as they chat excitedly amongst themselves. Finally, Ros wrenches free and flees the room, wailing. Marie pauses for a moment before turning and walking to the nook. After some time, I follow her. She stands, looking out at the window, though 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. I go to the carers, who are tending to Jim in the day room, to report what had just happened.

Here we see conflicts in the continuity of self – we see how the experience of dementia can move from dreamlike to fractured when certain paths cross. Of course, the symptoms of dementia are at the root of these issues – problems with memory, confusion – but much of the agitation experienced in the above encounter can also be ascribed to living together. The tensions of living together in a communal environment are bound to lead to some spats like those of Marie’s and Ros’s – it can be difficult to belong to a space as in-between as a dementia care ward. McCarthy & Wright (2015) use the work of Elspeth Probyn to explain this sort of belonging in community. Probyn talks about a sort of social life that emerged in her Montreal neighbourhood:

> *In her area, as soon as spring arrived, balconies became the places where people spent most of their time at home. People lived on the outside for the summer in close proximity to neighbours yet also drawing new frontiers. There, Probyn would sometimes talk to her neighbours and at other times they all proceeded as if they were*

> *alone in private walled gardens, the boundary between conversation and privacy marked by what she thinks of as an inaudible rhythm of engaging with and tuning out. In this outside belonging, people learned to engage and to disengage, to participate in the social life of the community and to be invisible or hard of hearing when appropriate. Probyn's outside belonging finds ways to participate in community while respecting people's space, difference, and singularity, ignoring what is visible or audible for the greater good of the community.* (p. 95)

The ways in which these neighbours curated their communal experiences are difficult for people with dementia – for many of these people, whose realities intersect but are often 'dreamed up' due to their progressive dementia, there is no coherent sense of belonging to a community. They did not move of their own volition into a set of balconied apartments – they cannot, or will not, participate in these quite socially sophisticated ways to ensure a smooth experience for their neighbours. Can it be said that there is any sense of community in a dementia care unit? Or are they, as Reed-Danahay suggests, non-places?

> *... in key features* [nursing homes] *more closely resemble what Augé (1995) calls 'non-places', which are spaces of transience and movement. Augé contrasts 'place' and 'non-place' by suggesting that the latter is a product of supermodernity and the excesses of space, time, and 'self' that it promotes. Places of travel (airports, highways) are archetypes of the non-place for Augé, but other contexts such as supermarkets and hospitals also can be viewed in this way. The non-place is characterized by relative anonymity and 'are there to be passed through' (Augé, 1995: 104).* (Reed-Danahay, 2001, p. 50)

Whatever the structural and sensory affordances of the place, the fact that people live here, together, sometimes for significant periods at the end of their life, means that they form some

kind of erstwhile ‘community’ – one which is fractured, and is full of shifts and changes. At this point, it is too early to take up an entirely negative view of these living arrangements; we must look closer in the more intimate interactions between people to see what forms of intersubjective communication are going on here. We will return to this question later, where we will discuss the meaning of belonging in community.

At about 3pm, Rosie, the activities coordinator, arrives to run an art workshop. Billie tells me that I can accompany Rosie to the empty St Brigid’s Unit and help. She explains that only some of the residents enjoy art or are ‘up for activities’ more generally, and begins to pick these residents from their seats. ‘Veronica will go with you,’ she says, and along with Veronica comes Ben, Micheál, Marie, Claire, and Máire. In St Brigid’s, Rosie explains, we will make cards to send to our families and friends. On the table is an array of coloured card, some felt-tip pens, colouring pencils, and crayons. There is also a tall tube of PVA glue and a bag that is full of confetti, stickers, and glitter. At one end of the table there is a stack of old colouring books for children.

We set to work. Most of the residents needed to be coaxed or otherwise motivated to begin: without this, they simply sit, staring at their art materials or else look around to each other or chat quietly. Towards the end of the table, the card has run out, and Micheál has been set to work on the colouring pages. He is leafing through the book, trying to select something to draw and wrinkling his nose at the childish or ‘girly’, as he calls them, options. About twenty minutes into our session, Rosie asks if we would like to sing. There’s a moment of quiet before she herself begins to sing, launching into ‘Sally Gardens’:

Down by the Sally Gardens

My love and I did meet

She passed the Sally Gardens

With little, snow-like feet

At once, the residents engage much more with the song and the singing than they do with the bright array of art in front of them. Marie sings along, and so does Ben, their voices high and clear; next to me, Veronica hums along, looking into the faces of those around her, and grasps my hand tight. As the singing continues, with Rosie urging one resident, then another, to lead, the work surrounding the art begins to 'loosen' up and lose its self-consciousness – Micheál colours a page, engrossed in listening to the music; Marie turns to me to show her card. It's lovely, a pink card with purple flowers, green shading and her name written inside in her own shaky hand. She points to a flower we drew on the back.

'I want to do something with this,' she says.

I look towards the bag of sparkly stickers, and take out two joke 'googly' eyes, placing them on the flower to create a silly face. Marie dissolves into laughter, holding up the card first to me and then to her neighbours. Rosie looks over. She approves, but warns us not to use too many of the stickers.

Csikszentmihalyi (1990) is invariably invoked to describe this sort of 'flow' experience – even by Killick & Craig, who dedicate a chapter to achieving an experience of flow when doing creative work with people with dementia:

> *Flow gives the person with the condition the opportunity, however temporary, to feel together again. It is inherently pleasurable and promotes growth. Nakamura and Czikszentmihalyi also stress the health-giving aspects of flow and the enhancement of self-esteem. They end their article with the sentence:*
>
> *"Although it seems clear that flow serves as a bugger against adversity and prevents*

> *pathology, its major contribution to the quality of life consists in endowing momentary experience with value." (Nakamura and Czikszentmihalyi, 2001, p. 102)*
>
> *Since by force of circumstance people with dementia are obliged to live largely in the moment, it is difficult to exaggerate the importance of this concept in the development of strategies for helping them live fulfilling lives.* (Killick & Craig, 2012, p. 27).

How closely is this sense of flow connected to that of aesthetic experience as described by McCarthy & Wright? They point to Dewey, who says that aesthetic experiences are refined forms of prosaic experience in which the relationship between the person and the object of experience is particularly satisfying and creative, and Shusterman, for whom aesthetic experience is above all an immediate and directly fulfilling experience. Aesthetics, therefore, is *in* the relationship between self and object, constituting a dialogical aesthetics. Sawyer, in writing about group improvisation in jazz sessions, includes the following quote from Barbara Harris:

> *Improvisation swept us into another realm, another consciousness. ... You forget yourself as the process takes hold. You sort of become part of the form itself. It's suddenly so natural, like going from crawling to walking.* (Sawyer, 2003, p. 41).

Flow is easy to recognise – an absorption in the work, a narrowing of concentration that does not otherwise occur in dementia. For those who sang, a leaning back in their chairs, a folding of their arms, a closing of their eyes. Killick & Craig 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.

Not everyone can lose themselves in painting. Residents begin to tire of this session after about 40 minutes or so, and are allowed to leave the unit (guided by me). 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.

‘There,’ she says. ‘That’s enough for now.’ She had sat with her arms folded for the rest of the session, though she did sing along when Rosie began to sing herself.

Dinner was served in the day room once all residents were back in Eithne’s Unit – the chrome trolley, the tables pulled out from the wall, Aideen complaining once more that the time was too early to eat (‘we’ll not get anything to eat for the rest of the day now,’ she said, eyeing the clock on the wall. I am quite certain that this was not true). From my seat near the window to the garden, I saw Charlie, at a far table, try and fail again to reach a small pot of pepper that had been placed on his table: Mell, on the other side of his table, stood up in her place, reached for the pot and set it down closer to Charlie. Mell was like Ros in that she herself had been a carer for most of her life, and had even worked in Tobermore Community Hospital – she very much felt as though she were at work during her time in the unit, and as the days dragged on past what she felt was a reasonable ‘work day’, she could begin to display some agitation. Later, I sit with Mell in the parlour and we chat about whether or not I have a boyfriend, when Una walks in and comes over to us. She is dressed in a light floral pyjama set and her face is full of anxiety.

‘Look at what they’ve done to us,’ she says, holding her arms out to me.

‘What do you mean, Una?’ I asked. I knew she must have been upset at being changed into her pyjamas by carers.

She shook her head and walked away, sitting down upon the far leather couch and curling up into herself, deep in thought. Later, this encounter would stick with me, and years later still,

reading HIQA (Health Information and Quality Authority) reports on Tobermore Community Hospital, I would learn that the early changing of residents into night clothes was a practice that they severely disagreed with on the grounds that it was not good person-centred care. This echoes back to Aideen's earlier dismay at being bathed by a carer. Writing about domiciliary care, Twigg (2000) acknowledges that semi-undressed states are personal:

> *There are garments and ways of dressing that pertain to private life in the home: dressing gowns, slippers, wandering about in semi-undress. These are forms that belong to the times when the house is closed to the public, and they are part of the temporal structure of privacy that parallels the spatial one ... The coming of care potentially disturbs and disrupts these structures as it does spatial ones, and careworkers find themselves pitched directly into the intimacy of people's private lives.*

Twigg's focus here is on domiciliary care, and as such the above extract focuses on the 'pitching' of careworkers into the private spaces of their clients. The problem is this: in St Eithne's, what space is private? Who consents to being dressed, washed, changed into their pyjamas at 5pm? Who has the power here?

Residents began to arrive back into the parlour, clad in their pyjamas, and once more took up their seats in front of the television. The hours which passed between now and bedtime for many residents were slower-paced – although the effects of sun-down syndrome were seen in anxious residents like Una, for the most part, carers were finished activities such as bathing residents and preparing food for the day, and now many of the carers came to sit – for the first time that day – with residents in the parlour. During this time, residents watched the news, familiar to them in its sound and format, though they passed no comment on the events reported. Following this was a slew of soap operas, all very familiar in their formats, or

retrospectives on Irish life on RTE. This was a time where television became less active than earlier (when residents would often sing along to concerts on DVD) yet perhaps more soothing, familiar, and conducive to a sense of 'home'.

Carers take this time, too, to engage one-on-one with residents; I have brought along a ball of knitting and sitting with Máire, tell her about my failed attempts to knit a scarf for my sister.

'Máire's great at knitting,' interjects Billie. 'Let her show you.'

The three of us sit together and watch Máire's fingers deftly push out row after row of neat stitches atop my own large, messy, loops. Although she tires easily, Máire is happy to show me how to do a certain type of stitch I haven't yet mastered.

Across the room, Una is up and wandering, trying the doors and the windows, first for a way out, and then to prop them open to allow her cat, Micky, to enter the 'house' if needs be. Eithne's first few months in the unit were characterised by this confusion of place – something which led other residents to scorn her for what they saw as disruptive behaviour: propping open windows, closing doors, taking pillows and bags to their 'rightful' place. Georgina takes Una by the arm and leads her over to the piano.

'I know you can play well, Una,' she says. 'Why don't you show Kellie what you can do?'

Una lifts the lid of the piano suspiciously, then slams it down again.

'There's no hot water in here!'

She had been looking for a kettle earlier, I remembered. I asked her to play for me, and she did, begrudging but very able. Before long, however, she had snapped the lid shut again and, like Claire earlier, declared that that was enough of that and took up once more her wandering about the unit.

By 9pm, some residents were dozing in their seats. Carers, at this point, made an attempt to put most residents to bed – some resisted, wanting to watch the television a little longer, but most went willingly between 9pm and 10pm. Although some residents would rouse in the night to use the bathroom or to wander the unit, most slept through the night – all except Una, who, in her first few months in the unit, would not go to bed easily nor stay asleep long. This evening, she either wandered the unit, trying its doors and windows over and over again, or perched, forehead furrowed, on the edge of an armchair in the unit, the dull noise of the television rumbling in the background.

Towards a picture of belonging in dementia care

The above section describes a day in Eithne's Unit as well as giving an insight into the experiences of some of the residents who lived in the unit during my time there. This 'typical day' has been compiled and then told in a way that demonstrates several aspects of life in the unit (the occurrence of art sessions, the routine of meals, spats between anxious residents); however, in reality, the 'action' in St Eithne's was less frequent. Residents spent significant amounts of their time seated in front of the television, where they would only occasionally engage with the media they were presented with, and even then only with particular media. Mornings and evenings were spent with little stimulation bar the television, and could result in long periods of inactivity or even dozing for residents. Anxious residents were 'set aside' for the most part – the anxious Una set herself apart from other residents by refusing to engage in group activities, or even passive activities such as television-watching: instead, she wandered the unit, opening and closing windows and doors in order to either escape the ward or to try and make sense of it as her own home. This behaviour also irritated other residents, who would shout at her to sit. Over time, residents come to accept their new environments, and are more amenable to everyday life there. Erving Goffman describes a similar process in 'mental patients' or inmates who at first resist the status quo of the nursing home, calling it

‘making oneself available: “*sometimes this making of oneself available is called "settling down" by the attendants. It marks a new stand openly taken and supported by the patient*” (p. 147). Una would not come to openly take and support this stance, but she would settle down over a period of months.

The parlour, and in particular, the television, dominated activities in the unit – after breakfast, it is the first place that residents are led, and their day is organised and dominated by the television. Within this day, the routine is broken only by mealtimes and occasional, organised activities, and even then, only for certain residents. The effect of this is that life in Eithne’s Unit plays out in front of the television, with residents in their seats. The television is something that is familiar and perhaps comforting for residents, who may have spent much of their ‘down time’ at home in front of the television, but in the absence of tailored, organised activities, it becomes something which seems to be there to monitor residents as much as it is monitored by residents.

Organised activities in the unit, such as the art session, might occur twice or three times per week. As the months drew on, I saw that residents struggled to engage in these sessions, or had to be coaxed into them – whereas situated, opportunistic ‘creativities’ such as knitting and singing along to hymns at mass seemed to be something which they engaged in easily. In particular, singing and music were important for residents: music was something that seemed to bring residents into somewhat of a reverie (i.e., Fionnuala and Daniel O’Donnell), wherein they were both soothed and easy to engage; on top of this, engagement with music was typically something which was clearly open to participation for these residents – something which can be contrasted with the passive inactivity of hours spent in front of the television.

Goffman describes the importance of such activities in ‘total institutions’ as so:

> *This sense of dead and heavy-hanging time probably explains the premium placed on what might be called removal activities, namely, voluntary unserious pursuits which are sufficiently engrossing and exciting to lift the participant out of himself, making him oblivious for the time being to his actual situation. If the ordinary activities in total institutions can be said to torture time, these activities mercifully kill it. Every total institution can be seen as a kind of dead sea which little islands of vivid, encapturing activity appear … Yet it is precisely in the insufficiency of these activities that an important deprivational effect of total institutions can be found. In civil society, an individual pushed to the wall in one of his social roles usually has an opportunity to crawl into some protected place where he can indulge in commercialized fantasy-movies, TV, radio, reading-or employ "relievers" like cigarettes or drink. In total institutions, especially right after admission, these materials may be too little available. At a time when these resting points are most needed, they may be most difficult to obtain.* (Goffman, 1961)

This is interesting in the context of what we have discussed above – is to '*lift the participant out of himself, making him oblivious for the time being to his actual situation'* the same endpoint sought by Killick and Craig when they talk about flow? If so, it's a negative spin on what they position as an opportunity to reclaim a more whole sense of self. However, Goffman seems to acknowledge the importance of activities for people who live in institutions – without the diversions, 'relievers' he refers to, people who live in dementia care units have no personal refuge to turn to in times of need. The likelihood that the sort of art session I describe above, or a Daniel O'Donnell DVD, is the sort of reliever everyone would like is probably not true, however – instead, we need to spend time with people who find out what they would like most.

Did residents seem to feel a sense of belonging in Eithne's Unit? Residents new to the unit (such as Una) demonstrated such an intense wish to leave that no-one could be left in doubt as to whether she believed she belonged or not – she did not know quite where she was, but she certainly was not supposed to be here. Other residents, who had been in the unit for quite a while, showed something that was a little bit closer to belonging – they were happy to engage in the activities of the unit; happy to be roused in the morning, sit at breakfast, doze at mass. They did not try to leave the unit; they did not (habitually) engage in spats with carers and other residents. Residents such as Aideen, though she grumbled at food quality and meal times, were 'at home' in the unit: she knew where she was, knew the layout of the unit, and day after day inhabited the same chair, chatted to her friend, Mo and was happy to sit and read the newspaper. Aideen's experience of belonging, however, was occasionally fractured by carer intervention into hygiene – as we saw, she was very irritated when she was to be brought for a bath by a carer (often running away from them through the unit), and was similarly infuriated by a chiropodist who arrived to tend to her feet in front of other residents in the parlour one afternoon.

Living with strangers for the first time is usually difficult, and this is amplified for people with dementia, for whom 'behavioural difficulties' are often experienced and for whom 'at-home' care is typically considered to be best but which cannot be provided. In describing the work of Gaver et al in the Jacob House study which produced the Photostroller, McCarthy & Wright (2015) observe:

> *As elderly people, many of whom are unable to live independently, the residents live outside a society that valorizes independence. They must be sick of hearing about the problem and burden of an aging population. Some may feel betrayed by the state and society that sees them in that way and also by their own bodies and health for putting them into that position. Jacob House itself also turned out to be temporary. Although*

> *it was not an immediate issue during the project, it turned out that Jacob House would close a couple of years later. The residents were moved to other council-funded homes in the area. Knowing that this could happen at any time—could happen to you, not that you decide to make it happen—has to be unsettling. In the height of adapting to their changing health and circumstances, they are also expected to live together with others whom they have not chosen as neighbours in a community that is always in between living and dying, being and gone.* (McCarthy & Wright, 2015, p. 104)

The residents of St Eithne's formed a community of sorts – they were all similar in age, most from the same area – but they did not choose to be a part of this community. If we wish to examine what it means for people with dementia living part of their lives in care as experiencing community, it is clear that any conventional notion of community needs to be questioned.

Bauman (2001) questions the way in which we prefigure community as something inherently good; he points to it as a reified notion:

> *Raymond Williams, the thoughtful analyst of our shared condition, observed caustically that the remarkable thing about community is that 'it always has been'. We may add: or that it is always in the future. 'Community' is nowadays another name for paradise lost - but one to which we dearly hope to return, and so we feverishly seek the roads that may bring us there.* (p. 6)

Bauman positions community as a relational state to which we work towards rather than something we enter; a set of social configurations that predates us and that has somehow always been awaiting our presence. Cohen describes this relational idea further: *"members of [a community] (a) have something in common with each other, which (b) distinguishes them in a significant way from the members of other putative groups. 'Community' thus seems to*

imply simultaneously both similarity and difference. The word thus expresses a relational idea: the opposition of one community to others or to other social entities." (1985, p. 12)

What happens when all that you (potentially) have in common with your fellow community members is a) a diagnosis of a neurodegenerative disease and b) collocation in a nursing home? What happens when you strongly desire to be 'on the outside' – but the outside is no longer where you belong? Again there rises inherent tensions to this sort of belonging; Bauman, who picks apart the notion of community as "*like a roof under which we shelter in heavy rain, like a fireplace at which we warm our hands on a frosty day*", describes instead the difficulty of ensuring security vs. enjoying freedom in a way which echoes the difficulties of (in)dependent living for people with dementia:

> *Promoting security always calls for the sacrifice of freedom, while freedom can only be expanded at the expense of security. But security without freedom equals slavery (and in addition, without an injection of freedom, proves to be in the end a highly insecure kind of security); while freedom without security equals being abandoned and lost (and in the end, without an injection of security, proves to be a highly unfree kind of freedom.* (p. 20)

What is preferable – to live alone with dementia and to face dangers such as wandering, becoming lost, falling, forgetting to eat, to go out, to take medication; or to face the final years of your life with a group of strangers in an unfamiliar place? This choice is illustrated in too-stark terms; the experiences of people living in St Eithne's was somewhere in the middle of that. This thesis is concerned with modes of participation and the exploration of any possible forms of community – what I found was not necessarily a coherent, constant swell of communal feeling; instead, like the experiences of my participants thus far, it was a

series of fragmented moments of being together, sharing a common humanity. To borrow Goffman's phrase, "little islands of vivid, encapturing activity" occurred.

Much of the rest of this thesis will centre around residents' engagement with music. In terms of interaction design, this engagement with music presents some interesting opportunities for intervention and design – whether it be low-level (changing and personalising musical media for each resident) or something which affects the entire unit (changing the method of delivery of music – as it stands it is delivered through the television entirely). In the following section, I will look more closely at moments of engagement with music, and consider how these bring about group encounters and moments of togetherness which are otherwise missing from the residents' daily lives.

Engaging and belonging: experiences of being in-between

The first few months of full-time care for almost every resident is comprised of a sense of 'unbelonging' – they do not want to be here, and they will try all that they can to get out. With time, this tended to settle, but the situation remained the same - residents have been placed in the unit, and have not come of their own volition. They live out their lives alongside others who often feel like strangers to them, and these lives are 'managed' by carers, nurses, and a wider hospital and HSE administration. Though these people may once have belonged to a larger community, here on the inside, residents form a community that is somewhat 'inbetween', though it is difficult to describe residents as experiencing a conventional sense of community.

Elspeth Probyn's account of 'balcony living' in a Montreal neighbourhood speaks of participants in a community (brought together because they lived very near one another) navigating and coming to form ways of being through a changing, plural configuration of relations. These ways of being, she writes, are 'outside belongings', spaces on which social relations are produced through manners of responding to participants within a social setting.

This results in a moment-to-moment, responsive way of being-with-others which might better help to understand ways of being, and perhaps belonging, in dementia care – not where one is 'on the outside looking in', or otherwise, but rather where residents are caught up in a multiplicity of belongings between various relations and institutions.

Community moments and the role of music in St Eithne's: results from Grounded Theory Analysis

Residents were at an inbetween stage of their lives, a stage which proved to be transient for many: as time went on in the unit, residents moved in and out of stages of dementia and in and out of care as they went from day-care to respite to full-time residents. Residents rarely engaged in hobbies which interested them within the unit, and though some found friends (Aideen and Mo), the mood in the unit was amiable but tended to be quiet and fairly solitary. All of this made for an inbetween existence for residents who were not in pain or uncomfortable, but who no longer truly 'belonged' to a larger community or to the community of St Eithne's.

I carried out some artistic sessions with residents, partly as a way to begin to understand how future creative design sessions might happen for us, and partly in order to see if active engagement with creative materials would interest and enliven them more than the hours spent in front of the television. One such creative session was described in the previous section as happening under the supervision of an activities coordinator in the hospital – as time went on, the residents and I carried out our own art sessions. Despite my initial hopes, painting and drawing were usually not very engaging for the residents – presented with a wide range of materials, some objects to paint for still life or lists with small project ideas, in a quiet and relaxing environment, some residents could be coaxed to sit and paint for a while, but most were uninterested.

The activity and its products generated some chat among residents, seemed to be soothing for some, and so wasn't a waste of time, but it was clear that it did not engage them meaningfully. As time drew on, I realised that this was likely because of the activity's unfamiliarity. Painting, art, was most likely not an activity of choice for these residents throughout their lives: most had been on a low income, busy with bringing up many children, working long hours, often overseas, and simply not of a generation to sit down and carry out the relatively introspective hobby of art or painting. Free time, for residents, used to be spent with others, and even group painting sessions could not fully replicate this sense of being together. Moreover, many residents were not confident in their ability to paint and draw, and refused to take part because of this perceived inability.

One resident, Ros (the resident who had hit me and raised the ire of Marie in the last section), had been a painter throughout her life, but now, her dementia having reached a far stage and with her constantly in 'carer mode', believing as she did that she was at work, she could not be coaxed to sit and paint. The legacy of Ros's interest and proficiency in art, however, was visible once you opened up the folder which contained residents' artwork – in there were some paintings from early on in her stay in St Eithne's, still life paintings which were vivid, brash, very alive. As the years went by, the quality of her painting degraded – the colours were still vivid, but the complexity, the lines going – and somewhere along the line, she stopped painting completely.

Image 5: above, earlier artwork by Ros; below, some of her recent artwork

For a while I took the art to the parlour, sat alongside residents with felt-tips and colouring pencils and pastels, a large sketchpad on our knees, and tried to engage residents to sketch and draw and colour in a more comfortable and less formal setting. This was slightly more successful – as residents chatted about their lives, I would nod and sketch and draw symbols from their stories, or else we would write out our names several times in different curving scripts, different colours, and talk about our names, surnames, maiden names, and the names of those we loved.

However, as the research drew on, I began to realise that a different creative modality was engaging residents much more successfully – that of music. On my first day in the unit, as residents crowded round some of the carers who were carrying out some baking, I had thought it odd that they had begun to sing, and took turns to perform songs to one another. I had never thought of myself as a singer, or a musician – I was excited to carry out storytelling, poetry and art sessions, but balked a little at singing along. I had gone in with a relatively fixed idea in my head of what 'making' with people with dementia might look like, and music was not the creative medium I had hoped to employ.

Over time, I began to realise that meaningful creative engagement in dementia could not be forced while sitting at a table with materials that are unfamiliar to the participant: this kind of engagement is, instead, an opportunistic and somewhat ephemeral thing that emerged in response to certain configurations of space, people and things within the unit on any given

day. What is more, it was driven by participants: residents would 'go along' with art sessions seemingly to satisfy my coaxing, but they would take the helm in song sessions. Almost every resident had a song that was important or special to them, and most relished the chance to stand and sing it. Musicality was prompted and supported by residents' responses to everyday technologies within the unit – music players and the television in particular. Within these moments, the passivity described in the previous sections dissipated as residents began to actively participate in the activity at hand. This engagement constituted rare experiences of 'belonging' for these residents – belonging in the moment, in an activity, in relation to co-participants – and beyond this, allowed a sense of connection to time, place, self and other which had been missing in the quiet, fragmented passivity of St Eithne's Unit. The following section details the results of a Grounded Theory analysis which focused on the engagement of residents through musical interactions.

Overarching themes of GT analysis of St Eithne's ethnography		
Performance and spectatorship	**Personal connection in and through music**	**Being a part of a larger community activity**
Residents engaged in often collaborative but also opportunistic performances to music.	Music provided a background against which to come to know and connect with others in the unit.	Music allowed residents who would normally spend time apart to come together in 'community moments'.
Key ideas 1. Taking up and putting down the performer 'mantle' 2. Audiences as collaborators in an overall performance; performing *through* spectating 3. Performing becoming a balm for anxiety 4. Performing as empowering	*Key ideas* 1. Music as a 'way in' as well as a way to level the playing field 2. Touch as a way to connect without words 3. Dancing as a 'ruse' to engage with others in different and more comfortable ways – not patients, but partners	Key ideas 1. Being on the outside because of different ways of behaving – often due to being new in the unit or having a very progressed dementia 2. Music bringing people together who would otherwise spend time apart 3. Community as co-created, momentary but re-occurring

Table 3: summary of themes from analysis of ethnography

Theme 1: Taking the stage and finding your seat: performance and spectatorship

Residents were prompted to sing by carers during baking or art sessions: as I mentioned above, on my first day in the unit, resident Lizzie and carer Carmel carried out a baking demonstration for other residents, making Lizzie's favourite 'curnie' (currant) cake. As Aideen worked, [carer] Carmel encouraged the residents to sing. Veronica, sitting next to me, began to sing a jaunty song about olive oil. Her eyes moved gently around the room as she sang from her seat, seeming to regard her audience. Sometimes, she closed them. When some of the residents began to chat, her voice wavered until Carmel encouraged her to 'sing up'. When she had finished, Marie began "Danny Boy" with which almost all of the residents sang along.

This invitation to sing seemed to open up a potential space for performance which was completed by Veronica's acceptance of the invitation and her beginning a performance, which seemed to denote that 'this is the time for singing'. This was confirmed by Marie's immediate beginning of 'Danny Boy' once Veronica had finished: no more coaxing needed to be done – Marie had been prompted and took her place 'onstage'. Once the spotlight moved on, and the performer was in the midst of their song, participation from the audience was often something that was unwelcome, rousing sharp glances and *shush*ing from the performer: Veronica didn't like participation by the audience, seeming to see it as a dilution of her time to shine. In this way, the performer role further set residents apart from each other (while bringing them together) by acknowledging the performer as someone with a rich, personal history (carers would say "sing *your* song, Marie," knowing that Marie favoured a particular song or connected it to events in her past).

However, most performances were bolstered by the participation of others. One day, as he was preparing for a concert he would perform in that night, Charlie (at the behest of carers) sang "The Moonshiner", a favourite of his, aloud – a little falteringly at first. He smiled as he

sang – he enjoyed singing, and he knew the words well. He held the sheet with the lyrics on it on his lap and looked down at the lyrics through his glasses, chuckling at the humour of the song as he sang along.

I'm a rambler, I'm a gambler, I'm a long way from home,

And if you don't like me, well, leave me alone.

I'll eat when I'm hungry, I'll drink when I'm dry,

And if the moonshine don't kill me, I'll live til I die.

The melody of the song began to escape him in the final verse, and he began to falter, his voice shrinking and his words ran together a little – seeming to sense his lapse in confidence, from across the room, Marie and Veronica joined in and the performance strengthened. The idea that participative performance leads to an emergent creativity is not a new one. Collingwood (1934) emphasised the role of the audience in any given performance (creation) in a way which namechecks 'community':

> *The work of artistic creation is not a work performed in any exclusive or complete fashion in the mind of the person whom we call the artist. That idea is a delusion bred of individualistic psychology. This activity is a corporate activity belonging not to any one human being but to a community. It is performed not only by the man whom we individualistically call the artist, but partly by all the other artists of whom we speak as "influencing" him, where we really mean collaborating with him. It is performed not only by this corporate body of artists, but (in the case of the arts of performance) by executants ... and ... there must be an audience, whose function is therefore not a merely receptive one, but collaborative too. The artist stands thus in collaborative relations with an entire community.* (p. 324)

To set up their account of participatory projects, McCarthy & Wright (2015) offer a reading of Jacques Rancière's 'The Emancipated Spectator' that chimes with Collingwood's configuration of audience-as-collaborators:

> [Rancière] *argues that emancipation is not brought about by trying to make everybody the same but by starting from the assumption that all participants, though different from each other, are equal. Rancière's thesis suggests that members of an audience, students in a classroom and users in a participatory project, are all already active to the extent that they observe, select, interpret, integrate, critique, and imagine. They discuss the event afterward with friends and colleagues and share stories that help make sense of the experience for others. Seeing all of this as passive diminishes the cognitive and emotional in favor of the behavioral and, in the process, risks losing extremely important positionings in dialogue.* (p. 42)

The notion that 'audience members' are integral to performances is not a new one in HCI - Hodl, Kayali, & Fitzpatrick (2012) describe a study which sees audience members' smartphones controlling aspects of a musical performance while Veerasawmy & McCarthy (2014) provide an account of how technological interventions can fundamentally change crowd experience at a football game. Throughout this chapter, I have provided several observations from music sessions in St Eithne's that see participants as occupying a space designated as performer: Veronica (who through her own actions, positions those around her as an audience), and Charlie (who welcomes the participation of an audience into his performance, and has his performance strengthened because of this participation). For Rancière, both audiences – those who are visibly participating and those who resume the role of the 'observing and interpreting' audience – are active. This extends beyond song sessions in St Eithne's – Sawyer notes that:

> *… many jazz performers regard only jazz performed in a club atmosphere, with a live audience, as "true jazz." Interaction with the audience is considered a key component of the resulting creative product. Musicians often state that the performer is a "channel" from the music to the audience. Knowledgeable jazz audience members sometimes respond to creative moments with applause, shouts, and whistles.* (Sawyer, 2003, p. 72)

For Charlie, other residents' applause and whoops of encouragement as the song ended saw Charlie blush with pleasure and laugh. In this way, performing became somewhat of a balm for the anxiety that affected many residents during their time in the care home. Several residents, who were in the process of transitioning from at-home to long-term care, frequently engaged in behaviours that are often termed 'problematic' in the dementia care literature, such as seeking exits and constructing elaborate stories to explain their presence in the unit. This inability to make continuous sense of their experience leads many residents to feel as though they have lost something. For instance, Charlie, having transferred in the autumn of 2013 into long-term care, kept talking about 'the power [he] used to have' and how he no longer was 'able to do the things [he] wanted to do'. He spoke frequently about 'getting a car' and getting his children to take him home:

> *'My only problem now is how to get home. I would get my power back at home.'*

When Charlie spoke this way he seemed to fall back into the furniture and cast his eyes downward. Charlie's sense of a loss of power seemed directly tied to his transition from home-care (where he lived with his ill but loving wife and was frequently visited by his four daughters) to care in St Eithne's, where family visits were not as frequent. Conversation with Charlie became full of self-denigrating comments; however, singing, familiar songs, and the performer role seemed to bring a sort of coherence to his fractured experience in the unit.

I knew that he liked to sing, but even he seemed to forget this as he settled into life at St Eithne's. As the staff rotated (due to staffing issues), with the only constant often being the head nurses (who were busy for much of the day), I wondered if many people in the unit remembered Charlie's love of music and his proficiency as a singer. During the time in between visits, I came back to my workplace and created for him a songbook of the songs he used to love – this was not much more than a collection of bound and printed pages with his name on the front, but in it I put songs that I knew he liked to sing and that I hoped would be special to him, even if we only used it the next day I was in.

That next day, sitting together as he recounted his worries since joining St Anthony's as a full-time resident, I reassured him that to me he seemed just like the same old Charlie and that everyone in the room was a friend to him. I presented him with the book I had made for him, and we sang 'The Moonshiner' and 'Danny Boy' together several times. Like many times in my time in the unit, I was left lagging as Charlie sang on ahead of me, knowing the words and the music much better. He brightened during this time, and even changed the way he sat in his chair – as we talked about his 'loss of power' days before, he sat far back in his chair, shoulders slack and eyes alternatingly 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.

Afterwards I complimented Charlie on his singing, and as I prepared to leave, he thanked me for our chat, telling me that he felt better.

> *"All my worries are gone. You told me I'm good at singing and I had forgotten that. That's all that matters."*

Charlie's transition to St Eithne's had been one which had left him feeling confused and powerless as he struggled with carer intervention in mealtimes, hygiene and dressing; as

simple an artefact as it was, this printed booklet and the activity it supported – singing and thereby performance – saw Charlie reclaim a sense of personhood (and perhaps even the power of which he spoke) which he had felt was lost in the transition to care. The performance space and performer role saw Charlie's voice grow stronger and stronger until he was singing along, in full possession of the performance space. I don't doubt that, within an hour or two, Charlie's recollection of our time together may have dissolved along with any positive emotions he had – in this way, I present this set of interactions not as 'proof' of 'all of [his] worries] being gone – rather, to indicate the potential here of working with music to promote a sense of self-efficacy achieved in positive relational encounters.

Performing their favourite songs seemed to restore a sense of continuity to the lives of residents whose transition to the unit had been difficult – in Charlie's case, it seemed to enable him to feel a sense of pride and power in a skill he had forgotten about. So, too, can performing support a sense of the person with dementia as the expert or the professional when it comes to their own experience. During one song session, I sang along with a resident named Esther during a performance when other residents seemed a little shy. As she began 'Galway Girl', I sang along with her to make up for the lack of participation by her audience. She was very impressed – she turned around to beam at me in approval, and then latched onto me for the rest of the session. 'I'll teach you,' she said. 'Don't worry about that.'

Performers often required spectators in order to feel as though they were performing; and in some sessions, the transition between spectator and performance was rapid and shifting. Once a performer had finished their song, they would sit, and another would rise; this shift represented a reassumption and a confirmation of each other's place within the performance space. To become a spectator in this performance space required a physical 'positioning' just as the performer's does: when Veronica told me, during an art session, that she would like to

sing, I announced her wish to the room. She stood up, ready, and hearing this, everyone else turned their desks and chairs towards Veronica.

This prefiguration of the space was something residents did without being instructed to by carers or by me. Similarly, Kontos (2005) describes a sense of embodied selfhood which she recognised among members of a nursing home in the US:

> *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. Despite the fact that some of their actions presuppose practical learning, the crucial point here is that no aspect of the coordination of visual, tactile and motor aspects of the body that facilitates their practical competent bodily actions is reflective or discursive. Hence, as Merleau-Ponty notes, in their first attempts at reaching for an object, children look not at their hand but at the object, the implication being that the various parts of the body are known to us through their functionality without their coordination ever having to be learnt (Merleau-Ponty, 1962, p. 149*). (Kontos, 2005, p. 561)

The felt experience of spectating was one which could be quiet and seemingly – seated, hands on laps, listening but not participating visibly – but was most usually active – rapt, lively, clapping hands, tapping toes, cheering the performer along, fully engaged in a communal experience. The key here as to whether or not the spectator fully engaged or not seemed to be often rooted in the familiarity of the experience for them – did they know this person (or was this person friendly)? Did they know the songs? Esther, mentioned above, performed to the group using a commercial book of Irish folk songs that had been bought for her by a caregiver; although some of the songs were not known in the region, she sang them anyway,

having made up her own melodies. Standing in front of the group, face buried in the book but voice loud and feet tapping, she began to sing a song I hadn't heard before – and which most of the group hadn't, judging by their faces. This lack of recognition became, in turn, a lack of response and eventually restlessness: spectators chatted amongst themselves, faces turned blank and eyes glazed over.

In contrast, familiar songs sung by Veronica in the same session saw her spectators seeming to lose themselves in the music. During the same session, she seemed unsure of what song she would sing – I had heard her sing 'Red is the Rose' before so I mentioned this to her and started off singing the first few words, until she promptly took over. This is a song most of the group knew, and most joined in. Ben in particular closed his eyes and sat back in his chair, singing loudly.

Red is the rose that in yonder garden grows

Fair is the Mona of the valley

Clear is the water that flows from the Boyne

But my love is fairer than any.

Spectators who engaged with the performance space did so almost solely with material which was familiar to them; not only did this music create a warm and a familiar atmosphere within the often unfamiliar care home, their preference of familiar music suggested that spectators who participated fully within the space were able to see something of themselves within the music. Veronica, for instance, took pleasure in singing 'I'll Take You Home Again, Veronica', which would trigger carers asking her about her husband and their life together.

Residents engaged in the act of spectating in the unit responded to engaging performances by cheering on the performers – even if these performers were merely onscreen. As I described

in the last section, Fionnuala in particular revelled in these shows. The energy with which certain residents cheered performances along seemed to spread to other residents in the usually-quiet parlour; if Fionnuala clapped after Daniel finished a song, so too would the residents who sat behind her or next to her. Claire was often roused by songs that she found familiar, and, like Fionnuala, would '*light up for music*'. A typically quiet woman, as I sat alongside Claire during music sessions I would be startled by her bursting into song; her voice came always in a loud, sudden burst, and other residents, once they'd recovered from the surprise of her sudden song, would imitate her by '*caw*ing' harshly, like crows.

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 '*woohoo*s' and '*yoohoo*s' which garnered many curious looks from other residents; this yelping of hers was, I thought, designed to whip up participation from others. She would look to others as she shouted, shout '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, therefore, 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.

This was interesting for Claire, as her short-term memory was poor, but unlike many of the other residents, she also had very little long-term memory of her life. My early meetings with Claire were difficult for this reason alone: she was a bright lady, friendly and well-turned out – she wore her hair in a fair bob and sported thick glasses - but a little reserved first thing in the morning, and she had no real 'chat' in her as she had nothing she could chat about. She seemed to me to be someone almost floating in her everyday life. I wasn't able to engage with her meaningfully until I saw her 'open up' to music: as she seemed to live only in the 'now', chats about family homes and old pets weren't making our communication any better.

What ended up being our point of connection was a hoot and a holler over a country music DVD.

Theme 2: Transforming self and other: personal connection in and through music

Claire's whooping was a way of setting herself apart from other residents but, in doing so, also tie herself more closely to those who surrounded her; music allowed residents to perform, spectate, but also to connect with each other. In a collective of people living together in what was ostensibly a community, with its tensions wrought on the surface – 'I don't want to go to breakfast with you,' 'I don't want to sleep in a communal dorm' - this moment of connection might be the only one residents experienced all day.

Music allowed me 'a way in' to the experiences of these residents; through seeing who stepped up to perform and who sat to spectate, through seeing their choices of song and the ways in which they'd sing, through observing the way faces would light up, laughter would come easily, I learned about the ways in which residents engaged with and through music. On a very basic level, music acted very much as a sort of 'social lubricant' for these residents; sitting down one day to chat with Aideen, my questions were rebuked by her when she considered them to grow 'too nosy' – however, once we'd joined in a round of 'Báidín Fheilimí', she was considerably more open to chat.

It was my participation in music sessions with residents that allowed us to carve out an 'even playing field' on which our relationship took root and thrived. I often felt, in the early days of my time in St Eithne's, that my presence was highly incongruous to the point of ridiculousness –though I was always engaged in the setting, with residents, and carers, everyone within found my role a little difficult to work out: was I a nurse? A doctor? A clinical psychologist? Taking down some quick field notes, my notebook would draw fleeting, curious glances from residents and carers alike no matter how stealthy I was. I was also young, much younger than even the youngest carers – I was 22, 23 at the time, and my

youth was remarked upon frequently by residents. It was often clear that I was not ‘one of them’; not a carer, not a resident. And not a singer – I didn’t know the songs that they’d grown up singing with families in pubs, at weddings, with friends. Why, then, should Aideen engage me? My questions *were* nosy, I *was* an outsider, or at least I was different to them; I did not engage in the activities which they engaged in, did not disappear into the bathroom with the carers, was not served my lunch on plastic plates in the communal dining room. I was on the outside until I began to sing along.

My participation in these music sessions seemed to uncover something within myself that made me both less incongruous and yet more visible to the residents; during Esther’s singing session described above, she began to truly take notice of me when she saw me singing. I became a performer and a participant, and our language transcended the language of care I had been speaking as a facilitator in a creative session – our language became music, singing and performance. It said something more for me to sing along in this group than it did for me to sit with them with my notebook and ask prodding, poking questions. Finally, this setting and its actors and the moment we were in made sense to us all, and through this engagement, we two could connect and know one another within a fulfilling, aesthetic experience. Following on from Rancière (2007), music and participation within music reconfigured what was visible and therefore sensible for us, and though we both were different, we found ways to communicate within music.

In the following chapters, I will expand on how this connective function of music allowed for insights into the delineation of a design space surrounding musical experiences in dementia care. One of the stand out moments concerns the ‘cheerer’, Claire - despite unfamiliarity with one another, at Claire’s behest one day, Ben (the resident with early-onset dementia) invited her to dance. In the passive, quiet St Eithne’s, this was fairly remarkable to see – the two

performed a quick two-step around the parlour, spinning and twisting, giggling together all the time before falling down and chatting together for some time afterwards.

Another moment of connection which will be expanded upon occurred between Veronica and I early on – sitting together and listening to music, she suddenly reached her hand out to take mine and guided my hand in an elaborate dance to the music for a minute or two, before bringing it to her face and kissing it softly. Veronica also carried several keepsakes on her person – a carved and oiled set of rosary beads coiled in her pocket; a small book of religious poetry with a leather cover which she had purchased on a trip to Lourdes with her family several years earlier – and she would often take out these items and run her fingers through the pages or through the beads. This meditative touch was something she employed particularly during stressful situations – when the group was playing a game she couldn't quite grasp or when she was seated near new and unfamiliar people – and here I felt she sought the same connection and communication in and through the music as we listened.

In both of these moments, connection was achieved through bodily means – dance, touch, holding one another's hands. Tactile senses came to the fore during music sessions as well; those who were singing would often take the hand of a person sitting next to them, seemingly for a sense of comfort and confidence as they performed. This was often initiated by the performer themselves – sitting next to resident Marie one evening early in the ethnography, I was surprised to find that, as she began to sing, her hand found mine and, once grasped, we gently swayed our hands from front to back as she sang.

What was different between the sort of touch which Marie, Veronica, Claire initiated – which to them, seemed therapeutic, soothing, connective – and the sort of touch which Twigg's participants describe as infantilising, invasive? For Twigg, touch is "*structured according to gradations of intimacy and power … different parts of the body may be touched by different*

people according to gender and the closeness of the relationship. Touch is also a vector of status, authority and dominance, with the more powerful touching the less powerful, superiors touching inferiors." (p. 41). I can only speak from my own experience, but the dance with Veronica, the hand-holding with Marie felt less like an attempt to control and more like an expression of intimacy, connection and friendship.

It's clear that music performs certain social functions which are communal but often deeply personal; in a later chapter, musician Lisa will describe how a resident with dementia approached her to thank her for her performance as it reminded her of songs her husband using to sing. We think of dancing as a joyous act, one of abandon, but it can also be one which is slow, personal, expressing deep feeling. I thought of the songs that moved me, the ones that made me want to clasp onto the hands of my friends and family. I was never a musical person, yet I still had a curated list of songs, which – changing every five years or so – meant something special and strange to me. Some of them made me want to dance; others made me want to sit still, be alone. Some I listen to even though I know they will make me remember painful times in my own life. This does not stop when you have gotten a diagnosis of dementia – that much was clear to me now. Nigel Hartley (2001) reflects upon his personal experiences of using music therapy with people facing the end of their lives in this way:

> *Why should it be a surprise to "fall into music"? Isn't it just as surprising to fall in love, or even fall into meditation? In order to fall, of course, we must feel safe, be ready to be surprised and … feel worthy of the experience that we fall into. Is this kind of abandonment, of letting go, something that we all long for during our lives? Creating music with those close to death, has enabled me to experience what I can only describe as a longing on their part. What can this longing be?* ***A longing for life, a longing for intimacy, a longing for connection with another human being, a longing for love, a longing for God****? This kind of intimate meeting, somehow and in*

> *some way, in the experience of abandonment and letting go into shared improvised musical experience, enables us to be stronger and more defined as individuals. (p. 5)*

I felt this 'longing on their part' when I interacted in these moments with Marie and Veronica – for a moment, I thought I felt something of what they must have been feeling as our twisting hands became a language in the air; as I felt Marie's hands squeeze mine, the soft, papery skin, the half-moon of her fingernails pressing lightly into my flesh. I wondered if Claire and Ben had felt something of each other's joy as the weight of their bodies twirled around the room, hands tightly grasped, each other's palms flat, firm on the small of the back. In the present moment, music rewrote the relationships between residents to create a relational space that transgressed the boundaries of 'patients' and 'residents'. However, not only did relationships between residents change in the mediating space created by music, but so too did residents' relationships to the larger group. Music helped residents to belong together.

Theme 3: Placement and displacement in time, space and community: being a part of something

Some residents traced out the anxiety of being in the care home in bodily ways – Una would tread the halls of the unit ceaselessly, her brow furrowed, her hands clasped loosely behind her back, eyes downcast. This anxiety set her apart from others: residents grew irritated as she weaved between to try the handle of the windows behind them. 'Strange' behaviour was seen as disruptive by most residents, and though Una's anxiety manifested itself in these quiet, introspective ways, the ways in which it prompted her to interact with her environment disrupted the 'quiet and polite' status quo of Eithne's Unit.

The onset of serious illness and death in the unit also separated the ill from the rest of the residents – the ill resident would often be given a private room (in the re-purposed Sensory Room), and would see family and doctors much more frequently. Early on in the research process, I witnessed one resident, Olive, growing steadily more unwell and eventually dying.

Prior to her death, she was able to sit up at tables with other residents and eat with them, but would constantly call for the nurse – 'Nurse, nurse, nurse, nurse, *nurse*!' – and rap her knuckles sharply on the table. As Olive began her call, Veronica would stop what she was doing (put down her pencil, or her spoon), scowl, turn around in her chair and yell at Olive to stop, to shut up, even threaten to come over and hit her. Here we see again the tensions that come with living together; only now they are worsened as community members' differences are so much more pronounced than their similarities. The progression of dementia (along with other situational factors) brings with it a significant amount of change: those in the early stages and those in the late stages often engage (and disengage) in entirely different ways. Describing how members of two different assisted living facilities "come together and pull apart", Sandhu et al (2013) have the following to say:

> *Residents come together physically by means of helping each other and by engaging in different health-related conversations. Meeting, greeting, and asking about each other's health and well-being can make residents "come together" socially. Sympathizing, showing concern, and sharing problems related to health also can bring them together emotionally. In other situations, functional status can "pull" residents apart physically, socially, and emotionally, creating self- or other-imposed barriers to the development of positive or meaningful co-resident relationships. Maintaining social distance, complaining, othering, showing frustration or intolerance for, and avoiding contact with each other are examples of how residents can be physically, socially, and emotionally "pulled apart" from one another as a result of variations in functional status.* (p. 34)

In similar ways, the 'new' to the unit (like Una, described earlier) were shown intolerance when they behaved in ways which irritated or disrupted other residents who were more 'settled'. For some, this tendency towards disruption meant that they spent much of their time

alone. Jim, the almost-blind resident described earlier, resisted engagement with other residents. Men in the unit were in the (relative) minority: they slept in the smaller dorm, and though some (like day residents, Ben and Charlie) spent time with the larger resident group in the parlour, full-time male residents did not seem to engage with each other in the same ways as the female residents did. Tom spent most of his day in the day room, sitting at a table, his hands folded neatly in his lap or in his chair. Once in a while he would be amenable to conversation, or would even seek it out, but for the most part he spent his time alone and seemed to want it this way. He was a stern man, and attempts to engage with him when he was not ready would result in him 'shooing' the would-be conversation partner away.

One day in the summer, he was sitting with the larger group, having been coaxed to stay by a carer. I sat about two metres away from him, the room otherwise full with the usual residents. We were listening this day to a new CD which had been brought into the unit, one with a particular kind of Irish traditional music that focused less on lyrics and more on rhythm. As we tapped our toes and clapped along, I noticed from the corner of my eye that Tom was also clapping from his chair some metres away. He carried on for about thirty more seconds of music and then rose from his chair and came over to us, where he stood in front of us, bending a little, and clapping along with us until the music had ended. Though he soon returned to his chair, Tom kept clapping through the rest of the time we spent listening to the CD. Carers who were also present at the time were surprised by Tom's engagement – he had very rarely engaged with others before in this way.

I don't wish to present this observation as empirical evidence of music as a 'magic bullet' for residents in the unit – rather to indicate that there are multiple ways of being in community, even for people with dementia. These plural ways of being mean that a resident can 'play his part' as seeming totally disengaged, but then engage with music in a way which brings him into close participation with his fellow residents. Music is not a 'magic bullet' – clearly not,

as indicated by Tom's avoidance of the parlour when Daniel O'Donnell was playing – but the right kind of music can be a 'way in'. To return to Nigel Hartley, he quotes one of his clients, an elderly man with AIDS, who before his death, reflected:

> *You know, my body is fading away by the day, the outside of me is dying. When we improvise, the focus is on the inside - the inside of me is living, and when we play, it grows and expands. We have two very clear things. I refer to these as your music and my music. Initially we are separate, and then, almost always, something special happens. Then, what we have is what I would call 'our' music. Here, we are totally one, totally equal - in balance. During these times there is no illness, I am completely well. In fact, I never felt so alive!* (p. 6)

I reflected above upon the use of music as being an 'equalising force' which allowed me to participate in the unit in the ways I saw residents participating – when I write about this, I cannot help but think of Dewey's insistence that art is a language: "… *each art speaks an idiom that conveys what cannot be said in another language and yet remains the same*" (1934, p. 106). My participants were creating performances, but not necessarily speaking words of their own while doing it, but it is clear that Dewey does not privilege the verbal. This same sentiment is expressed by Killick and Craig (2012), who give the example of a resident who sang what seemed to them to be a 'nonsense' song:

> *"I had recorded her and I played the recording back to her. To my surprise she sang along to the tape, reproducing the exact sounds she had made the first time. Although the words made no sense to me, they clearly did to Ella. ... [W]e have to find what process suits the person, however unconventional it may seem."* (p. 31)

It is unconventional to use music to try to understand people a bit better, but this engagement allowed us another insight into Tom's experience – we knew he was a quiet, stern man, who

disliked commotion and (seemingly) show band-type music, but now we saw that he was not someone who necessarily sought to be alone all the time. More than that, we knew that he could be reached with music – just not the sort of music that we typically played in St Eithne's.

Similarly, Charlie's anxiety about his stay in the unit was assuaged by singing some of his favourite songs, and so too was Máire's – though her early days in the unit saw her constantly poised to attempt to leave, she could be drawn into participating in a song session which seemed to give her respite from her anxiety, even if just for a half an hour or so. Music, for residents, was often the only time that they could be together in a meaningful way – though they might spend most of their days alongside each other, real recognition of each other and of themselves as a part of an activity or a group happened much more frequently during song sessions such as these, where fingers began to wiggle, toes tap, and hands clap. This infectious sort of bodily participation saw residents engaged sometimes in group-wide performances that would emerge out of seeming passivity and disappear in a flash once more. The 'eventness' of this experience is echoed by Pavlicevic, who describes a children's choir in South Africa 'riffing' on a song during a choir rehearsal:

> *The back-row "claims" or "borrows" for itself this song (Kan'n man dan nie) and makes it its own. In this sense, the song represents the larger social domain (the choir), to which all participants belong. In that distinctive time and space, i.e., the "formal" part of the rehearsal, the song has a particular role and function. In this "magic moment," equally, the song's everyday idiomatic form and content "frames" how the back-row "moves'n grooves" together. Here, however, the song's everyday conventions are interwoven with idiosyncratic musicing that seem to belong in <u>this time and space</u>.* (emphasis in original - 2010, p. 103)

RCT studies of music therapy for people with dementia often end with negative results (Ueda, Zuzukamo, Sato & Izumi, 2013; McDermott, Cellin, Ridder & Orrell, 2013), which sometimes made me (and other healthcare staff) question the use of what I was doing with these residents. Were these moments anything more than moments if they disappeared? What use is it to offer my hand to swing and dance in a group if this group will disperse in five minutes and be forgotten in ten? I soon realised that if we follow this thinking all the way back, we might as well stop trying to enact person-centred care at all; we might as well treat people with dementia as husks who won't remember so don't matter. Maybe this sense of 'doing-together', of a community joined in song wouldn't persist, but it did for the moment – it transformed people into performers, dance partners, audiences in a way which is reminiscent of jazz musicians, comedy and theatre improvisers – and thus pursuing this must be worth it.

Whereas the previous section detailed instances of intimate connection between one resident and another (Ben and Claire's dance, Veronica's handholding with me), this section has shown how participation in music can facilitate being a part of a larger group interaction as well – even for those residents who are so often set apart. Over the course of the next chapters, I will describe how this budding sense of community as belonging in *experience* comes to grow over several music sessions in care settings. For now, it is important to consolidate some of the themes and concepts that have emerged in this account in order to explain how they are built upon by the design work of the forthcoming chapters.

Summary & observations from this research

Though I initially expected creative activities with the residents of St Eithne's to centre around painting, drawing and more typical 'making' tasks in order to explore future ways of designing with the group, engagement with my designed workshops paled in comparison to 'naturalised' engagement via music and music technologies in the unit. This chapter has

detailed some of this engagement in terms of how it allowed residents to feel a sense of belonging in care through performing and spectating, connecting intimately with one another, and participating in larger group activities. Beyond this description and loose framework of belonging via engagement with music, I would like to also set down several overarching observations which I are carried through into informing the next phase of the research.

The role of experience and the present moment in connection and community

Earlier in this chapter I have described my initial frustration at working with music within dementia and likelihood that these experiences would be forgotten by the people who participated in them, along with most beneficial effects (according to extant research on music therapy). Working with people with dementia seems to require an attenuation to the present moment – to direct experience. The concept of experience is one which is frequently muddied – even the term 'lived experience' can be used in a variety of ways which position it, typically, in the past, to be recalled from memory when the situations calls for it. For people with dementia, many experiences are inaccessible in this way. Bruner uses the work of Turner and of Dilthey to differentiate between different forms of experience and its articulations:

> *Turner ... refers to Dilthey's distinction between mere "experience" and "an experience": the former is received by consciousness, it is individual experience, the temporal flow; the latter is the intersubjective articulation of experience, which has a beginning and an ending and thus becomes transformed into an expression.* (p. 6)

I cannot access the experiences of my participants; I work only with their expressions of experience. However, placing them into the temporal flow which Dilthey (and others) describe can be difficult when those expressions are bodily, are non-verbal – may even be just a wince or a smile or a wink. To return to Bruner:

> *… an expression is never an isolated, static text. Instead, it always involves a processual activity, a verb form, an action rooted in a social situation with real persons in a particular culture in a given historical era. A ritual must be enacted, a myth recited, a narrative told, a novel read, a drama performed, for these enactments, recitals, tellings, readings, and performances are what make the text transformative and enable us to reexperience our culture's heritage … Experience and meaning [are] in the present; the past was a memory, a reproduction; and the future was always open, linked by expectation and potentiality. However, present experience always takes account of the past and anticipates the future.* (p. 8)

There is obviously something about the nature of experience that is 'immediate' and immersive. I can capture that, I can write about it – I can recall it later. For some of my residents with dementia, their past being eroded by their condition, much of these abilities are lost to them. But they can still experience – they are experiencing. Dementia has not robbed them of the present moment – as Turner writes, through participation in these music sessions, "*performances are what make the text transformative and enable us to reexperience our culture's heritage*" (p. 7). Later in this chapter we will describe what it means for participants to sing songs which are not 'theirs' and what that means for notions of creativity and 'making' – for now, I would like to move ahead slightly to the words of Lisa, a musician in many of the music sessions to come in the following chapters. A fellow PhD student, her research was on the nature of time perspective and how the ways we experience time can affect the ways in which we live our lives:

> *… as we get older, ahm, without illnesses like dementia and things like that, we tend to find that they* [older people] *are like really future-oriented, all they want to do, especially with their health, all they want to do is help themselves live longer, and it's all kind of like what can I do to make myself fit, healthy, and then, when you introduce*

> *something like dementia, it just robs the future orientation from them, they're back – in a way they regress back to – in a sense – to a young child that can only think about the past and what's happening at the present and what they want in the immediate moment. And it's, it's a really sad thing to work through your whole life to try and better yourself and becoming more focused on what you want and what you need to make yourself better and then just to be robbed of that. It's really sad.*

To a degree, I think that Lisa is right – dementia does make it difficult for people to comprehend a future. But it 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 in order to lead a partner in a dance. Sawyer (2003), writing about the nature of improvisation, holds that:

> *This 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.*

Working with people with dementia is nothing if not unpredictable, which in itself indicates the vast amount of potential participants might have to offer via their inclusion in design settings. For now, what is important to take away from this ethnography is the value of working within the present moment – with an eye half-open to the future – and that, 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.

Technology and the boundaries of community moments

The role of the 'low-tech tech' in St Eithne's bears mentioning if we are to consider how to open the design space in dementia care. I have described earlier in this chapter how, following breakfast each morning, residents were led by carers into the day room where the day began with a 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 Anthony's Unit. 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. This has been described in detail throughout this chapter, but it is important to consider the ways in which the pre-existing technologies in the unit enhanced this – the presence of the television, to which everyone was oriented spatially, in particular. Beyond providing music, some residents even seemed to 'enter' the media being shown on-screen – i.e., Fionnuala and her engagement with Daniel O'Donnell DVDs.

A lot of time has been spent arguing that people with dementia and older people in general are not willing to learn or to use new technologies – Vines et al (2015) demonstrate that this is not necessarily so; however, if some individuals who are older or who are dealing with a progressive condition resist using new devices it is not necessarily because the device is too complex or because the person is somehow lazy or incapable; it is more likely that they do not feel that the device belongs in their life; it is not meaningful to them. In this way,

barraging care homes with interactive touchscreen displays and giving iPads to people with dementia and expecting them to use it in a meaningful way is not likely to yield much in the way of insight about their use of technologies. We would do better to start with what is familiar – what has become so salient and so important that it has effectively disappeared (Norman, 1998; Streitz & Nixon, 2005) – and work from there to identify the interactions that emerge that are interesting for the purposes of design. For this thesis, it has been the ways in which particular forms of music (played by televisions and occasionally stereo systems) help some residents to engage in spontaneous, creative, group participation and improvisation. Having taken what we need from these ethnographic observations, we will see how these learnings can be used in working in new technological spaces to create new designs with the input of people with dementia.

The role of the body in expression and participation

If this chapter has emphasised the role of the body in expression and in participative activities carried out with people with dementia, it is only because it is so salient and so pervasive in my field notes and in my own recollections of my experiences within the care home. The importance of the body in older people and in particular older people with dementia has been acknowledged by Twigg (2000) and Kontos (2009, 2010) who use their observations to craft accounts of the relationship between careworker and cared-for, and to describe a sort of continuous selfhood that is emergent from the activities of the body, well into dementia. Although the phenomenological 'lens' of the body is one which has been fruitful for writers like Twigg and Kontos, it is one which did not seem to translate over to those who work with the aged bodies of the residents of St Eithne's. Twigg (2000) describes the reluctance of many "managerial accounts" to engage with the body thusly:

> *The body has little place in these analyses; indeed it represents just those qualities of embedded, messy, concreteness that such forms of analysis aim to transcend.*

> *Managerial accounts of home care are notable for their disembodied, aetherialising quality; and it is hard from reading them to gain any real sense of what the work entails. … An emphasis on the bodily is seen as potentially demeaning to disabled people.* (p. 6)

Most of the residents I worked with were not only living with a diagnosis of dementia, but many other concurrent illnesses. Others still had been through significant bouts of illness which made walking and moving around difficult, and, for some, which left them blind, mostly deaf, or sometimes unable to talk (Gerry, one of the more progressed residents, had had throat cancer and so his ability to speak was impaired). Moreover, residents did not tend to die of dementia alone – they died because of infections, of heart problems. The physicality of the body is hard to dismiss when working in dementia care, but the problem is that we tend to work with it in instrumental ways, much like the carers in the introduction chapter who believed that good care was not much more than keeping residents fed and warm. This analysis of my fieldwork has presented a different picture – one that is shot through with the tensions of occupying a body that may be, on many fronts, essentially failing – but which also recognises the expressive potential of that body, through its many surfacings with others in touch, dance, holding. The embodied nature of communication is one which is important here – and will be brought forward into the design space.

Power and equality in the care home

Chapter 2 described the power imbalance that can come about in the care relationship, while chapter 3 described the colonialising tendencies of ethnography, which can position participants as informers and not as much more. Earlier in this chapter, I describe research by Sandhu et al (2013) which describes the divisions along which people with dementia find themselves, which are ascribed in the paper to ‘functional status’:

> *Oakridge Manor residents with good functional status sometimes complained that they did not receive quality of care because staff paid greater attention to lower functioning residents, a situation leading to pulling apart, as illustrated in the following field note excerpt:*
>
> *Mrs. Forest then leaned over and said in a hushed voice while pointing to the man in the wheelchair, "He is the problem." Ms. Garland and Mrs. Forest were very upset for a couple of reasons… they both voiced concerns that the amount of care that "certain residents" require diminishes the quality of care that can be provided to the higher functioning residents.* (p. 40)

We have seen from observations in this chapter that different versions of reality and different progressions of dementia can lead to power differences which can see residents doing the sort of 'pulling apart' that Sandhu describes. For some, this pulling apart is almost permanent, and residents quickly become isolated as their behaviour drifts further and further away from the behaviour that is denoted as acceptable both by fellow residents and by carers. In the above extract from musician Lisa, she likens the progression of dementia to a return to childhood – this is a fiercely contested one in much of the literature, but one which I saw persevere in St Eithne's. Carers approached residents in ways that were similar to the way in which you would approach a small child – patronising and excessively servile, perhaps not always seeming to be sincere. Goffman describes how:

> *… total institutions disrupt or defile precisely those actions that in civil society have the role of attesting to the actor and those in his presence that he has some command over his world-that he is a person with "adult" self-determination, autonomy, and freedom of action. A failure to retain this kind of adult executive competency, or at least the symbols of it, can produce in the inmate the terror of feeling radically demoted in the age-grading system … the inmate may find that a kind of rhetorical*

> *use of language occurs: questions such as, "Have you washed yet?" or, "Have you got both socks on?" may be accompanied by simultaneous searching by the staff which physically discloses the facts, making these verbal questions superfluous.* (1961, p. 37)

The 'service model' of the healthcare system as observed by Goffman was clearly in full-swing; however, carers retained a strong sense of their own power over the residents. I do not wish to blame the carers for the ways in which they approached residents – again, the difficulty of working with people with dementia in a way which does not patronise them is raised later by Lisa, again (*"even the very sick ones, the ones who you do have to change the way you communicate, like they're still much older than me, and much more experienced, and I, if someone were 70 and if I saw a 70 year old on the street, I wouldn't go up and say* [loudly, in a sing-song voice] *hello, how are you now?"*).

For me, music was an equalising force – it made us all the same. As I describe above, even when someone stood up and 'monopolised' the space for performance, we could join in, tap our feet, tap our fingers – we, as an audience, had a collaborative role to play. Sometimes, we were not even equal – I was far, far outdone by many of the performers in St Eithne's, who not only knew the words much better than I did, but whose confidence in singing them was extremely strong. Within this participation, some people were sometimes left to the side – sometimes this was because they had no interest in performing or participating, and that was fine – in the case of Tom, he made a clear choice to avoid the parlour when Daniel O'Donnell was the order of the day. However, when we occasionally rose to dance on our feet, some of the less mobile residents would be unable. Their participation would fade, fall to the side as a result. Although music was a balm for many, and helped to equalise the performance space, it clearly wasn't a perfect solution just to throw on a record and have at it.

The role of the ready-made

There is a significant amount of attention being paid in HCI at the moment to 'making' – part of this is probably ascribable to Ingold's book of the same name (2014) which positions the act of making as 'knowing from the inside'. Ingold writes that this is because we are accustomed to talking about making as a project which produces an artefact, whereas making should be thought of instead as a process of growth. Much of *Making* hinges upon the idea of the maker as a participant in a world of active materials, which Ingold writes, are substances in becoming, always on their way to becoming something else. Materials are ineffable, and cannot be pinned. So far this processual account is sounding a lot like the ways in which McCarthy & Wright and Dewey before them write about the process of creating and experiencing art (or other objects of experience):

> *In seeing a picture or an edifice, there is the same compression from accumulation in time that there is in hearing music, reading a poem or novel, and seeing a drama enacted. No work of art can be instantaneously perceived because there is then no opportunity for conservation and increase of tension.... It follows that the separation of rhythm and symmetry from each other and the division of the arts into temporal and spatial is more than misapplied ingenuity. It is based on a principle that is destructive ... of aesthetic understanding.* (Dewey, 1934, p. 182-183)

I have been hesitant in the past about extending Ingold's metaphors to my own work because of this focus on materials and also because of the focus on generativity. Are people who sing old Irish rebel songs being creative? Are they making *anything*? Even Killick and Craig (2012), whose account of creativity in dementia encompasses multiple modalities and types of experience, write that "*there is a making process involved. Nothing was there at the beginning but at the end of the activity something, whatever its scope and quality, will have been achieved.*" (p. 13) Throughout the course of the PhD, I have come up against 'arts-based

approaches' because really, what my participants do isn't considered creative because it doesn't make something – something material isn't there at the end.

I have already quoted Sawyer in an earlier chapter, who points to the use of motifs in jazz and creative use of already-existing expressions as still *creative* – and I firmly believe that my participants are creating something – even if that thing is as ephemeral and as passing as a performance. Is Veronica's performance of 'Danny Boy' a creative and expressive act? Hicks (2000) describes a process of 'accenting each other's words'; she writes that, for Bakhtin, "*the individual becomes the unique ways in which one accents the words of others, and the ways in which one orchestrates a resulting system of discourses.*" For Bakhtin, accenting others' words ultimately leads to a kind of pluralistic consciousness where understanding as a process is much like that of the artistic representation of another's words. We sing songs because they mean something to us – the words of their writers echo through our own. For most of the music sessions which I will describe in the following chapters, which are hosted by a musician, songs which were particular to the locality are requested most often – 'On the Banks of My Own Lovely Lee', which is about Cork City:

How oft do my thoughts in their fancy take flight

To the home of my childhood away,

To the days when each patriot's vision seem'd bright

Ere I dreamed that those joys should decay.

When my heart was as light as the wild winds that blow

Down the Mardyke through each elm tree,

Where I sported and play'd, 'neath each green leafy shade

On the banks of my own lovely Lee.

There is no easy answer to the question of making and generativity that I can give at this point in the ethnography – for me, the particular nature of each performance, the constructive nature of the memories that are reached to make the song, the expression of the performer as they sing; these are the factors which make these performances creative. We will return to this question later in the thesis, when we will consider what it means to 'make' a performance for a performer with dementia.

Conclusion

This chapter has detailed observations from a longitudinal ethnographic study of life in a dementia care home in terms of how these observations related to a sense of belonging via engagement with music and music technologies, which was an exceedingly rich theme emerging from data analysis. From this chapter, I have laid out a) a framework for participation via interactions mediated by engagement with music for residents of the care centre (performing and spectating, connecting with another, belonging in group activities) and b) a set of insights from this framework which will structure the rest of the thesis – the role of experience in the present and future; technology and the boundaries of community; the role of the body in expression and performance; power and equality in the care home; and the role of the ready-made. These outcomes guide a deeper process of inquiry, mediated by design sensibilities, in the next phase of the project.

Chapter 5: Opening the design space

"The second floor was devoted to art, mostly local paintings that, however clumsy and quaint and mistaken, nevertheless radiated this innocence and hope, the hope of seizing something and holding it fast, that enters whenever a brush touches canvas." – **John Updike, The Centaur**

Introduction

In chapter 5, I discuss the approaches taken to turning insights from ethnographic fieldwork into a series of design spaces, ultimately culminating in the design and use of an interactive prototype, SwaytheBand, a response to the study discussed in previous chapters. SwaytheBand was designed to respond to the non-verbal forms of communication that were displayed by residents in St Eithne's during music sessions and to explore additional dimensions of the communal experience of joining in during musical sessions.

Image 5: using Swaytheband in various states

The prototype consists of a series of batons which are pre-programmed to light up and switch colour gently to the beat of music that is being played in the background. Initially conceived as a sort of 'visible metronome', a way to 'inform' the user as to a possible way of performing (stemming from the knowledge that not everyone was a performer, or may have felt unsure in their performance), the prototypes quickly became enfolded into an ongoing series of music sessions at several local care centres, where their use by people with dementia quickly transgressed our initial expectations of how they might be used. Linked to a central computer via Bluetooth, the prototype initially used a series of PS Move controllers fitted with a gentle light on top. As we watched the prototypes use changing and shifting during the

music sessions, we experimented with participants' experiences of materiality, craft and 'making' to temporarily change elements of these batons.

As a psychologist interested in the design and use of technology for and with people with dementia, by the end of my time in St Eithne's I was relatively agnostic on whether my participants wanted or needed design. What was clear was that if designed objects were going to be enriching for people with dementia, they needed to make sense to them in terms of their own experiences. I describe in the previous chapter how 'everyday technologies' such as televisions, DVD players, radios and music media were used in the unit to entertain residents, sometimes to keep them occupied and out of trouble – this could sometimes result in periods of passivity, where residents would disengage from their surroundings and even fall asleep, but it could also result in moments of communality and aesthetic experience. Sometimes this communality was important in terms of maintaining a sense of continuity from residents' own personal and cultural histories (e.g., the quiet participation in the televised mass each morning); sometimes it was spontaneous, explosive, joyous (dancing, cheering, clapping); and sometimes it was quiet and served to connect people in intimate moments (e.g., holding hands and sitting together). The previous chapter reported a framework derived from a Grounded Theory analysis of field notes which described participants' engagement with music through *performing, connecting* and *belonging* – in this chapter I describe how these insights were brought forward into a process of design and adoption of technologies by a community of people with dementia and their carers within a set of music sessions. However, this process of design is balanced in this chapter with a description of external events which led to my leaving St Eithne's unexpectedly and taking up the research process in two different care centres in Cork, Ireland.

Phases of design

This chapter describes two phases which took place between August 2014 and December 2015, which are described here as *ideation and concept refining*, and *collaborating and creating*. A third phase of design, entitled *testing and enfolding*, is visited in the next chapter, and concerns the ways in which the designed object found its place within care settings. Meanwhile, the phases of *ideation and concept refining* and *collaborating and testing* helped move the project from the analysis generated by the qualitative study in chapter 4 to ideas for design interactions.

Ideation and concept refining, the first phase, took place between August 2014 and May of 2015. This process saw me analyzing and writing up preliminary stretches of ethnography in order to consolidate some of my findings. It also saw me disseminate work which aimed to sketch out preliminary design spaces in the dementia ward as I had seen it. As this phase came to an end, and as some design ideas began to solidify, early workshops in St Eithne's were interrupted by a change in management which saw communication being cut off to the ward and my research process in St Eithne's ending.

The second phase, *collaborating and creating* (May – December 2015), occurred as a process of targeted design (of the SwaytheBand prototype), and was conducted in collaboration with design researchers from Newcastle University as I attempted to negotiate access to new care settings. It describes how the prototype came about as part of a design response to my own field notes during a hackathon dedicated to dementia care, and how we modified the prototype afterwards in order to get it ready for engagement in new care settings.

Testing and enfolding (January – May 2016), the final phase of the process, describes how the SwaytheBand prototype was enfolded into everyday practice in music sessions in the care centres visited during this phase. Alongside the acceptance and creative use of the batons, this phase describes a collaborative process of co-designing or co-*deciding* the ways in which our

music sessions should be run in order to allow participants to have a voice and a space to perform, connect and belong during these music sessions. This phase is visited in full in the next chapter.

Developing a design rationale

As I began to reach a point of saturation in my ethnographic research, I started to think about possible ways in which design processes and designed objects might help to create new possibilities for interaction and aesthetic experiences in St Eithne's. What was now clear was that more conventional notions of art-based workshops with people with dementia would not work here – at least, not in the way I had initially configured them – and instead, music was a modality whose expressive potential for people living in St Eithne's was enormous. I was nervous about this – I wasn't a musician, and at that point did not have research funding enough to bring in musicians to St Eithne's to work with my residents – but from the outset the aim of this project was underpinned by a commitment to participants' values and experiences. At this point, it may be important to revisit the initial research aims and questions of this project before considering how the data gathered so far provide answers to these:

Revisiting research questions & addressing approach so far

Research aims/questions	**Addressed by data so far**
To identify ways in which people with dementia living in care can participate in group activities and in community settings, with a view to understanding how this participation can become a part of meaningful communication and involvement in research	Identified: modes of participation through music and moving together (performance, connection, belonging)
To explore ways of being together and community for people with dementia living in care, with particular attention paid to the ways in which technologies can/could mediate this being together.	Notions of community for people with dementia living in care as fractured and individually complex; technology as facilitating this through opportunities to be together in the present moment
What does it mean to participate in a group activity when you have a diagnosis of dementia?	Nuanced account of what participation looks like for people with dementia in music sessions with reference to bodily communication

To what degree can this participation be considered as co-authorship (of research, of designed technologies, of the experience that the person might be living)?	**To be explored**
How can embodiment, making processes, and doing together be configured in dementia to facilitate communication between participants with dementia and researchers?	It is clear that the notion of embodiment for people with dementia is experientially rich, and can facilitate and deepen moments of 'richly seeing' (Hicks, 2000); remains to be seen how designing for/with embodiment can enrich experiences of people with dementia
How can any prototypes developed be used and evaluated to support community practices within groups of people with dementia living in care?	**To be explored**

Table 4: revisiting research aims and questions

The data collected so far have provided an account of the rich participation by people with dementia in music sessions. From this investigation, which hinged on notions of community and participating for people with dementia, and contributed a model which described this as *performing*, *connecting* and *belonging*, other insights were also gleaned. At the end of chapter four, these were described as:

1. **The role of experience and the present moment as constitutive in community moments**: the importance of paying attention to phenomenological expressions of experience in order to enrich the present moment
2. **Technologies and the boundaries of community moments**: the potential everyday technologies have for demarcating the boundaries of community moments and allowing for participation
3. **The role of the body in expression and participation**: the value of 'listening' to bodily expressions of experience by people with dementia, and becoming comfortable with responding in kind
4. **Power and equality in the care home**: shifting roles of 'performer' and 'spectator' and claiming space through performance
5. **The role of the ready-made**: can an authorial voice 'accent' the words of others – is singing a creative act?

These insights and critical questions helped to drive on the next phase of the research project. Beyond informing the sort of design work we ended up engaging in with participants, they were also questions which, I came to realize, concerned several staff members in the 'new' care homes in which I worked. Many of the above insights tap into key concepts in person-centred care plans which inform much care work in Ireland at the moment – however, these concepts had not been explicitly considered in terms of running music sessions with people with dementia. In many ways, although our work produced a digital technology, its production coincided with the development of a body of knowledge which allowed us to deploy this prototype in a way which was conscious of community, embodiment, power and creativity and how these may each be experienced in turn by participants.

Why open the design space? Critical reflection on the role of design and dementia care

If so much technology for people with dementia ends up by the wayside, why should we design for this population at all? At many points throughout this project, I questioned whether or not technological design would change anything about the lives of my participants for the better. St Eithne's was a relatively low-tech space – there were the aforementioned televisions, radios, as well as sensor technologies, alarms which restrained access to certain parts of the unit – and I couldn't see something like an iPad changing much about the community itself; not unless it was commandeered for at least a short time by a staff member who then spent time with residents in using the technology for activities which might connect them. However, staff in St Eithne's had such little time that only one resident had life story books, created by families and delivered to the unit – moreover, these books were very rarely used and stored in the (inaccessible to residents) nurse's station. The unit had a sensory therapy room which, as described in the previous chapter, was fitted with a light-and-sound system which could project soothing, attractive lights on the walls and play relaxing music or earth sounds; again, this room was never used for this purpose that I saw in St Eithne's.

Instead, the privacy afforded by the small room meant that it was often used to house residents who were severely ill or even dying.

St Eithne's was not a paragon of care; that much is clear from the HIQA reports resulting from inspections of the hospital. But all over the world, staff in care homes do not have enough time or enough training to engage with participants with dementia in ways which prioritise intimacy, one-on-one interaction, and non-verbal ways of communication. To put a design into this very tight space without thinking about how it might impede ways of working which these staff members have consolidated over years is to deploy a design destined to fail. For staff in St Eithne's, the Sensory Room meant giving up one staff member to sit with just one person. When there are only four on duty (after 5pm, only two), this is not feasible. However, to prioritise automaticity and to erase communication and connection with others is also unlikely to produce a design which is enriching to the lives of people with dementia who live in care.

There is an interesting challenge here inherent to working with design in dementia care, and that is in delineating a very specific design space – a 'cutting out of time and space' – in which the technology will be useful and will enrich the experiences of those who use it. Ultimately, I did not engage in design within the context of dementia care to create an object; although the process of research resulted in an object, this object was one which was unfinalised even to the end of the PhD, and resulted less in the solution of a problem for the participants I worked with, and more of a probe which helped us to understand expressions of their experience in ways which prioritized intersubjective embodied communication. The process allowed for discursive practices surrounding the value of music and creativity in framing participation for people with dementia. The ethnographic approach described above has offered several different opportunities to explore potential design spaces. A later section of this chapter – ideation and concept refining – will describe three of these opportunities,

one of which is the SwaytheBand prototype, which we ended up pursuing through to various stages of prototyping and use within music sessions.

Ideation and concept-refining

This section traces a process of ideation surrounding design for the community of St Eithne's through the description of three different potential projects, one of which was eventually pursued in the form of the SwaytheBand project. All three of these projects touch upon performance, connection and belonging through music to varying degrees; however, the context of use is extremely different from one to the other. Two projects are technological – one concerns event design but does not hinge on technology. This ideation phase lasted from August 2014 to May 2015, when a final project idea was decided upon and action began to be taken on designing and rolling it out.

Potential project #1: a songbook for Charlie

In chapter 4, I describe how performing familiar songs appeared to help resident Charlie reclaim a sense of 'power' (his words) following a difficult move from day residency to full-time residency. What mediated much of this reclaimed power was the use of a songbook which I had printed and filled with Charlie's favourite songs. Not only did this serve as a useful tool as we sat together and sang, Charlie's carrying it around the unit offered a 'way in' for carers to access part of Charlie's life and to experience singing together – something the carers themselves attested to. At the same time, I was struck by a small prayerbook carried everywhere by resident Veronica, which she frequently took out and thumbed through, despite the fact that she herself had never learned to read. She also had a beautiful set of rosary beads her family had gifted to her from a trip to Lourdes, again an object which she frequently produced from her purse and ran through her fingers.

At home, my mother, whose father spent much of his final years in care, described how he fretted over the lack of his wallet in the hospital, which he had previously kept in the front pocket of his jacket. My uncle had printed out banknotes on printer paper, had 'crinkled them up', and placed them in a wallet which was in turn placed in my granddad's pocket of his pyjamas. Since all Noel wanted to do was reach into his wallet and ensure the money was there, this worked well and calmed him down considerably. The solution even translated to others in the ward:

K: And was it like, the fact that there was money in the wallet or the particular wallet –

L: No, money.

K: It was the money in the wallet.

L: His money, he wanted his money. Mammy still says to this day, Libby, if he knew where his money went… and Mrs, Johnny Enright's wife, said – you told me about the wallet you had for Noelie, could you get some for Johnny? And they gave Johnny half of dada's money, some of dada's money, in a wallet for Johnny, and Johnny was delighted with his money.

As described in chapter 2, several design projects in dementia have emphasized the importance of objects and tried to create or embed familiar objects with digital technology in order to transform their capabilities (Wallace et al, 2012; Ou, Kuan, Wang, Tsai, Chen, 2015). Things remind us of home, says Twigg (2000):

> … home is a site of identity and self expression, **an opportunity to extend the self in material surroundings**. For many older people, home is particularly significant as embodying the memories of a partner; and its material surroundings are a daily remainder of continuity with past identity and relationships. (p. 78)

Our material surroundings are inextricably tied to continuity with our past identities and relationships. For people with dementia, for whom this past identity may be fractured and difficult to access, materiality and 'things' have even more important parts to play. It was clear that the interaction between Charlie and I – the singing, the sitting down together – was what was really fruitful here, but it disappeared once I (or other familiar people) went out the door. It needed some support, which is what I tried to do in creating the simple songbook. It worked, for a time, until the flimsy and fairly innocuous looking book was lost in the unit.

What is more is that Charlie was able to name some songs when asked what his favourites were – however, I didn't know these. It was likely that most others my age (in my twenties) would also not know these songs, which provided a barrier between our singing together. This was even more complicated when carers from other countries and other cultures came to sit with Charlie – about now, a new carer was starting who was from India. Kind and caring, she still faltered a little during music sessions. I was reminded of my own sense of obtrusiveness and cluelessness when, during a visit to a nursing home on a research trip to Aarhus, Denmark, all I could do during music sessions was to hum along.

I began to sketch out some ideas about what a more interactive, personalisable, sturdier, more aesthetically pleasing songbook might look like for Charlie. At the same time, the coordinator for the MSc in Interactive Media in my university put out a call for simple project proposals to the larger university – ones which might take only a few months of design and evaluation, but also serve larger research purposes. I submitted initial ideation surrounding two versions of 'Charlie's songbook'.

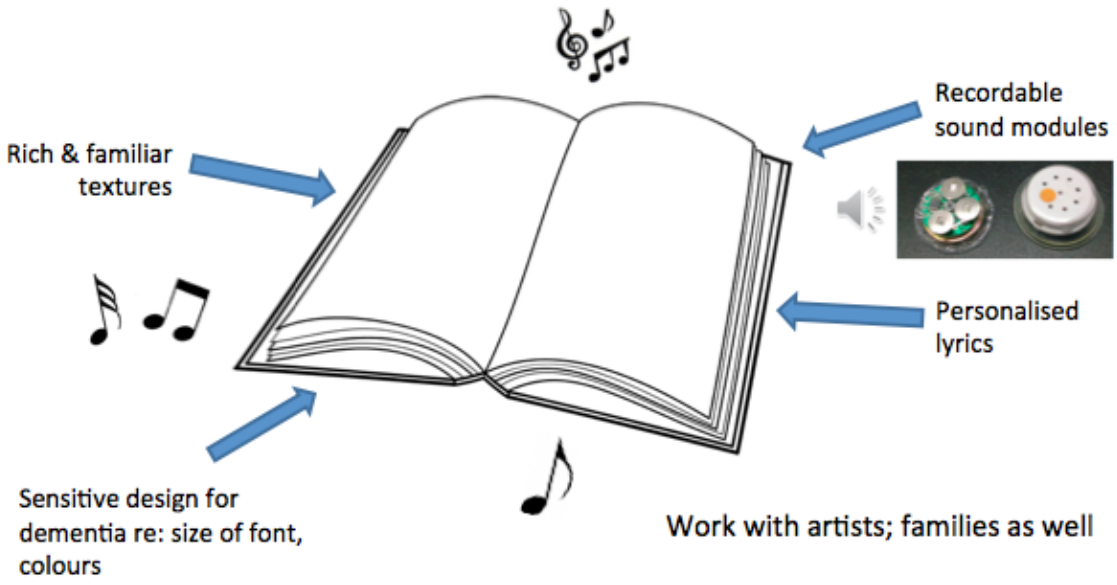

Image 6: a more material songbook

The first idea I had come up with was one that was not much farther removed from the simple bound songbook I had created for Charlie, but was instead a songbook that was sturdier, personalized, and interactive in very simple ways. This songbook would be filled with Charlie's favourite songs, bound in an attractive fashion using colours, textures and materials that meant something to him, and would feature recordable sound modules which could be loaded with instrumental versions of the songs on each page to facilitate singing along both alone and together – even if initially the song was unfamiliar, the instrumental version would allow the carer or other singer to sing along to the correct tune. The songbook would also be a lesson in cognitive ergonomics, and would be designed with features in mind for Charlie, whose eyesight was slipping, as well as with considerations for how his condition may progress.

One of the themes which had emerged from the Grounded Theory study was connection – and this was a connection that was often facilitated through physical closeness, sitting together, holding hands, and bonding over a shared experience of music. I felt that this

songbook answered to this theme very well, as well as to the theme of performance. Though performance in the unit was much more likely to be 'acted out' in larger, more noticeable ways, sitting together and singing quietly was also often a type of performance, whether it was one meant for the other, or one meant simply to exercise the ability to sing, or to dance. Again, the songbook could facilitate this 'quieter' performance. There was something missing, however, that hinged on the larger, louder performance of music and songs that I had seen in St Eithne's previously; not just communicating to another but instead communicating to a larger group; to community. Could a songbook facilitate that sense of community?

There were other questions about this design. The materiality of the thing would be valued by Charlie, I had no doubt, but we would have wanted it small enough to carry around – would it then get lost, as so many other things did in the unit? Would the recordable sound modules be loud enough for Charlie, whose hearing was also declining – and what if he changed his mind, decided he didn't like the songs that had been printed down permanently in ink into the (expensively made) book; or if we discovered another song he liked better? I had to think also of the people who would be helping me create this – would the project hold much interest for an Interaction Design student?

Because of these concerns, I also put forward an idea for a more digitalized version of the songbook that I hoped would go a way towards. This songbook would function as an app on a tablet, where the lyrics themselves would be easily personalisable to Charlie's tastes and the music could be linked up to play over the far louder tablet speakers. Again, issues concerning usability and cognitive ergonomics for people with dementia would come into play here – but as Charlie progressed, they could possibly be changed to accommodate for his changing abilities (changes in font size, colour of font and background). It loses some of the materiality and familiarity of the songbook, but it could be embedded into a larger frame which might

enhance the user's experience of the artifact; or else be housed in a textile cover which held similar meaning or aesthetic qualities as the cover of the material songbook.

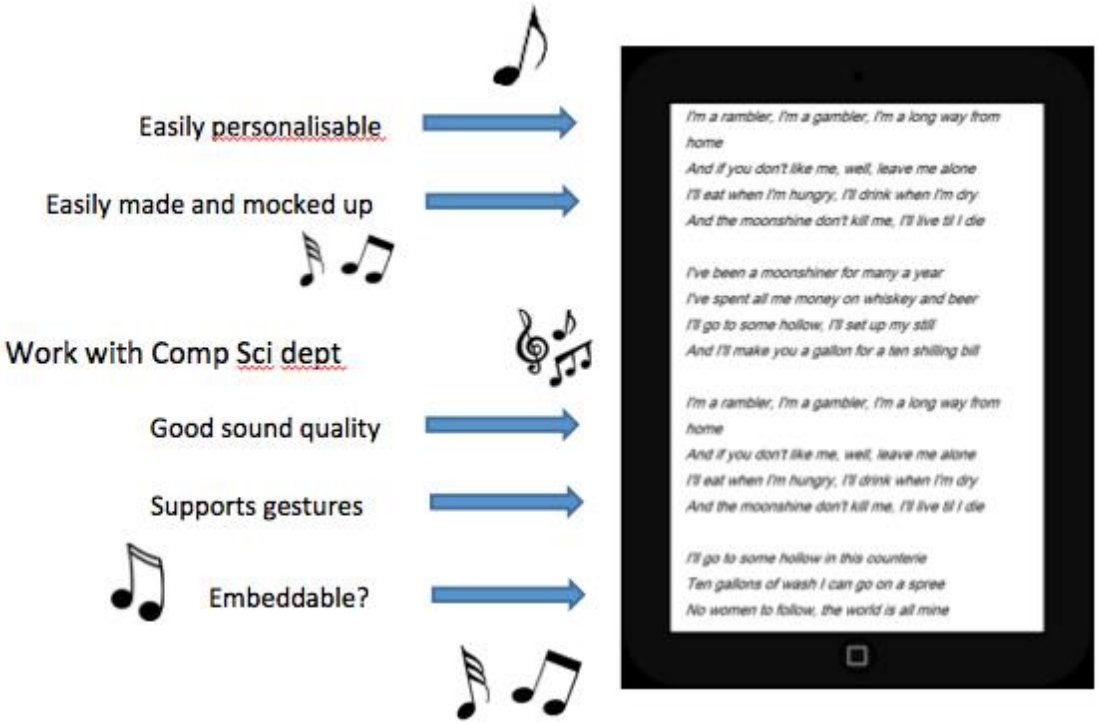

Image 7: a digital songbook

As I began to sketch this idea out a little more, I began to think that the digital songbook could be something not only for Charlie, but for other residents of St Eithne's, if we created an application that allowed for multiple user profiles. If I decided this was the direction to go in, however, I would be forfeiting one of the values of the original idea – the idea that having the songbook carried around or in the personal possessions of Charlie would act as a 'key' into his experience and his life, because instead the songbook would belong to the unit and not to just him. It was possible that either of these designs could be tailored to encompass aspects of the person's life history – I had already noted that life storybooks were useful in the unit, but not used to their fullest potential. There was precedent for the combination of digital life story-telling for older people and the 'listening' to this by a larger, younger community – Harley & Fitzpatrick present an in-depth case study of an older Youtube user

who finds an audience in the "…telling of his life story. For Peter [user], this is an opportunity afforded by YouTube that might not have arisen in the mundane concerns of everyday family life" (p. 20-21).

Although these ideas were interesting and I had a feeling they might be received well, I was somewhat skeptical of the richness that something like a tablet could offer residents of St Eithne's. I decided to carry out some small workshops concerning the potential of using a tablet as part of this design regardless, if only just to examine some of the possibilities that might arise.

On the day that the iPad workshop was scheduled, Charlie was out at the doctor. Instead I decided to take a one-on-one approach (since that was the imagined use context of the songbook), and first sat with Aideen for a while, holding out the iPad. I wanted to see what she did with it. I loaded up the pictures – a set of 'reminiscence' pictures I'd used a few times before - and held it out to her. The first set were pictures of ladies wearing 1920s, 1930s style, and strangely for Aideen, she was transfixed.

We got a good way into the slideshow before I asked her to use the device on her own. She took it from me readily, feeling the weight of it in her hand first but not remarking one way or another on it. I thought she would – it was a strange object, after all, but the novelty of the object doesn't seem to bother the residents that much. During these sessions, residents didn't have any anxiety over using something that's absolutely unfamiliar to them, but that behaves in a pretty familiar way – displaying pictures or moving like the television screen.

I told her how to flick through the pictures and she did so, very easily following my instructions. Her fingers flicked the 'pages' of the album slowly and deliberately, but the movement itself was not a problem to her – she was still transfixed by the content, making comments on the 'old style' and the 'grand girls' in the slideshow itself. She even shouted to

one of the passing carers to look at the iPad, holding it up and trying to pass it to her. The carer looked at me, warily.

‘Mind she doesn’t drop it now,’ she said.

We soon moved on to pictures of babies, which I knew from experience was great to stimulate conversation, but as the slideshow moved onto vintage cars, Aideen grew tired of it and began to touch the iPad in other ways – she was interested in the cracks in the object, where the button to turn the screen on/off was indented. Her fingers worked the grooves in the objects for a while, and then she spread her palms flat on the surface, seeming to feel the cool, flatness of it and handed it back to me.

‘Here you go,’ she said.

Resident Naomh’s interactions with the iPad were a little more laboured but quite intensive. For one thing, the object was somewhat familiar to her.

‘I’ve seen one of these before,’ she said, looking hard at it. ‘I think my granddaughter has one.’

We looked at the slideshow together first, and though Naomh got the swiping movement down quite easily, she pushed *hard* on the surface of the tablet – so hard that the tablet was forced down in my hands and I had to struggle to hold it up. I corrected her once or twice, but she kept up with this motion and so I just held tight.

We went through the whole slide show – Naomh was quite alert that day – and then engaged in chat about the iPad. She really liked it – said it was ‘handy’ and that she’d like one herself. She wondered a little more about where she could have seen it before, and asked what else it could do.

I moved into the music app and showed her the playlist I'd created for today – mostly old Doris Day songs. I hit into 'Que Sera, Sera' and asked her if she knew this one. She inclined her ear to the tablet, listening intently, but then looked up once more, shaking her head no.

I opened up the iBooks app, where I had a PDF of all the song lyrics from the song. I held the screen to her and she took the iPad in her hands. She peered at the lines and I saw her face register recognition.

'Yes, I know this,' she said, and began to sing along with the lyrics. We sang along until the end of the song and then chatted a bit about Doris Day, about the song itself. I could feel it wasn't a day for a singalong – the rest of the room was sleeping now, or else up and wandering – so we stopped there.

It wasn't enough data to begin to extrapolate from, but using the iPad in mini-interactions with Aideen and Naomh seemed fine. They weren't put off the unfamiliarity of the object – indeed, Naomh had even seen one before and remembered it. If we did build the songbook app, it would almost always be used with a carer, and so issues such as Naomh's pushing down on the tablet surface too hard could be dealt with within that interaction. It remained to be seen how residents would deal with navigating the application itself. I had some trepidations about going forward with this idea – the idea was to provide a space where Charlie could connect with another person, show them his strengths and indeed part of his history; if I tried to make 'something for everyone', I was going to lose this. Beyond this, who was going to compile the playlists for residents; who was going to get the song lyrics to embed them into the app? What about copyright permissions? These were questions for which I could readily see answers from my point of view – buy the songs in the iTunes Store, grab the lyrics from a myriad of song lyrics sites - but in the care home, I knew time was short and staff availability was even shorter. Not to mention the IT skills of some carers were

hardly better than the residents themselves. I could imagine a sort of project surrounding the songbook being 'filled' by volunteers or placement students (or even researchers) who, in doing so, would spend meaningful time with residents, engaging them in musical activities and, if allowed, contacting their families. This could function as a piece of participatory action research, and was a way forward with the project that I could foresee being quite fruitful.

However, something twinged when I considered this songbook against the backdrop of wild, unhinged participation that occurred during group music sessions. It was missing something infectious that spread from person to person until almost everyone was visibly participating in something quite joyous. It might disappear as quickly as that, but that sense of spreading vibrancy and coming-to-life was missing from the quite, calm, sedate one-on-one interaction allowed by the songbook. I didn't park the idea yet – but I put in a simple application to the MSc programme and continued to develop the idea while keeping an eye open for others.

Potential project #2: an event

During this time, I refined and re-refined my analysis and watched as the theme of *performance* emerged very strongly. Before now, I had been thinking of the sorts of activities that would best lend themselves to design, thinking that if I could see how easily someone painted a picture then I could 'tap into this' and translate it to how this might work in design sessions. It was now becoming clear that if I really wanted a window into the experiences of people with dementia, I had to put myself in their shoes – what were the participative activities that they carried out thirty, forty years ago? The ones they really enjoyed? It might have been sport, and for some it was. It might have been work, and some residents, who had been nurses or carers themselves in their past, often seemed to believe that they were at work in the care home, and acted this way. But for most, it was not art; most of these people had spent their lives working hard, travelling the world for jobs, bringing up children and

spending time with family and friends. For these people, a sing-song in the pub after work, at a wedding, a christening, a party, surrounded by family and friends, was the last social group activity they participated in with any regularity, and it turned out that that was what was evocative for them all these years later in care centres and care homes, though everything else might have changed. Interviewing Eleanor (the head nurse with whom I initially worked in St Eithne's) later, she confirmed my thoughts:

P I think, Kellie, if you're talking about the older generation, they would never have studied art. They would never have sat down and painted a picture, or drawn a picture. It wouldn't have been part of I suppose their upbringing, or, whereas maybe for groups for like you, yes, now we all have these colouring books and we're all colouring them in.

K I have like three of them at home. [*laughing*]

P A lot of people I would have worked with, would have found it – a little bit degrading. And a little bit – infantilizing.

K Yeah, absolutely. Yeah, cos if you -

P We – we didn't use it a lot, and I, I didn't like it, myself. I withdrew from it myself. Music is different, I would like every kind of music myself, and if I ever get a dementia, Kellie, and you're around – music. It doesn't matter what kind of music, and most people would have their preference, but they love all music. It, ahm, I found it a lifesaver, if they were ill I could use music, if they were happy I could use music, if they were sad I could use music… if they were, I suppose, being in any little way, I suppose presenting with responsive behaviours, music would calm them. It's amazing.

This sentiment was echoed once again at a song session I attended in Mallow, Co. Cork for people with dementia and their carers. 'Are you a singer?' I asked the lady beside me.

'No,' she admitted. 'Not really. Only with friends, you know. In a group, down the pub.'

The song session I attended was a session of 'Singing for the Brain', a six week pilot singing group undertaken as part of the activities of the Crystal Project, which hoped to help Mallow to become a "dementia-friendly community". It took place in the ground floor of the expansive Mallow Primary Healthcare Centre, and was facilitated by a trained singer.

The session itself was full to bursting, and the facilitator had us singing scales and rounds and with this, incorporating bodily movements, swaying, and interactions with those around us. Only some of the participants had dementia – others came as carers, family members or people with worries about their memory. You could see that everyone was enjoying themselves, joking along, chatting and grinning ear-to-ear. The session was pretty lengthy and punctuated in the middle by a tea break, where we got to sit and chat with one another in a little more depth. The second half of the session focused on familiar songs and was, in effect, a participant-led singing session; the facilitator passed out some songbooks but participants had come ready with some songs that they wished to perform as well. Everyone was allowed a spotlight for at least a brief moment – as I left I heard several ladies excitedly planning their 'party pieces' for next week.

Image 8: performers at the Purple Pops concert

Shortly after my attendance at the Singing for the Brain session, I attended a concert entitled 'The Purple Pops', staged by people who received some of the services of the Alzheimer's Society, Cork along with some staff and carers. The performers were twelve people with dementia, and the night featured music, song, dance and recitation from the performers. It

was raucous but fun – the performers were relaxed, enjoying themselves, in excellent humour and clearly this performance had been built around their particular talents and their party pieces. What is more is that the performance involved the audience to a large degree as well: family members and friends in the audience were invited to join in the performance via song and dance, and at one point, we were provided with large swatches of shimmering cloth to move along with performers to 'Shrimp Boats' by Jo Stafford. I was so struck by the public nature of this event – it was in a local theatre, was advertised in the paper, and anyone could attend.

In Ireland, people with dementia are still, to a large extent, hidden away from the public; they are institutionalised in care homes, or at best are cared for in their own home or in their family's own home. They rarely become a part of the larger community, though many residents in St Eithne's still spoke about the community from which they came with pride and a sense of belonging, like Gilly, whose pride and joy was the large family she had brought up on her own, her husband not an active participant in the rearing of the family:

> *'I'm from Ballymac… it's a small town, it's beyond Duncoillte. But they all know me there. I have five sons and two daughters, and they all know the McGoverns in Ballymac.'*

Although both are towns/cities in the south of Ireland, the differences between Cork and Tobermore with regard to differing attitudes to people with dementia can be seen just in this category alone; however, although Cork ran many innovative events for people with dementia in the community (such as tea days, Singing for the Brain, art events), they were largely an invisible portion of this community. This is why the Purple Pops concert impressed me so much – it literally put people with dementia front and centre, as the performers, and even then it did not stop with this 'privileged position' – it invited family members onto the

stage to sing along, gave the audience props to participate in their own way. It must have been tempting to beg for quiet and allow the performers all of the spotlight on the night, but it went beyond this to create a community of performers within that one room, for that one hour. It was hard not to think of my own experiences of 'community moments' in St Eithne's, and how they could come together and dissipate. As I left the theatre that night, I heard a family member congratulating one of the performers on his rendition of a particular song. 'What song?' asked the performer, bemused.

I began to think of how an event like this might play out in Tobermore, how it might play out with residents from St Eithne's as the performers. I could already see some of the residents standing up at a stage, performing their party pieces, and knew I could anticipate very little in the way of problems there, given that we were sure that residents were not coaxed or coerced to perform. I was concerned a) that staff would object, and b) that we would not be able to fully replicate the sense of participation from the Purple Pops concert. Moreover, I knew it was not enough to simply recreate the Purple Pops event – at the very least, a recreation must be set up in a way that we might learn from the process.

Early ideation around this concept hinged on two ideas: either involving residents from St Eithne's as performers in a public concert <u>or</u> including members of the public as performers (along with performers from St Eithne's) in a concert that was to be held either within St Eithne's or in the larger setting of Tobermore Community Hospital. The first was tricky – I had run into issues with Tobermore Hospital before – it was difficult to get them to contact members of residents' families in order to run projects like life storybooks, etc, and I did not anticipate them being particularly welcoming about a project like this. If I had been surprised at the ease and openness with which the Alzheimer's Society had made their clients performers, then staff of a small dementia ward in a smaller town with no local support from

the Alzheimer's Society and relatively little support from the HSE would, I thought, be even less open to the idea.

The second option was more likely – not turning a 'concert' public, but labelling it a concert anyway, and inviting selected members across Tobermore Hospital to the concert itself. An idea I had at this stage, building on the 'community feeling' present at the Purple Pops gig, was to invite members of the local community to St Eithne's to host a concert together – one where the 'audience' was either fairly selective, or not an audience at all, instead a group of performers, who would each take turns at performing, or join together in a performance. I had been part of a choir in my 4th year of secondary school, and had retained some good links with teachers at that school – it might be a good idea to invite some of these young girls, the newest iteration of the choir, and not only create a concert, but lay down a link that might re-occur once or twice a year: a coming together of communities of performers. Such a link would not only foster connections with an 'outside' that was longed for by many members of St Eithne's (an outside not only of place but of youth), but would result in co-learning experiences for the students and the staff who could come to learn about the experiences of people with dementia.

There was a ready-made space for this performance already in St Eithne's – twice a year, the hospital would open up to host a 'fair' of sorts – if the weather was fine, residents of many wards would make their way to the green space outside the hospital, where food was served, family members would visit, and games such as bingo and dice would be played while live music was performed in the background. The space was already there – or something like it. Though there was no technological element to this idea so far, I was not entirely worried – there didn't need to be as long as there was an opportunity for learning about themes of connection, community and performance as they had already come up within my studies so far.

The concert didn't come to be, for numerous reasons, but before I describe why this did not happen, it is important to consider for a moment why a concert featuring people with dementia as performers is intellectually interesting. First of all, as already stated, it is a bold act, one which is radically opposed to conceptualisations of people with dementia as unable to participate or to perform with skill. It need not be that the person with dementia be given a privileged position as performer – though some, like Veronica, would perhaps enjoy that – instead, it can simply function as a space for their participation to be seen and to be valued as equal to that of people who don't have the condition. In describing 'the distribution of the sensible' or the way in which social order is 'policed', Rancière writes that the "*apportionment of parts and positions is based on a distribution of spaces, times, and forms of activity that determines the very manner in which something in common lends itself to participation and in what way various individuals have a part in this distribution".* The challenge here is to conceptualise a performance as an opportunity for all kinds of people to participate – whether that participation be doing a reel across the stage or sitting quietly in the background of the stage, having made a choice (communicated verbally or non-verbally) to be there.

Holding a concert like this would undeniably be a political act, but it would also be one which had something interesting to say about aesthetics. This concert is one which is far removed from the afternoons spent watching Daniel O'Donnell in the day room; there is something *live* about this performance. The word *live* here chimes with the way in which music seemed to bring to *life* many residents across St Eithne's, but the distinction to be made here is one between representation vs repetition (Auslander, 1999). The once-off nature of the concert meant that it couldn't be repeated, unlike the televised concerts resident sat through day after day; there was something *special* about that day, something particular. In my initial ideation about this concert, it would represent a coming together of communities

once or twice a year, and include planning and workshops that would be aimed towards sustaining such activities after I had left. In this way, organising a concert such as this was aspirational concerning its eventual reoccurrence within the community – but although it would reoccur, each concert would not be a replication.

I did not get to plan the concert out beyond initial stages of ideation – as I returned to St Eithne's in early 2015, I discovered there had been a change in management which meant my line of communication with the unit would be cut, and would require me to go elsewhere to continue working with communities of people with dementia.

An aside: leaving St Eithne's

Having spent the latter part of 2014 carrying out research visits abroad as well as organizing and beginning analysis of my ethnographic data, I contacted St Eithne's unit in early 2015 to arrange a new set of visits (one of which would be the earlier-mentioned workshop using the iPad). I learned that Eleanor had decided to take an early retirement and was no longer working in the unit. Contacting her, she agreed to put me in contact with the new Head Nurse – Marjory. Marjory was welcoming, professed some interest in the use of music in dementia as a spiritual intervention, and asked me to come along for a visit. I held about three sessions in St Eithne's before communication ceased from the ward's side.

My field notes from the final session in St Eithne's bely a creeping discomfort I was feeling in the change of management – while Eleanor had joined in in our sessions, supervised, or occasionally just 'let us be', checking in on us from time to time, I felt that Marjory was watching me very closely from the Nurses' Station's glassed wall. In my notes, I write that "*… the arrangement and the mood of the unit today told me that today wasn't going to be great for music and exploring as I walked in*." Although I would usually walk around the room, saying hello to everyone and reminding them of who I am and why I was there, there

was something about the presence of the new head nurse, Marjory, that warned me off going about my usual trek that day. I felt as though I'd better stay out in the open, not engage the men who sat alone in the parlor, nor talk too long to the newer residents with whom I didn't have the same history. Marjory stood in the Nurses' Station with the other nurses and carers, chatting, for the entire hour or so that I was there. I felt a little bit under surveillance here, in a way I hadn't before. It made sense to be protective, but I found myself constantly glancing at the glass of the Nurse's Station in a way that I'd never done before. I felt that my business here had better be just that – business – not the usual ramble through media and materials and chat, punctuated by comfortable silence, but a sequence of activities that made sense to an onlooker. Just for now at least – "*until she trusts me a little bit more*", my notes say.

It made sense for Marjory to keep a close eye on me – I was a strange figure in the unit, disconnected from my initial connection to the unit, Eleanor. Although many of the carers welcomed me warmly into the unit, my familiar way of engaging with Una, Aideen and others may have seemed a little strange. Compounding this was my role as a research psychologist – I know I did not act like the sort of psychologist that most often frequented units such as this. This session was again, perhaps less interesting than it might have been because of this discomfort. I had, in earlier sessions in St Eithne's, felt maybe quite nervous or unsure and uncertain, but this was the first time I had felt discomfort.

Nevertheless, I finished this visit by carrying out a short engagement with textiles with the residents. I called into Marjory before I left – I brought along some documents explaining my research, its ethical approval, my own training, degrees, experience and Garda (police) Vetting, along with some of the documentation we had co-created with the hospital at the start of the project detailing my involvement in the unit. I passed along these documents to her, and she asked if she could keep them and pass them along to the administration of the hospital. I agreed, and offered to come and meet her and any others to explain more about the

research process, how we initially configured consent with participants and suggested that if she had any worries, that we could contact families and appointed caregivers again. She told me she would pass the documents onto management and be in touch shortly.

Although I tried many times and many routes in the following weeks to get in contact with Marjory or with others at the hospital, I was not successful, and to this date have not heard from them again (though I later contacted Eleanor – an interview with her forms part of the thesis, as can already be seen). My emails went unanswered, and I was unable to get Marjory on the phone – St Eithne's had always been a little difficult to contact via telephone, but when I called she was never available. I contacted people whom I had known in management as well as activities coordinator Rosie, but I received no reply. This silence coupled with the unease I had felt on my last two visits to Eithne's made me rethink the unit as a setting.

It was very difficult for me to make the decision to discontinue my attempts to contact the unit, most notably because of the people I had met and grown to know – people like Aideen, Máire, Una and Charlie. Having spent a lot of time in the unit, I was aware at how quickly people could become ill and pass away, especially with comorbidities such as dementia, and not knowing how they were getting along was painful. I still think about Charlie very frequently, but it was clear to me that the unit was uninterested in continuing the involvement we had set down in the preceding years. This was further complicated by my engagement in my PhD thesis – I was funded only for a particular period, and at that time the year-mark until my funding ended was encroaching. It became clear to me that I needed to seek out new settings. If I had been in an earlier year of the PhD, it would perhaps have been worth it to wait for some time to see if contact could be re-established, but for now I needed to get back in. This represented several challenges:

1) I could no longer create the bespoke songbook for Charlie (though the 'communal' songbook still remained an option);

2) The 'concert space' (via the bi-annual fair) in St Eithne's was no longer available to me; nor were my community connections in Tobermore any good without a community of dementia care to connect them to, and;

3) Any future engagement with new communities would mean the 'testing' of the analytic framework from the St Eithne's study, as well as any design ideas that had come from engaging with particular St Eithne's residents.

For a study which had, from the outset, included a strong focus on experience and an orientation towards the irreducibility of this experience as mediated through bespoke designing-with-communities, the third point above was a particular challenge. I had anticipated that any 'testing' of the framework would occur during an evaluation phase with the same population it originated from; here was a more imposing challenge, and one which interrupted a clean narrative flow of an account of engaging with a community. Nevertheless, it was clear that new connections had to be forged in order to bear out the rest of the project. In mid-2015, I focused on contacting care communities in Cork City, where I was living and studying, in an attempt to engage them in the research project. At the same time, I began to work with a team of designers from Newcastle University on a design response to my initial ethnographic findings.

Collaborating and creating

Potential project #3: SwaytheBand

In May of 2015, as I was contacting care communities in Cork City with regard to engaging with my project, I also took part in the Create4Dementia hackathon, a 48-hour design event funded as part of the EPSRC – NIHR HTC Partnership award: Social Computing and Mental

Health Research Network, and hosted by Newcastle University in the nearby Great North Museum.

Engaging with Gavin Wood and David Green, other PhD students at Open Lab, Newcastle, I described some of the rich interactions I'd seen surrounding music in the care home. As interaction designers and musicians, they latched onto these ideas – at first we were more taken by the fantastical idea of Fionnuala's delusions and the ways in which she seemed to 'enter' media she was presented with, and spent most of those first 24 hours thinking up of rich virtual-reality environments which we could present Fionnuala with. We eventually gave up – although I had these notes on Fionnuala and what she seemed to be experiencing at this time, it was too difficult to explain to ourselves what we wanted to do here in a way that would also make sense to Fionnuala. And what was the use of a VR headset if she was already imagining herself in the audience of a Daniel O'Donnell concert? It was clear that Fionnuala's imagination was already rich enough.

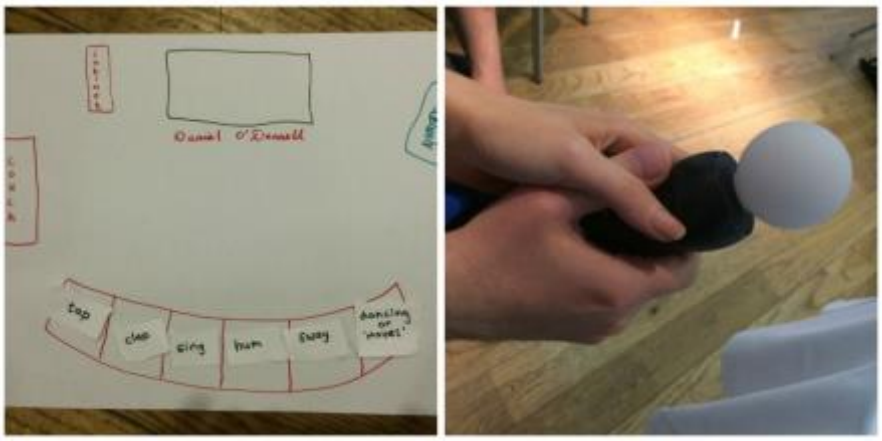

Image 9: left - ideation around moving in the care home, right – PS Move controllers used as SwaytheBand batons

Plus, it was such a solitary activity. So much of my notes concerned group activities – group moments – in a day which otherwise stretched on as residents spent their time alone. It was then that we reverted to an idea we had tossed around in the pub the night before – a prop, or a musical instrument; something that would meld seamlessly into the music sessions which

were carried out in these care homes, but which would add something to the performative experience. I showed the video of the Purple Pops performers using the swathes of cloth to sway from side to side as they sang 'Shrimp Boats' – this group movement enchanted my teammates as it had me. I described how, in St Eithne's, when I had tried something similar out, how Aideen had 'given out' as the large swathes of cloth confused her and made the parlor seem messy; how Malachy was 'sealed in' by the bar of cloth, and how carers were worried about others tripping on it. I described the modes of participating which I had seen in the unit, the tensions between spectators and performers, the rich opportunities for connection via touch and group activity.

Building on research such as Harley, Fitzpatrick, Axelrod, White & McAllister (2010), which explored the use of game controllers in sheltered housing for older people, Gavin had the idea to use PS Move controllers as a central device to explore these themes. They could become metronomes of sorts which would help keep the time of the music being played via a pre-programmed beat. In this way, the device was instructive; it illustrated the beat of the music being played, and invited you to move along with it. Ideally, using the system would encourage participants to sway or otherwise move to music being played by a computer system (in these sessions, linked up to a PA system) by illustrating a song's tempo using a series of sequenced (gentle) coloured light flashes to correspond to changes in beat. Each participant is invited to hold a PlayStation Move controller (or baton). During a song the band members hold the controller as the LED light at its top changes colour in time to the beat of the music. The controllers are connected to a central computer via Bluetooth (using the PS Move API), with the computer dictating the colour and timing. This configuration is able to support up to eight participants with the computer being additionally responsible for playing the music. For the hackathon, the timing of the lights was hardcoded to accompany "Shrimp Boats", a song by Jo Stafford.

Image 10: some of the comments we received during the Hackathon, and centre, our team

The hackathon was well-documented; as seen in the above picture, as we progressively demoed our prototypes throughout the 48 hours, we received notes from the other competitors as well as the judges, comprised of occupational therapists, dementia care-centre CEO, and interaction designers. These notes helped to shape the questions we asked of our prototype as it developed, and echoed through to the use of the prototype in the care homes. At the end of the day, we won the Grand Prize. Over the next few months, we communicated from our respective labs in order to set up a new set of prototypes to use in care settings that

coming September, which had been decided as the point at which I would enter these new care settings.

To begin with, I purchased a set of 8 PS Move controllers as well as the accompanying chargers, and, in a collaborative meeting in July of 2015, the three of us met up to set up a new list of songs which I had selected from my field notes as being enjoyed by residents – 'It's A Long Way to Tipperary', 'Shrimp Boats', 'Let's Face the Music and Dance', and Charlie's favourite, 'The Moonshiner'. The system can be configured for multiple songs and different timing arrangements: we specify the beats of the song in XML file (a format used to create and share data so it can be both easily read and edited). We discussed ways in which the batons could be decorated – we initially decorated the batons with rope-textured handles to thematically link them to the original song, 'Shrimp Boats', and its maritime theme, but meetings since then that I had held with caregivers had them remarking on the easy grip of the 'naked' baton, and the smoothness over the rough rope handles – for initial sessions, therefore, we decided to leave the batons as they were. From my knitting sessions with Una in St Eithne's, I was eager for participants to create their own 'clothing' for the batons – but for now, that was an idea to be explored later. It was more important to see how participants used the batons in real care settings.

Although we had not yet had a chance to use the batons with participants with dementia, it was heartening to have our ideas recognized by people who had first-hand experience in the field; however, on reflecting on the process, I wonder how it fits as a 'design process' – we relied heavily on my field notes, on video clips of people I had worked with, on actual design ideation sessions surrounding the use of cloth, but there were no people with dementia at the table, or at the hackathon, not even people in the earlier stages. Did this continue the participatory approach which I was hoping to take in my research? We had input from experts, from those with real experience in the field; but the fact remained that this portion of

the research existed outside of care homes, outside of the experience of people with dementia. The design responded to the ideas I had had surrounding liveness, performance, group activity – but it wasn't enough to stop here. It wasn't even enough to evaluate the prototype with people with dementia. If I wanted to explore in depth the ways this tool could be used in participative music sessions, I had to spend real time in care settings again to figure out its place, both as a design object (an object to be used in a process of engagement in design) and a design(ed) object (a 'final' product).

In choosing to pursue SwaytheBand over the other options, I realised I was doing something slightly risky – though I had not yet engaged in prototyping ideas such as the songbook, or advancing my ideas surrounding the concert to St Eithne's, they were relatively well-fleshed out, and through my extensive notes and creation of Charlie's songbook, were, to an extent, proofs of concept – I had seen these concepts working with real communities. SwaytheBand, I had not yet seen – but as a design response to the ethnography detailed in chapter four, it came to touch upon versatile aspects of *performing*, *connecting* and *being in community*. Moreover, it became a fruitful lens through which to view and re-frame the communication and participation of residents in dementia care.

Summary

This chapter has described three potential projects which arose as part of two periods of design within the larger PhD project; these are traced out alongside an unfolding narrative of engagement and later, discontinuity of engagement with the community of St Eithne's. The final prototype, created in an interdisciplinary design team with particular reference to field notes produced through my time in St Eithne's unit, is entitled *SwaytheBand*. The final phase of designing within this project – *testing and enfolding* – is described in the next chapter, where SwaytheBand is evaluated not only as a 'useful' and enriching object within the

context of dementia care, but is also used as a tool to learn more from engaging with this community.

Chapter 6: Enfolding: using SwaytheBand in care settings

Introduction

This chapter builds on the design work described in the previous chapter to explain the ways in which SwaytheBand was introduced and later 'enfolded' into a series of music sessions in two care homes in the south of Ireland. Beyond this, I describe the process of re-entry into both care settings that was necessitated by shifting the ethnographic focus from St Eithne's. Engagement within these care settings on the part of staff and residents was much more involved, and because of this, the planned music sessions became a reciprocal process between the care providers and us as researchers. In this way, the methodological shift in this chapter is from ethnography to a form of participatory action research embedded within a design intervention. This shifting of the dialogue space is reflected in the analysis and results presented in this chapter – I have included excerpts from interviews held with care staff, co-researchers and musicians which add moments of reflection and connection with the aims of the project as we began and as it evolved. With the previous chapter having discussed the SwaytheBand batons themselves, this chapter primarily focuses on engagement and participation as outcomes of the research process.

Re-entering the field: Clermont Place and Rosebank Nursing Home

As we developed and prepared the SwaytheBand system, I was also engaged in contacting local care homes in Cork City (where I was studying and based) in order to query the possibility of carrying out some research in these settings concerning music and using our SwaytheBand system. At the time, I did not necessarily want this new phase of research to focus entirely on the SwaytheBand system itself – but rather to try to understand the place of the designed system within the care homes. At this point, we had not trialled it with participants with dementia, and I was ready if the system proved to be uninteresting to them. Having elucidated from the first ethnography the three central themes of performing, connecting, and belonging as constitutive of participation within music sessions for people

with dementia, I was interested to see how our prototype could answer to these three themes, and how it could show us new forms of participation by people with dementia, or shed light on instances which I had only glanced in St Eithne's. In this way, my analysis, articulated through this designed object, was about to be explored for evaluation and validation purposes.

Two of the three care centres I initially contacted returned my calls and letters quite quickly, and were positive about the opportunity to carry out some work in the area of music for their clients and residents with dementia. In particular, both settings – unlike St Eithne's – were interested in what they could get from my presence and my involvement as a researcher within the setting. These two settings, introduced briefly earlier in the thesis, are Clermont Place and Rosebank Nursing Home. It is advantageous to briefly revisit both settings in order to explain the ways in which our involvement began.

Rosebank Nursing Home (RNH)

RNH is a private nursing home in a suburb of a small city in the south of Ireland. It is large, with four floors and 100+ residents. RNH has an active culture of 'activation' and a heavy focus on activities for residents, and music was already a large part of this schedule in different ways – musicians of all types would visit on a weekly basis, with Wednesday tending to be the 'music day'. RNH and their activity coordinators – Kylie and Maria - were interested in evaluating the ways in which music was already used in the setting, particularly with those with dementia. They were also interested in a number of other research questions – concerning pet therapy, massage and beauty therapy, among others, and because of this, I set up connections with my university department, with the idea that these questions could be the focus of small-scale final year project and masters students. The expansive RNH stands atop a hillside in Rosebank, Cork City, where it looks out over the harbour and the south side of the city. The four floors of the centre are named after local suburbs in the city itself, and

residents are assigned to particular floors based on their own needs and cognitive status. Although most did, not all residents have received a diagnosis of dementia: those who have were identified prior to the sessions by care staff so that field notes could focus on interactions with these participants. Involvement with RNH lasted for a shorter amount of time than it did with the next setting, Clermont Place. This was due simply to time constraints as well as a particularly strong bond that was forged with Clermont Place's staff and clients.

Clermont Place (CP)

CP is an assisted living facility that also has an expansive day care facility. CP is also a mental health centre which caters not only to the elderly and people with dementia, but also to young people seeking counselling services. My engagement with CP was mainly focused on the day care service, which catered to about 25-30 different clients each weekday, with Wednesdays (our visiting day) particularly set out as a day on which clients with progressed dementia would visit. CP is in another suburb of Cork City, about 25 minutes' drive away from the city centre, and caters to clients from all over Cork City. Although the campus of the centre is mostly given over to assisted living for full-time residents (who must not have a diagnosis of dementia in order to reside there), our research was mostly confined to a large hall in the main building which functioned as the day centre, and smaller rooms to the back of the building in which we worked with smaller groups from time to time. Our main contacts in CP were Glenda, a carer who was also the activities coordinator, and Breda, a nurse, though we engaged with many different members of staff during the process.

Bringing on board: research assistants and musicians

It is worthwhile at this point to mention that this move into new care settings was accompanied by an enlarging of our research group. I was accompanied on these visits to care settings by two final year project students in Applied Psychology – Hannah and Aoife – as well as by several musicians. Hannah and Aoife were also supervised by my PhD supervisor, and had particular interests in working with clinical populations in order to prepare for

postgraduate careers. At first I was a little wary – bringing students into sensitive and private settings such as care centres could be slightly risky, especially given the cut off of communication that had just happened in St Eithne's. I didn't want to delay my research process any further – and by now, I was also involved with the Open Lab researchers, to whom I also felt a responsibility to begin this new phase of data collection. A lot was at stake, and I was worried about the inclusion of two new students, when I often felt like a novice in these care settings. However, Hannah and Aoife proved to be a valuable addition to the research team – their participation brought something special to these music sessions, and their voices have been included in the thesis going forward as co-researchers. Although their research interests diverged from my own, their presence and participation will be revisited in the next chapter to consider what their contribution to the larger process was. Hannah and Aoife attended the music sessions run as part of this research phase as they were interested in dementia care – however, their work was entirely observational within these research settings. They did not make any choices or changes to the research methods and objectives undertaken at this point, but rather observed the sessions as I ran them, their observations focusing on interactions happening within the session. We did not share data, but did talk about the research process at length. Parts of this conversation make up some of the data in the following chapters.

My decision to include a musician as part of our research team was based on two things – one is a point made by Claire Craig & John Killick (2013), who stress the importance of using quality materials when working creatively with people with dementia. They refer to art materials in the original context, but this is extendable to music as well. By now, I had picked up several sources of research funding which meant that I could pay a musician a good rate for 1-2 hours of music in care centres each week. Coming from St Eithne's, where Daniel O'Donnell was played every day on the television system, I was eager to provide these new

care settings with something different and more responsive. A musician can chat, can talk to the participants – something a television cannot do.

This speaks to the second point which influenced the addition of a musician to the research team: this is the earlier point made concerning 'liveness' in music sessions, or replication vs. representation (Auslander, 1999). Although the music sessions in St Eithne's had an element of liveness in the way that people would use the aforementioned Daniel O'Donnell concerts as jumping off points for their own performance (and connection, and belonging), these were static materials; replications which were played sometimes up to twice a day. Although it is heartening and indicative of the kind of creative experiences people with dementia can still have just by engaging with media in certain ways, there were questions emerging from the previous analysis concerning engagement which could not be explored with such a lack of human presence – in this way, engaging a musician in these sessions allowed me to explore different ways of participating which emphasised liveness, 'coming to life', and keeping experience alive during music sessions – just enough to work with it, and to build on previous analyses.

I worked with five different musicians over the course of nine months of this research; however, the one who features most prominently in the upcoming analysis is Lisa, a fellow PhD student in my department who was also a good singer and an able guitar player. She is also the only musician who was not a professional musician; however, she received the same rates of pay and was by far the most popular musician among clients in these sessions. I asked Lisa back so often because her rapport and ability to talk to and respond to clients in both settings was unparalleled – so much rested on her ability to talk to clients in between songs, to joke about particular requests, and to give space to the clients themselves to participate and perform. Reflecting on her experience at the end of the sessions in a group interview, she said:

> *… there was so many times where my voice went at the low notes, or I hit a bum note, played the wrong thing on the guitar, and for a second I'd have this like, social mortification where I was like, oh my god… just wanted the ground to swallow me up. […] [T]he more I felt less, actually less like a musician and less like somebody that was going in to do a job, and more like a human being who was going in to have a bit of fun, I felt like that was really good for me to think about it like that – and as well, I kind of like tried to train myself into thinking that every time I would be embarrassed or do something wrong, I tried to think it wasn't about me like, it wasn't about you, you hit a bum note like get over it, you're here to try and make people a bit happier, brighten up their day – so it doesn't matter like.* […] *Those feelings were there at the start of every session, but they'd go away really quickly, especially when the props come out, I'd love when the props come out cos I'd feel it's more of a group effort.*

Lisa's understanding of the sessions as less of a concert or gig and more of a 'group effort' or conversation carried out through music and responses to music links the social and phenomenological experiences of participants during these sessions, who were given a space in which their "voices" could be heard.

Building something: designing a music session

Given a stated focus on liveness, to talk about designing a music session is perhaps analogous to describing how we can "design an experience", a phrasing which ignores both the variety and particularity of experience. However, over the course of 9 months in each setting, visiting each setting at least once a fortnight, we co-created with residents and staff a sort of a 'format' of a music session as we tried out different forms of engagement and different order of songs and activities. Although each session was different from one to the other and as such was not a 'replication', by the end of the nine months of music sessions, we had done the following:

- Created an expansive list of songs which were popular with residents – ascertained by 'trial and error' based on songs enjoyed in St Eithne's, but also by paying attention to

bodily expressions of enjoyment, talking to staff and learning about preferences, and asking for requests during each session;

- Experimented with different running orders of activities and songs to play around with different patterns of engagement until we found a way of 'doing things' which seemed to work best;
- Created and assembled an array of digital and non-digital 'props' which helped to broker different forms of engagement within the music sessions – described in more detail in below section;
- Created a poetry booklet with familiar poems in order to introduce ideas of rhythm, rhyme and percussion – again, going through several iterations based on engagement in poetry sessions (running within music sessions);
- Developed a sensibility or a way of working within the music session in a way which fostered different forms of communication and represented an invitation to participate and 'let loose'.

The final point is perhaps the most important – for myself and the other co-researchers, learning how to help to facilitate these music sessions as non-musicians – instead, as psychologists by training – was a difficult one. Reflecting on this in the group interview, the following exchange describes the tensions inherent to trying to not take ourselves too seriously but also helping residents to understand that we were not being patronising, but playful. Prior to this, Lisa expressed a discomfort with approaching people in an infantilising way (*"…if I saw a 70 year old on the street, I wouldn't go up and say* [loudly, in a sing-song voice] *hello, how are you now?"*) or treating every person with dementia as though they were the same:

Kellie … I think there's something kind of inherently stupid about the stuff we do, like it is dumb – like it's going along and it's singing music – when I say dumb I mean silly

and stupid, and not serious. And that's why we're at the point where we're handing out the cloths and stuff, and they're like, what on earth, and I'm trying to make a fool of myself, and when I hand out the boas and the tinsel stuff, I try to put one on myself to show that I'm doing this, I'm not putting, I'm not making a fool of you, I'm being a fool and I'm inviting you to be kind of silly with me.

Lisa That's a good approach.

Aoife Some people do like it, do respond to those sort of things, y'know. So it is worth doing it and making the effort and making a fool out of yourself because some people definitely are -

Kellie And some people just say to you – and some people just say to you, it's like the woman who said to me, does she think I'm a child – I would hope that you would be able to build in – maybe you should build in space into these sessions where people can refuse you in a comfortable way. Where people can say – like I was handing out maracas last time and I was showing them to a lady and she was like, get away from me. And I was like, OK, I will and she was fine for the rest of the session, she was just like get those away from me or something like that. What can you do? You just listen to her like.

Lisa 'Cos of the nature of the disease. You don't know whether they're enjoying it or whether they feel patronized. I think, I think it's a natural part of what we're doing anyway because I don't think it's something we can just do it and fix, I think that's gonna come up. But it's something that I find is hard to grapple with.

I hope that no-one in the sessions we ran felt patronised – and in general, if someone did not want to participate in the ways which we invited, they were free to leave (and did upon occasion) or else to sit back and participate in different ways. As I indicate in the above extract, if someone refused to join in in the invited ways, I left them alone for at least some time, having learned from art sessions at St Eithne's that coaxing and coercing someone into participating was not participation at all. At the same time, given more time to explore participative music sessions, it became clear that there are ways of participation that are more about disengaging than engaging. Later in this chapter, I will describe the different forms of participation I saw within these music sessions – some of which are a stark contrast to the sort of raucous 'joining in' that typify the sessions at St Eithne's and for the most part in Clermont Place and Rosebank.

Props

In the above extract, there are several references to props, which proved to be an integral part of running our music sessions. SwaytheBand was only one of these props, and it is worth describing the ways in which we deployed various materials during these sessions in order to invite people to participate and express themselves in ways which were ambiguous and could be creative. Each music workshop utilized a variety of props. Props changed from session to session, and were initially chosen because of the likelihood of their provoking participation from participants – for example, simple percussion instruments were typically given out at the start of every session along with the invitation to become part of 'the band'. Props were also introduced based on their visual or tactile attractiveness – for instance, pom-poms with tassels that are bright and reflective as well as soothing to hold and stroke. Some props were introduced due to thematic links to the day's music – i.e., feather boas and fedora hats for sultry, burlesque or jazz music.

Props were often used to encourage participants to interact with one another – for instance, large sheets of shimmering cloth were stretched across the laps of some participants and they were invited to 'sway' along to the music using the cloths. Ribbons and thin 'ropes' of cloth were also stretched across the 4-5 meter diameter of the seated horseshoe, which allowed participants to connect with one another and dance without leaving their seats. This use of materials was influenced by time spent visiting with the Alzheimer's Society's Purple Pops music group as well as by conventional tools used in music sessions for participants with dementia such as the Octaband.

SwaytheBand was 'rolled out' as part of these music sessions, typically near the end of the session. Although the batons are designed to work with pre-programmed beats and pre-chosen music, most of our musicians would continue to play along to this music, usually via guitar – although Lisa would often switch to the spoons, bringing the microphone close to her

hands in order to do so. We handed the batons out one by one, and although we only had eight up and running at the time, we ensured that everyone who was interested got to use and hold the batons as we switched through 3-5 songs to finish the session. Beyond this, we also deployed the batons as a part of a comprehensive group of props, so that if someone didn't have a baton, they would have a musical instrument or pom-pom. Alternatively, if people weren't interested in any of these props, they did not have to use them – they could sit back, watch, and listen instead.

Adapting methodologies

From ethnography to participatory action research

This phase of the research brings together several different approaches to research and data collection which are slightly different to the straightforward ethnographic approach described in chapter four. Having gotten a sense of life in dementia care as well as some of the challenges inherent to working with people with dementia in ways which might be conducive to design, we had produced a system which we hoped would answer to some of the opportunities, challenges, and broader research themes emerging from the earlier analysis. However, with time tightening up, I did not have the time to carry out an in-depth ethnography of either RNH or CP; instead, I visited approximately three times for 6-9 hours in each setting to meet members of staff and spend time with clients.

Once we were cleared to begin research in each setting (September 2015), the music sessions we carried out ran very straightforwardly and were likely indistinguishable from any music session carried out by other non-researchers – what differentiated our running of the sessions was the amount of time spent at the start visiting with participants one-on-one or in small groups of 3-4 to introduce ourselves and describe the activities we were about to run and the ways in which these would function as a research study. Beyond this, each of us were so busy

during these sessions and so engaged in the activity of the session itself that we barely had time to take short notes.

We were also, for the first time, answerable to the care settings in that we had agreed to document our own sessions, evaluate what 'worked' and what didn't, and present our findings to the care settings afterwards. Although at the beginning, our scope to explore these sessions was left open to us, we were shaped by the interests of the care setting as well. In the below extract, taken from an interview near the end of our engagement, activities coordinator Glenda expresses a wish to have seen smaller sessions:

Kellie How have you felt about the involvement with the UCC project over the last – I suppose it's been -

Glenda 9 months. Yeah. Ahm, I thought it was well presented, you made an effort to introduce yourself to the clients and get to know them. The music you provided was just long enough in the sense of to keep their attention you know. I didn't get enough to see of the smaller groups, but that wasn't your fault, we didn't have the space – I'd like to have seen more of the evidence of the feedback of what would happen in a smaller group with more challenging clients.

Kellie That's a good point.

Glenda But that wasn't, let me stress, your fault really, but. The props and everything were good, the tambourines, the scarves, all that kind of intervention was good. I think you got a good response back.

Although Glenda was happy with the response of participants to the sessions we ran, she expressed several more times during the interview a wish to have witnessed and helped to organise smaller sessions. We usually worked with up to 30 residents at a time – however, Clermont Place was moving towards a model of care and activities that focused on smaller groups if clients had dementia – as most did (*"We try not to keep the groups big anymore. We think you can do more in a smaller group, better feedback and better participation."*) Although at this stage our data collection was over, I still had some time and some funding left over and I suggested we arrange to have some smaller sessions before our time in the centre came to an end. Glenda agreed, and the following sessions (in May 2016) took place in

smaller rooms, with up to 10 residents, each chosen by the centre purposefully to provide an even 'spread' of clients at different stages of dementia. Having passed data saturation (as indicated by Charmaz [2014]), my notes during these sessions were focused on the kind of information I thought could be useful in assembling materials to give to the centre at the end of the engagement period.

Glenda refers to intervention in the above interview extract – coming from a psychological background, the word 'intervention' is one which I have been hesitant to use, particularly because of the ethical barriers it can throw up. However, this phase of the research represented a design intervention in many ways – not only through the introduction and the focus on the SwaytheBand batons, but because of the changes the settings made to accommodate us and make space for our contributions within their culture. We became a part of the advertised programme of the centre, and fliers and social media posts went out advertising the sessions we ran:

Glenda … [Y]ou'd have all kinds of things happening.

[Liz is handing out sheets to us in the background]

Kellie Look at that.

Glenda These are all the things that are happening, that we have on our weekly activity schedule. So we have a variety of things to tailor them and try to suit them to the individual. So we have all sorts of things from creative dance -

Kellie My god. [*laughing*]

Glenda You didn't think we had all this going on!

Kellie I didn't know there was aromatherapy!

Glenda We have community art programs, we have a lady that comes in and does knitting groups. […] We have – that's you! UCC doing music and dance.

Having spent a lot of time feeling on the outside in St Eithne's, and eventually having communication cut off from the centre, it was heartening to become a part of everyday life in Rosebank Nursing Home, and in particular in Clermont Place. Beyond this, it helped us to see

the place of these sessions, and within them, of the SwaytheBand system and the sort of participation it offered. This chapter continues in this vein to describe our engagement in the settings as a process of enfolding (rather than unfolding) – for us, becoming a part of a community of people who were involved in working and living with people with dementia, and for the technologies we brought with us, becoming a part of activities to transform, enrich and make visible parts of them which have hitherto not been visible.

Some more on settings

It is worth taking a moment to describe the settings in which these music sessions took place. In Clermont Place, as previously mentioned, music sessions either took place in the large hall, and involved up to 25 clients, or in smaller rooms at the back of the complex – typically the prayer room or the 'multimedia room'. These smaller rooms would house sessions of up to 10 residents at a time. Each room was easily configurable with a number of tables and chairs and a stage at the top of the room nearest the door – however, we never used the stage and instead sat at ground level with participants.

In Rosebank Nursing Home, our sessions were held in the day rooms of each floor. The building itself was extremely well-kept but quite old, which made each floor and each day room different – however, in general the rooms were relatively large, and resembling the parlour of St Eithne's. These rooms were not as configurable as those in Clermont Place, and though most were ringed round the outside with comfortable chairs, so too were 'pockets' of chairs and small tables set facing away from other pockets – this gave the rooms a "café" type feel. Our numbers varied in RNH, but we typically worked with 10-25 residents per session, most of whom had a diagnosis of dementia. Unlike CP, where carers would dance with residents during music sessions, care staff rarely became very involved in these music sessions, and in general the energy was lower – perhaps because of the progression of most people's dementias and a lower level of mobility among the residents.

Findings: participation in music sessions

This section describes the overarching theme of the analysis, *participation* within music sessions. Again, like the earlier ethnographic analysis, data have been summarised and analysed here via Grounded Theory in the same process described in the methodology chapter (chapter 3). The overarching analytic theme of participation is developed here by means of five analytic categories – touch and intimacy, connection and movement, shifting roles, materiality, and using props to disengage – which describe the complexities of participation for people with dementia and the active role that participants with dementia can play in music (and potentially design) sessions.

Touch and intimacy

For many participants in both care settings, music sessions and the activities carried out within allowed opportunities to be physically present and close to others.

Music sessions were initially explored in St Eithne's as a way to connect with residents during a low-intensity, enjoyable activity. As described in earlier chapters, the space created during these sessions allowed residents to connect not only through music, but through touch and presence. Interactions with residents during early sessions in St Eithne's surprised researchers due to participants' willingness to engage via touch and hand-holding, where they had been reticent during attempts to chat earlier.

These moments of coming together to enjoy music were significant in terms of their social role, with residents in St Eithne's in particular, as they frequently complained about the lack of interaction ('*I come here every day and all these people do is sleep*' – Maggy, day resident). However, although these early music sessions were typically enjoyable for residents, they were not particularly rousing or participative – they centred almost totally around the television, and residents would frequently slip in and out of sleep if not engaged by the presence of others around them.

Bearing the importance of physical presence in mind, we designed the SwaytheBand prototype to ensure that physical proximity and touch would be encouraged by its use. The initial configuration of SwaytheBand was that each baton was designed to be held by two hands at once, with thumbs folding over one another to press the trigger at the back together. In early prototypes, strong enough force on this trigger (the kind of force exerted by two thumbs pressing at once) was designed to trigger a different quality of light (brighter/different colour) to signify the joined efforts of two 'dancers'. We also played with the idea that SwaytheBand could function as a musical controller (Kiefer, Collins & Fitzpatrick, 2008), where different gradations of touch would change the music being played.

When using the batons, smaller groups (< 6 participants) preserved this sense of touch: even though participants were 'supposed' (invited by the researchers) to hold the batons with one hand each, some ended up simply holding hands and swaying. In this way, the use of the baton prompted touch in many different forms: one participant, Cathy, earlier seeming to be too shy to join in in dancing sessions, took the lead researcher's hand during SwaytheBand sessions and, holding it tight, circled her thumb around and around the palm of the researcher's hand as they danced together using the prototype. For many participants, touch and intimacy seemed to foreground the larger need for human presence and contact.

Connection via social movement

As well as being physically close to others, moving together in rhythmic, choreographed or opportunistic ways allowed participants to 'be together', joined in an activity. During these interactions, the props (including the SwaytheBand system) helped to make visible some of the fledgling relationships within the care session, as well as the creative ways in which residents related to one another.

For example, in Clermont Place, the ropes we stretched across the horseshoe allowed participants to be playful – during one session, participant Neasa deviated from swaying

gently with the rope in time to ‘That’s Amore’, instead flicking it at her partner like a whip and laughing hard. She then moved her grip along the length of the rope, a look of intense but playful concentration on her face, and mimed a struggle of ‘tug of war’. Although the use of ‘ropes’ was illuminating, it was occasionally unsafe – care staff worried about participants tripping over the material as it stretched across the floor.

The use of SwaytheBand addressed these concerns while maintaining the sense of connection. During sessions using SwaytheBand, participants communicated easily using just their own gestures, facial expressions and the SwaytheBand batons – in one interaction, a participant named Moira begin swaying her baton at the lead researcher (who stood across the room) in a winding motion while winking. As the researcher began to do the same, she grinned approvingly, and moved onto another movement. These chained movements, initiated by the participant, soon became a sort of ‘dance’ from afar which echoed the interaction detailed in earlier chapters with Glenda in St Eithne’s. In conversation on the ways in which materials help to introduce participants to larger activities, Glenda reflects on the SwaytheBand system:

Glenda They have to get in the rhythm. What was those things you brought with you…

Kellie The batons, is it? SwaytheBand.

Glenda That was great wasn’t it, they changed colour as they moved. And it wasn’t so much about the colour thing, that was for the other side or for people around them. It was the actual holding of it and the movement of it. It was everybody kind of could participate in this – what was it called?

Kellie We called the system ‘SwaytheBand’ – it, it came from this sort of design thing, event we created them at. But, ah, what I really like about those whenever used them and I was able to reflect on what I saw, was people using them to nearly talk to each other across the room, but non verbally. So they’d be waving it like that, not necessarily swaying to the music but they’d be using it to say hello to a friend or a carer.

Glenda It made them socially interact. It was fun. That’s good isn’t it, when you get that positive feedback.

In other interactions, we did not see a chained set of ‘calling’ and ‘answering’ movements, but instead practices of mimicking and echoing others’ movements. During an early session in Clermont Place in which both SwaytheBand batons *and* percussion instruments were handed out, participants using SwaytheBand used the batons as musical instruments or ways of engaging with the larger movement of the crowd – if the group swayed to the right, so too would those using SwaytheBand. Those using the device were able to take account of what was happening around them as well: one participant using the device next to another participant who was using a shaker filled with rice mimicked his neighbour’s up-and-down motion of the shaker with his SwaytheBand baton.

The SwaytheBand system engendered cohesive group movement when used in small groups where almost everyone held a baton – in smaller groups of 5-8, participants tended to move together in swaying motions which rippled through the group. These motions were sensitive to the overall group cohesion; if one person was off-time, the person next to them was likely to also fall off-time. However, this also meant that improvisations and variations on the swaying movement were quick to ‘transmit’ down the group.

In developing the system further, we wished to examine this ‘dance’ in more depth, focusing on an intersubjective exchange between two participants. We decided to test this with the lead researcher and another participant, Maud, who was experiencing periods of disassociation. Both held the batons while listening to a song the researchers knew that Maud enjoyed (a traditional song, Báidín Fheilimí). Slowly, the lead researcher began to move the SwaytheBand batons in time to the beat of the music, and Maud soon followed suit, her eyes fixed on the soft glow of the baton, closing occasionally before opening again. As the song finished, the lead researcher finished with a gentle flourish, and Maud followed, slowly extending the baton in the same direction and smiling softly. ‘Is rud iontach é sin’ (*it’s a wonderful thing*), she said afterwards.

Shifting roles

Exchanges which were 'set to music' often allowed participants to explore and inhabit roles that were different to those of their everyday lives – i.e., patient, care resident – but which were enriching for them in the moment. These roles might be imagined ones (performer at a large concert), opportunistic ones (dance partners), or past ones. For example, a client of Clermont Place, Maidhc, used opportunities during live music sessions in the Home to showcase his skills as a set dancer, and would tell his dance partners about his past wins at All-Ireland competitions. In a set of notes, the lead researcher describes how this 'dancer' role extended also to 'dance teacher':

'You're awful stiff,' he said, *'but keep practising. You're not as bad as you think. I'll teach you again when I see you next.'*

Music and the activities and interactions it 'unlocked' were emancipatory, and taking on the performer role was important for many residents. Despite the spryness of some residents, many residents were not as physically fit – in order to dance on her feet Maud had to be held about the waist by two carers, for instance – and thus large sessions tended to have many 'wallflowers', unable to join in. This potential to 'perform' was crucial to reflect in the iterative design of SwaytheBand.

Although not configured specifically for participants who have mobility issues (the system was also used standing), SwaytheBand allowed participants to perform together through movement from various positions. It was primarily used seated, often as a 'breather' between energetic dancing or as a way to 'cool down' at the end of an energetic session. SwaytheBand did not inhibit participants from singing along or dancing along, but its bright and flashing light and focus on rhythm allowed participants to play an important part in the performance – as part of the titular 'band', whose synchronized movements allowed them to perform

together with the live musicians or with recorded music. It served to equalise the performance space during music sessions —musician Lisa reflected upon the system in the following:

> *Yeah. I felt much more at ease when they came out. It was also about easily seeing someone was enjoying it, even if it was just someone there with a baton and all they were doing was this [waves hand slightly] – they were participating. So they must have liked it at some level. I think it's a good way of checking in. For people who are like non-verbal or not able to communicate verbally anymore it was a good way to see they are participating.*

Other participants remarked upon the use of SwaytheBand as similar to the cigarette lighters held up at concerts to pay tribute to the musicians, meaning that participants saw themselves taking on the role of the spectator using the SwaytheBand system. In all of these configurations, different movements and uses of the prototype transformed the space into different spaces for different users – whether it be into a stage, a dancefloor, or seating at a concert, and whether they are performers, spectators, or both.

Image 11: SwaytheBand in action

Materiality, having, holding and giving

The material nature of the props and probes used proved to be much more important than we anticipated they might be. Early sessions in St Eithne's (often featuring limited props and focused solely on viewing material) contrasted greatly with larger workshops in Clermont Place and Rosebank, which utilized many more material props. In these sessions, the use of

props became a *probe-in-motion*, allowing glimpses into the experience of participants by paying attention to their interactions.

The importance of materiality was pronounced when using visually and tangibly attractive objects – in particular the large, shimmering cloths used to 'dance' together, the sea-green satin of the 'ropes', the silvery-blue tendrils of the pom poms, and the 'fun' feel and look of the feather boas. To return briefly to St Eithne's, in a later session focusing on ideation surrounding materiality of possible designed objects, I decided to bring in coonskin caps as props to accompany hunting songs. Aideen refused to touch them, muttering under her breath as I reached out to touch her hand with the fabric, jerking her hand back. Another resident, 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. At a session in Rosebank, resident Gill (often wheeled in in a chair to join music sessions but who was non-verbal) took the cloth offered to her to help her dance in her chair, instead holding it about her head like a veil, pinching the ends together under her chin.

Participants' verbal responses were (typically) not rich – although it indicates pleasure, 'it's lovely' does not provide description rich enough to work with in design research. Instead, we found that paying attention to participants' actions with these objects as more fruitful for the design process. In this way, we recycled some of the same shimmering cloth which residents enjoyed stroking and to which we had seen their gaze drawn to clothe the SwaytheBand batons. This added a layer of tangible and visual interest to the devices and made handing the

batons to participants a pleasurable exchange – 'What is this?', one resident, John asked. 'A present for me?'

The material attractiveness of the props frequently meant that participants wished to keep them for themselves – one resident, Áine, asked to keep a feather boa and a pom-pom after a session, while resident Nicola approached a researcher post-music session asking to keep one of the SwaytheBand batons to use to play with her grandson. The reluctance to give back an object that seems to have been given as a gift tells us something about the solidity of these props and their value to participants as part of a 'gift-giving' process between researchers and participants.

Using props to disengage

Many participants with whom we worked were unable or unwilling to 'move along' to our music sessions, though they would often attend. This was due to many reasons – whether the progression of dementia, physical frailty, or their own choice. For others, their participation may not look like the participation of their more active co-residents but may be seen to constitute engagement. All of these situations are complex, and deserve to be considered as 'negative cases' that throw other actions into relief.

At an early session in Rosebank, I observed a visiting harpist. In one room, some residents and staff gathered to hear the music – however, one resident (Mona) remained totally silent, and read a newspaper in a chair, seemingly ignoring the music. She was almost totally turned away from everyone else, her feet pointing almost to the door. When the harpist left, carers asked Mona if she enjoyed the music. She said she did not. Carers later explained to me that Mona's attendance in the first place was an anomaly. Mona very rarely sits in company with anyone else. Her using the newspaper, carers thought, was a ruse of sorts – a way to seemingly disengage from the situation but also attend to hear the music. In this way, Mona's subterfuge echoes the 'resistance strategies' of McColgan's study, where residents pretended

to sleep in order not to have to engage with others when they didn't wish to, and perhaps constituted a way for her to control her level of participation in the music sessions she wished to attend.

During another session in Rosebank, Jill, a resident who had just joined that week and was yet to say one word, surprised everyone when she took a baton offered during the SwaytheBand session and held it gingerly, at first just watching the changing colours of the baton and then swaying it very slightly. Initially guided by a carer, she then began to move the baton very gently between her fingers. I caught Jill's eyes and saw her smiling, softly mouthing the words of the song. Carers approached the research team after this session and expressed amazement at this engagement, which, for them, had indicated a possible new way to communicate with Jill.

Choice in dementia is complex and can be mediated through the body and configurations of the body in space. These observations have indicated to us the subtleties inherent to designing with participants with dementia – in particular, interactions with Jill have indicated that, even though she may not be able to create the large, swinging, swaying motions of other users of SwaytheBand, her seeming inability to move belies the subtleties of her wish to engage with the movement in quieter ways.

Discussion

These findings show how *participation* in music sessions for people with dementia can take many forms (touch, moving, inhabiting roles, interacting with materials and more subtle forms of participation). Further, this work shows how props – simple and digital – can engage participants with dementia to participate in several ways in music sessions but notably create participation that is *meaningful* to them and provide researchers with ways to leverage this meaningfulness in/for design. Most importantly, this work shows how props can create

participation that is meaningful for people with dementia, and can provide researchers with ways to use this participation to drive forward design.

The concept of participation has been a historically important one in HCI; however, the term has rarely been applied to design work with people with dementia. Where it has, it has applied to people in the mild stages of dementia and has constituted conventional workshop type methodologies. Following from Killick and Craig, these engagements provided a set of examples that explore the possibility of participation by people with dementia living in care in ways that have both sparked and driven forward a design process.

Although our participants were rarely able to reflect verbally on the design process, we believe that the above evidence begins to advance a picture of participatory research with people with dementia using a sensitive, Experience-Centred methodology. The following discussion subsections will unpack the categories (and combinations of these categories) discussed above in relation to extant design work, and will indicate ways in which they might be considered in future work.

Unpacking participation for people with dementia

Feeling

It is now clear that building the potential for tactility within design processes and other activities is important when working with people with dementia. These findings indicate the importance of touch and presence for people with dementia within music sessions – for these people, music sessions are social and concrete events where multiple physical factors come to play. For some participants, this physicality was most emphasized in being able to reach out and touch another person, and the person's availability within that exchange is integral. For many design researchers, working with people with dementia can bring numerous emotional difficulties, and this has been reflected in some extant research. As mentioned earlier in the thesis, much dementia care literature has emphasized the importance of the intersubjective

physicality of care work, and I suggest that this physicality deserves attention in design work as well. These exchanges (from our work: a willingness to hold hands, to dance with arms around another's waist, and even to embrace and be kissed upon the cheek) are deeply emotional and intimate and can be learning events for researchers, who should not be afraid to engage with these bodily forms of expression as long as it is appropriate and welcomed by participants. For us, building the potential for hand-holding into SwaytheBand reflected this automaticity with which many participants would reach for another, similar to the work of Killick and Craig, which sees creativity and expression in dementia as important ways to connect with one another.

The materiality of objects also became important within these design sessions. The wish of many participants to keep particular props – hats, feather boas, even SwaytheBand batons – made us reflect on the process of participatory action research and the process of 'giving back' to settings in which we research.

Moving

Creative expression through movement has been widely acknowledged in HCI literature for many years – from the use and development of creative gesture interfaces through technological systems that support and augment aspects of dance and performance. In most of this, movement has been construed as communicative – which brings us back to the work of Sabat and Lee, cited earlier in this thesis, whose observational research indicated the rich interactions people with dementia could carry out wordlessly. This held true in this section of the research.

For people with dementia, even slight movement can be highly intentional and meaningful. Again, returning to the literature review, Pia Kontos' extensive ethnographic research into expressions of the body in dementia care highlight numerous instances of this, i.e., a resident who will not eat until she is allowed to rearrange her clothes to make visible a string of pearls

she particularly valued. Given the larger HCI literature that has expressed an interest in the role of movement in design, it is perhaps surprising that movement by people with dementia has not yet been explored in depth as a process of communication during design. Building opportunities for gesture and movement into designing for and with people with dementia has the potential to capture a dimension of communication that goes unnoticed too often.

Voicing

This engagement showcased the possibility of using SwaytheBand as a 'beacon', which we hadn't anticipated before deploying it. This is shown in several categories where participants a) wave to one another and to researchers using the baton and b) indicate their wish to 'dance' using a set of chained movements with the baton, shared with another dancer – who can often be far away.

The SwaytheBand prototype reflects the essentially social nature of these music sessions. In many ways, these sessions looked very much like typical 'pub' sing-along sessions that may or may not involve amateur musicians but which typically either constitute social events on their own or come as part of a different social event – a wedding or a funeral. In these occasions, similar to the SwaytheBand sessions, what matters to participants is not necessarily the performance itself but the fact it is being performed together. For those who do perform, being heard is paramount – resident Veronica, when standing to command the performance space in St Eithne's, would stop and glare at those who dared to sing along with her. For people (not just people with dementia), being heard is important.

The analogy of 'giving a voice to the voiceless' has run strongly through much participatory research and design – in work such as Ariyadasa & McIntyre-Mills (2007), and Grover (2004), these voiceless participants are typically those often described as 'vulnerable'. In our work, it became obvious that the voices themselves are always there, and can be accessed by researchers through the use of skilful design processes – here, through the use of props. In

this way, I believe that this research approach helps to answer McCarthy & Wright's (above) question pertaining to the authorship of design processes. By providing 'blank slate' objects such as the SwaytheBand, participants are free to author their own intentions using methods of communication such as touch and movement. In this way, within a reciprocal design relationship, the research, and the design, moves forward.

Playing

Much like props, role-playing has long since been an activity in design processes. Our sessions saw participants shift effortlessly from role to role, which allowed creative freedom – participants shifted from clients, residents, patients to become instead performers, dancers, dance partners, and spectators. These observations echo how design that considers the social construction of dementia can open up new possibilities: given a valuing and creative environment, the possibilities for 'ways of being' for people with dementia can multiply.

The uncontrollable nature of this 'role switching' meant that our music sessions often became 'improv' sessions, where participants would 'turn up' in a particular role and we would just have to play along. These sessions had much in common with conventional improv comedy sessions, wherein partners create a comedic or performative space wherein the only rule is to never say 'no'. It is in this way that we found our use of 'props as probes' most useful. For instance, when talking to residents about swathes of cloth which they decided were parts of pyjamas, a costume to pull over their heads, or a rope to stretch to a friend who had sat far away that day and help her to 'swing' to the music. These interactions helped us to make sense of the experience of participants much more than their words did, and in many places (the use of rope and cloth to sway) helped us to conceptualise and drive forward the SwaytheBand prop.

This performative aspect of this research has much in common with Spence, Frohlich & Andrews' notion of 'performative experience design (PED)' (2013), the hallmarks of which

include the observance of 'rules' within the performance frame, interactivity that creates different roles and the expression of self to another in the form of verbal or non-verbal dialogue. Spence et al's description of PED as helping to explore '*a rich, as yet almost untapped body of research that addresses interactions between two or more groups or individuals, all of whom are engaged in a designed, mediated, and often technologically influenced experience*' (pg. 2055) resonates with our work in particular. Future design work that examines the role of performance in particular in dementia may be fruitfully combined with a PED approach.

Nestling

For us, placing or 'nestling' the context of our research within music sessions was a valuable approach to working with participants. The earlier work carried out in St Eithne's indicated the success of music sessions over art sessions or 'chats' with residents. Music sessions typically saw much more interest and participation by our participants, whereas art sessions would often see residents 'clam up' and disengage.

For almost all of the participants we worked with, music sessions were seen as a safe space – even if they were prefaced with the explanation that we were researchers and this was part of a study. We attribute this to the many ways in which participants could participate within music sessions – they could sing, dance or simply sit and listen (like Mona, above). They were freed from the expectations of workshop-type approaches to art and design sessions where a diminished ability to reflect and think into the future may have been apparent and embarrassing for them. Instead, as we have indicated above in the section on movement, music sessions allowed them to communicate on their own terms. We believe that these 'safe' spaces, and use of 'failure free' props such as our SwaytheBand batons and pieces of cloth, can help create an enlivening and freeing space for participants with dementia who might be anxious in participating in a more formal design workshop.

The place of SwaytheBand

In describing the ways in which we became ‘folded in’ to the community of CP and RNH, it is clear that the objects we brought with us were a part of brokering that connection. Despite being a purposefully designed object with uses we anticipated prior to deployment, music sessions saw participants interacting with SwaytheBand batons in ways which were as disparate as when they had been using materials and pom-poms – SwaytheBand served not as a solution but as a probe which posed still more questions. It is this use of the system as a probe which I have presented here – however, we feel it is worth mentioning that the system has been popular not only with participants but with staff who have asked that we provide them with a complete system at the end of the research. The system also won first prize in an international design competition aimed at designing for/with people with dementia and was evaluated by care professionals as an object which they would use in everyday scenarios with their patients. Beyond this, we are now engaged in late stages of getting the project funded for an additional period of time to develop the prototype into an independent system that reflects design suggestions from fieldwork that were not possible to add in its current configuration. This has been heavily supported by a director of a care home in the north-east of England, whose comments can be seen in image 12, below.

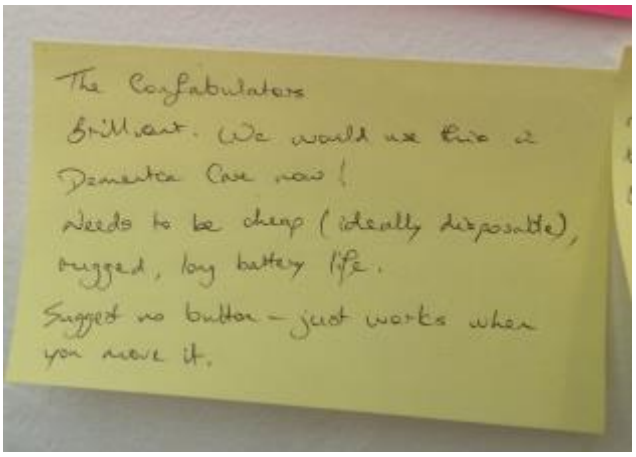

Image 12: evaluator comments by head of nursing home who helped move the SwaytheBand project forward from the initial competition and engagements described in this thesis

In this way, SwaytheBand functions as both a probe and as a relatively 'finished' object, useful and enriching for people living with dementia and their carers in both scenarios.

Summary

This chapter has continued and finished the description of the third design phase – enfolding – as introduced in the previous chapter. Beyond this, I have introduced and described the beginning and unfolding of our involvement within two care settings – CP and RNH – whose open attitudes to research and wish to learn from our presence in the settings enabled our broadly ethnographic approach to encompass aspects of participatory action research, using our design intervention as a way to gain new forms of knowledge that could serve both our agenda as HCI researchers and serve to inform the practice of care centres. However, the main contribution of this chapter has been an analysis of field notes from these sessions using the SwaytheBand system in a way which serves as both an evaluation of the prototype itself, but more notably a validation and extension of the earlier GT analysis of music sessions in St Eithne's. The next chapter will consider these findings in light of the earlier analysis as well as in light of the literature review in chapter 2 which posed challenges for design work with people with dementia. I will also revisit the research questions set out at the beginning of the thesis, revisited in the in-between chapters, and consider to what degree I have answered these challenges.

Chapter 7: Discussion

"The word 'however' is like an imp coiled beneath your chair. It induces ink to form words you have not yet seen, and lines to march across the page and overshoot the margin. There are no endings. If you think so you are deceived as to their nature. They are all beginnings. Here is one." - **Hilary Mantel, Bring Up the Bodies**

Introduction and recap of the literature review

This thesis has explored experiences of participation by people with dementia, and has investigated how this participation can be made a part of a design process which values the contributions of PWD as equal to those of designers. Beyond this, the thesis has showcased how objects – including design objects – can serve not only as final 'designed' objects which typically cap off a research project, but how these objects can function as tools in research-through-design studies. Finally, the thesis presents insights into researcher and designer reflexivity within the design process, through elaborated accounts of unfolding design processes mobilised by interpersonal relationships with participants with dementia, as well as through a negotiation process with several caring institutions. These interpersonal relationships are not like the relationships typically created by researcher involvement in the field - they have been negotiated carefully, over time, but are unavoidably refracted through participants' unfolding dementia. Responding to this refraction through design has been the aim of the thesis.

In chapter one, I presented a significant amount of research from the HCI literature which aimed to design for and with people with dementia; I divided this research into three broad categories of a) compensation approaches, b) connection approaches, and c) working with experience. In the latter part of this chapter, as well in the methodological chapter which followed, I identified experience-centred design (McCarthy & Wright, 2004; 2010; 2015), as the approach I would take for the work about to be undertaken. In the final pages of chapter one, I justified this choice due to the following characteristics of ECD – 1) its suitability to explorative research-through-design, 2) the attention it gives to small-scale contexts in research, 3) its strong focus on the imaginative documentation of methodology, and 4) the

scope in ECD work to imagine futures together, often with participants facing difficult challenges in their everyday lives.

Beyond this, I began this thesis with the intent to examine what it means to 'keep experience alive' in participatory projects which engage in design processes. Although many HCI projects deal with user experience, it is often articulated as the solicited opinions of users, i.e., through workshops or prototype evaluations rather than the felt experience of participants – in this case, participants who might find it difficult to express these opinions in conventional ways. Exploring what it means to 'keep experience alive' has meant a commitment to felt life and phenomenological experience, and articulations of this philosophy in dementia research (i.e., the work of Pia Kontos), which prioritise bodily communication in dementia. Seeking to keep alive the experience of my participants from St Eithne's despite an upcoming shift in research settings, I ensured that the design of the SwaytheBand batons was evidenced with field notes, an overarching Grounded Theory analysis of my ethnographic engagement, and by recordings of participants, analysed to emphasise the communicative potential of their movements and physical exchanges.

At the end of chapter two, I identified a number of challenges for studies which aim to address the 'problem' of dementia in ways which honour the personhood of participants with dementia as well as seeking to design in ways which are meaningful to participants. I will now revisit these gaps in the literature and address how this thesis has answered this call.

Major findings and how this integrates into previous research

Chapter two describes a series of challenges proceeding from a close reading of available HCI literature on dementia. These are 1) the place of design in dementia, 2) the nature of designed objects and systems in dementia care, 3) the potential for creativity in dementia, 4) the meaning of participation for people with dementia, and 5) the value of keeping experience

alive when designing in a dementia context. Although these function as a set of challenges that could be answered in a variety of ways, the thesis since that point has responded to these challenges within its own unique context.

The place of design in dementia

Most of the literature reviewed in chapter two attempted to design for generic 'participants with dementia' in abstract settings by aiming to address the deficits that often characterise the condition – for example, short-term memory problems (Alm et al, 2004). Beyond this, many of the papers reviewed were short papers and aimed only to show technical feasibility rather than designing and evaluating the technology in a particular context. This is understandable – memory problems are distressing in dementia, are frequently the most public symptom of the condition, and it is not always useful to design with specific users in mind if we want to create scaleable technologies – however, what is somewhat problematic is the lack of attention paid to appropriate and meaningful *places* for design in dementia. There is a tendency to create technologies, trial them, and write about them without considering their ultimate place in the life of the person for whom – or with whom – they are created.

In chapters 4 and 5, I provide a rich account of the ethnographic approach I employed while working in three different care homes. I spent a significant amount of time in the field during this research, and even throughout the latter half of the PhD process, was in care homes almost every week and often up to three times a week. In chapter 4, I provide an extended account of my ethnographic research in St Eithne's Ward, a publicly-funded care unit in a small town in the south of Ireland. Through describing both the setting itself, the typical routine of carers and residents, as well as a Grounded Theory analysis of field data from this research, chapter 4 provides an empirical basis for the design work which comes afterwards. Although the research moved on from the setting of St Eithne's in 2015, my focus on the value of music as a participative experience for residents with dementia in St Eithne's set up

a context for understanding how this experience may work with participants with dementia in other settings; through exploring this in different contexts (primarily in other care homes, though I also visited with other dementia care centres around Ireland, the UK, and Denmark), my Grounded Theory framework of participation in music activities as being constitutive of *performing and spectating*, *connecting with one another* and *being in community* was validated.

Using an ethnographic approach allowed me to identify and explore spaces for design in the experience of dementia care. These arose naturally from everyday experience of the care setting. This is evidenced by my own process; in chapter 4, I detail how I entered St Eithne's with the intention of learning more about life in care from the perspective of people with dementia, as well as having an interest in how scheduled creative workshop sessions might play out – however, within these sessions I was anticipating using conventional art and design methods. As I describe in chapter 4, the use of music arose entirely from my observations of, and interactions with, participants – not in workshop settings, but as they sat together during recreational or free time, and engaged with music technologies. Beyond this, I had to learn a large number of these songs – though they were old Irish songs, snatches of which I briefly remembered from my parents and grandparents, I learned the words from my participants.

Early in the research process, I was sceptical of the place of technologies for people with dementia. Spending significant time in the care unit made obvious the important yet unstated value of technologies as mediating many activities within the care unit. In St Eithne's, this was evidenced by the use of the television as well as the limited media available to residents as making possible these participative musical experiences; in Rosebank and Clermont Place, the use of technology and music media was more purposive and intentional on the behalf of carers in particular. For instance, carer Kylie's music clubs in Rosebank made use of a laptop

and HDMI cable linked to a television system to facilitate the playing of Youtube videos at residents' request. Although carers were often proxies for the use of the (admittedly simple) technologies within the unit, it is clear that many of the activities in these care homes were mediated by the use of these technologies. In this way, as I suggest in chapter 4, perhaps we should be less concerned with creating new, semi-familiar technologies for people with dementia and instead look to the value of using technologies which are present and already in use in care. I could imagine a new project which focused on providing carers and care staff with the knowledge and tools to use fairly commonplace technologies in order to provide an enriching and engaging environment for residents and clients.

Nature of designed objects and systems in dementia

Throughout this thesis, I have emphasised the importance of design processes as constitutive of research methodologies in their own right – something echoed by Gaver (2012), Dalsgaard & Halskov (2012), and Bardzell, Bardzell, & Koefoed Hansen (2015) – as well as producing interesting and hopefully useful and enriching artifacts. The latter aim – the creation of objects evaluated as useful - is however often integral to publishing research as well as gaining funding, and therefore should not be overlooked. In the second chapter of this thesis, I analyse extant literature on the topic of design and dementia, with one common conclusion being that many systems and objects designed for people with dementia do not make it outside of intensive trial and study environments, and when they do, they are typically not taken up for use in the everyday life of people with dementia. I suggest that this seems to be due to their unfamiliarity (Topo, 2009; Lazar, Koehler, Tanenbaum, & Nguyen, 2015), but perhaps also through a sense of the object as being something that isn't experientially warm, rich, or aesthetically pleasing to use. For instance, many of the technologies reviewed in the second chapter require the use of smartphones. Although increasing numbers of older people, including carers of people with dementia, are using smartphones (Armstrong, Nugent, Moore,

& Finlay, 2010; Parker, Jessel, Richardson, Reid, 2013), my own experience with the approximately 100 older people and people with dementia attending care settings saw no-one using a smart phone; in fact, it was more likely that participants would use an old-style, limited functionality phone or use none at all.

Systems such as the CogKnow DayNavigator as well as Lazar's ambulatory system are unfamiliar systems, designed in a utilitarian way, which may be useful in the early stages of dementia, but which are not inviting and indeed can be extremely complex. Other systems such as the Microsoft SenseCam as well as wearable technologies i.e., GPS devices and alarm systems, can highlight the presence of dementia in participants – indeed, several of Lindsay et al's participants (2012) balk at the use of such technologies, instead preferring to 'hide' them in items of clothing which they might have worn anyway or canes which they carry ordinarily. In a review of CSCW papers on healthcare technologies, Fitzpatrick & Ellingsen (2013) note that although initially innovative, more participative ways of configuring such systems for elderly people are needed.

In this same way, complex systems are difficult for people with dementia to use due to their cognitive issues which worsen as the condition progresses. We must tread a fine line here between creating technologies that are too complex for participants with dementia (in reality, overly complex systems are rarely inviting even to cognitively healthy individuals) and creating technologies which are simple to the point of being patronizing. Although our SwaytheBand batons do not attempt to 'solve' complex problems, they are simple objects that are at once familiar enough to use in meaningful ways (or are at least deployed in familiar and personally-enriching contexts), and also include an element of challenge and creativity – i.e., in order to use the system you are asked to move to the 'beat' of the music, but the way in which you do this is very much up to you. As detailed in chapter 5, the use of SwaytheBand is useful not only as a 'designed object', but as a probe which told us more

about the types of communication possible for participants at that moment in time – for instance, Jill, whose murmuring of the words and slow swing of the baton proved to be a 'way in' for carers to whom she had not yet spoken a word. In designing SwaytheBand, we designed not only an artefact, but also designed a context in which to deploy those artefacts – the music sessions. The challenges surrounding "designing" an event in which to deploy a piece of technology will be explored in more detail later in this chapter, but for now it is important to note that both the nature of the 'object' and the nature of the 'place' were important for us in ensuring that our object survived outside of the hackathon context in which it was created.

Potential of creativity

At the end of the literature review in chapter two, I write that few approaches to designing in dementia care make use of the creativity of people with dementia. In the general literature concerning psychological changes concomitant with a diagnosis of dementia, creativity is seen to decrease in people who have not been creative throughout their lives (de Souza, Volle, Bertoux, Czernecki, Funkiewiez, Allali, & Kas, 2010). There is a larger question here surrounding the ways in which emergent and context-sensitive constructs such as 'creativity' are tested in dementia – like the concept of social cognition, which Sabat & Lee (2011) argue is too often decontextualized. In this thesis, the work of John Killick and Claire Craig is used to call this under particular question. Beyond the evidence provided in this thesis, the potential of creativity in dementia is backed by a significant amount of research which uses creative methodologies in therapeutic settings for people with dementia (Rylatt, 2012), and which indicates that the use of creative methods in working with people with dementia may indicate alternative channels for communication and expression with people whose dementia is advanced.

More specificity is needed in detailing and documenting the ways in which we can make room for the creativity of our participants. The research carried out as part of this PhD, as noted above, began with an intention of first observing and then carrying out 'creative sessions'; inspired by the values behind Scandinavian participatory design research, I was interested in how the workshop approach would translate to a dementia context. As described in chapter 4, it was not very fruitful. Participants had to be coaxed to join in with the sessions, or would seem to tolerate the sessions for a few minutes only – in this way, going into these sessions seeking forms of participation by people with dementia was slightly compromised. Early analysis of this data from St Eithne's had me construct a category entitled 'negotiated participation' – where residents would participate in some artwork, but have much of the work carried out by care staff or even by myself. For me, this felt wrong, and it certainly didn't feel creative. It often felt almost traumatic for residents. As I describe in chapter three:

> *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.*

In earlier field notes, I describe how I try to prevent the use of colouring books during art sessions by sitting and drawing with residents – noticing resident Stiofán's mixed reaction to a therapy dog visiting the unit (alternately dismissive and interested), I spent some time sitting with him and talking about dogs our families have had in the past. He seemed to enjoy this avenue of conversation, and he told me a little about his childhood dog. As we were sitting together later in an art session, I took the opportunity to begin drawing a dog as he had described it. When I was about halfway done, I invited him to draw more parts of the dog with me. He hesitated. I asked him just to draw the tail. He couldn't locate the part of the picture on which the tail was supposed to go. 'Here?' he asked, and drew a tail off to the side

of the picture, completely away from the figure of the dog on the page. When he drew back and viewed the picture in its entirety, he was clearly embarrassed, and shuffled some papers in a way which hid the mistake.

Reflecting upon this, years later, while revisiting the field notes I created surrounding the incident, it is clear to me that I was working with a reified notion of what it meant to engage in 'creative' activities without questioning what those activities might have felt like. Having spent a decent amount of time immersed in literature which utilised approaches such as art and drama with cognitively healthy participants, I assumed that this would translate fairly straightforwardly to working with people with dementia. I had not thought about the experience of the person who was sitting with me, drawing – and I was looking so hard for signs of participation that initially I mistook behaviour that had been elicited through my coaxing or through their not wanting to displease me (as a visitor and a friend) for full participation.

It is worth returning to Killick and Craig at this point to consider what they believe are the hallmarks of a creative process when working with people with dementia. They talk about creativity as involving a making of something for its own sake, where pleasure is taken in the activity, and a sense of flow is experienced. Neither of the interactions described above fit this description of creativity, because I was not using experience as a critical concept. As described in earlier chapters, McCarthy & Wright's notion of experience in design is not only something which seeks to engender designs which are aesthetically pleasing and enriching to the lives of those who use them; as a concept, experience is a tool we can use to test whether we are reifying particular notions in our design processes. In the above interactions, I was reifying both 'creativity' and 'participation' because I was not fully connecting and considering the situation from my participants' point of view; in my early experiences, it was enough that someone *created* something – that very engagement, however momentary or

however coaxed by myself or by carers, was evidence for me at that point of *participation*. It wasn't until I observed participants during interactions with music that I saw full creativity and full participation in flow – to a certain extent, it wasn't until I began to participate myself that the emotional and relational nature of participation for my participants became clear for me.

Meaning of participation for people with dementia

In chapter six, I present a short analysis of a series of conversations involving some of the people who engaged with the research process – final year project students, musicians, and care staff. Following (student) Aoife's proclamation that '*there's just something about dancing'*, we discuss how, for us, dancing with participants in Clermont Place seemed to be the ultimate affirmation of acceptance and full participation in a process. Even earlier in the thesis, I discuss how the participation of people with dementia in qualitative research is integral to the amelioration of design and services, but how that participation is problematized by institutional ethical processes which themselves reify consent processes and capacity to consent. All of this is to say that, if some conceptualisations of what it means for PWD to consent and engage are occasionally ill understood, the reverse held true for participants' engagement within these music sessions.

Chapter five describes the design and use of a series of props – technological and not – within the larger 'design' of a series of musical sessions carried out with people with dementia living in and attending care settings. This paper explicates not only this design element, but also reports a number of ways in which participants were seen to participate within these sessions, including: *1) touch and intimacy, 2) connection via social movement, 3) role-shifting, 4) having, holding and giving (materiality),* and *5) using props to disengage from situations*. The goal of which at the outset was to explore the experience of participating for people with dementia, and the thesis has contributed an overarching framework which

describes the social and emotional aspects of participation within music sessions for people with dementia (*performing, connecting, belonging)* and the above themes, which delineates particular *modes* of participation.

Although the SwaytheBand tool was used most frequently in music sessions in Clermont Place, this analysis draws not only on this data but also refers to data from the earlier ethnographic work in St Eithne's. Taking the insights from interactions with participants such as Valerie from St Eithne's, what is notable about these modes of participation is that they are connected to the body and to non-verbal communication; although they are often explicitly performative (as described in chapter 4), my analysis privileges phenomenological experience and co-experience of our bodies in these performative spaces. As the ethnography moved on, it became clear to me that close attention to the bodily expressions of my participants was the most appropriate and most accurate way of representing the reality I was faced with in these care settings. As I note throughout chapters four and five, verbal communication with many participants was often pleasant but sparse – for instance, trying to talk to Claire about her negative feelings surrounding art sessions did not garner much more than '*that's enough*,' or '*I am useless at it*.' Instead, from early on in the project, I had to ensure that I was sensitive instead to the particularities of embodied communication, as well as watch keenly what people did rather than what they said. In this way, although I initially feared it would be difficult to carry out and not hold the weight that a method like interviewing might, ethnography was a useful method in the care homes.

The modes of participation I have described here are usually non-verbal – they speak to the experience of the participants as communicated through their bodies; hands, feet, and faces. It is a form of participation that is difficult to 'write down', as Aoife notes in chapter six – and it doesn't give itself over easily to being described in a 'guide to getting people with dementia to participate', which is often what is sought out (and published). For instance, although it is

an important and sensitive paper, Lindsay's 2012 paper on using workshop-like approaches with people with dementia is able to offer up a set of much more concrete guidelines and challenges. This is in part based on a) the workshop approach itself, which is contained and familiar; and b) the fact that participants are in the early stages of dementia and are accompanied by caregivers. Although both Lindsay and I have worked with people with dementia in ways in which we broadly call participatory, his work is more likely to be accepted as such seeing as it so resembles previous 'participatory design' studies, which use workshops. Taken together, I believe that these studies highlight the particularity of what it means to have dementia or to try to work with participants with dementia – that there is clearly no one way to work with 'people with dementia'.

To reflect upon my own research, I do not think that that I was always successful in involving people with dementia in the research itself – some people were in such advanced stages of dementia that they were almost totally non-verbal. Most participants I had to remind week to week who I was and why I was there. Although many were able to give their opinions on SwaytheBand as well as ways which they'd like to have seen them change, others I had to watch keenly in order to see how their use of the objects could inform and iterate future design. This may just be the nature of dementia – ideally we could involve participants in the planning phases, the design of the software itself, in workshops – but as the condition progresses, this becomes more and more inappropriate. Once we try to do this, we run into issues such as the 'coaxing' problem I describe above, as well as the difficulties that Lindsay et al describe surrounding untangling carers' opinions and feelings from the true wishes of participants, as well as being careful not to put words into participants' mouths. What this thesis offers, therefore, is an account of working with participation from people with dementia – in all stages – in a way in which communication is configured as bodily, felt and phenomenological.

This work will not find itself being presented in participatory design conferences; many participatory design researchers would not consider it a participatory project – for one, it lacks a clear articulation of how participants' wishes fed into the SwaytheBand design process. This is not because I did not bring my data to designers and musicians and ask them to sit down and think with me, because I did, but because having dementia can mean that articulating your wishes and wants verbally is a challenge. As dementia progresses, it often gets even more difficult. Does this mean that we shouldn't include people with dementia in participatory studies – does it mean that people with dementia can't participate? I argue that sitting people with dementia down at a work table and asking them to engage in participatory design activities – brainstorming, sketching, paper prototyping, acting out scenarios – might lead a designer to believe that people with dementia can't participate. But music, dance, movement provides a medium upon which many people with dementia *can* participate – this project, once it began to understand this, made its first steps towards harnessing this medium to direct design activities. It is my hope that future design activities with people with dementia might benefit from the analytic work carried out as part of this thesis to continue exploring how music might become a language for participative work with some people with dementia.

Keeping experience alive

A critical concept for this thesis quickly became how I could 'keep experience alive' in both the documentation and process of working with participants. This is a methodological issue confined not only to working with people with dementia or working in design research, but is instead a larger issue in all qualitative research. McCarthy & Wright (2015) write that, in participatory projects which concern design:

> "*... the aim is not to capture lived experience in order to abstract and reduce it to design requirements ... the aim is to keep the experience alive in the design process so*

> *that it can be brought into dialogue with design expertise and ground the creation of a technological imaginary.*"

McCarthy & Wright suggests that participatory action research approaches resonate with this notion of 'keeping experience alive'. As my research moved from ethnography to a more dialogical series of engagements in the Clermont Place and Rosemount, I felt the process become much more of a conversation – which is reflected in the shift between chapter four to chapter five. McCarthy & Wright write that '*participatory projects attempt to keep experience alive within the project in order to make sense of it*'; in doing this, we exert an effort to do what comes much more naturally to us – place experience in the past and form categories out of it; solidify it into knowledge. It is tempting to do this in dementia - this is why so many design projects situate themselves within 'reminiscence therapy' and 'cognitive prostheses' (Astell, Malone, Williams, Hwang, & Ellis 2014; Lazar, Thompson & Demiris, 2014). Many other research projects see engagement in the field with participants as 'requirements gathering' upon which to build a design. In participatory projects, however, experience is always up in the air, always in the present but extended into the past and reaching into the future.

In chapter six, Lisa, the musician in many of our music sessions, notes that:

> "… *our usual definition of something when we do something good and meaningful for people, is that we would have a lasting impact, something that the person will like remember and take with them,* […] *but I think that just the nature of dementia is that people* […] *they generally live in the past or in the present, so instead of making, trying to do a good thing to have a lasting impact, I think we all know that we won't have a lasting impact, that it's really just momentary.*"

Working with this sense of participants with dementia as always inhabiting a 'present' – with a past that is accessible sometimes only in limited ways, and a future that is difficult to imagine – forced me to 'keep experience alive' within the project. Working within St Eithne's, at first, was difficult for me because of the unpredictability of every day. Although this 'difficult behaviour' was challenging, it also meant that almost every day I entered the setting, for many participants it was as though I was meeting them for the first time. Moreover, I could not respond to their stories as though I'd heard them a million times before – I had to be responsive and listen each time as though it were the first time. When I did this, I could often learn something new about the person each time, or at least learn something about the way their stories were re-woven each day in the context of their dementia. Listening to resident Samantha's story of her hometown and the pride she held in her family for about the third time one day in St Eithne's, she dropped in a detail, almost an afterthought, that though she had remained married to her husband, he was largely a toxic force in her and her children's lives.

This is not to say that everyone working with people with dementia necessarily looks upon each encounter with a patient or resident as a new interaction, full of potential – indeed, after I'd met client Micheál at Clermont Place for the first time, I chatted briefly to the nurse on duty, Louise, about his story. I mentioned how emotional he had become and what a difficult time he had seemed to have had.

'Oh yes,' she said. She rolled her eyes. 'He tells that story to everyone. It's very sad of course, but he just can't seem to snap out of it.'

Louise had spent much more time with Micheál than I had – and her response was one that was most likely to allow her to respond to Micheál in a way which was appropriate and which still allowed her time to get to other clients (I had spent 20 minutes out of a whole hour

talking to Micheál, and imagined he could have spoken to me longer). Beyond this, nursing is a difficult job, and those caring for people with dementia in particular face elevated risk of physical and mental poor health and burnout (Lee, McKeith, Mosimann, Ghosh-Nodyal, & Thomas, 2013) – focusing too much time and attention on Micheál, having too much of an empathic response, would be to the detriment of her own mental health. **But designers, and researchers, are not nurses;** allowing myself to treat each encounter with a participant as a new one allowed me to learn more about them, and allowed me to rest and re-test design tools and principles over and over again within these personal interactions. What is more, as people who respond in such present-focused ways, their experience, in my field notes, was kept alive through a moment-to-moment connection with a new and responsive participant.

Limitations of the research

This research is not without its limitations. In particular, there is a clear division between the work carried out in St Eithne's and the work carried out in Rosebank and Clermont Place – this is due, as described earlier, to a change in management in St Eithne's which was not amenable to carrying out the rest of the research in that setting. In this way, the research may feel slightly lopsided in what it has been able to deliver – Rosebank and Clermont Place (already relatively 'privileged' settings, serving a larger population area, running on private funds) 'benefit' from the research which has been 'laid down' to a certain extent by ethnographic research with participants in St Eithne's. This has been of great concern to me as the research progressed – having spent so much time in St Eithne's, and having formed (at times) quite intimate relationships with participants such as Marie and Charlie, it was difficult for me to have to cut off contact and essentially not know how they are doing anymore.

Beyond this, what was facilitated by a move to the later care settings was a more open dialogue with care staff and management which led to a week-to-week negotiation over the directions in which the research would go. Although this was of benefit in the thesis as a

whole as it led to the development of a PAR-type approach which I was then able to critically reflect upon. Although I am glad that we were able to do this, as mentioned above, it would have been advantageous to have been able to implement a PAR approach from the start – however, I believe it is the reality of working within institutions such as hospitals, care homes, that delays happen, gatekeepers are encountered, and research progresses by way of what is possible rather than what is ideal.

Image 13: Lisa and Wayne, both performing at Clermont Place

In chapter three I describe the application of PAR to this phase of the research as retrospective, and emerging through responding to the wishes of care staff and participants rather than being a planned element of the research. Given the difficulties of working within St Eithne's, I wasn't sure that a truly participatory piece of design research could be carried out in dementia care in Ireland at the time – this research has indicated that, given the right partners, it is possible. The place of SwaytheBand, taken with the ideations surrounding songbooks and other concerts, means that this research functioned more as a piece of research through design – learning about a set of experiences through an iterative unfolding of designing objects – rather than a true PAR study. The design and use of SwaytheBand in particular is akin to a design probe rather than a co-designed 'object'.

A final limitation specific to this research is grown out of the ethnographic approach taken as well as with the settings itself, and that is the reliance within on field notes rather than on data such as interview or conversational data with participants; beyond this, the protectiveness of the care homes in which we worked meant that we were rarely able to photograph within the settings itself, and never photograph the residents. This was due to issues surrounding consent – although in most cases we had gained proxy consent from appointed caregivers, the care settings themselves still disallowed photography. In this way, most photography and film of this research focuses on the researchers, musicians and care staff involved in individual settings. It is interesting to note that although photography was disallowed by us, carers often photographed us as we engaged in the music sessions – in many cases, photographing us dancing with residents. These photographs were usually taken for the purposes of the care centre itself; to circulate within internal newsletters and document that residents or clients had been engaged in particular ways; however, on more than one occasion, Clermont Place took pictures of us and published them on their social media accounts, thanking us for entertaining their residents that day. It is my hope that the qualitative research described within the thesis has been enough to give a sense of the type of energies that are felt in the various spaces explored in this research – the passivity and quiet of St Eithne's, the vivacious energy of the music and dance sessions in contrast – however, as we lament in chapter six, there is something about 'the feeling in the room' that you can't quite write down in field notes.

It is worth also to revisit the final sections of the literature review to think about why experience-centred design was useful in this project but also why it may not be suitable in others. Experience-centred design is an enriching approach to configuring relationships between people and technology (or other objects or services), especially when deployed in small-scale, limited projects. In chapter two, we briefly visit research such as Anja Thieme's,

Rachel Clarke's, and Jayne Wallace's, which each produced a piece of bespoke technology as responses to rich engagement within temporally- and geographically-bound researcher-participant relationships. A common argument against the experience-centred design approach has been its inability to scale. My research, too, is predicated on not much larger a sample – three nursing homes over the course of three years, all within an hour's drive of each other in the south of Ireland – yet there is considerable interest in bringing SwaytheBand forward as a product in other nursing homes and dementia care contexts. It remains to be seen if it can scale – but it is worth noting that the deep researcher involvement that the approach necessitates cannot be done quickly, and so the tendency for the work to be bound to its initial contexts is likely one that will persevere.

Beyond this, experience-centred design is a unifying approach in that it focuses on aspects of immediate and felt experience (which we all have); but there is also a focus on relationships and personal histories, which are highly particular. Although empathy and relating are at the heart of ECD, the approach is not meant to represent a way of doing design that ensures a total synchrony between researcher and designer. It can be surprisingly easy to construe 'empathy' as 'telepathy' (Peters & Calvo, 2014) – and an approach that promises a negotiated understanding on which to build affecting, meaningful technologies is seductive. However, gaps in shared understandings always happen, and technologies produced by ECD are as liable to stimulate conflict and disagreement as any others. What this thesis does is illustrate how working within a ECD framework has helped me (and other researchers involved in this project) to think about the experience of people with dementia, and respond to that in a way that is meaningful and sensitive.

Contributions to knowledge

The literature review in chapter two places an emphasis on research by Wallace (2012; 2013), Hendriks (2014; 2015), Gaver et al (2011), Holbø, Bøthun & Dahl (2013), Killick and Craig

(2013) and Lindsay et al (2012), which have all engaged in participative ways with people with dementia in designing technological experiences. It is worthwhile at this point to briefly revisit and consider these papers before asking what this thesis has contributed against this background: Wallace's work in dementia care settings and family settings used bespoke design to a) promote social interaction in a memory care unit and b) preserve and celebrate a sense of enduring personhood (via design) in a person recently diagnosed with dementia. Gaver et al's work, carried out in a care home for aged people (many of whom have a diagnosis of dementia), similarly attempted to engage people within in social and community interaction. Lindsay's projects – as well as the projects of Hendriks and Holbø – ran workshops with people with dementia (mostly in the earliest stages of the condition) in order to abstract from the experiences to lay down preliminary guidelines for working with the population. In this section, I will briefly detail the contributions my work has made to several of the research themes that these projects (and other work described in the introduction) showcase.

Personhood and care

In chapter two, I refer to Jayne Wallace's research with participants with dementia using an experience-centred design methodology. The most prevalent theme within her research is that of *personhood* for people with dementia, which she describes as:

> *"... something internally changing and externally nurtured through relational and social contexts, continually constructed by the peculiarities of experience and relationships. From this perspective, experience of dementia is an evolving dynamic that embraces the whole person and covers ethical, social-psychological and neurological significance."* (p. 223)

For people with dementia, the notion of self- and personhood is often contested by language which appears in the media as well as in some academic literature surrounding a 'dissolution

of self' (Herkovits, 1995). Recent approaches hold that personhood for people with dementia is also communicable through the body. Kitwood (1997) describes the following scenario from his own experience as a carer, entering a bathroom in a nursing home:

> "*... the door was wide open; all four ladies were sitting on their commodes, and the smell of feces permeated the air. There were no curtains or partitions to screen the ladies from each other or anyone else walking past. My colleagues Rosie and Mary were feeding two of the ladies, and talking about the night out they had just spent together. Rosie was feeding Mrs. T. As soon as there appeared a little room in her mouth, more food was inserted. Her cheeks were bulging with food she hadn't had a chance to swallow. Mrs. T started to gag; food began to spill from her mouth; then she coughed and sprayed Rosie with half-chewed food. Rosie proceeded to clean herself up, while leaving Mrs. T with food debris all over her clothes and exposed thighs."* (Kitwood, 1997, p. 45)

The notion of person-centred care for people with dementia is not a new one; instead, it is something which is commonly practised in care institutions around the world. When I entered St. Eithne's, I was spoke to at length by Nurse Eleanor about the model of care in the unit, which was modelled on Kitwood's person-centred care. Kontos, reflecting on the above scenario from Kitwood, writes that "*assuming a loss of selfhood with advanced dementia implies that there is no affront to human dignity in treating those who are cognitively impaired as though they are unable to experience humiliation*" (p. 118). Although I never saw situations as extreme as the above scenario, several examples from chapter four and my ethnography in care saw the ways in which carers could, in the words of Kontos, '*reduce those afflicted with dementia to dehumanized units of work*' – for instance, the quick, economic dressing-and-undressing that left resident Una so shaken in her first days in the

unit, and the rapid-fire serving of dinner which saw toast with jam served on top of savoury sausages.

Through ethnographic research combined with a design intervention, my research contributes accounts of creative 'work' with people with dementia which both a) treat them as a homogenous group (early sessions in St Eithne's) and also b) take time to engage and understand them in the creation of creative and responsive moments (music sessions in all care settings). When we work with people with dementia in ways which have become reified and stultified (ironically, often through their successful use with other groups), we do not interact with them as people with histories. This can be seen in the interactions, described earlier in the thesis, where art sessions with participants in St Eithne's Unit consisted of the use of colouring pages and colouring books as well as 'coaxing' them into art which may not have meant very much to them at all.

Although the SwaytheBand batons are the sole digital design from this research which reached a stage of prototype production, what became extremely clear as the research progressed was that music, props, and even specially-designed props such as SwaytheBand, were not of much use without human interaction to foreground their use. Even the alternative designs described in chapter five are not about offloading care or distracting participants, but are about enriching moments of connection and belonging within community. Within this acknowledgment lies the difference between treating participants in our design work as the equivalent of Kontos' 'dehumanised units of work' (p. 2) and instead *caring* for them. In this way – as Kitwood and other colleagues predicted in the mid-1990s – we respond to their personhood and not an abstracted idea of a user who fits our purposes. This isn't to say that our music sessions were always enriching for every resident – from week to week, we fielded requests and complaints from residents who wanted different musical choices, or who actually disliked our singers. However, the way we responded to these complaints, and within

the interactions during the music sessions, was responsive in the way that Hicks (2000), writing on Bakhtin, describes as constructive of dialogic understanding, sometimes to the point where "two voices interanimate each other in a single phrase".

Community and connection

Both studies by Wallace & Gaver created designs to engender or enrich social interaction in closed care-units (many of whose members had a diagnosis of dementia). In Wallace's *Tales of I*, a particular section of the unit is closed off in order to create a 'reminiscence room', which contained of an old-style television and unit of shelves which were filled with thematically-ordered 'orbs', which, when placed on the television, would trigger a short film that was linked to the orb's theme – e.g., football or a day by the sea. The room was meant to engender community in the unit – but was instead most commonly used by participants and their family members who were coming for a visit. Similarly, Gaver's work with the Photostroller involved observational research carried out with members of a nursing home which produced a mobile design which functioned similarly to Wallace's reminiscence– a mobile 'stroller' fitted with a television-like screen and dials which could be used to change the media.

Both of these projects attempt to broach the difficult question of community in care for people with dementia by designing ways in which these community tensions may be changed or enriched. In writing about Gaver's work in their 2015 book *Taking Apart*, McCarthy & Wright have the following to say:

> *"When people come to live together due to circumstances outside of their control, for example, declining health or independence, developing new relational practices may be a regular reminder of betrayal to them. When people come to be together in a community group or center that is other to them because of dissatisfaction with what they have or because of fear of not belonging, the irreducibility of their individuality*

> *may present them with difficulties when it comes to opening up to others in the new community. The idea that there is any new community for them when their experience is so in-between has to be questioned."* (p. 101)

In chapter four, I describe the difficulties residents in St Eithne's had with coming to terms with living within a community of people who had not chosen to live with one another. For residents of Jacob House – the nursing home in Gaver's research – this is difficult for the reasons McCarthy & Wright give, above – in particular for residents of St Eithne's, who faced moving into care along with progressive dementia. As I detail in chapter four, the everyday 'feel' of life within St Eithne's Unit was one of passivity, and though residents engaged in activities such as mealtimes, watching television together – even sleeping in the same room – it is difficult to say that they experienced any coherent sense of community. This is not to say that attempts were not made at community-making within the care home – nurses and carers took pictures of residents and placed them on the walls; summer time brought trips to the beach in a rented bus, and bi-yearly the hospital held a 'fare' in its grounds where local families brought cakes for bake sales, and music was played, and residents (under the supervision of care staff) sat out in the green and the sun.

However, if we take these as the sole markers of community in care, we are beginning to work with relatively static notions of what it means to participate within a community, using 'community', as Baumann suggests, as 'another name for paradise lost - but one to which we dearly hope to return, and so we feverishly seek the roads that may bring us there.' For the residents with dementia – who lived in the erstwhile community of St Eithne's for the rest of the year – these experiences of fares and beach trips were pleasant but rare and probably not particularly meaningful for them.

My thesis positions community as a momentary phenomenon achieved and created in moments of interaction, and I have focused on musical interaction. This is something which is common to Gaver's research, although the final design of the Photostroller does not reflect this; earlier in the observational fieldwork which led to the design of the Photostroller, researchers employed a portrait artist to sketch portraits of residents. Upon finding that the activity was popular but relatively solitary (not everyone could watch the portrait taking form in a room of 10-20 residents), the researchers linked the artists' sketching up to a projector so that the work unfolded in real time, and now was viewable by all residents.

I have positioned music as community-making in chapter four, where residents who were otherwise solitary would come together in heightened moments of aesthetic responsiveness to take part in a music session; as the work matured and we introduced the idea of the 'music session' in Clermont Place and Rosebank, the divisions I articulated in earlier fieldwork as 'performer' and 'spectator' fell away to a certain degree as the whole room (of 20-30 people) participated in a community experience. Of course, upon occasion participants would seek the spotlight as performers on their own – Mike, who played the accordion as mentioned in chapter five, 'stealing the spotlight' for about 20 minutes one day – but on the whole, there was no privileged position of performer and spectator. Writing about this division in theatre as well as in education, Rancière argues:

> *"There is no privileged position usurped by philosophy in its various attempts to speak for others, be it the proletariat, the poor, or anyone else who is not 'destined to think' […] those who have no name, who remain invisible and inaudible, can only penetrate the police order [politics] via a mode of subjectivization that transforms the aesthetic coordinators of the community by implementing the universal presupposition of politics: we are all equal."*

Equality in difference is something which has united various human rights and social activism projects over the years, but still people with dementia who live in care tend not to be treated as equals to people living on the outside, or as equal to the nurses and carers who work in the same setting. Working with a group of caregivers in her study on bathing and community care, Twigg relays a quote from one: "'In a residential home they're in your environment, but when you go to their house, you're in theirs – it is quite different, you can't treat people the same." An alternative version of this thesis could be written about the power differentials in care.

Instead, in chapter four, I write about the ways in which music created a 'level playing field' within St Eithne's; this, for me, is enmeshed with the Craig & Killick's notion that, if there is a problem connected to dementia, it is that communication changes, and can be difficult to achieve by verbal means. If we insist on engaging with people with dementia in ways which 'make sense' to us, we might end up achieving nothing at all, at which point it is easy to say that people with dementia can't participate, and engage only with their carers instead. It can be difficult to engage with new forms of communication: it may be time-consuming, and not as easily subjected to our tried and tested methods of analysis. However, if we truly want to respond to the lived experience of our participants, it is something which we must begin to learn how to do, and in ways which produce research findings that can achieve improvement in the communities in which we work.

Participation and design approaches in HCI

This last point is imperative when considering the impact of this thesis on current contributions to knowledge and practice in interaction design with people with dementia. Although the earlier points in this section have spoken to contributions regarding the way we position and work with concepts such as 'community', 'connection', and 'personhood' in dementia, this thesis has also contributed an account of a design process which attempted to

use multiple modalities of communication and creative practice in order to include people with dementia in both the research and the design process. The ways in which the work can be considered against common conceptualisations of participatory work with people with dementia has been addressed in the above section ('Meaning of participation for people with dementia'), and so this section will focus on how the approach taken within this thesis intersects and adds to already existing methods of design.

The approach taken within this project has been primarily that of experience-centred design, where I have worked with experience as a critical concept in both the fieldwork and the design phases of the project. As described above, I have contributed to knowledge that has already been laid down by previous ECD projects with groups of people facing challenging circumstances. My research, although it takes for its basis aesthetic and musical experiences in dementia, is mostly about what a participative experience might be for a group of people with dementia, living in care. Considerations of this participation is then interwoven into a series of possible future designs, and in refining the resulting prototype – SwaytheBand – we engage using the prop in a series of music sessions, rather than sitting around a table and trying to engage people using a workshop approach which – with people in the middle stages of dementia, some earlier, some more severe – is almost definitely bound to fail.

Many different researchers have asked 'what counts as participation?' – Halskov & Hansen (2014) write that, in PD projects, it is often implicit, but tends to focus around mutual learning and taking users' views into account. This thesis presents a piece of research which does not fall into the boundaries of participatory design, but which attempts to take a participative approach whenever possible, not just in its deep engagement with participants but in understanding how that technology is used and appropriated. This thesis is about design, and its overt theme is that of the possibility of participation by people with dementia in programmes of research and innovation which end up impacting upon their lives. I might

have hoped for a set of outcomes and findings that would have seen the potential for people with dementia to sit on boards and workshops that discuss future plans and designs in frank terms – however, this was not to be. Instead, what I have found is a gap in working imaginatively with members of this population in a way that is conducive to strong, meaningful engagement.

There is precedent for this sort of design work, not just in experience-centred design. Spence, Andrews & Frohlich (2013) describe their 'performative experience design' (PED) approach, which they indicate is an extension of ECD. Its hallmarks, they write, include the inclusion of rules that set the performance frame and guides actions such as turn-taking, interactivity that creates different roles and the expression of self to another in the form of verbal or non-verbal dialogue. They offer this approach as a way to unite disparate uses of performance-related language. Although performativity is likely to be a fruitful area of research for designing experientially-sensitive technologies within the area of dementia, my research differs from PED in that it focuses on specific and particular non-verbal interactions arising from the use of props and probes during workshops which are then used iteratively to drive the design further – although these interactions may be performative, they are often not intentionally performative, and instead interpersonal and indicative of underlying emotional and psychosocial needs (as detailed in our results section). However, Spence et al's description of PED as helping to explore '*a rich, as yet almost untapped body of research that addresses interactions between two or more groups or individuals, all of whom are engaged in a designed, mediated, and often technologically influenced experience*' (pg. 2055) resonates with our work, and I would argue that an approach that emphasizes the body offers another 'way in' to the experience of people with dementia.

The body may have been so important in my work because it allowed me to literally trace the steps of people with dementia, hold their hands and interact bodily with them in ways which

were communicative – sometimes sad, sometimes celebratory, sometimes engaged and sometimes bored or even agitated, rebellious against the system in which they were living. With the relative absence of extended reflective conversation about our activities, I knew I had made a real connection when, about a month after the first session in Clermont Place, a resident named Imelda strode across the room upon my entering and kissed me on both cheeks, then drew back, beaming. Her memory was a little better than other clients – she also remembered the SwaytheBand batons very well from one session to the next – but to have received such a welcome, and such a strong, assured and bodily one, was so heartening for me. For most of this research process, I felt my way.

This 'feeling my way' was very strange for me – a psychologist with a solid and immovable sense of what research methods were and should be – but it is echoed by Ingold, who, in 'Making', talks about knowing as an active following or 'going along', which again reverberates within the work of Belenky et al, whose 'women's ways of knowing' are all about valuing what it means to 'know for yourself'. Ingold, differentiating ethnography from anthropology, writes that participant observation is not enough, and that we need to know from the inside. He describes a scenario where students sit by a riverside to create a series of baskets woven from reeds – the goal not being to create a beautiful or even functional basket but instead to know what it is like to sit outside in the cold, in the wind, and to gather materials, feel the tug of them in your fingers, the whipping of them in the breeze – what it feels like to plait them together and have an object emerge out of materials. Making, he writes, should be thought of as a process of growth.

My engagement within these communities has been a process of growth, but so too has been what has emerged from the work – the SwaytheBand prototypes directly respond to the themes of performing, connecting and belonging from the ethnography, and help to illuminate and demonstrate further instances of participation in their use in music sessions.

The question is, what have they emerged from? Ingold writes of making as "*a process of correspondence, not the imposition of preconceived form on raw material substance, but the drawing out or bringing forth of potentials immanent in a world of becoming*" (p. 31). What are the materials in this design process, and what has been created? Is it right to call this sort of engagement one which is creative if participants are not painting pictures or creating songs, but instead singing ones which they have learned throughout their lives? In chapter four, I note that Hicks (2000), describing a process of 'accenting each other's words' writes that, for Bakhtin, "*the individual becomes the unique ways in which one accents the words of others, and the ways in which one orchestrates a resulting system of discourses*" (p. 31). In chapter three, I quote Sawyer, who writes that '*most jazz musicians can't imagine the possibility of never playing a phrase or motif that had ever been played before—that's not the way jazz works. Jazz is heavily motif-based, but that does not diminish the creativity of the performers*' (p. 116).

The language of music, particularly of improvisatory jazz music, has become a valuable resource for me throughout this thesis. It has allowed me to talk about different forms of group creativity, and to describe moments both of group dissent and group harmony. Despite most of the music we played and songs we sung in these care homes being familiar to many residents, moments occurred when the next step was one open to any number of possibilities – what order the verses went in, whether to repeat a chorus, how high a note to sing. Sometimes, between songs, we would pause, wait for someone to move or to sing – these were anticipatory moments. Sawyer brings together accounts of improvisatory jazz with improvisatory comedy to note 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*" (p. 7).

From Ingold's accounts, 'combinatorial complexity' is something present in design and making as well, and this must be amplified when many people come together to engage in design processes over time, particularly when what is at stake is something difficult or sensitive to address or approach. This is, or at least was, the case in many participatory design studies, and is of course central to research which puts participation at its centre or decides that participatory methods are most suitable. Sawyer writes that we '*need to think of intersubjectivity as a process of coordination of individual contributions to joint activity rather than as a state of agreement*' (p. 9) – in HCI research, we can reify and chase that state of agreement above all else, and it is easy to believe that it is the unavoidable end point of participatory research. In this thesis, I hope that I have instead presented analytic accounts of individual contributions and their places within a joint activity – not as a series of agreements but of arguments, dissents, and instances of togetherness, intimacy and belonging.

Conclusion

This thesis has presented an experience-centred account of engagement in music sessions for people with dementia, and has used this account to explore imaginative ways of participating and belonging for my participants. In particular, I have explored the potential of a simple digital technology to highlight elements of communication within these sessions that are particularly participative. The main contributions of the thesis, however, are threefold:

First, the thesis extends experience-centred design approaches by using them as a methodology for inquiry into the lived experience of people with dementia living in care. This application of experience-centred design has produced an understanding of life in "communities" of care which is brought to a head by sensual and bodily engagement in musical experiences. The thesis contributes to an understanding of the practice of dialogical aesthetics to inform the building of relationships within communities of care where the tensions of protection and safety for its clients are balanced with the need to provide fulfilling

and meaningful engagement. This is achieved through an in-depth long-term study with three care settings in the south of Ireland.

Secondly, the thesis further contributes to understandings of how participation via creative, expressive embodiment can help to drive forward a design process. The thesis uses data collected through these ethnographies to question the meaning of participation for people with dementia in the context of challenges set by experience-centred design approaches. This is achieved through the design and deployment of the SwaytheBand prototypes within two care centres.

Thirdly, the thesis contributes to interdisciplinary approaches that seek to use participatory methods in the design and evaluation of technical devices within care contexts for and with people with dementia. This is achieved through a critical questioning of participation by people with dementia within the design project, and an attenuation to the ways of communicating of individuals with dementia within the project in terms of how they can be considered as constitutive of participation and included in processes of design and evaluation.

References

Albert, S. M., Castillo-Castaneda, C., Sano, M., Jacobs, D. M., Marder, K., Bell, K., & Stern, Y. (1996). Quality of life in patients with Alzheimer's disease as reported by patient proxies. *Journal of the American Geriatrics Society*, *44*(11), 1342-1347.

Algase, D. L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and Other Dementias*, *11*(6), 10-19.

Alm, N., Dye, R., Gowans, G., Campbell, J., Astell, A., and Ellis. E. (2002). Designing an interface usable by people with dementia. In Proceedings of the 2003 conference on Universal usability (CUU '03). ACM, New York, NY, USA, 156-157.

Alzheimer's Society of Ireland. 2015. Performance by People with Dementia Set to Challenge Perceptions. Retrieved from: https://alzheimer.ie/getattachment/About-Us/News-and-Media/Press-Releases/Purple-Pops-Final.pdf.aspx, 17th January 2016

Alzheimer's Society of Ireland. 2016. Mental Capacity Act 2005. Retrieved from: https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=354, 23rd March 2016

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.

Andersen, K., & Wilde, D. (2012). Circles and props: making unknown technology. Interactions, 19, 3 (May 2012), 60-65.

Argyle, E., Downs, M. and Tasker, J., 2010. Continuing to Care for People with Dementia: Irish Family Carers' Experience of their Relative's Transition to a Nursing Home, [Lecture to Bradford Dementia Group], Bradford, The Alzheimer Society of Ireland, Dublin and St Luke's Home, Cork**.**

Ariyadasa, E., & McIntyre-Mills, J. (2015). Quality of life of Sri Lankan children: participatory action research to address the governance issues of voluntary children's homes. *Systemic Practice and Action Research*, *28*(5), 453-478.

Armstrong, N., Nugent, C., Moore, G., & Finlay, D. (2010). Using smartphones to address the needs of persons with Alzheimer's disease. *Annals of Telecommunications*, 65(9-10), 485-495.

Asaro, P. M. (2000). Transforming society by transforming technology: the science and politics of participatory design. *Accounting, Management and Information Technologies*, *10*(4), 257-290.

Astell, A. J., Malone, B., Williams, G., Hwang, F., & Ellis, M. P. (2014). Leveraging everyday technology for people living with dementia: a case study. *Journal of Assistive Technologies*, *8*(4), 164-176.

Auslander, P. (2008). *Liveness: Performance in a mediatized culture*. Routledge.

Azermain, M. 2015. Dealing with behavioral and psychological symptoms of dementia: a general overview. Psychology Research and Behavior Management, 8 (2015): 181.

Bachelard, G., & Jolas, M. (1994). *The poetics of space*. Beacon Press.

Bakhtin, M. M. (1993). *Toward a philosophy of the act*. M. Holquist & V. Liapunov (Eds.), V. Liapunov (Trans). Austin: University of Texas Press.

Bakhtin, M. M. (1981). *Discourse in the novel*. In M. Holquist (Ed.), The Dialogic Imagination: Four Essays by M. M. Bakhtin. Translated from Russian by C. Emerson & M. Holquist. Austin: University of Texas Press.

Bakhtin, M. M. (1984). *Rabelais and His World*. Translated from Russian by H. Iswolsky. Bloomington: Indiana University Press.

Bakhtin, M. M. (1986). *Speech Genres and Other Late Essays*. Translated from Russian by C. Emerson & M. Holquist. Austin: University of Texas Press.

Bakhtin, M. M. (1990). *Art and Answerability: Early Philosophical Essays.* Translated from Russian by M. Holquist & V. Liapunov. Austin: University of Texas Press.

Bardzell, J., Bardzell, S., & Koefoed Hansen, L. (2015). Immodest proposals: Research through design and knowledge. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (pp. 2093-2102). ACM.

Barkhuus, L., Arvid Engström, and Goranka Zoric. (2014). Watching the footwork: second screen interaction at a dance and music performance. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '14). ACM, New York, NY, USA, 1305-1314.

Basting, Anne Davis. 2006. Arts in Dementia Care: 'This is not the end... it's the end of this chapter.' *Generations*, 30 (1): 16-20.

Bauman, Z. (2013). *Community: Seeking safety in an insecure world*. John Wiley & Sons.

Beck, E. E. (2002). P for Political. *Scandinavian Journal of Information Systems*, *14*.

Behar, R., 1996. *The Vulnerable Observer: Anthropology That Breaks Your Heart*. Boston: Beacon.

Belenky, M. F., Clinchy, B. M., & Goldberger, N. R, & Tarule, J.M. (1986). Women's ways of knowing. Basic Books.

Bermingham, A., O'Rourke, J., Gurrin, C., Collins, R., Irving, K., & Smeaton, A. F. (2013). Automatically recommending multimedia content for use in group reminiscence therapy. In *Proceedings of the 1st ACM international workshop on Multimedia indexing and information retrieval for healthcare* (pp. 49-58). ACM.

Bharucha, A., Anand, V., Forlizzi, J., Dew, M. A., Reynolds, C. F., Stevens, S., and Wactlar, H. (2009). Intelligent assistive technology applications to dementia care: current capabilities, limitations, and future challenges. *The American Journal of Geriatric Psychiatry*, 17(2): 88-104.

Biswas, J., Jayachandran, M., Thang, P. V., Fook, V. F. S., Choo, T. S., Quiang, Q., & Kiat, P. Y. L. (2006). Agitation monitoring of persons with dementia based on acoustic sensors, pressure sensors and ultrasound sensors: a feasibility study. In *International Conference on Aging, Disability and Independence, held in St. Micheálsburg, Florida.* (pp. 3-15).

Blythe, M., Wright, P, Bowers, J., Boucher, A., Jarvis, N., Reynolds, P., and Gaver, W. (2010). Age and experience: ludic engagement in a residential care setting. In Proceedings of the 8th ACM Conference on Designing Interactive Systems, pp. 161-170. ACM, 2010.

Blythe, M., Steane, J., Roe, J., & Oliver, C. (2015, April). Solutionism, the game: design fictions for positive aging. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (pp. 3849-3858). ACM.

Bødker, S., Ehn, P., Sjögren, D., & Sundblad, Y. (2000). Co-operative Design—perspectives on 20 years with 'the Scandinavian IT Design Model'. *In Proceedings of NordiCHI*, pp. 22- 24.

Brooker, D., 2003. What is person-centred care in dementia?. *Reviews in Clinical Gerontology*, 13(03), 215-222.

Brotons, M and Susan Koger. 2000. The impact of music therapy on language functioning in dementia. *Journal of Music Therapy*, 37 (3): 183-195.

Bruner, J. S., & Austin, G. A. (1986). *A study of thinking*. Transaction Publishers.

Bruner, J. S., & Bruner, J. S. (2009). *Actual minds, possible worlds*. Harvard University Press.

Brynskov, M., Christensen, B. G., Ludvigsen, M., Collins, A. M., & Grønbæk, K. (2005). Designing for Nomadic Play: A case study of participatory design with children. *In Proceedings of the 4th International Conference for Interaction Design and Childre*n, pp. 24-34.

Cahill, S., O'Shea, E., & Pierce, M. (2012). Creating excellence in dementia care: A research review for Ireland's national dementia strategy. Retrieved from: http://tinyurl.com/pslky5z

Cahill, S., O'Shea, E., & Pierce, M., 2012. Creating excellence in dementia care: A research review for Ireland's national dementia strategy. Available at https://www.tcd.ie/Communications/content/pdf/Creating_Excellence_in_Dementia_Care2012.pdf. [Accessed 10 January 2015].

Campbell, A., 2014. *What are the factors that influence person centred care in public residential care settings for older people*?. PhD Thesis, NUI Galway.

Caris-Verhallen, W., Ada Kerkstra, and Jozien M. Bensing. 1999. Non-verbal behaviour in nurse–elderly patient communication. *Journal of Advanced Nursing*, 29 (4): 808-818.

Charmaz, K. (1990). 'Discovering'chronic illness: Using grounded theory. *Social science & medicine*, *30*(11), 1161-1172.

Charmaz, K. (2003). Grounded theory. *Qualitative psychology: A practical guide to research methods*, 81-110.

Charmaz, K. 2014. *Constructing Grounded Theory.* London: Sage Publications.

Chenoweth, L., & Kilstoff, K. (1998). Facilitating positive changes in community dementia management through participatory action research. *International Journal of Nursing Practice*, *4* (3), 175-188.

Jonas-Simpson, C., & Mitchell, G. J. (2005). Giving voice to expressions of quality of life for persons living with dementia through story, music, and art. *Alzheimer's Care Today*, 6 (1): 52-61.

Chu, H., Chyn-Yng Yang, Yu Lin, Keng-Liang Ou, Tso-Ying Lee, PhD, Anthony Paul O'Brien and Kuei-Ru Chou. 2013. The impact of group music therapy on depression and cognition in elderly persons with dementia: a randomized controlled study. *Biological Research for Nursing*, 16 (2): 209-217.

Clarke, R., Wright, P., Balaam, M., & McCarthy, J. (2013). Digital portraits: photo-sharing after domestic violence. In *Proceedings of the SIGCHI conference on Human factors in computing systems*, 2517-2526. ACM.

Clement, A., & Van den Besselaar, P. (1993). A retrospective look at PD projects. *Communications of the ACM*, 36 (6), 29-37. Cohen-Mansfield, J., Golander, H., Arnheim, G., & Cohen, R., 2014. Reactions and interventions for delusions in nursing home residents with dementia. American Journal of Alzheimer's Disease and Other Dementias, 15 (33), pp. 317-344.

Cole, J., (2001). *Forget Colonialism*?. Oakland: University of California Press.

Collingwood, R. G. (1938). The Principles of Art. Case Press.

Colomer, J., & de Vries, J. (2014). Person-centred dementia care: a reality check in two nursing homes in Ireland. *Dementia*, 1 (47), 121-130.

Cowl, A. L., & Gaugler, J. E. (2014). Efficacy of creative arts therapy in treatment of Alzheimer's Disease and dementia: a systematic literature review. *Activities, Adaptation & Aging*, 38 (4), 281-330.

Csikszentmihalyi, M. (1996). Flow and the psychology of discovery and invention. *New York: Harper Collins*.

Dahl, Y., & Holbø, K. (2012). Value biases of sensor-based assistive technology: case study of a GPS tracking system used in dementia care. In *Proceedings of the Designing Interactive Systems Conference* (pp. 572-581). ACM.

Dalsgaard, P., & Halskov, K. (2012). Reflective design documentation. In *Proceedings of the Designing Interactive Systems Conference* (pp. 428-437). ACM.

Davies, C. A. (2008). *Reflexive Ethnography: A Guide to Researching Selves and Others.* London: Routledge.

de Quetteville, H. (2008). Fake bus stop keeps Alzheimer's patients from wandering off. Retrieved 04 June 2016 from http://www.telegraph.co.uk/news/newstopics/howaboutthat/2071319/Fake-bus-stop-keeps-Alzheimers-patients-from-wandering-off.html

de Souza, L. C., Volle, E., Bertoux, M., Czernecki, V., Funkiewiez, A., Allali, G., & Kas, A. (2010). Poor creativity in frontotemporal dementia: a window into the neural bases of the creative mind. *Neuropsychologia*, *48*(13), 3733-3742.

Dewing, J. (2007). Participatory research A method for process consent with persons who have dementia. *Dementia*, *6* (1), 11-25.

Dickson-Swift, V., James, E. L., Kippen, S., & Liamputtong, P. (2007). Doing sensitive research: what challenges do qualitative researchers face?. *Qualitative Research*, 7(3), 327-353.

Dindler, C., & Iversen, O. S. (2014). Relational expertise in participatory design. *In Proceedings of the 13th Participatory Design Conference*, 41-50. ACM.

DiSalvo, C., Clement, A., & Pipek, V. (2013). Participatory design for, with, and by communities. In Simonsen, Jesper and Toni Robertson (Eds.), *International Handbook of Participatory Design*, 182-209. Oxford: Routledge.

Dourish, P. (2006). Implications for design. In *Proceedings of the SIGCHI conference on Human Factors in computing systems* (pp. 541-550). ACM.

Beck, E. (2002). P for Political: Participation is not enough. *Scandinavian Journal of Information Systems*, 14 (1), 1-16.

Ehleringer, E. H., & Kim, S. J. (2013). The wearable lullaby: improving sleep quality of caregivers of dementia patients. In *CHI'13 Extended Abstracts on Human Factors in Computing Systems* (pp. 409-414). ACM.

Elsden, C. (2014). Situated remembering with digital technology. In *Proceedings of the 2014 companion publication on Designing interactive systems*. ACM, New York, NY, USA, 145-149.

Etters, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners*, *20* (8), 423-428.

Evans, F., & Lawlor, L. (2000). The value of flesh: Merleau-Ponty's philosophy and the modernism/postmodernism debate. In Fred Evans & Leonard Lawlor (eds.), *Chiasms*. State University of New York Press.

Favilla, S., & Pedell, S. (2013). Touch screen ensemble music: collaborative interaction for older people with dementia. In *Proceedings of the 25th Australian Computer-Human Interaction Conference: Augmentation, Application, Innovation, Collaboration* (pp. 481-484). ACM.

Fitzpatrick, G., & Ellingsen, G. (2013). A review of 25 years of CSCW research in healthcare: contributions, challenges and future agendas. Computer Supported Cooperative Work (CSCW), 22(4-6), 609-665. Chicago.

Fox, F. (2010). Remembering daddy: Autoethnographic reflections of my father and Alzheimer's disease. *Text and Performance Quarterly*, 30 (1): 3-20.

Frauenberger, C., Good, J., Fitzpatrick, G., & Iversen, O. S. (2015). In pursuit of rigour and accountability in participatory design. International journal of Human-Computer Studies, 74, 93-106.

Frayling, (C. 1993). Research in art and design. *Royal College of Arts Research Papers*, 1 (1), 1-5.

Gaventa, J. (2004). Towards participatory governance: assessing the transformative possibilities. *Participation: From tyranny to transformation*, 25-41.

Gaver, W. (2012). What should we expect from research through design*?*. *In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12)*. ACM, New York, NY, USA, 937-946.

Gaver, W., Boucher, A., Bowers, J., Blythe, M., Jarvis, N., Cameron, D. & Wright, P. (2011). The photostroller: supporting diverse care home residents in engaging with the world. In *Proceedings of the SIGCHI Conference on Human Factors in Computing System*s (pp. 1757-1766).

Gawande, A. (2015). *Being Mortal*. Metropolitan Books.

Gibson, G., Newton, L., Pritchard, G., Finch, T., Brittain, K., & Robinson, L. (2014). The provision of assistive technology products and services for people with dementia in the United Kingdom. *Dementia*, 14 (7), 121-130.

Gillespie, A., & Cornish, F. (2010). Intersubjectivity: Towards a dialogical analysis. *Journal for the Theory of Social Behaviour*, 40(1), 19-46.

Goffman, E. (1961). *Asylums: essays on the social situatioon of mental patients and other inmates*. Doubleday Publishers.

Gonzalez, B., Carroll, E., and Latulipe, C. (2012). Dance-inspired technology, technology-inspired dance. In Proceedings of the 7th Nordic Conference on Human-Computer Interaction: Making Sense Through Design (NordiCHI '12). ACM, New York, NY, USA, 398-407.

Gonzalez, M. C.,(2003). An ethics for postcolonial ethnography. In *Expressions of Ethnography: Novel Approaches to Qualitative Methods*, 77-86.

Griggio, C. F., Romero, M., & Leiva, G. (2015). Towards an Interactive Dance Visualization for Inspiring Coordination Between Dancers. In *Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems* (CHI EA '15). ACM, New York, NY, USA, 1513-1518.

Groger, L. 1995. A nursing home can be a home. *Journal of Aging Studies*, 9 (2): 137-153.

Grover, S. 2004. Why won't they listen to us? On giving power and voice to children participating in social research. *Childhood*, 11 (1): 81-93.

Gubrium, J. (1975). *Living and dying at Murray Manor*. Charlottesville: University of Virginia Press.

Halskov, K., & Hansen, N. B. (2015). The diversity of participatory design research practice at PDC 2002–2012. *International Journal of Human-Computer Studies*, *74*, 81-92.

Hammersley, M., & Atkinson, P., 2007. Ethnography: Principles in Practice. London: Routledge.

Hanley, I., & Hodge, J. (1984). *Psychological Approaches to the Care of the Elderly*. New York: Methuen Ine.

Hara, M. (2011). Music in dementia care: increased understanding through mixed research methods. *Music and Arts in Action*, 3(2), 34-58.

Harciarek, M., & Cosentino, S. (2013). Language, executive function and social cognition in the diagnosis of frontotemporal dementia syndromes. *International Review of Psychiatry*, *25*(2), 178-196.

Harding, N., and Colin Palfrey. (1997). *The social construction of dementia: Confused professionals?*. London: MacMillan Publications.

Hargreaves, D., and North, A. (1999). The functions of music in everyday life: Redefining the social in music psychology. *Psychology of Music*, 27(1): 71-83.

Harley, D., Fitzpatrick, G., Axelrod, L., White, G., & McAllister, G. (2010). Making the Wii at home: game play by older people in sheltered housing. In *Symposium of the Austrian HCI and Usability Engineering Group* (pp. 156-176). Springer: Berlin Heidelberg.

Harley, D., & Fitzpatrick, G. (2009). YouTube and intergenerational communication: the case of Geriatric1927. *Universal Access in the Information Society*, 8(1), 5-20.

Hartley, N. (2013). *End of Life Care: A Guide for Therapists, Artists and Arts Therapists*. Jessica Kingsley Publishers.

Haslam, N. (2006). Dehumanization: An integrative review. *Personality and social psychology review*, *10*(3), 252-264.

Heggestad, A. K. T., Nortvedt, P., & Slettebø, Å. (2012). The importance of moral sensitivity when including persons with dementia in qualitative research. *Nursing Ethics*, 9 (6), 97-113.

Hendriks, N., Huybrechts, L., Wilkinson, A., & Slegers, K. (2014). Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2* (pp. 33-36). ACM.

Hendriks, N., Truyen, F., & Duval, E. (2013). Designing with dementia: Guidelines for participatory design together with persons with dementia. In *IFIP Conference on Human-Computer Interaction* (pp. 649-666). Springer: Berlin Heidelberg.

Herskovits, E. (1995). Struggling over subjectivity: Debates about the “self” and Alzheimer's disease. *Medical anthropology quarterly*, *9*(2), 146-164.

Heslop, L., Elsom, S., & Parker, N. (2000). Improving continuity of care across psychiatric and emergency services: combining patient data within a participatory action research framework. *Journal of Advanced Nursing*, 31(1), 135-143.

Hicks, D. (2000). Self and Other in Bakhtin's Early Philosophical Essays: Prelude to a Theory of Prose Consciousness. *Mind, Culture and Activity*, 7 (3), 227–242.

Hödl, O., Kayali, F., & Fitzpatrick, G. (2012). Designing interactive audience participation using smart phones in a musical performance. Ann Arbor, MI: Michigan Publishing, University of Michigan Library.

Hoe, J., Hancock, G., Livingston, G., & Orrell, M. (2006). Quality of life of people with dementia in residential care homes. *The British Journal of Psychiatry*, *188* (5), 460-464.

Holbø, K., Bøthun, S., & Dahl, Y. (2013). Safe walking technology for people with dementia: what do they want?. In *Proceedings of the 15th International ACM SIGACCESS Conference on Computers and Accessibility* (p. 21). ACM.

Holter, I. M., & Schwartz-Barcott, D. (1993). Action research: what is it? How has it been used and how can it be used in nursing?. *Journal of Advanced Nursing*, *18* (2), 298-304.

Hopper, L., Paulina Piasek & Kate Irving. 2015. Ethical Challenges Associated with Technology use with People with Dementia. *International Association of Geriatrics and Gerontology*, Dublin, April 2015.

Hornberger, M., Piguet, O., Graham, A. J., Nestor, P. J., & Hodges, J. R. (2010). How preserved is episodic memory in behavioral variant frontotemporal dementia?. *Neurology*, *74* (6), 472-479.

Hughes, J. C., Stephen J. Louw, Steven R. Sabat. 2006. *Dementia: Mind, Meaning, and the Person.* Oxford University Press.

Huisman, K., 2008. “Does this mean you’re not going to come visit me anymore?”: an inquiry into an ethics of reciprocity and positionality in feminist ethnographic research. *Sociological Inquiry*, 78 (3), 372-396.

Ingold, T. Making: Anthropology, archaeology, art and architecture. Routledge.

Irwin, K., 2006. Into the dark heart of ethnography: The lived ethics and inequality of intimate field relationships. *Qualitative Sociology*, 29 (2), 155-175.

Iversen, O. S., & Nielsen, C. (2003). Using digital cultural probes in design with children. In *Interaction Design And Children: Proceeding of the 2003 Conference on Interaction Design and Children*. 1 (3), 154-154.

Iversen, O. S., Kortbek, K. J., Nielsen, K. R., & Aagaard, L. (2007, June). Stepstone: an interactive floor application for hearing impaired children with a cochlear implant. In *Proceedings of the 6th international conference on Interaction design and children* (pp. 117-124). ACM.

Jorgensen, D. L. (1989). Participant observation. *Emerging trends in the social and behavioral sciences: An interdisciplinary, searchable, and linkable resource*.

Kessels, R. P., Kortrijk, H. E., Wester, A. J., & Nys, G. (2008). Confabulation behaviour and false memories in Korsakoff's syndrome: Role of source memory and executive functioning. *Psychiatry and Clinical Neurosciences*, 62(2), 220-225.

Killick, J. and Claire Craig. (2011). *Creativity and Communication in Persons with Dementia: A Practical Guide*. London: Jessica Kingsley Publishers.

Kindon, S., Pain, R., & Kesby, M., 2008. Participatory action research. *International Encyclopaedia of Human Geography*, 90-95.

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health*, *1*(1), 13-22.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society*, *12*(03), 269-287.

Kitwood, T.. 1997. The experience of dementia. *Aging & Mental Health*, 1(1): 13-22.

Klein, D. A., Steinberg, M., Galik, E., Steele, C., Sheppard, J. M., & Warren, A. (1999). Wandering behaviour in community-residing persons with dementia. *International Journal of Geriatric Psychiatry*, *14* (4), 272-279.

Klonovs, J., Haque, M. A., Krueger, V., Nasrollahi, K., Andersen-Ranberg, K., Moeslund, T. B., & Spaich, E. G. (2016). Monitoring Technology. In*Distributed Computing and Monitoring Technologies for Older Patients* (pp. 49-84). Springer International Publishing.

Kontos, P. C. (2011). Rethinking sociability in long-term care: An embodied dimension of selfhood. *Dementia*, 11 (3): 329-346.

Kontos, P. C. and Wendy Martin. (2013). Embodiment and dementia: Exploring critical narratives of selfhood, surveillance, and dementia care. *Dementia*, 1–15.

Kontos, P. C., & Naglie, G. (2007). Expressions of personhood in Alzheimer's disease: An evaluation of research-based theatre as a pedagogical tool. *Qualitative Health Research*, 17 (6), 799-811.

Kontos, P. C., & Naglie, G. (2006). Expressions of personhood in Alzheimer's: Moving from ethnographic text to performing ethnography. *Qualitative Research*, 6 (3), 301-317.

Kontos, P. C. (2005). Embodied selfhood in Alzheimer's disease Rethinking person-centred care. *Dementia*, *4* (4), 553-570.

Kopelman, M. D. (1991). Non-verbal, short-term forgetting in the alcoholic Korsakoff syndrome and Alzheimer-type dementia. *Neuropsychologia*, *29*(8), 737-747.

Kosugi, N., Kodama, N., Shimizu, S., Saruwatari, S., Terada, T., Kazui, M. D., & Hata, M. (2013). A Prototype System of Remote Music Therapy Using the Latest Communication Technology in Japan. In *Proceedings of International Conference on Information Integration and Web-based Applications & Services* (p. 671). ACM.

Lai, C. and David G. Arthur. 2003. Wandering behaviour in people with dementia. *Journal of Advanced Nursing*, 44 (2): 173-182.

Landau, R., Werner, S., Auslander, G. K., Shoval, N., & Heinik, J. (2009). Attitudes of family and professional care-givers towards the use of GPS for tracking patients with dementia: an exploratory study. *British Journal of Social Work, 39* (4), 670-692.

Langa, K. M. (2015). Is the risk of Alzheimer's disease and dementia declining? *Alzheimer's Research & Therapy, 7*(1), 1.

Lauriks, S., Reinersmann, A., Van der Roest, H. G., Meiland, F. J. M., Davies, R. J., Moelaert, F., & Dröes, R. M. (2007). Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Research Reviews, 6* (3), 223-246.

Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation*. Cambridge University Press.

Lazar, A., Koehler, C., Tanenbaum, J., & Nguyen, D. H. (2015). Why we use and abandon smart devices. In Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp '15). ACM, New York, NY, USA, 635-646.

Lazar, A., Thompson, H., & Demiris, G. (2014). A systematic review of the use of technology for reminiscence therapy. *Health Education & Behavior*, 41 (1), 51-61.

Lee, D. R., McKeith, I., Mosimann, U., Ghosh-Nodyal, A., & Thomas, A. J. (2013). Examining carer stress in dementia: the role of subtype diagnosis and neuropsychiatric symptoms. *International Journal of Geriatric Psychiatry, 28* (2), 135-141.

Lee, K., Cox, D. J., Garnett, G. E., & Junokas, M. J. (2015). Express it!: An Interactive System for Visualizing Expressiveness of Conductor's Gestures. In Proceedings of the 2015 ACM SIGCHI Conference on Creativity and Cognition (C&C '15). ACM, New York, NY, USA, 141-150.

Leong, T. W., Wright, P., Vetere, F., & Howard, S. (2010). Understanding experience using dialogical methods: the case of serendipity. In *Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction*. ACM, New York, NY, USA, 256-263.

Lerum, K. (2001). Subjects of desire: academic armour, intimate ethnography, and the production of critical knowledge. *Qualitative Inquiry*, 7 (4), 466-483.

Leuty, V., Boger, J., Young, L., Hoey, J., & Mihailidis, A. (2013). Engaging older adults with dementia in creative occupations using artificially intelligent assistive technology. *Assistive Technology*, 25(2), 72-79

Liamputtong, P. (2006). *Researching the vulnerable: A guide to sensitive research methods.* Sage Publications.

Lillis, T. (2008). Ethnography as method, methodology, and "Deep Theorizing": closing the gap between text and context in academic writing research. *Written Communication*, 25(3), 353-388.

Lindsay, S., Brittain, K., Jackson, D., Ladha, C., Ladha, K., & Olivier, P. (2012). Empathy, participatory design and people with dementia. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '12). ACM, New York, NY, USA, 521-530.

Lipowski, Z. J. (1969). Psychosocial aspects of disease. *Annals of Internal Medicine, 71* (6), 1197-1206.

Ljungblad, S. (2009). Passive photography from a creative perspective: "If I would just shoot the same thing for seven days, it's like... What's the point?". In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '09)*. ACM, New York, NY, USA, 829-838.

Lopresti, E., Mihailidis, A., & Kirsch, N. (2004). Assistive technology for cognitive rehabilitation: State of the art. *Neuropsychological Rehabilitation, 14* (1-2), 5-39.

Lucero, M. (2002). Intervention strategies for exit-seeking wandering behavior in dementia residents. *American Journal of Alzheimer's Disease and Other Dementias*, 17 (5): 277-280.

Lucero, M., Hutchinson, S., Leger-Krall, S., & Wilson, H. S. (1993). Wandering in Alzheimer's dementia patients. *Clinical Nursing Research, 2* (2), 160-175.

Maiter, S., Simich, L, Jacobson, N., & Wise, J. (2008). Reciprocity: An ethic for community-based participatory action research. *Action Research*, 6 (3): 305-325.

Malthouse, M. (2011). An autoethnography on shifting relationships between a daughter, her mother and Alzheimer's dementia (in any order). *Dementia*, 10 (2): 249-256.

Martins, J., Carilho, J., Schnell, O., Duarte, C., Couto, F. M., Carriço, L., & Guerreiro, T. (2014). Friendsourcing the unmet needs of people with dementia. In *Proceedings of the 11th Web for All Conference* (p. 35). ACM.

Martins, J., Carilho, J., Schnell, O., Duarte, C., Couto, F., Carriço, L., & Guerreiro, T. (2014). Friendsourcing the unmet needs of people with dementia. In Proceedings of the 11th Web for All Conference (W4A '14). ACM, New York, NY, USA.

Mayer, J. M., & Zach, J. (2013). Lessons learned from participatory design with and for people with dementia. In *Proceedings of the 15th international conference on Human-computer interaction with mobile devices and services (MobileHCI '13*). ACM, New York, NY, USA, 540-545.

McCarthy, J., & Wright, P., 2004. *Technology as Experience*. Cambridge: MIT Press.

McCarthy, J., & Wright. P. (2006). A Dialogical Approach to Experience: Uncovering Critical Potential. *The Virtual*, 1-11.

McCarthy, J., & Wright, P. (2015). *Taking [A]part: The Politics and Aesthetics of Participation in Experience-centred Design*. Cambridge: 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.

McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: a narrative synthesis systematic review. *International Journal of Geriatric Psychiatry*, 28 (8), 781-794.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19 (13-14), 1935-1943.

McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R., Kawas, C. H., & Mohs, R. C. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia*, *7* (3), 263-269.

Merleau-Ponty, Maurice. (1961). *Phenomenology and Perception*. London: Routledge.

Meulen, E. F. J., Schmand, B., Van Campen, J. P., De Koning, S. J., Ponds, R. W., Scheltens, P., & Verhey, F. R. (2004). The seven minute screen: a neurocognitive screening test highly sensitive to various types of dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, *75* (5), 700-705.

Michael, K. (2013). For now we see through a glass, darkly. *IEEE Technology & Society Mag*, *32* (4), 4-5.

Michael, K., and MG Michael. (2013). No limits to watching?. Communications of the ACM, 56 (11), 26-28.

Mimica N, & Kalini D. (2011) Art therapy may be beneficial for reducing stress-related behaviours in people with dementia— Case report. *Psychiatry Danube*, 23(1), 125–128

Monchamp, A. M. (2011). The other side of the story. *Memory Studies*, *4*(1), 53-62.

Monchamp, A. M. (2014). *Autobiographical Memory in an Aboriginal Australian Community: Culture, Place and Narrative*. Hampshire, UK: Palgrave Macmillan.

Moore, T. (2014). Aboriginal agency and marginalisation in Australian society. *Social Inclusion*, 2(3), 124-135.

Moss, S., Emerson, E., Kiernan, C., Turner, S., Hatton, C., & Alborz, A. (2000). Psychiatric symptoms in adults with learning disability and challenging behaviour. *The British Journal of Psychiatry*, 177 (5), 452-456.

Mullender, A., & Hague, G. (2005). Giving a voice to women survivors of domestic violence through recognition as a service user group. *British Journal of Social Work*, 35 (8): 1321-1341.

Mulvenna, M., Martin, S., Sävenstedt, S., Bengtsson, J., Meiland, F., Dröes, R. M., Hettinga, M., Moelaert, F., & Craig, D. (2010). Designing & evaluating a cognitive prosthetic for people with mild dementia. In Proceedings of the 28th Annual European Conference on Cognitive Ergonomics (ECCE '10). ACM, New York, NY, USA, 11-18.

Murphy, E., & Dingwall, R. (2007). Informed consent, anticipatory regulation and ethnographic practice. *Social Science & Medicine*, 65 (11), 2223-2234.

Naples, N. (2003). *Feminism and Method: Ethnography. Discourse Analysis, and Activist Research*. London: Routledge.

Newman-Bluestein, D. (2015). *What was the colourful thing with arms on the finale of Blunt Talk?* Retrieved from: http://www.dancetherapymusings.com/2015/11/what-was-the-colorful-thing-with-arms-on-the-season-finale-of-blunt-talk.html, 17th January 2016

Nolan, L., McCarron, M., McCallion, P., & Murphy-Lawless, J. (2006). Perceptions of stigma in dementia: an exploratory study. Retrieved from: https://www.lenus.ie/hse/handle/10147/299918, June 17th, 2015.

Norman, D. A. (1998). *The invisible computer: why good products can fail, the personal computer is so complex, and information appliances are the solution*. MIT press.

O'Shea, E., & Murphy, E. (2014). Evaluation of the Genio Dementia Programme. Galway, Ireland: Irish Centre for Social Gerontology, NUI Galway.

Oakley, A. (1981). Interviewing women: A contradiction in terms. *Doing Feminist Research*, 30 (6), 1.

Olivier, P., Xu, G., Monk, A., & Hoey, J. (2009). Ambient kitchen: designing situated services using a high fidelity prototyping environment. *In Proceedings of the 2nd International Conference on PErvasive Technologies Related to Assistive Environments (PETRA '09)*. ACM, New York, NY, USA, , Article 47 , 7 pages.

Oppenheimer, C. (1999). *I am, thou art: Personal identity in dementia*. In Hughes, J. C., Stephen J. Louw, Steven R. Sabat. 2006. Dementia: Mind, Meaning, and the Person. Oxford University Press.

Orrell, M. (2012). The new generation of psychosocial interventions for dementia care. *The British Journal of Psychiatry*, 201 (5), 342-343.

Ou, Y., Kuan, T., Wang, J., Tsai, A., & Chen, P. (2015). A GPS Tracking Device Embedded in Prayer Beads for Early-Stage Dementia Detection. In *Proceedings of the ASE BigData & SocialInformatics 2015 (ASE BD&SI '15).* ACM, New York, NY, USA, Article 58 , 4 pages.

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.

Palmiero, M., Di Giacomo, D., & Passafiume, D. (2012). Creativity and dementia: a review. *Cognitive Processing*, *13* (3), 193-209.

Parker, S. J., Jessel, S., Richardson, J. E., & Reid, M. C. (2013). Older adults are mobile too! Identifying the barriers and facilitators to older adults' use of mHealth for pain management. *BMC Geriatrics*, 13(1), 1.

Peters, D., & Calvo, R. (2014). Compassion vs. empathy: designing for resilience. *Interactions*, 21(5), 48-53.

Phillips, L. J., Reid-Arndt, S. A., & Pak, Y. (2010). Effects of a creative expression intervention on emotions, communication, and quality of life in persons with dementia. Nursing Research, 59 (6), 410-417.

Pollack, M. E. (2005). Intelligent technology for an aging population: The use of AI to assist elders with cognitive impairment. *AI magazine*, *26*(2), 9.

Rancière, J. (2009). The Emancipated Spectator. London: Verso.

Rascovsky, K., Hodges, J. R., Knopman, D., Mendez, M. F., Kramer, J. H., Neuhaus, J., & Hillis, A. E. (2011). Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia. *Brain*, *134* (9), 2456-2477.

Reed-Danahay, D. (2001). 'This is your home now!': conceptualizing location and dislocation in a dementia unit. *Qualitative Research*, *1*(1), 47-63.

Reese, D. J., Ahern, R. E., Nair, S., Joleen, D. O., & Warren, C. (1999). Hospice access and use by African Americans: Addressing cultural and institutional barriers through participatory action research. *Social Work*, *44* (6), 549-559.

Rogers, J. C., Holm, M. B., Burgio, L. D., Hsu, C., Hardin, J. M., & McDowell, B. J. (2000). Excess disability during morning care in nursing home residents with dementia. *International Psychogeriatrics*, *12* (02), 267-282.

Royce, J. 1908. The philosophy of loyalty. Vanderbilt University Press.

RTÉ, 2014. Survey shows shortfall for dementia sufferers. RTÉ News, 23 May. Available at: http://www.rte.ie/news/2014/0523/619178-dementia/. [Accessed 14 January 2015].

Rylatt, P. (2012). The benefits of creative therapy for people with dementia. *Nursing standard*, *26* (33), 42-47.

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.

Sakai, Y., Nonaka, Y., Yasuda, K., & Nakano, Y. I. (2012, March). Listener agent for elderly people with dementia. In *Proceedings of the seventh annual ACM/IEEE international conference on Human-Robot Interaction* (pp. 199-200). ACM.

Sakamoto, M., Hiroshi Ando, and Akimitsu Tsutou. (2013). Comparing the effects of different individualized music interventions for elderly individuals with severe dementia. *International Psychogeriatrics*, 25 (05), 775-784.

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.

Särkämö, T., Altenmüller, E., Rodríguez-Fornells, A., & Peretz, I. (2016). Editorial: Music, Brain, and Rehabilitation: Emerging Therapeutic Applications and Potential Neural Mechanisms. *Frontiers in Human Neuroscience*, 10, 103.

Sarne-Fleischmann, V., Tractinsky, N., Dwolatzky, T., & Rief. I. (2011). Personalized reminiscence therapy for patients with Alzheimer's disease using a computerized

system. In Proceedings of the 4th International Conference on Pervasive Technologies Related to Assistive Environments (PETRA '11). ACM, New York, NY, USA.

Sawyer, R. K. (2003). *Improvised dialogues: Emergence and creativity in conversation*. Greenwood Publishing.

Schacter, D. L., & Addis, D. R. (2007). The cognitive neuroscience of constructive memory: remembering the past and imagining the future. *Philosophical Transactions of the Royal Society B: Biological Sciences, 362* (1481), 773-786.

Schelle, K. J., Gomez Naranjo, C., ten Bhömer, M., Tomico, O., & Wensveen, S. (2015). Tactile dialogues: personalization of vibrotactile behavior to trigger interpersonal communication. In *Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction* (pp. 637-642). ACM.

Shidende, N. H., & Mörtberg, C. (2014). Re-visiting design-after-design: reflecting implementation mediators connectedness in distributed participatory design activities. In *Proceedings of the 13th Participatory Design Conference,* pp. 61-70.

Slegers, K., Wilkinson, A., & Hendriks, N. (2013). Active collaboration in healthcare design: participatory design to develop a dementia care app. In *CHI'13 Extended Abstracts on Human Factors in Computing Systems* (pp. 475-480). ACM.

Simonsen, J., & Robertson, T. (2012). *International Handbook of Participatory Design*. Routledge.

Siriaraya, P., & Ang, C. S. (2014). Recreating living experiences from past memories through virtual worlds for people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 3977-3986). ACM.

Smit, D., de Lange, J., Willemse, B., Twisk, J., & Pot, A. M. (2016). Activity involvement and quality of life of people at different stages of dementia in long term care facilities. *Aging & Mental Health*, 20 (1), 100-109.

Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith, P. & Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, 9(10), 1-93.

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.

Spence, J., Frohlich, D. M., & Andrews, S. (2013). Performative experience design. In CHI '13 Extended Abstracts on Human Factors in Computing Systems (CHI EA '13). ACM, New York, NY, USA, 2049-2058.

Spinuzzi, C. (2005). The methodology of participatory design. *Technical Communication*, 52 (2): 163-174.

Stacey, J. (1988). Can there be a feminist ethnography? *Women's Studies International Forum*, 11(1), pp. 21-27.

Steptoe, A., Shankar, A., Demakakos, P., & Wardle, J. (2013). Social isolation, loneliness, and all-cause mortality in older men and women. *Proceedings of the National Academy of Sciences*, *110* (15), 5797-5801.

Stige, B., Ansdell, G., & Elefant, C. (2010). *Where music helps: Community music therapy in action and reflection*. Gower Publishing, Ltd..

Streitz, N., & Nixon, P. (2005). The disappearing computer. *Communications of the ACM*, *48* (3), 32-35.

Suchman, L. A. (1987). *Plans and situated actions: The problem of human-machine communication*. Cambridge University Press.

Tandon, R. (1988). Social transformation and participatory research. *Convergence*, *21* (2), 5.

Thieme, A., Wallace, J., Johnson, P., McCarthy, J., Lindley, S., Wright, P., Olivier, P., & Meyer, T.D. (2013). Design to promote mindfulness practice and sense of self for vulnerable women in secure hospital services. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, pp. 2647-2656.

Thornberg, R., & Charmaz, K. (2014). Grounded theory and theoretical coding. *The SAGE Handbook of Qualitative Data Analysis*, 153-169.

Topo, P. (2009). Technology studies to meet the needs of people with dementia and their caregivers a literature review. *Journal of applied Gerontology*, *28* (1), 5-37.

Tse, C. S., Balota, D. A., Yap, M. J., Duchek, J. M., & McCabe, D. P. (2010). Effects of healthy aging and early stage dementia of the Alzheimer's type on components of response time distributions in three attention tasks. *Neuropsychology*, *24* (3), 300.

Twigg, J. (2000). *Bathing: the body and community care*. Routledge Psychology Press.

Ueda, T., Suzukamo, Y., Sata, M., Izumi, S. (2013). Effects of music therapy on behavioural and psychological symptoms of dementia: a systematic review and meta-analysis. *Ageing Research Reviews*, 12 (2), 628-641.

van Haeften-van Dijk, M., Hattink, B., Meiland, F., Bakker, T., & Dröes, R. (2016). Is socially integrated community day care for people with dementia associated with higher user satisfaction and a higher job satisfaction of staff compared to nursing home-based day care?. *Aging & Mental Health*, 1-10.

Veerasawmy, R., & McCarthy, J. (2014). When noise becomes voice: designing interactive technology for crowd experiences through imitation and invention. *Personal and Ubiquitous Computing*, *18*(7), 1601-1615.

Vernooij-Dassen, M. J., Moniz-Cook, E. D., Woods, R. T., Lepeleire, J. D., Leuschner, A., Zanetti, O., & Iliffe, S., (2005). Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. *International Journal of Geriatric Psychiatry*, 20 (4), 377-386.

Vines, J., Pritchard, G., Wright, P, Olivier, P., & Brittain. K. (2015). An Age-Old Problem: Examining the Discourses of Ageing in HCI and Strategies for Future Research. *ACM Trans. Comput.-Hum. Interact. 22, 1, Article 2 (February 2015), 27 pages*.

Wacquant, L. (2005). Carnal connections: On embodiment, apprenticeship, and membership. *Qualitative Sociology*, 28 (4), 445-474.

Walker, M. P., Ayre, G. A., Perry, E. K., Wesnes, K., McKeith, I. G., Tovee, M., & Ballard, C. G. (2000). Quantification and characterisation of fluctuating cognition in dementia with Lewy bodies and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, *11* (6), 327-335.

Wallace, J., Thieme, A., Wood, G., Schofield, G., & Olivier, P. (2012). 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 (CHI '12). ACM, New York, NY, USA, 2629-2638.

Wallace, J., McCarthy, J., Wright, P., & Olivier, P. (2013). Making design probes work. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '13). ACM, New York, NY, USA, 3441-3450.

Wallace, J., Wright, P. C., McCarthy, J., Green, D. P., Thomas, J., & Olivier, P., 2013. A design-led inquiry into personhood in dementia. In Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, pp. 2617-2626.

Wan, L., Müller, C., Wulf, V., & Randall, D. W. (2014). Addressing the subtleties in dementia care: pre-study & evaluation of a GPS monitoring system. In *Proceedings of the 32nd annual ACM conference on Human factors in computing systems* (pp. 3987-3996). ACM.

Wang, H. X., Karp, A., Winblad, B., & Fratiglioni, L. (2002). Late-life engagement in social and leisure activities is associated with a decreased risk of dementia: a longitudinal study from the Kungsholmen project. *American journal of epidemiology*, *155* (12), 1081-1087.

Wang, X., 2012. The construction of researcher–researched relationships in school ethnography: doing research, participating in the field and reflecting on ethical dilemmas. *International Journal of Qualitative Studies in Education*, 26 (7), 763-779.

Wherton, J., & Monk, A. 2006. Designing cognitive supports for dementia. *SIGACCESS Access. Computing*, 86, 28-31.

Whyte, W. F. E. (1991). *Participatory action research*. Sage Publications, Inc.

Woodward, J. (2010). *Between Remembering and Forgetting: the spiritual dimensions of dementia*. Bloomsbury Publishing.

Wright, P., & McCarthy, J. (2010). Experience-Centred Design. Cambridge: MIT Press.

Yatczak, J. (2011). The power of ritual and hobbies: engaging in favorite pastimes can help people with Dementia. *Generations*, *35*(3), 71-73.

Zhang, Y., Han, T., Ren, Z., Umetani, N., Tong, X., Liu, Y., Shiratori, T., & Cao, X. (2013). BodyAvatar: creating freeform 3D avatars using first-person body gestures. In *Proceedings of the 26th annual ACM symposium on User interface software and technology (UIST '13*). ACM, New York, NY, USA, 387-396.

Zheng, H., Nugent, C., McCullagh, P., Huang, P., Zhang, S., Burns, W., & Davies, R. (2010). Smart self management: assistive technology to support people with chronic disease. *Journal of Telemedicine and Telecare*, 16 (4), 224-227.

Zimmerman, J., Forlizzi, J., & Evenson, S. (2007). Research through design as a method for interaction design research in HCI. In *Proceedings of the SIGCHI conference on Human factors in computing systems* (pp. 493-502). ACM.

Appendices

Proof of ethical approval

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14th August 2013

To Whom It May Concern:

Re: Ethical Approval Confirmation

I can confirm that Kellie Morrisey received full Ethical Approval from the School of Applied Psychology's Ethics Committee on the 01/08/13 for her study which intends to develop a participatory design method that would facilitate persons with dementia and their carers to be fully involved in the design of assistive technology to support their needs and enrich their lived experience. This study forms part of Kellie's PhD. If you have any further queries please don't hesitate to get in touch with me.

Sincerely,

Dr Ciara Staunton

Ethics Committee Secretary

Professor John A Groeger
Head of School of Applied Psychology

Ollscoil na hÉireann, Corcaigh
National University of Ireland, Cork

Worked example(s) of field notes and other notes on analysis

Charlie – initial coding

Charlie	*Initial coding*
Charlie, like Marie, is a day resident in St Eithne's, usually only coming in on Fridays. He has always seemed to me to be much less severe in his dementia than the other residents – he loves telling stories about his life, which to me has always seemed very rich and very well-travelled; several years in Canada, the US, the UK and France. He lived with his wife, who was very ill, from what he told me, though he wasn't quite sure what her illness was, and has a large and supportive family. He is very intelligent – reads and writes poetry and recently won first prize in a singing competition in the town hall in Tobermore. He occasionally seems to suffer from temporal & spatial displacement – thinking that he's in a cafe, etc – but has always seemed one of the more present and lucid residents.	Less severe dementia among some residents Telling about life Having a rich previous life Telling about travels in youth Telling about 'outside' family situation Uncertainty over wife illness Part of a large, supportive family Enjoying the written word Rich recent 'outer' life Unsure of time and place Misconception – unit as café
Eleanor told me today that just this week Charlie has been entered into long-term care in St Eithne's, much like Marie, and the Charlie I met today was a slightly different one than I remember. Physically he actually seems better than ever, he usually walks with not one but two canes but today didn't need even one, but he is at once on edge and keenly aware that he is not at home, but also seems somehow less engaged than he did before.	Long stay in unit results in difference in persons with dementia Physical improvement following stay in unit Anxiety concerning staying in unit Awareness of being somewhere 'wrong' Less engaged yet more engaged (anxious) – paradox
Unlike say Peg, whose chatting and speech does not make much narrative sense except in fleeting moments, Charlie is quite present usually – but not today. He kept talking	Chatting and speech not following narrative Feeling a loss of power

about ‘the power [he] used to have’ and how he no longer was ‘able to do the things [he] wanted to do’ – he didn’t explicitly reference the unit (he doesn’t seem to be entirely aware of where he is) but he spoke about ‘getting a car’ and getting his children to take him home. ‘My only problem now is how to get home,’ he said, before telling me that would mean him ‘getting his power back’.	Remembering ‘powerful’ youth Frustration over inability to control situation Planning to escape Planning to involve children in escape Getting home as a major concern Leaving unit connected to a rise in power
So in this way Charlie was quite alert, but he also did not want to engage in talking about his past like he usually does – any attempt at doing so ended up as a story about his ‘lost power’. He sang a little with me, and I promised to bring him a booklet next week of songs that I know he enjoys singing, but on the whole he was uninterested in chat or storytelling – which to date is something that has characterised him to both myself and the nurses.	Charlie alert and on edge due to stay Refusal to engage in ‘soothing storytelling’ when on edge due to stay Turning stories around to change topic Singing working to distract when talking won’t Uncharacteristic disinterest in chat/storytelling
So I’m not sure really if these changes in Marie and Charlie are due to the decline often documented in persons with dementia who enter long-term care having lived at home previously (perhaps due in part to excess disability) or whether I’m just witnessing two previously ‘able’ residents transition to the middle stages of dementia. Change was always going to be a huge part of this research, but I suppose that today was the first time I’ve really witnessed such a large change.	(memo to self)

Art session – initial to focused coding

135	*Art session*	*Initial coding*	*Focused coding*
150	No-one was very interested in the session today – it	Disinterest in art sessions	Disinclination to 'do art' as an art session
151	was a bit of a quiet day all around, usually there are		
152	more people in but today it was [redacted for	Differential attendance in the unit	
153	anonymity]. Some of the more extroverted residents		
154	(usually day residents) weren't in – [redacted for	Activities depend on who is in	Activities depend on their participants
156	anonymity], people who tend to join in and lead others	Adapting activities to suit interests of	
157	in doing so. Fiona managed to rope in [redacted for	residents	
158	anonymity] (she is always up for everything) and	Identifying some residents as 'leaders'	Inhabiting roles in group
159	[redacted for anonymity] (who did not enjoy our last	'Roping' residents into art sessions	Coaxing residents to participate
160	art session). I had brought the following with me:	Expressing dislike for art sessions	
162	- 2 x palettes of watercolours		
163	- 10 paintbrushes		
164	- 2 x sets of poster paints		
165	- Craft glue		
166	- Stick-on pom-poms and felt shapes		

167	- Luggage labels (original plan was to make		
168	bookmarks)		
169	- Coloured card, A4		
170	- 2 x sets of colouring pencils		
171	- Set of drawing pencils		
172	- Set of markers		
173	- Printed-out colouring pages specifically for adults		
174	The colouring pages were something I sought out		
175	specifically – I usually don't use colouring books as it	Colouring books childish	Age-appropriate activities needed
176	is somewhat infantilising (something which I've	Fear of infantilisation	
177	witnessed firsthand in previous art sessions run in the		
178	unit) and inhibits creativity. However, it can be	Colouring books not creative	Need to 'create' something via activities?
179	daunting for residents to be presented with a blank	Nervousness at being asked to draw	Feeling incapable of art
180	page and the suggestion to 'go draw' or even more	Difficulty of initiating creative activities	Initiating art is difficult
181	gentle suggestions (such as Craig's 'taking a line for a		
182	walk' approach). On the other hand, orders to 'draw a	Ordering to draw	Positioning in artistic sessions

183	dog' or 'paint a daisy' are just as generalised and	Generalised tasks are not creative	Positioning in artistic sessions
184	infantilising as presenting residents with colouring	Infantilisation in art sessions	
186	books. With this in mind I sought out colouring pages		
187	on the internet that were specifically targeted at adults	Specifically picking materials for adults	Age-appropriate activities
188	from this site - http://www.coloring-pages-for-all-		
189	ages.com/adult-coloring-pages.html. They're usually a	Properties of materials important to	
190	little more detailed, a little more abstract, with more		
191	sophisticated lines and themes.		
194	So the ladies when seated immediately gravitated to	Strong preference for 'easier' material	Difficult to gauge preference for certain
195	the colouring pages though I'm not sure if that's	Preference for more familiar creative	materials over others
196	because they were probably the most visually	activities	
197	interesting things on the table or proximity or		
198	familiarity. I suggested they look through them while I	Picking up what is closest to hand in art	Going for ease of access in art sessions
199	fetched some water for the watercolours but when I	session	
200	came back they'd both just selected two from the top		
201	of the pile.		

St Eithne's framework in progress

Name	Sources	References
Affective space of participation	0	0
Anxiety, agitation, annoyance	0	0
Agitation	4	4
Anger	4	8
Anxiety	8	31
Confusion	4	8
Deception	2	3
Distress	6	9
Feeling abandoned	5	6
Frustration	3	4
Paranoia	2	2
Shame	5	9
Calm	7	12
Disengaging	4	14
Alienation	4	7
Delusions and hallucinations	2	4
Disengagement	5	15
Imprisonment	1	1
Displacement	9	22
Escaping	5	10
Leaving	3	3
Imprisonment	3	5
Outside	7	16
Pride	2	4
Sickness	7	22
Age-related body changes	4	5
Drugs	3	4
Illness and injuries	3	5
Needing help	3	5
Not recognising the sickness	2	2
The importance of physical health	3	4
Agentic space of participation	0	0
Ownership	5	8
Laying claim	5	8
Owning the self	3	5
Deception	1	2
Power	4	7
Standing up and speaking out	7	20
Privacy	3	6
Speaking out	7	21
Taking charge	4	5

Name	Sources	References
Starting a dialogue	5	8
Becoming	0	0
Becoming a part of the unit through art	1	1
Becoming through media	1	1
Status in unit	4	8
Belonging	1	2
Belonging in activities	6	7
Belonging in delusions	5	11
Enjoyment and flow	5	14
Settling	5	8
Religion and rituals	7	27
Somewhere I am not supposed to be	3	3
Creating and performing	0	0
Anxiety in creating and performing	5	14
Attitudes to participation	6	8
Soothing	6	8
Barriers to participation	5	8
Disengagement	6	12
Interrupting	6	9
Non-verbal communication	2	5
Physicality, old age and sickness	8	14
Space	1	2
Communicating during participation	2	4
Touch and participation	1	5
Democracy	4	7
Enjoyment and flow	6	15
Making it communal	9	19
Joining in	4	5
Participation from afar	3	5
Making it incidental	3	4
Materials in participation	6	18
Media as a 'way in'	2	2
Situating	1	1
Using media to explore personas	1	1
Negotiated participation	8	43
Performing	3	13
Singing	3	3
Storytelling	6	27
Spectatorship	7	13

Name	Sources	References
Audience	2	3
Ownership	2	7
People-watching	1	2
Transformative participation	0	0
Laddering	2	6
Roles in dementia	11	32
Use of space	6	8
Unconventionality	2	5
Miscellaneous	3	3
Artifical routines and carer intervention	0	0
Uncaring care	6	12
Necessity of adaptation	4	8
Personal relationships	4	9
Communicating	0	0
Chatting	6	7
Humour	3	5
Confiding	1	4
Friendship & companionship	0	0
In-unit friendships	5	8
Caring for friends	6	15
Soothing	5	11
Gratitude	4	5
Intimacy	5	9
Outside family and friends	6	13
Seeking companionship	10	23
Social space of participation	0	0
Chatting	8	27
Chatting as soothing	2	5
Humour	5	9
Media as a 'way in'	9	19
Non-verbal communication	9	13
Defining a social group	7	15
Ill-feeling among residents	1	6
Referring to others	5	8
Seeking companionship	3	4
Status in unit	4	8
The behaviour of others	7	21
Watching out for others	3	5

Nodes

Name	Sources	References
Hidden spaces	3	3
People-watching	1	1
Social niceties and manners	9	18

Image 13: the above screenshots show a slowly emerging framework – would eventually become three broad themes of performing and spectating, connecting, and being a part of community: all articulated through music.

Reflecting on using NVivo to help form my analysis

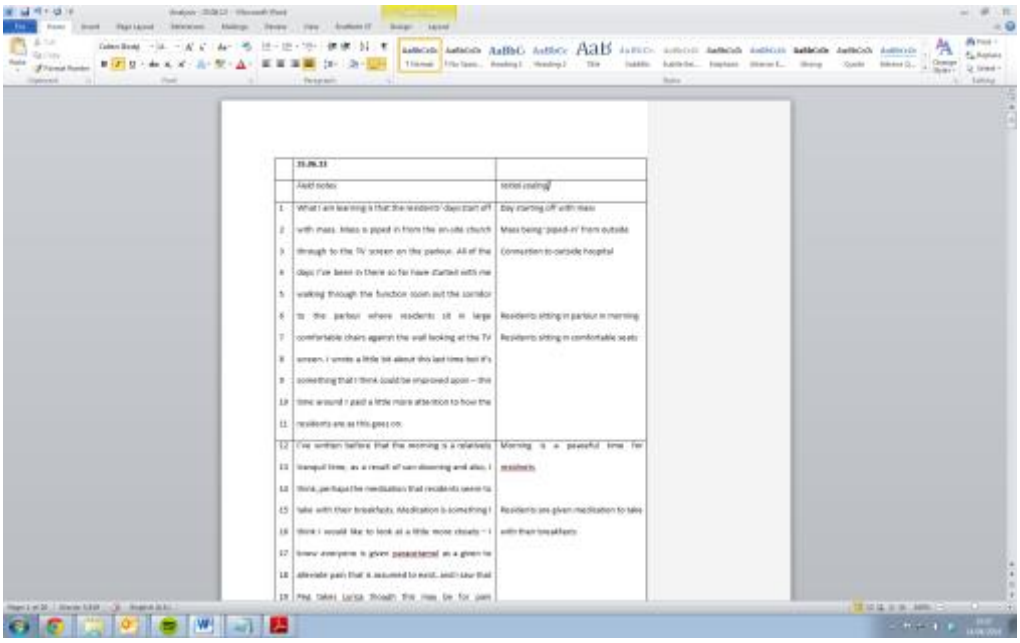
Computer-assisted qualitative data analysis has enjoyed a long tradition in the social sciences since early analysis packages surfaced in the 1980s (Banner & Albarran, 2009). Such packages provide a way of managing and organising large amounts of qualitative data; something which can be difficult using conventional methods of qualitative analysis. More recent criticism of these packages has centred round accusations that the software goes beyond organising and managing data to actually analysing the data (Bringer, 2004).

This criticism, which speaks to our inherent distrust of artificially intelligent machines, is not unwarranted – for example, the 'autocoding' tool in NVivo displays the mechanistic coding available by the 'machine' of NVivo (see Screenshot 1).

Screenshot 1: autocoded responses in NVivo

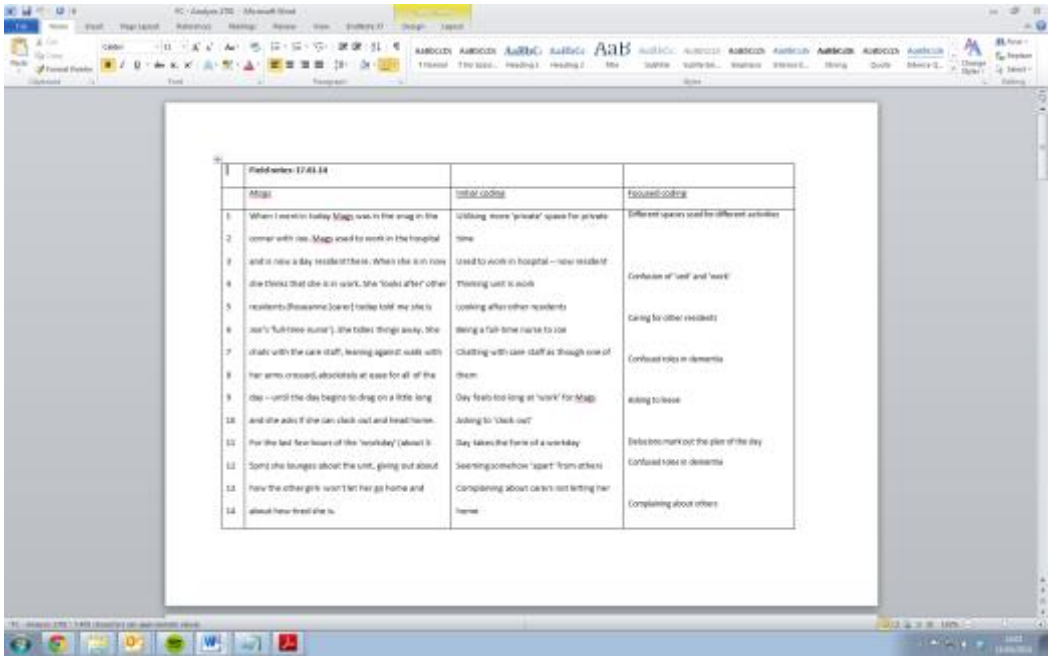
It works as follows: if the document to be analysed is formatted in a certain way, this tool will create 'nodes' for certain headings and will file data under these nodes as it sees fit. Having encountered this tool in NVivo workshops, I was sceptical – I believe that most forms

of qualitative data analysis *at this level* require a human researcher. The framework under which I am working is, as cited above, Grounded Theory, itself a systematic although flexible (Hutchison, Johnston & Breckon, 2010) method of analysing qualitative data. Unlike many forms of qualitative analysis, GT has fixed steps through which the research progresses in order to create an explanatory model or theory of what is occurring in her/his collected data. Even at the level of initial/open coding, where codes often simply summarise what is 'going on' in the data, deep sensitivity is needed in a number of arenas as the researcher takes into account the data itself and its context; what is the setting of action? What is the distribution of its actors over space and time? What do actors pay attention to (Charmaz & Mitchell, 2001)? Beyond this, the organisation and naming of codes is something which I took much time over as I wove a second interpretation over my analysis. It is not something I would entrust to a computer as it formed the foundation for my study; however, NVivo was a useful analytic tool when accompanied with other methods. I initially analysed my data in using Microsoft Word.



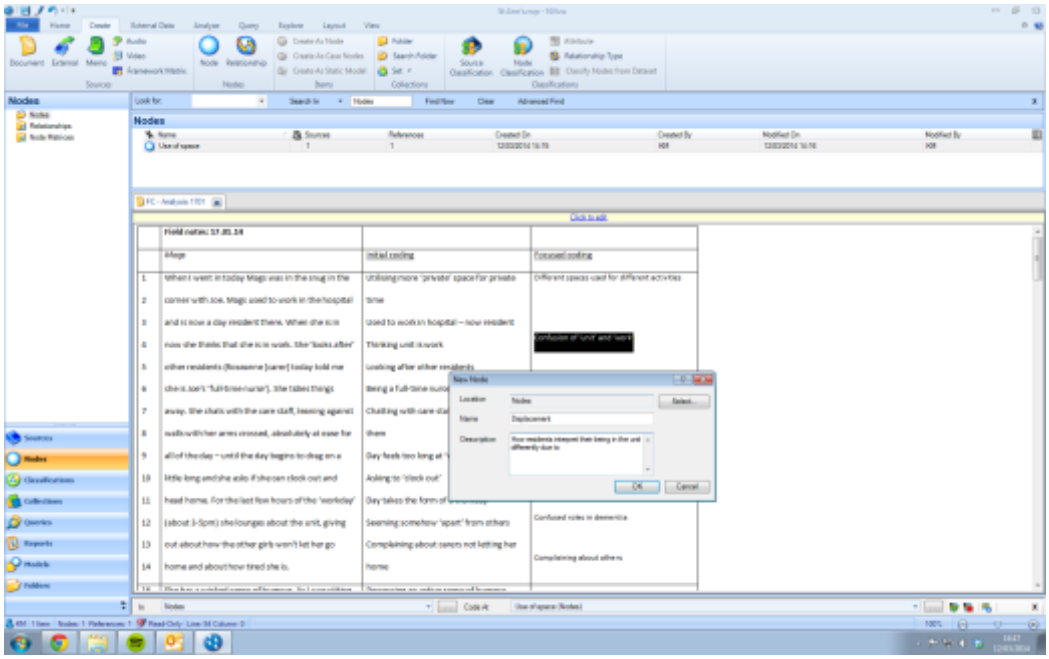
Screenshot 2: open coding in Microsoft Word

When working with a large dataset, the initial stages of open coding may be unwieldy in NVivo and result in a huge amount of nodes which are not easily reducible in later stages. Even if you do attempt reduction in NVivo at this stage, it doesn't keep a log of what's been merged into where and why – which runs counter to common protestations of the software's transparency.



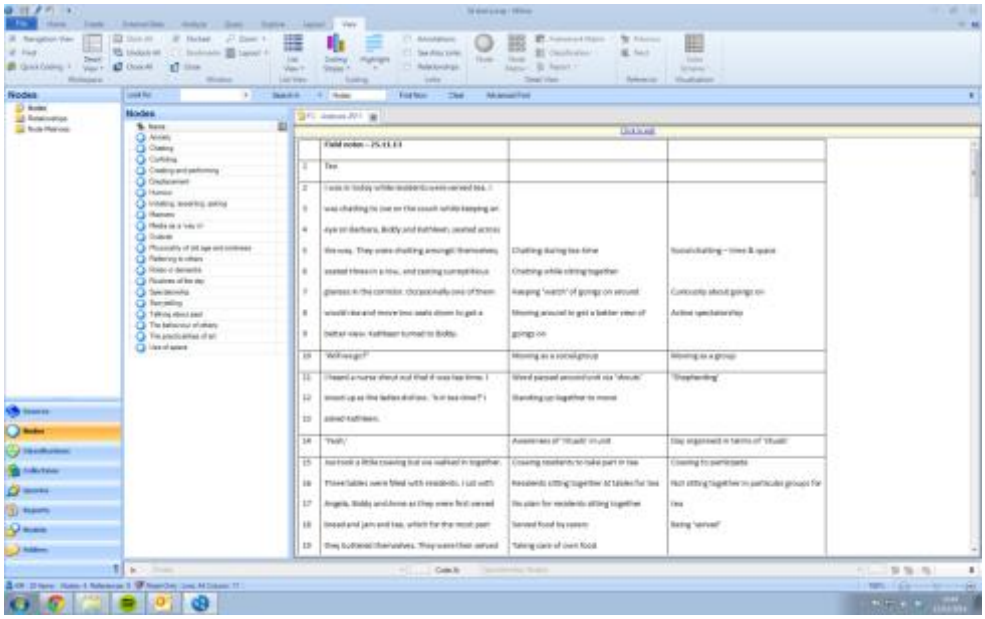
Screenshot 3: initial and focused coding in Microsoft Word

Screenshot 3 shows an example of how I coded my field notes up to the stage of initial coding. It was at this stage that I imported my notes into NVivo in order to better analyse my work into emergent categories and complete axial coding.



Screenshot 4: compiling codes into categories

Here I loaded up my notes and coded the codes under *focused coding* into categories which suggested themselves as I worked down through my data.



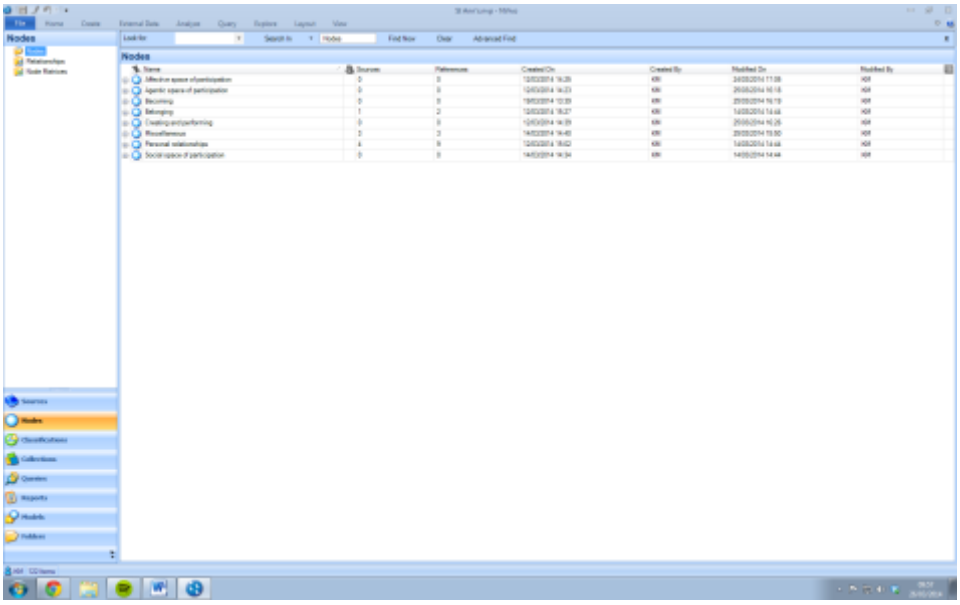
Screenshot 5: accumulating categories

My nodes quickly built up – with most GT studies using about 4-6 themes, I was worried as the number of my categories quickly built up. While I enjoyed the ease of NVivo and the fact that it kept all my notes (and nodes) together in one place, I think it was very easy for me to end up compiling, compiling, compiling without being particularly selective about what I was compiling. It was time for me to move away from my computer for some time and to do some critical thinking in order to think critically about the relationships evolving in my research. I used some of the least technical solutions possible in order to do this – I cut out sheets of paper with my emerging nodes (see image 14) in order to physically represent the spaces between them, and I spoke to my supervisor.

Image 14: moving away from the computer in order to think about themes

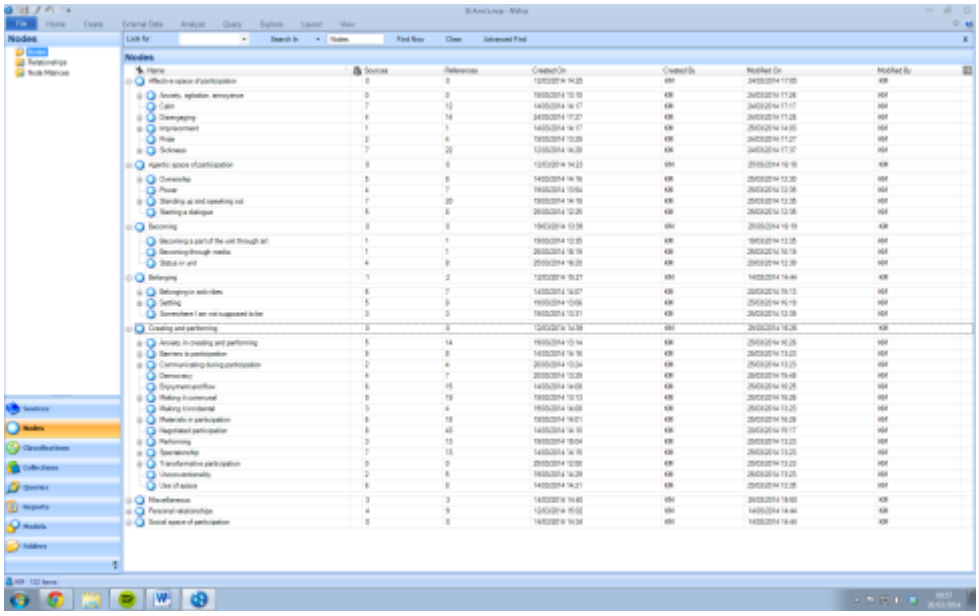
While I think the 'click and drag' method I was employing with NVivo perhaps contributed somewhat to my confusion at this stage, GT itself is an iterative process, and furthermore, I

am a second year PhD student – confusion is unfortunately not avoidable at this stage and meetings with supervisors always go a ways towards clarifying most research issues. NVivo, I was learning, will not magically dispel confusion – though in using it, I was certainly avoiding the usual mess of switching between notes, Word documents and original research output.



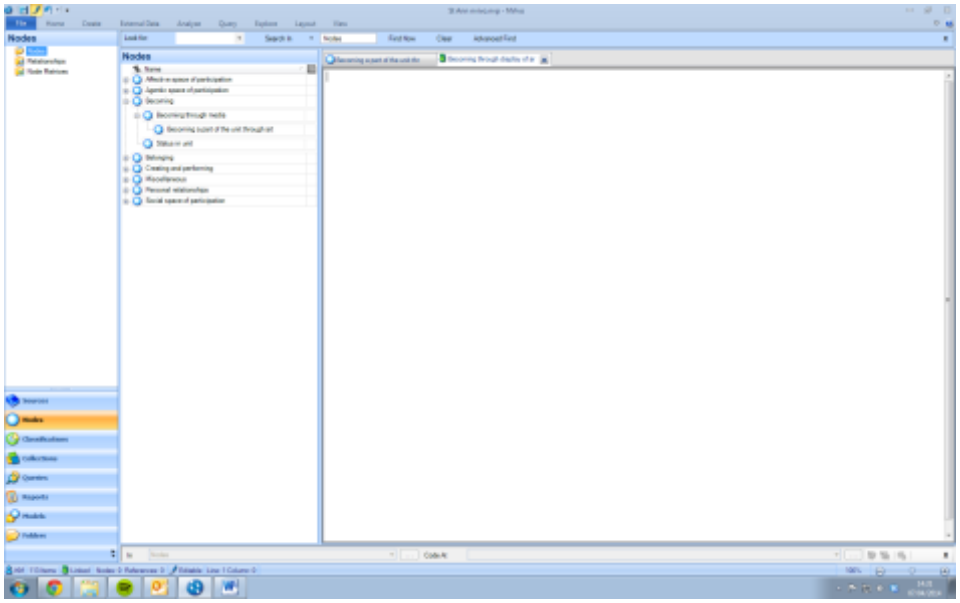
Screenshot 6: structure of analysis

My research question was exploratory – what is the experience of participation in everyday and creative activities like for people with dementia living in long term care? – and my almost-final (I am still working on the research) analysis structure uncovered 6 facets of this experience of participation. Screenshots 7 and 8 show some of the structure of this analytic model.



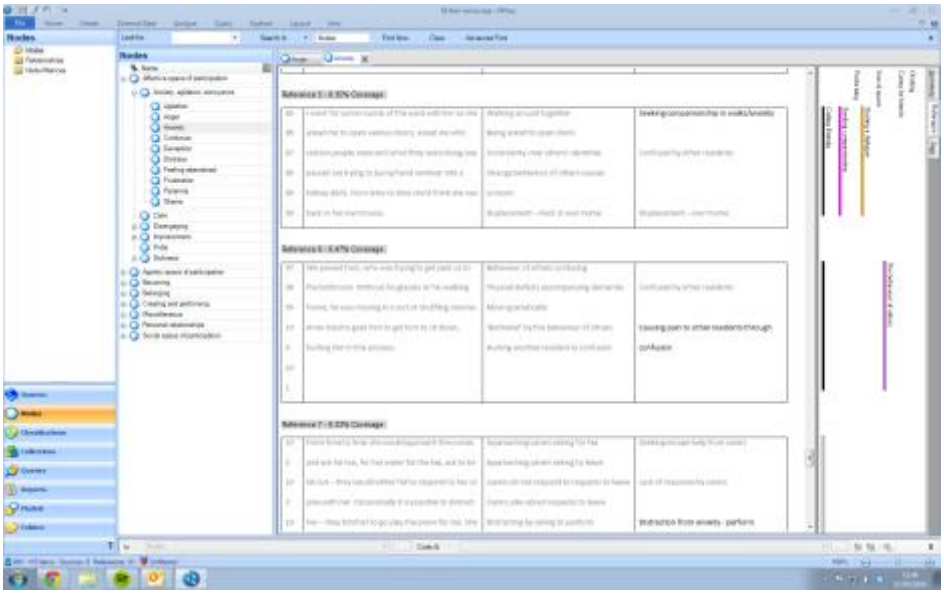
Screenshot 7: inner structure of analysis

NVivo allowed for the easy visual organisation of subthemes within overarching themes, and the sources and references count allowed me, at a glance, to see which themes were denser than others. In earlier studies, during my undergraduate, this part of the process quickly became very confusing, with parts of the analysis scattered throughout various folders, email accounts and notepads on my desk. NVivo as a data management system is invaluable in qualitative research for this alone: after an intensive meeting with my supervisor wherein he suggested I restructure part of my analysis, all that was required was some cutting, merging, clicking and dragging and the analysis was restructured. In earlier times, this would have been much more of a mentally intensive process as I worked to revisualise my analysis inside my mind before updating my notes – here, the visual and interactive nature of NVivo's GUI meant this process was offloaded onto my computer screen.



Screenshot 9: memos in NVivo

The process of memo-making is integral to most forms of qualitative analyses, and NVivo makes it very easy to link memos to parts of the analysis. An issue I encountered here was the fact that memos aren't too visible – although memos do show up as green icons on the node screen and have their own section on the sidebar to the left, once or twice I 'lost' a memo that I'd attached to a line of my field notes instead of attaching it to the node itself. Perhaps these sort of in-analysis memos should be flagged somewhat more clearly.



Screenshot 10: coding stripes in NVivo

Coding stripes in NVivo allow you to see, at a glance, which parts of your data have been coded at several different nodes. I did not initially anticipate that I would use this feature as I feared that the 'tabled' look of my field notes would mean that the coding stripes were inaccurate, and I also found the various toggling that is required a little irritating to do. However, nearing the end of my analysis, my supervisor suggested that I take one of my categories ('affective participation') and use it as somewhat of a 'glass' to see the more active themes through in order to understand how affect plays into activities. This would have been somewhat of a time-consuming process had I not used the coding stripes function in NVivo, which allowed me to note the intersection between several of these nodes. I must note, however, that this is something that requires a human interpreter – several of these coding stripes appeared in places which had no bearing to my task at hand and though I was quickly able to dismiss them, I'm not sure my computer counterpart would have made the same decision.

Text of interview with Eleanor

(tape begins)	
E	Brendan… Professor Brendan.
K	That sounds very familiar, Brendan, Professor Brendan -
E	McCormack. He came down and he asked me if I'd do an interview with him.
K	OK, so you're happy, you're happy to do an interview?
E	No problem at all.
K	Great, that's brilliant. I'm not going to ask about anything crazy -
E	Ask anything at all and if it can't be answered it can't be answered -
K	That's it – no comment! Yep, OK, Eleanor, so again this is going to be a chat – a chat, it's nice to just make it feel… Can you tell me a little bit about your history as a nurse and maybe how you made the decision to work with people with dementia?
E	OK, Kellie, my, originally I'm a general nurse, generally trained nurse, and I trained in Waterford, it was then called Ardkeen Hospital, it's now Waterford Regional. And when I finished my training I moved out of nursing for almost 20 years and didn't nurse at all. And then I came back to nursing almost 20 years ago and I ahm, came to work in Tobermore Community Hospital, at that stage I would have no knowledge of dementia.
K	Mm.
E	The dementia unit in Tobermore Hospital I suppose isn't everybody's favourite place to work in, and very often what happens is the new nurses go there.
K	OK.
E	As would happen in any organization. And I think that's probably what happened with me, but I was very fortunate to meet a nurse who was actually a long term nurse on the ward there who was amazing on dementia, and she was about 25 years before her time. And straightaway I decided, I like this, and shortly after that we had a change of director of nursing, and the director of nursing we got, he was a man, and he had a history of ah, psychiatric nursing was his background, he was very very, ahm, supportive of the unit outside. And he asked me straight away would I do some dementia training. At that stage I just did the basic training that were all, I was a student if you know what I mean, HSE training. And I then went and did my behavior therapy. First of all I did the certificate and then I did the cert in it in UCC. A lot of people would say that behavior therapy and dementia don't mix, but what I actually found was it was hugely benefical to me in working with dementia later on. It was applied behavior therapy and analysis, was the course. Ah, stemming on from that we then had another change of a director of nursing, and the new director of nursing asked me if I would do some training for the HSE, as a trainer. Before I did that, I did what's known as the Dementia Champion course, which was a 6 month course in DCU. And that was devised by Dr Kate Irving, and she was a great advocate for dementia, she was actually a nurse who went on to do a PhD like yourself. She trained in Australia and did a lot of work in Australia and she is and still is a fantastic advocate of dementia and everything dementia. It was an excellent course, which gives you the title of dementia champion, and for a very long time I was the only Dementia Champion in Waterford City or County, which is a very sad reflection on the long term care facilities we have. From that I did a H Dip in Person-Centred Care and then I did my masters in dementia. And then I retired.

	[laughs] And then I started to work.
K	Wow, I had no idea you had done so much training. That's amazing.
E	Yeah, so for the last 2 or 3 years I have worked mainly with the HSE as a trainer. And it was a generic course, an advice course by the HSE, a 3 day course initially and then a 2 day course on dementia awareness. That was given to all staff who work with people in dementia. It would be healthcare assistants, nurses, doctors, anyone really who was interested in dementia. Excellent course, delivered all over Ireland. It was then dropped to a 2 day course because of staff shortages, because getting staff to attend was difficult because of the embargoes, you know. Actually ahm, having ran that course, I'm not involved directly with the HSE anymore, I work privately. So the courses I give now on dementia awareness would be devised by myself normally. But let's face it, dementia is dementia. So that's where I'm at with dementia training now, I did a lot of work in assessment when I was in St Eithne's Ward, I would go to Waterford Regional, I would go to Patrick's Hospital in Waterford, Wexford General. And if there were issues with residents there, if staff were having problems with residents, mainly with responsive behaviours, some type of difficulty, the department of Psychiatry might suggest that I come in and maybe look at ways that we could use maybe behavior therapy, ahm, to alleviate the distress that these people would be under.
K	It's interesting actually, I remember studying behavior analysis and behavior therapy in my undergrad but I don't think I've ever really seen it applied to dementia.
E	Yeah, I was the only 'dementia nurse' if you know what I mean when we did the course, and there was always this query, will it work for them? And it does work from the point of view that, particularly if we're talking about the things we have overlearned in life, you can reignite that in people. You know, the simple things we have learned in life, like how to wash your hands. Well the person with dementia may forget that, but with a little bit of direction, you can bring back those overlearned skills to people again. I found that, I always found it beneficial, I mean it was never going to solve anything.
K	Well earlier we were talking about person-centred care, well person-centred care is the big thing obviously in dementia and in dementia care. Do you find that a useful practice, a useful lens on people with dementia?
E	Person-centred care -
K	Yeah.
E	OK, so -
K	That's Kitwood, and… isn't it, Brooker?
E	Yes, yes, Dawn Brooker and Tom Kitwood. I suppose the original person centred care was devised by Carl Rogers, you can go back to him to the practice of care, Kitwood honed in on Rogers. Which of course was the thing to do. And he came up with person-centred care. Kitwood, he wrote several books on it and every one was more difficult than the next to understand. He was originally a priest and he moved from that and he married and he started work in psychology and he worked in Bradford.
K	Oh, yes.
E	And he devised person-centred care with a person, Dawn Brooker, Brooker was a nurse originally. She went on, she studied psychology later on. She had a better way of expressing what person centred care is and was. I suppose there is no real definition, Kellie, but it's just, I

	spose, it's a term used to bring together ways of working with the experience of people with dementia.
K	That's interesting that you say that because I think experience is such a big concept there.
E	Yeah, so, it's probably a misunderstood form of care at times, and a lot of people think, if I know their name, if I know where they're from, and I know some of the things they like, that's person-centred care. It's better than not knowing their name, but it's much deeper because when you get into something like dementia you really need to know the nitty-gritty of their past lives, the good and the bad. So the more you know, the easier your job will be.
K	And, ahm, that's something I don't have the kind of… the insight that carers and nurses might, but I found it hard sometimes when the person with dementia doesn't have the same ability to tell you about their life. And sometimes the carers or the nurses, if there, it depends on the place, but if there are staff shortages, sometimes they don't know either, and then the family has to come in really really strongly. But some places don't have that kind of family involvement either. It depends on the place, most places do I suppose. But then when you see things like life storybooks, I think they can be a way to get into people's experiences.
E	Yeah I mean there are some I spose simple ways that you can introduce person-centred care into the life storybooks and photographs… I always found that the best people to tell you about somebody was a friend. Family are very selective in what they tell you. When I would be trying to delve to get information to help me in delivering person-centred care, I don't care what people tell me. I don't care if the person with dementia has had 15 children with 15 different partners, if they had spent 2 years in jail for anything.
K	I know.
E	That's not why I want to know. I need to know these things but I need to know them in order to judge the person. It means nothing to me, however it might be really really important information. Sometimes the family comes in and they won't tell you this, and that's only human nature. So sometimes you get a friend in, and the friend will tell you about the fun things, and the laws they broke together.
K	[laughs] Yeah.
E	The night they stole the bicycle together. The night they stole the car. I remember a fella telling me about the time they stole a hearse. But it was something I could bring back to this fella so many times, to bring him back to me. So what I would say to you is that you need to know everything. Now that's one side of person-centered care. When someone becomes institutionalized or when somebody is actually put into residential care, that's where the issues, that's where the person-centred care issues arise. Let's say Eleanor Hannon likes to get up every morning at 11 o clock and eat three pieces of Weetabix and drink 5 cups of black coffee. Can she do that if she is in a care of the elderly setting – or does she have to get up at 8, because it is 8? And does she have to have tea, because it is tea? And does she have to have corn flakes or porridge. So until we can deliver to Eleanor Hannon everything that she wants, at the time she wants it, we're not delivering person-centred care. So if she wants to listen to Daniel O'Donnell at 3am, the facilities should be there to allow her to do that.
K	Yeah, and you say institutionalization – so that is a barrier, that is obviously a barrier to person-centred care?
E	Residential care is a barrier, because obviously you have to have, I suppose, up to a point, law and order too. So if everybody wanted to eat at different times of the day and everybody wanted

	to have their own music on – if you're doing it in a communal setting, that is a barrier to person-centred care. So that's why residential care for people with dementia, it's recommended that you have nine to ten people, max. In any setting. It's also recommended that each one of those people have their own space, their own private room, so that they have opportunities to be individual. The other issue with person centred care in a residential setting is of course, well the hairdresser comes on Friday, and this happens on – blah, blah. Well that's not person-centred care.
K	Because it's not -
E	Well you know what I'm saying. So. The person who goes into residential care with dementia, for them it's very difficult. Now if you put them into a setting like St Eithne's in Tobermore, you can probably do more for them if you put them into another ward for long term care. Because you're a little bit more designed for it, but you're still not… so the ideal place for person centred care is with their own family, in their own home.
K	You said a few really interesting things there and I'd like to go back and unpick a few of them. Do you think that there is a time in many people's dementia journey that delivering that kind of care at home is just not feasible?
E	Yeah. There is a question of at what stage, with the proper supports, can they not cope anymore? I like to think of dementia in a very positive way and you probably do too, we like to think of all the positive sides of dementia, but of course like any illness there is a negative side. And depending on the type of dementia you have, that will determine your journey and the trajectory of the illness, OK? Depending on the lobes of the brain that are affected, it will determine how you react and respond. Perspective has a huge part to play in dementia, and you might be aware of that from the psychology literature. It has a huge part to play in all of our lives, how we see things. So let's take a very good typical family and they're caring for a mam or a dad at home, let's take somebody at home, fully mobile, 75, and things are going good. The physical changes that will occur with the neurological impairments will be possibly speech difficulty, there may be swallow difficulty, and there will of course always unfortunately be continence issues. Because our continence is controlled by our central nervous system. So when your CNS… it would be safe to say that about 95% of people who get dementia will present with continence issues. Now continence is the big issue for families, they can't cope with that. It's the biggest burden of all – I hate to call dementia a burden, but care burden for families. The next burden for families is the lack of support, the actual community support, it's awful in this country and almost every country in the world. What I'm talking about now and putting it in inverted commas is these "packages of care" that personally I think, I abhor the term because what is a package of care?
K	Yeah.
E	You send someone home with a prescription, with some pieces of continence wear in a bag, and that's the reality, and everybody will tell you that's the reality. And then a decision has to be made at some stage, somebody needs residential care, and that's where the guilt aspect comes in.
K	Yeah. I've seen that so keenly in families.
E	And conflict.
K	Mm.
E	And of all the illnesses that I suppose the World Health Organisation recognizes at this stage, the most that causes the most guilt and conflict is dementia.

K	And we were just talking about stigma – I don't mean to interrupt your thought process there – do you think much of that stigma is less about oh this person is "demented" now, they're old, they're crazy – that kind of stereotype – and how much of it is, links up with the idea that now I need to make the decision to put my mom into care or my dad into care. I just remember one family who, it was clear as day that their dad had some form of dementia but they didn't want to face up to it and he wasn't getting the care he needed. And I think if they had been able to face up to it then they probably would have faced a lot of guilt and a lot of conflict but he would have gotten the care he needed.
E	And the earliest intervention is so important Kellie for the family and it's really important for the person, because while we haven't made huge advancement, I'm talking about chemical management, drug management, of dementia, yet the few drugs that are available – with early intervention they can hold a person for much longer. The first reason that the early intervention doesn't happen – if I go to my GP tonight and I say, I'm 61. I go to my GP tonight and say, John, I really have problems with my memory, I don't want to go out anymore, everything seems to be wrong, I can't remember things, I'm forgetting this, he will diagnose me 99% of times with depression.
K	Depression.
E	And he is right up to a point, but the reason I am depressed is because I know there is something wrong. I tell him I'm not going out to people, I don't want to, but the reason I am not doing that is because I can't remember their names, I don't want to. And I am put on an antidepressant which I may actually need, but that's another 6-12 months where I have still not being diagnosed. Now it happens more with the younger onset – if I go in and I'm 65, the GP will say, shur she's getting a little bit doddery, is it really dementia, and he will put me on sometime. The other reason is because the families won't acknowledge it. If they see their mom or their dad with the slight bit of memory loss they think it's just part of the aging process, a normal part of the aging. But dementia is not a normal part of the ageing process. It's an age related illness but not a normal part of ageing. We will not all get dementia. But some of us will.
K	And it's interesting, because when some people get mild cognitive impairment, it doesn't necessarily…
E	… no, it doesn't necessarily mean dementia. They're actually two distinct illnesses. I don't know if you've ever met Professor Willie Molloy.
K	I have met him, I don't know if he would remember who I was but I have met him.
E	He's great on the mild cognitive impairment and the dementia, and he has a great attitude towards dementia. Wrote a great book called 'Let Me Decide' about advanced care directives.
K	Oh brilliant, that sounds fantastic. I'd love to read a bit more on that.
E	But he is very good on the mild cognitive impairment and he has some very good tests devised.
K	Yeah, that's right he did some really specific tests didn't he?
E	That's right, he's great on them. The thing – where are we at, person-centred care, family, early intervention, and ahm, in the ideal world, we would have early intervention, we would know everything about the person with dementia, to help us to deliver person-centred care. And we would have a very good understanding of perspective.
K	Perspective is an interesting one, I haven't come across – no, no-one has said that before to me. There's a guy in my department and he's working with ageing people, people over 65, and he's

	actually looking at how their perceptions of themselves are connected to their individual ageing process. And he's specifically looking at cognitive outcomes. So apparently the better you feel about yourself as an ageing person, the better your outcomes will be.
E	Oh very much. Very much, yeah. There is a school of thought there that says that people who age poorly because of the perception of ageing is poor are more likely to get dementia and age related illnesses than people who have a more positive outlook. It's a study and we don't know, it's so hard to draw those conclusions.
K	You've said a bunch of things now that are really interesting, so I might jump back if that's OK Eleanor.
E	OK.
K	So you didn't nurse for about 20 years, you went into Tobermore Community Hospital and you were placed in a Dementia Care Unit. And you pretty quickly decided – it sounds like you had really good leadership and guidance, that it was the place for you. So many people find that area a depressing area to work in – doctors don't tend to work in that area because there seems like there is no hope. What drew you to that area?
E	As I was saying I was working with a person who was so advanced, she was excellent, and she had a really positive outlook on dementia, and she said to me the very first day I went in, 'this is a happy unit, this is not a sad unit. We have fun here, and we laugh a lot.'
K	Mm.
E	And I always brought that with me because I always found that people with dementia are always very accommodating when it comes to fun. And they will laugh at themselves, and they will see you know, sometimes they say the wrong word, and rather than make it an embarrassing situation for them, if you laugh at them, they laugh with you, and you can have enjoyment and fun. It doesn't have to be a sad place to work and I always hoped when I worked in the unit that it was a happy place to work and that the residents were happy – of course different times of the day are different for all these people. But it had to be somewhere where there was not an atmosphere of fear or of something dreadful going to happen in here today, but something fun. And I always wanted young people to come, and I mean young people, grandchildren, babies, neighbours, friends. Of course you're going to have situations where a resident is doing to do something that you would prefer they wouldn't do, but that's going to happen in any care of the elderly setting. You don't know what draws you to a particular brand of nursing, it's like what draws you to a particular job. You often don't know. I liked to think that the people I cared for all had lives before they came to me. So I liked to think that they were the doctor, the housewife, the engineer, the nurse – rather than the person in the four-bed, the person in the second bed, the person that didn't sleep at night. They all had lives. And they all did things like you do, Kellie, and like I do. That is really the approach I took from the start, and I think it always helped me to see. To see a person.
K	That's, that's really interesting. And that's a really empowering view of the person, as that same person but maybe now slightly changed. I, I always see these depictions of people with dementia, and what is often said is that oh they're a completely different person. You don't agree with that.
E	No, I don't agree with that at all. Apart from the people who have fronto temporal dementia, they have behavioural issues because your frontal lobes control your behavior. But if we just leave them out and we talk about general dementia, I have always found that personalities never changed. So if a person came to you with dementia and the family said she was always contrary,

	difficult, odd, had to have her own way – that's what you will get. And if they said to you, this lady was so good, she always helped other people, that's what you will get. I always found that they held their own personality, other than when they had difficulties because of their frontal lobe dementias. It doesn't change people, no. And that's the sad thing that people say, they change so much or 'she changed so much'. They don't actually, but they now have an illness that is causing them to respond in a way which they wouldn't have done previously. But deep down they are still the same person. And the more time you spend with them, you will see that. Flashes of it will come out. You might have the old lady who loved to dance. Who went to dance with her husband three nights a week for most of her life. And now she is sitting in a corner and you find it hard to get her to do anything. And now of a Sunday three fellas will come in recorders and a banjo. And out of the blue, I guarantee you, she will hop up and ask someone to dance with her. And that just shows you, deep down this person is the same. And you have hit it, you have hit that spot. And that is better for her, that form of communication is better for her than trying to sit with her for five or six hours a day and trying to get her to do things that aren't meaningful.
K	So meaningful is a big thing.
E	It is, it is a huge word. Meaningful is a huge word Kellie. You have hobbies yourself, I'm sure and you have things you like to do, and I have. And if someone wanted me to do your things and me to do your things, it wouldn't be meaningful. And if it's not meaningful, it's harmful.
K	There seems to be this kind of orientation, so I'm very interested in creative work in dementia, so I initially was very interested in art but I eventually went down the music route. But a lot of people think that art is the way to go. But a lot of people with dementia are resistant to art, you know? And I kind of, I was thinking, why is it? Is it – well, when would – Charlie – ever have sat down and painted, you know? But actually, you know he's tapping his foot to music there, because maybe he would have been at the pub, at a session, and it's kind of like this mystery that you need to solve, bit by bit. But sometimes when you approach something bit by bit – I can see why it could be harmful. Because when you try to coax someone… is that what you mean?
E	It's interesting what you say about art because I agree completely with you. It was the one form of activation that I never found effective.
K	I really struggle with it, I tried to do it, once or twice really early on, just observing in St Eithne's, but then bringing it forward into other work in the PhD, it just, it flopped.
E	I think Kellie if you're talking about the older generation, they would never have studied art. They would never have sat down and painted a picture, or drawn a picture. It wouldn't have been part of I suppose their upbringing, or, whereas maybe for groups for like you, yes, now we all have these colouring books and we're all colouring them in.
K	I have like three of them at home. [laughing]
E	A lot of people I would have worked with, would have found it – a little bit degrading. And a little bit – infantilizing.
K	Yeah, absolutely. Yeah, cos if you -
E	We – we didn't use it a lot, and I, I didn't like it, myself. I withdrew from it myself. Music is different, I would like every kind of music myself, and if I ever get a dementia, Kellie, and you're around – music. It doesn't matter what kind of music, and most people would have their preference, but they love all music. It, ahm, I found it a lifesaver, if they were ill I could use music, if they were happy I could use music, if they were sad I could use music… if they were, I

	suppose, being in any little way, I suppose presenting with responsive behaviours, music would calm them. It's amazing.
K	I, I've found it so amazing, and what really spurred me on was an interaction I had with a resident in St Eithne's, and to be honest I'm not even sure if he's still there – do you remember Charlie Curran?
E	[nods] He's still there.
K	Is he? [laughing]
E	Better than ever.
K	Is he actually? I'm really glad to hear that, because I remember he used to sing the Moonshiner -
E	Yeah – yeah -
K	He'd be very stooped down some days or he'd be very down and then suddenly up and – and then he'd sing it for 2 hours straight -
E	But fine – but fine – if that was his thing, I meant if he did that for 2 hours then we would be delighted. But Charlie loved music, it would have been important for Charlie and it would have made him very very happy. Ah, and, ah – I don't think any of the residents in Eithne's didn't like music. An interesting thing about the art, the family would tell you yes, she liked art, she went to art classes, she may even have been very good at art. But we still couldn't get them to respond. And we don't know why. Whereas with the music, they would always respond. Ah, I know we had one lady who used to paint pictures and sell them, and she still wouldn't. But I think what can happen to is if you had been very good at something and suddenly you weren't very good at something anymore. You would feel…
K	Yeah, and I can see that. And there's something about art that shows up those kinds of, those problems that people can have. I was sitting at a table one day with someone at a care centre and we were doing art, and I was tr-, we were trying to draw something together, a dog or something, and I had drawn the body and I said now why don't you try to draw the tail, and he drew the tail, but he drew it about three inches off because, maybe some perceptual issue. And he was really embarrassed and I was like, oh god – I just made him fail at an activity. And there's something about music that you can participate in so many ways – you can tap, you can clap -
E	You needn't do anything, you need just sit back and close your eyes -
K	That's another form of participation. And you know there is this whole thing about failure free activities. And I like the idea but again it's kind of infantilizing, it's kind of like, oh you know – but it is quite weird to try something and suddenly find that you can't sign your name. So when you're saying that -
E	Even if you had played a musical instrument and you can't anymore, you can sit back and the music will still affect you. Whereas with the art or any of those things, if you can't do it, you can't do it. The other thing with art Kellie is that if you try to introduce art to people who have never done it, let's take an old country farmer, he comes into you, he's 80 years of age. And you have him a piece of paper like this and a pencil, you could actually have a very, very negative response immediately, and the reason for that response would be that an awful lot of people that age would never have learned to read or write.

K	That's so – I never realized that until I started working – I hope I didn't show it -
E	You would have lost him straight away. The saddest thing about that for me and the moment I realized it wasn't to do with a resident at all, it was a carer on the ward.
K	Really? A carer? A carer who – that's really interesting.
E	I, I was working on the ward about 5 years at the time, and the girl came over to me, and she highlighted it for me at the time how the resident would feel. And she would ask me to fill out an annual leave form for her – a yellow sheet, like you are writing on, but it would be pre-printed. All you needed to do was put in the date you needed the annual leave and then sign it. I did it for her but I was saying to another carer, god they would have you doing everything for them. And she looked at me and said, Eleanor, she can't read or write. And immediately I said god, imagine how the residents would feel if you did that. She could – she could bluff it, she could say oh, oh no, I'm busy, will you do that for me, or I'm not sure how you fill it out, but if you had a dementia and somebody put that in front of you, how would you feel? So that's another reason that the biro and the pencil and the paper comes in. And that's another area where the person centred care comes in, knowing their past history.
K	I wish that I had spent more time now – I would have been in places which have families visiting – but I would love to do a project where I get to sit down, and like you said, friends are really interesting. I remember there was one day in St Eithne's and there was a visitor that had come in, I assumed it was this lady's sister but it was her friend. I was like wow – I hope my friend comes to visit me – and friends are so important as you mentioned.
E	Yeah – and it's difficult to get them to call – and sometimes they won't call because they have a fear that the person won't know them and they won't know them. And the biggest problem when they do come in is Kellie they come in the door and they'll ask to see Eleanor and they'll walk over and they'll say to Eleanor, hallo Eleanor – do you know me? And Eleanor won't know them. So then you have conflict straight away, Eleanor will probably walk off straight away. So we have started meeting people at the door and saying to them, what's your name, and they'd say Kellie Morrissey, and we had to go ahead of them, and go to Eleanor and whisper to her, Kellie Morrissey is here – say hello, Kellie. This is where the lack of education coming in, the visitor coming in the door wants to 'test' the person's memory. It's awful.
K	It can be really ingrained then – because you can say something like 'd'you remember the time when' -
E	And 'they know me' – the kind of a, it's like brownie points if they know you. That's where the dementia awareness and trying to explain to family and to friends. The other thing is a family member coming to visit and the person they are coming to visit might speak to them for five minutes and then walk off. And to try to make them understand that's not a personal insult or an affront – and please come again another day! But you find that over time, they don't.
K	So do you see this pattern of people -
E	Yes
K	Slowly winding down their visits -
E	Yes. And also unfortunately have the pattern of their own children and their adult kids, they will all come and they will visit regularly but you will never see a grandchild.
K	Really? Yeah, I don't think I've ever seen a very young child.

E	We had one or two families who were great. And if you take a unit like Eithne's where you have a lot of walkways – there is loads of room for kids. But they don't come. It's like the families are trying to protect the children from this image of their granddad. Which is very sad – because they won't have any memories, you know.
K	You said this earlier, actually when you said one of the things you'd like to see would be to bring young children in and you're kind of touching upon it again there now. That's something that I found too, and it's something I didn't anticipate. Slight age difference now but one of the care centres I would have been in, I would have brought along final year project students so they would have been applied psych students, and they would be about 4 or 5 years younger than me. They would be noticeably younger than me! [laughing] But the two girls I brought along, Hannah and Aoife were their names, and they were very small, very slight, very pretty, and they would always dress in cute clothes. And there was something about their presence with the people with dementia and the older people that was just magical. You know – it was like a way in – 'oh you're lovely', 'are you sisters', 'I have a daughter like you' – you know.
E	Yeah – they love the young people.
K	And I was just thinking – why don't we do more of this intergenerational stuff? You know, and then I was thinking, I was talking to someone recently, who was saying, they were talking about the dementia friendly communities things that we kinda touched on – and they were saying something really similar to you – it was my supervisor, actually, saying look it's great that people are getting training but it needs to be more cohesive and it had to happen across the community. So – do you know Kinsale, they had the K-CORD project, one of the things that they did, they actually networked with transition year and secondary school students. And they actually started off at a fairly young age there, and there was something interesting about kind of getting people in who were younger – and educating at that basis. Ahm, and I supposed it showed that there was no need to shield -
E	No – and Kinsale is great actually, they have a very good GP down there who works very much with dementia – I think he lectures in UCC.
K	I know a few of the people on it.
E	Can't think of it now but he's on a lot of the steering committees and that now.
K	Oh – Tony Foley, no? Tony Foley?
E	Mmm… I don't think so.
K	No? There's a whole bunch of them. That was an active project for a while.
E	I don't think that's his name, I could be wrong now Kellie. But young people are very resilient you know – but they do have fears too of course and it's a fear of the unknown. And, ahm I had a little 5th year student out in St Eithne's a few years ago, and she was actually from my own area. A lovely little girl – you know when they come and do work experience? And while she was with me I was doing day 1 of the dementia training course, and because it's difficult to find things for a 16 year old to do on the ward, you know, all the time, I asked her if she wanted to go upstairs with me for the day to participate in the course. And she was absolutely brilliant, she participated, she spouted out her questions. So she was finished at the end of the week and the next week I was doing day 2. So I was thinking about it and I rang her at home and I said, do you want to come down and do day 2? You will get your certificate to say you have done a 2 day HSE course – and if you want to go nursing, which she does want to do, or even if you want to go working as a care assistant for the summer, it will be really beneficial. And she jumped at

	it, and she did the course. And I then did a day on responsive behaviours and she arrived again, I let her know again. And her mam drove her down each day. And one of her transition year coordinators in the school rang me and he asked me if I'd do a talk on dementia maybe for an hour or two, for the transition year students. Mainly because one of the students in the school, he had two boys in the school – we had a young man outside, I think you might remember him – Ben?
K	I remember Ben.
E	He had 2 kids in the school, and Ben had died. And they were kinda trying to open up -
K	Yeah.
E	Why he had died. And I went into the school and they were mixed, I had transition year boys and girls, they were only about 16. When they saw me they were frozen in the seats, literally frozen in the seats, and they were sitting rigid. And I'm sure they were thinking this is going to be awful, and we started out, we did a tiny little bit on the brain just about the lobes on the brain – nothing on anatomy or physiology, just what the purpose of them was. And we were getting really into this, and we spoke about dementia. And the first question I had asked them when I went in that morning was if anyone knew someone who had dementia. And nobody put up their hand, nobody responded. But anyway we chatted away for a while and by the time we left them two and a half hours later, everyone knew someone who had dementia, whether it was a granny or a granddad. And they were opening up and saying, I never knew that we could do this with them or I never knew that if I did this with them, if I said yes to them and not no, everything would be more positive. And I didn't know if we put a coloured toilet seat on the toilet then they'd see it better. And they would be so enthusiastic. And it just showed that if you gave them the knowledge, then they would lose their fear.
K	Yeah. That's really interesting. Yeah, cos -
E	Now there are some training projects ah, at the moment for secondary school kids, and they're being done under the HSE – it's privately funded by a man called Chuck Feeney, he's a national philanthropist -
K	Oh the Atlantic Philanthropies.
E	Yeah, yeah the Atlantic yeah. He's funding this, Chuck Feeney is his name, he's an American millionaire, and they're doing training with the schools at the moment, the Dementia Elevator project.
K	That sounds really interesting. Ahm -
E	And that's bringing in a lot of the secondary schools, they've done pilot studies in schools.
K	And that's one thing now -
E	That's really I think now like now, if you talk to me, we spoke earlier about Newcastle and trying to get communities together, you really need to start young and bring them up.
K	I really think so – and have you read, there's a book by – by Atul Gawande? He's a, he does all these ah fairly accessible kinda books about, he's a surgeon -
E	I know, I know the – there's a series -
K	Yeah, yeah that's right. This book is called Being Mortal. I think you'd really like it. I might

	send you a copy. But it's about how we as a society, a Western society, don't tend to value older people, and it's about institutionalization and meaningfulness is at the core of it. But one of the case studies in the book, it goes through different configurations of living with dementia, and in particular residential care, and some of the really good ones contrasted with some of the less good ones, you know. But one of the ones which really stuck in my mind was a residential care centre that was built adjacent to a school, like a primary school. So people with dementia but also people who didn't have dementia, who were frail or ageing, they had a communal space where the children could play but the children could also, you know, it was bound so -
E	And the children would just be aware of these people as people.
K	As people, exactly.
E	But you see this is it.
K	Also as experts cos when they were learning, it was a while back now but when they were learning about world wars, people would actually go into the classroom to participate and teach, and that just stuck in my head, because gosh. Cos young kids, I'd -
E	There are a few good books now for young children to understand dementia.
K	Is there? Really?
E	Now I will text on a few names to you after. There's new ones coming out every day, there's even a new one in comic form to deal with Lewy Body dementia which is one of the more unusual forms of dementia where you have hallucinations, which could be difficult for children to understand you know? Ahm – what I'll do is I'll message them onto you. I have a lot of them myself and I usually bring them to the ahm, to the different talks that I go to. But it's great, and the NEIL – you know that's the neuro enhancement in Trinity?
K	NEIL – I don't think so.
E	NEIL – it's a study being done on dementia in Trinity College Dublin, and they have three or four very very good DVDs in cartoon form. They would send them onto you Kellie no problem about that. Now you could download them even. If you go into NEIL you could download them even. And I think there's three or four different ones to explain dementia. And they're in cartoon form and they're brilliant. They're really really good, simple. My son is a primary teacher and he brought them to school one day, it was Care of the Elderly Week you know when they have these weeks and he teaches 6th class and he said they loved them. So there is lots being done with young people, but it's probably my age group, people between the age of we'll say 45 and 70 that have difficulty in changing.
K	OK, do you think so? Interesting. Ahm, I would like to, that's fantastic, I'd like to steal back a little bit to just talk a bit about you again – if that's OK, cos I think you might be able to give me some insight here. So, ah, when people – so again I'm in a psychology department, so when people know that I'm working with people with dementia, or anybody, there's someone in my office working with people from mother and baby homes, you know, so there's this big focus on self care and looking after yourself. I've met some people whose situation is really really sad. And I would have sought out supervision and things like that – how do you sustain your mental health, as a nurse who's working really closely with people who are facing these major challenges?
E	I often think of – dementia in three ways. And this is interesting, essentially it's an Australian theory about dementia and working with dementia, and they talk about the portrait, right, the

	mirror, and the landscape. And the portrait is the person with dementia, and everything to do with them from A to Z. The mirror is the person who works with the person with dementia, so let's say that's me, that's you. And the landscape is the actual environment in which all of this takes place. And very few people ever ask me the question you have just asked me there now, about the person working with the dementia, how they actually cope, and how they stay, I suppose, sane!
K	Yeah though, absolutely.
E	And that's the mirror, and that's hugely important component of dementia care. Because if you are working with people who have dementia, and you are in the wrong frame of mind, you have other issues going on in your life, you are physically unwell, or indeed mentally unwell, you are tired, you're hungover, you're worried, you're depressed, all of that will impact very negatively on two people, you and the person you're working with. More so on the person you're working with. So the better frame of mind you are in yourself and the more positive you are, the easier it is to work with people with dementia and the easier it is to get good results. But how do you sustain that? To work with people with dementia, first of all you have to want to do it. So if you are working in a residential care setting, and you are having to work with people with dementia, and you don't want to do it, then there's a collision course straight away. So that's the first thing – you have to want to work with people with dementia. The second thing is that the more you know about dementia, the easier your job will be. So knowledge is power with dementia, and I'm not saying for one minute that I know more than the next person, but what I'm saying is that every little thing you know as you go along will make your job easier this time. The third thing I'm saying is that you cannot do this job if you are mentally unwell yourself. You can't, so if that were to happen you would have to withdraw from that job. Now they do recommend that if you go in to work with people with dementia in the morning or in the evening or other times of the day you'll do what is called centering, I think you might know what it is. You literally go out, you spend a few minutes on your own, you breathe in, you breathe out, you clear your mind and then you go back in. It's good for people who start to work with people with dementia, but you will find I suppose as the years go on that you have more little tips, and more little tricks, you don't use them as often. But you do need breaks. You do have to have breaks. And you can't run a unit for people with dementia that same as you would run an ordinary hospital ward. So if somebody for instance, if your carer or your nurse is a smoker, she may need to go out and have a cigarette at a time that wouldn't normally be a break time – and that has to be taken into consideration. If she asks to leave the ward because she is having issues, well then you have to leave the ward, go away and clear your head. Equally, sometimes you will have conflict between a person with dementia and someone who is a carer. You may not know why, you may look like a family member, you may not look like a family member, so you have to step in and let another person take care of that person. I personally think that if you're working with people with dementia in a residential setting, you shouldn't work a 12 hour shift. I think you should have shorter shift hours. But on the other hand, for the person with dementia, having contact with a person for a longer time, can be beneficial – but then, you see, OK. So I spose the real answer is Kellie is that the more you know about the people the easier your job is and the less likely you are to have these difficulties. The other thing is a professional, these people are not your family and you have to be able to switch off. My, I found what worked for me is that I drove for 45 minutes to get to work every morning which meant I left the home behind with all the family problems, and by the time I got to work I had cleared my head of them. By the time I left in the evening, left Tobermore, I had all the work problems in my head, but by the time I got in home, I had cleared my head of them.
K	So there's actually just that space and time.

E	Space and time.
K	That's interesting. And ah, yeah, like I -
E	But it's that mirror between the portrait and the landscape, if it's not working, you're in trouble.
K	That is such an interesting way of looking at it.
E	It's an Australian model, it's a training model.
K	It's very responsive, it's about how you respond to the person and how they respond to you.
E	There's never enough emphasis in training sessions, when I do the training sessions, I talk about the person, the carer, you can see them sitting below and they're clamping up, they're thinking 'how dare she imply that if I'm doing this, well it's going to impact negatively'. Of course it does, and every day that I ever worked with a person with dementia, I made a mistake Kellie, and I knew why I made it and why they responded negatively, and I learned from it. And everyday it happened. But they don't like to think that way. So the mirror is hugely important.
K	I'm gonna put that in my PhD. [laughs]
E	Good, good. I like it too.
K	We've nearly touched on everything Eleanor, we probably didn't jump around the way that I thought we would but that's fine, I really feel like -
E	I, I probably jumped on -
K	No, that's fine, that's the way it goes, it's better to have a conversation rather than going here's question one, here's question two. But I, just before I finish up, there's a few things I'd like to follow up because I didn't anticipate some of these things. Ahm, so, you you know a lot about typologies of dementia, and you were talking about Lewy Body dementia and I know at some stage I think you were talking about a resident with Korsakoff I think? The one -
E	Korsakoff, the alcohol related one.
K	And there's such a tendency to lump everyone into 'Alzheimer's'.
E	Alzheimer's. 60% of dementia that we would normally see in, in any country would be dementia of Alzheimer's Type. Ahm -
K	I suppose what I'm wondering is -
E	It is the most common type of dementia, Alzheimer's. The – there are 100, I think about a hundred and forty recognized types of dementia now. There are well over a hundred. But if you were to break them down, some of them are like subsets. If you know what I'm trying to say. They are subsets of other dementia. The ones we would see in a unit like St Eithne's, we would see Alzheimer's Dementia, we would see vascular dementia, this is the one where older people get them – you know, mini strokes, which causes it. The third type would be mixed. It would be a, it would be when there was a certain degree of Alzheimer's, associated with age, and a certain degree of vascular, associated with age. The next one would be Lewy Body, and in the unit outside there now, I don't know what's there now but say when I worked there, normally we'd have maybe one Lewy Body dementia. It's a different form of dementia to Alzheimer's, and it was, it's very often confused with Parkinson's Disease.

K	OK.
E	And they are two very distinct things but they do present with a lot of the same symptoms. The one thing Lewy Body will always present of course are hallucinations – visual hallucinations and auditory hallucinations. So it would be a good marker for you for diagnosis, OK. The next type of dementia we would see outside a lot would be the frontal lobe and temporal lobe, and that's the one where the behaviours come into play. And the reason we would see that is that these are the people who have difficulty with staying in their own home. Those behaviours can become very erratic, and very very difficult, and you have a complete personality change with a frontal lobe dementia. You might have a very quiet man become a very difficult man, and a very nasty lady might become quite angelic. They could also become very unpredictable, they might begin to do the most unusual things, someone who might have never drank alcohol might decide to start drinking – someone who was always very frugal might decide to buy a sports car for thirty or forty thousand euro. That would be an early sign of a fronto temporal dementia.
K	That's dangerous.
E	Lovely dementia to study.
K	Yeah – I don't think -
E	Difficult to nurse. There was one, we had one outside, a gentleman, I'm sure you knew him, did you meet him, Cedric.
K	Cedric – I do remember -
E	Cedric was a frontal lobe dementia. He actually only died quite recently in Enda's Ward. He was lovely, he was a very – I was lucky, I knew Cedric before he came to the ward, so I knew him as a person. He was very difficult, we had a very difficult time.
K	Was he only in St Eithne's for a little while? Or was he there for quite a while?
E	He wasn't there very long, we had to have him chemically restrained to an extent that he had to leave the ward, and it would be the one dementia where chemical restraints have to be used – and antipsychotics, normally we would use none of them.
K	Yeah – yeah, yeah – I always -
E	So they'd be the, Korsakoff type then would be the alcohol, K-O-R-S-A-K-O-F-F, and that, you would, you would probably usually have one of those.
K	OK, yeah cos I remember when I was in St Eithne's, I remember – was it Fionnuala?
E	[nods]
K	OK yeah.
E	Fionnuala, she died. Fionnuala, was, yeah.
K	Yeah I know, Fionnuala died, yeah.
E	She was a Korsakoff type.
K	What I keep reading about Korsakoff is that, the confabulations – and the – the lies, they're not lies, they're just told to make up the gaps in memory. But I remember Fionnuala.

E	Yeah, I know, like god love them, they're just total [laughs] -
K	I remember she turned to me one day and was like, oh I called the doctor for you. And you were just like, oh my god, I have this kinda internal thing in my head and now I have to keep up with this. And I was like, oh thanks a million, and -
E	[laughs] yeah, yeah.
K	- she was looking at me and she was like, he's going to call for you now tomorrow. You have to improvise back at her.
E	She was lovely.
K	I remember – yeah – there'd be a lot I'd -
E	Interesting thing about the Korsakoffs is that if you stop them from drinking then they can hold quite well, depending on how much damage is done.
K	Yeah, OK. And I've been in some care homes where they've have a pub afternoon – did ye ever have anything like that?
E	They do it over in Carechoice, they have a pub upstairs, they have a room like, a bar and a thing for pulling pints.
K	That's really cool.
E	We never did it outside, on a Saturday they go to the dementia café type thing in the daycare centre. And I do know out in the hospital they have to do a dementia café type thing every three months, I'm doing a presentation at the next one, where they bring in the families including day cases and respites and that – and they would have coffee and tea, but they would have one formal talk as well. And it might be about activities, it might be someone talking about continence. It would be just one thing and that would be for the families. But we never had a pub outside, I think it's like, Charlie now, would have had alcohol issues. Sometimes depending if they're on medication too, you would have to be careful. They could have an adverse, ah -
K	Can I ask you too, it's about curiosity, not really anything to do with this – I just remember Maire, and ah – Aideen? Are they still going?
E	The sad thing with Maire was, I don't think I was left very long, and there was an issue with another resident from a ward, he needed specialized dementia care. And they transferred Maire to another ward, and I thought it was so, so sad.
E	But Maire -
K	They were such buddies.
E	They were such, it was always in my mind -
K	And that happens, what they call that 'buddy' type thing. Where you will have an attachment, and sometimes Kellie that attachment could be male-female. And they could decide to become like, partners in their own little mind, and it can cause conflict with families sometimes.
E	Yeah – spouses.
K	You remember we had a man, Micheal?

E	Micheal, I remember Micheal.
K	Micheal had a great attachment to a lady called Marie, and Micheal's wife used to come – Micheal's dead and Marie's dead now -
E	Is Marie dead? Ah -
	Micheal's wife used to come. She used to get so cross. She used to be literally abusive to me for allowing this to happen. She was convinced Micheal was having an affair with Marie. I remember she came in one day and they were walking up the corridor, oh Kellie, they were holding hands. And I, I really thought I'm going home today!
K	[laughter]
E	But most people, most families can respond positively to it, but this lady couldn't. It's just a little friendship thing really.
K	Yeah – well there might be a bit of infatuation there maybe.
E	Yeah -
K	I can imagine it would be difficult. To see your husband…
E	I suppose so. I suppose so. We've had it before and families were very good. You know. But this lady found it very hard.
K	OK. Oh gosh. OK – I just wanted to check in there because I remember so many of them so well. Eleanor, I think we've nearly touched on everything. Ahm – just going to quickly run through everything. [pages turning] Is there anything you feel like you haven't said that you'd like to say, or any kind of reflection -
E	No, I don't think so. I mean – I think you know my thoughts on everything, so if you want to juggle anything -
K	I know what you're saying, yeah.
E	You know where I'm at with it like.
K	I'm surprised at how active – not that I'm surprised – but I'm glad to see that you yourself seem to be really active, and also Tobermore seems to be getting quite good.
E	Yeah. Now Marjory now the girl who took over from me is very good, she is one year of her masters in dementia done in Trinity, and she works very hard you know within the community. It's good that Tobermore is becoming more of a dementia town but, I mean, they need to do a lot more, and I think the fact that they have a dementia unit should have impacted on them before now, do you know what I'm saying, to make them a dementia friendly town. Ahm, it would be lovely, you know, to think that anyone with dementia in this area could come into this town and feel that somebody understood them. But there's a long road there.
K	And I think there's very little in terms of models, cos you're talking about the dementia village in the Netherlands, but that's something that isn't very – applicable or sustainable. And I have kind of an issue with it, cos it's like, oh let's move 'Mary' into this dementia village made to look like this place. There's something nice about it aesthetically, but there's something else there, like this mightn't be the hometown Mary remembers. And there mightn't be a whole lot that's different about this that putting her in another kinda… do you know what I mean? I really

	appreciate it, but you can never recreate someone's past, you know.
E	You know, and sometimes you'd be thinking about it and you'd be taking someone from your own home and bringing them to live with a daughter, which will have to happen very often, or a son. And they can't understand how this person's behaviours become more responsive when they move. But when you think about it, you might have been living in a town for forty, fifty, sixty years – and you might know everything about it because you've lived there. But when you move into another setting, even when it's a family setting, and you have memory issues anyway – so yes, making a purpose built dementia unit would be grand because they'd know, they'd see, the colours would be right, the doors would be correct, the beds would be right height, the shop fronts would be perfect – but it wouldn't be home.
K	No. Cos home is – home is home.
E	Home is home. And the place where they really, really, really thrive is home. But as I said, we both said, it's not always possible, you know.
K	Yeah, I can understand that.
E	If some of the money that has been spent could be put into – more support for families at home. I spoke to a lady at home this morning, and she told me that she gets 45 minutes every week of home help. And she says by the time the home help says hello, gets her coat off, introduces herself again to the person who can't remember her, says will we have a cup of tea, there's 10 minutes gone. And she's saying goodbye for 5 minutes in the end. And she has to be in another place say 15 minutes after. So she gets 30 minutes. And you couldn't shower a person with dementia in 30 minutes.
K	I, I yeah – I can imagine.
E	So -
K	It's just, so – that's nearly worse than having…
E	So that's the area, if we could have more supports at home.
K	Yeah. Does the Alzheimer's Society have any presence in Tobermore?
E	[shakes head rapidly]
K	[laughs] No? We do a little bit of work with them in Cork, but – not too much.
E	Do you know, their funding was cut too. You see, there was an office in Tobermore. And people could ring the office there, and she'd offer you know, time, care time, and she would supervise them and she would get onto me and tell me when people needed more respite. But that office closed overnight and nobody in Tobermore ever seemed to know what happened to it. And I always said it was one of the biggest losses to Tobermore ever. So the coordinator was gone, all the home helps were gone, and the whole thing now is based in Waterford City. And the coordinator outside actually worked with me, Annie is her name, and if I had concerns as I often would still about somebody in my own area, I wanted to have a chat about it, I would say, OK, I'll ring Annie, and now – no, no. Nothing. And now she doesn't have anything.
K	OK, cos I know the home help and the volunteer service provided by the Alzheimer's Society in Cork is a great help to a lot of people. But just -
E	But, no, yeah. Now the national service is probably good from the point of view that we have a

	helpline and that – but that's no good to you from the point of view that it's four o clock in the morning and you have someone at home hallucinating.
K	We had a workshop there last week, we brought community groups together from all over Cork. So we had the Crystal Project from Mallow, [anonymous] from the Alzheimer's Society, we had a few care homes we worked in, we had [anonymous], and we talked about some of the things we were interested in and things we thought we might be above to work together on. And the overwhelming narrative from the Alzheimer's Society was one of a lack of resources, feeling overstretched. They don't seem to have very much support at all. They are still reeling from the cuts, they got slashed.
E	See there were issues too there and I don't know what they were to do – but Pat Kenny pulled out, he was their spokesperson and he was their front management.
K	And he pulled out. That's very strange.
E	And I think it's that Daithi O Se now, he's in now for Kenny instead. So I don't know what happened there. Personally I have never found them effective – other people will tell you they are. I often had to ring them if I had issues with funding, and young people and advice for families and all that. Normally at the other end of the phone you'll have a volunteer who will probably – who knows…
K	Less than you, yeah. Like I worked with them a few times, we did some workshops, trying to figure out technology and dementia and it wasn't actually part of my PhD it was something else. I worked nearly exclusively with care centres and places like St Eithne's, things like that. Cos I never found the Alzheimer's Society very forthcoming -
E	I couldn't agree more.
K	- they didn't seem to be interested. And I would have provided fairly good services in the end, like once I got there, but they…
E	I couldn't agree more. If the one thing that I had to say negatively after 20 years, it would be the Alzheimer's Society.
K	It's a pity, isn't it?
E	It is a pity.
K	It's just weird when those kind of places that are a community project could maybe do better – cos the Crystal Project, and the K-CORD – you know.
E	Yeah. Like if you had a good Alzheimer's Society you would have funding, you would have quite a lot.
K	Well if you see any funding in Ireland going to dementia, it's going to them, it's not going to… do you know, it's not going to community services.
E	In Dublin at the moment, you've three great centres or projects or education centres, the Trinity one, the NEIL one, in St James' Hospital you have the Dementia Services, Suzanne Cahill does it. And then you have, in DCU you have Kate Irving, she's great, you'd love her now.
K	I've never met her but I've been to conferences where she's been talking and she's -
E	She's the most person-centred of them all. Kate is the one who, would forget to, if she was doing

	a talk in Tobermore tonight, she would forget to take the money at the end. She would be in Tobermore because she wanted to be in Tobermore.
K	She's obviously passionate.
E	She's a super, super, super person. Suzanne Cahill is like very good at her job, very very, great speaker and everything, but for Suzanne, it's her job. I wouldn't criticize her or anything but if you were having a conference in Tobermore today she would come and if I were having another in Ballyduff, she'd come, and another next week in Waterford, she'd come, but… she'd be paid for them all, you know. But Kate is superb. So there's three very good centres, but then on the other hand none of them are there at 4 o'clock in the morning.
K	I know what you're saying. I feel like I have to ask you actually, we're trying to synthesise some of the research in Cork – and I'm leaving, but would you be interested in hearing more about what we're doing?
E	Yeah, no problem at all. Yeah.
K	Like I'll probably be much more removed, just because of where I am. Just a lot of what you're saying today really chimes with what came out from say that workshop and I wish that I'd gotten onto you and asked if you were interested. I'm not sure how interested you are in – it's not really research, it's kind of community based projects.
E	Yeah, yeah. Cos I mean Kate, like, any of her projects, she's doing an ethics thing now at the moment in Dublin, she'd email me about that. There's another on spirituality and dementia, I'd kinda be in contact with. So there would be different things but anything I suppose that you can learn something from, even if it's the simplest little thing, is huge. And I don't know… exactly what ye're at, but -
K	I can send you some information. But even now you're saying you provide training. Like, my supervisor, he wants to keep recruiting students who will be working with people with dementia. But a barrier can be a lack of training, do you know, they might have come up through psychology but what does psychology, sometimes that might mean that they have not studied dementia because of the modules -
E	95% of doctors in this country could not tell you three types of dementia.
K	It's just scary.
E	I mean I had my own GP on this morning to me, going help – help! Help, Eleanor, like – help. I'm here with my mother in law, she's up all night, what do I do? They have no training in it, none. And I mean I saw my own daughter was a GP before she went and did her ah consultancy, and she to this day, knows very little about dementia and goes to me, oh mammy! When I say something to her, I would be kind of, she would be palliative care, so I would be trying to fight the case for palliative care. She would say, I know the palliative care end, you know the dementia and that's no good, you need to know the dementia. Her husband equally is a psychiatrist and his knowledge of dementia would be limited. They would not have had that training, if they were coming from UCC, they would not have that training. New student nurses are coming out today and they are 4 years in college, a lot of training, very high points as you know and they couldn't spell dementia. It's very very sad.
K	It's very bad in chronic kind of care – acute settings, I mean, where someone presents -
E	Crazy.

K	- I would not wish it on anyone.
E	It's actually crazy. I actually do a presentation, it's a one day one, and it's called Barbara's Story, it's based on a DVD, an English health services one. You'll probably hear when you go to – and the whole DVD is about a lady going, she starts off in the morning going to a clinic, and it goes through, she has a dementia, she goes to a heart clinic. And it's the way she's treated inside in the hospital, which is absolutely acceptable for you and me. But she's there and she's frightened and she can't remember what clinic she's at – it's a real kind of an eye opener. But if you take St Cormac's Unit, I don't know if you're familiar with it, it would be the new unit out in Tobermore. That would be palliative care, chronically young ill, respite and convalescence. Obviously because they do respite they might get dementias, or they might get transfers from Waterford Regional, convalescence with a view to home, but they'd have a dementia. Oh Kellie, it's an eye opener. There isn't a sign, there isn't a – nothing to help somebody with dementia. None of the staff have training, none of them want to do it. I remember one training session that I went back to do after I left outside, and Pam said to me, there's 4 nurses from Cormac's who would need to go, she'd be giving me feelers, and – none of the four of them turned up. So – I mean she rang me now, I was in Kenmare and she rang me. Said I want you to come out and do some training, I said do you need anything specific, and she said yeah, communication, and I said who have we and she said Cormac's and I said oh no. It's almost as if they don't want to do dementia and if they do the training they're afraid they'll get more residents, more patients with dementia. So if they don't do the training they're safe.
K	That's just so -
E	And that's the way them in the acute hospitals – no champion in Waterford Regional Hospital. Now there is a lady in the Mercy Hospital, Doreen Lynch? And she's head of nurse education there and she's very involved in nurse training for dementia there, and she would have got a good few dementia champions in the hospital in Cork. But the last day I was at a conference in Cork, I think, I think that fella's name might be Tony alright? He was talking, that GP from Kinsale, and saying they have no clinical nurse specialist in dementia in any hospital in Cork. Imagine – Tobermore had one. There is no clinical nurse specialist in Waterford Regional.
K	Why – why – is it a lack? Where is that coming from, is it a lack of interest, is it a lack of education?
E	Ah, they just don't appoint them. You know, I used to have to go down to Waterford Regional. What they do in Waterford Regional if you're a person with dementia is they get security to come in and sit with them. Every day, 24 hours a day. We had a man outside, a lovely man, Malachy, that I actually assessed and brought up to Tobermore and he had been from Waterford City, and he had a history of alcohol abuse and violence and family issues and that – so he was a difficult resident anyway and he brought this personality with him. But I assessed him, and I, talk about music – this is funny. I decided I couldn't take him, because I felt with the females outside he might be difficult, and when we were coming away – the security guard standing with him the whole time, but when we were coming away he said to me, where are you from? And I said, it's called Ballyduff. And he started singing 'Come Back Paddy Reilly to Ballyjamesduff' – it's a song, and I thought – I like you. I'll take you. And I brought him up and he settled -
K	Wow!
E	- he's outside now with about two years.
K	Fantastic.

E	Yeah I know, the thing that swung me like. But he was five months in Waterford Regional with 24 hour security.
K	What is that -
E	Imagine the cost -
K	The cost, but also like the positioning of that person as like a dangerous person or a, d'you know, a flight risk or something like that – it's just -
E	And, he ahm, the security man used to come see him in Tobermore, they had become good friends. And he couldn't believe the changes in him. First of all he was dressed. He was walking around Waterford Regional for five months in a dressing gown.
K	Oh -
E	I don't know what the cost was. He was in a private room, because he couldn't be with anybody else, and he had 24 hour security.
K	Was he really that -
E	Well there's a whole lot of women with him now and he's fine.
K	I just can't get over it. I've never heard of anything like that
E	Yeah. We took him off his antipsychotics straight away and gradually reduced everything that by the time, after about three months he was on minimal. He loves the garden, he loves being out and he would have his moments, he has a dementia. But he was never in any way violent, never lifted his hand, never raised his voice.
K	And was he displaying those kind of behaviours in -
E	Well he was because he was basically locked in and wanted to get out. They had sent him to a nursing home and he had vaulted. He got out over the wall. And the funny thing was he took a load of spoons and knives and forks with him.
K	Spoons and knives and forks?
E	Bringing them home I suppose.
K	[laughs]
E	I know, it was funny wasn't it.
K	He sounds like a total character!
E	But I mean he just, he just, he settled so, so well. Now he can be volatile -
K	Yeah, yeah – unpredictable like – you could, that would be such an interesting case study, you could track his -
E	And he's always singing the songs.
K	Singing the songs?
E	I just thought, there was something in this man that we could hone into. Beautiful singer.

K	When I, am, when I – singing is -
E	And I saw the fun in him too. When I said I was from Killane he started singing the song.
K	Yeah.
E	And I remember bringing him up and Pam said to me, why did you bring this man up, he looks like awful trouble. And I said well he sang me a song, looked into my eyes and sang it. And she said, you're mad. But something touches you. Sometimes you see.
K	Yeah.
E	I remember the same night, assessing another gentleman from Tobermore. And I suppose the negative side of dementia, Kellie, the very negative side. This man had always been… difficult. His children said he was always difficult and very strict, his children said he was always strict. He had a drink problem when he was young, and he had given up drink completely. He had remained a very strict, stern man, and he had developed a dementia and they stupidly started to give him a drink at night to put him to sleep. And he was very mobile, and of course he soon started wanted to go to the pub. And when he wouldn't be allowed to go to the pub because he'd get lost coming back, he started to beat his wife because she wouldn't let him go. And she was tiny, she was smaller than you. He was a big strong man, in his early 70s. And they reported it to the social services, you know, the elder abuse office. And she came and obviously she mustn't have responded it to any positive way. And they reported it to the department of psychiatry and they came – Steve Cully now [local Health Service Executive psychiatrist] and he referred them to me. So they arrived to me one morning for an assessment with a view to day care and respite care, and the minute I saw him now, Kellie, I thought this was going to be awful. A big strong man. But he had two daughters and two sons with him, and he, and his wife. And he was sitting with his wife while I was just filling out a few forms inside the office, when one of the sons came in and closed the door and said, I need to talk to you. Took out his phone and flicked through these photographs – and if you saw the abuse. I couldn't take him. I just couldn't like.
K	No. That's a real -
E	So I had to do something really sad and I had to have him committed.
K	OK.
E	By the department of psychiatry, which I never had done ever before. But anyway to shorten my story he was in the department of psychiatry for about three months and the plan was just to get him back to Tobermore, so I got a phone call to know if I would go down and assess him with a view to coming back. And I had to refuse to take him back because he hadn't improved one bit and he was quite violent, and I – accidentally got access to his files in that nobody left him, there was always a nurse with him, but she was called out for some reason, and the notes were on the table, and I assumed, and I still think, and she didn't say I couldn't, that, she had no reason why I couldn't read them – they were horrendous Kellie. He was very violent, but we were not able to take him back, which was sad, do you know, I still see his family around Tobermore sometimes and I nearly turn away when I see them because I feel bad. But he never left the department of psychiatry. But he would have been a difficult man always, and I suppose a blackguard, and he didn't change.
K	But that's it and I suppose -
E	I suppose it was the first side of dementia where, for the first time in my life, I had to go against the person with dementia and take the side of the carer. Just a one off like.

K	But it just shows like, it's such a complex situation. And it's not like everyone who gets dementia was an angel all through their lives, it happens to all manner of -
E	You see everything – there's no boundaries.
K	I can imagine that they -
E	But they say that when you've seen one person with dementia you've only seen one. Because they're all different.
K	It's like someone like you say – who has cancer.
E	So when are you starting your new job.
K	Ahm – gosh. Next Tuesday is my first day and then I'm -
E	And what will you be doing Tuesday now?
K	Just settling into my desk, I think!
E	So what will you be doing at your desk next Tuesday month.
K	Next Tuesday month. OK, I actually think I'll be out in the community a lot, so it's going to be running workshops with people, and visiting people's houses. I don't think that people are in particularly moderate or severe stages, so there's, hopefully I'll be able to -
E	Some of the early stages of dementia who might be driving still -
K	Yeah, yeah, yeah and hopefully doing some interviews with carers and people with dementia if it's possible. I really like working creatively with people with dementia but I'm up against this thing with art, so I'm going to need to figure out some ways to do that. Ahm and I suppose it's going to be a lot of grant writing, proposal writing.
E	Yeah – research like?
K	Research, yeah yeah yeah, and some, I'm gonna try to repurpose some of the data from my PhD which didn't make it into my PhD.
E	Cool.
K	So I've gotten so much data so I'm going to try to make sure everything is disseminated, I'm going to try to get everything out. There are some things, like I really had this kind of interesting substrait that was about place and home and things like that, and that's hopefully going to go to the new project. Ahm -
E	About ageing in place and staying at home?
K	Yeah. And about – what really – when we say meaningful. I really keep coming back to this word, meaningful. And trying to figure out what it means. I know it's different from person to person.
K	What home means?
E	Yeah.
K	It means safe really. More than anything for somebody with dementia. The one thing Kellie that happens when you get memory loss or when you feel lost is – fear, you know. If you're in Cork

	today and you're in Merchant's Quay and for some stupid reason, and for some stupid reason but we all do it, you didn't remember to look to see where you parked your car, but you came out after and you have absolutely no idea, you're on the second floor or the fifth floor. And you know that kind of panicked fear? Like which is a really short-lived thing really. Or if you lost your wallet.
E	That kind of feeling, yeah.
K	Jesus Mary and Joseph, that kind of fear. That is very common in people with dementia hundreds of times a day. But home, home is safe. And I suppose if you think about it, if you were sick in Cork today and you had a really bad flu, and if your dad came up and said, come on away now. You'd go in home to your own mam and dad's house, and you'd go into the bed -
E	[laughs]
K	And you'd feel -
E	It's all those feelings.
K	And that's simplifying everything. But home is safe.
E	Yeah.
K	You know. And it's where they're in control. Nobody wants to be in residential care.
E	No. And then that's – I always wonder, am I fighting a losing battle when I think, oh, how do we make this more like a home, or like a community. I think I probably am. But then I think, you can only ever work with the present moment. So if you can get a group of people laughing together, or if you can sit down with someone -
K	But whatever situation you find yourself in with someone with dementia, you have to make that as near home as you can. But there is no substitute for home.
E	Yeah, yeah. I know.
K	And they would rather be in squalor at home and not being able to take care of themselves, and be setting fire to things, than to be safe in residential care.
E	What I've always found – I've seen in a few places – is people tend to 'invent' home in their heads. So they're in a care setting, and maybe they're only there for a few months at this stage, and maybe it's – I don't know now, you know more than me, maybe it's connected to hallucinations, but they, they wander and in wandering they say open doors expecting it to be their bedroom. Or they'll open a door and – in their head, or they'll be talking to me, they'll say – there used to be a stairs here.
K	Yeah, we would get that a lot. "I'll go upstairs to bed now."
E	Yeah! "Upstairs to bed."
K	Do you remember Maire?
E	Yes.
K	Maire would go down to the bedroom every single night at the same time, winter and summer, and we'd always know she was going down and we'll follow her, and she'd say I want to turn on my blanket. There's no electric blanket in the ward. And we'd just say, tis on. And she'd go off.

	And that was, you know, a part of home, and she'd think she was at home. And that's good, I used to often say to the girls, they'd say that's sad and I'd say no, it's not, it's good, she – she's happy to go into that bed, and she's – that's her place.
E	I think it's all about working with the experience of that person.
K	Yeah, it's a sense of place like, for them.
(tape ends)	