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An Experience-Centred Design Led Examination of the Struggle for Recognition in Dementia Care

By

Sarah Foley

A Thesis Submitted to

The National University of Ireland, Cork

For the Degree of

Doctor of Philosophy

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December 2019

Research Supervisors: Prof. John McCarthy and Dr. Nadia Pantidi

Head of School: Prof. John McCarthy

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Declaration

This dissertation is the result of research carried out in the School of Applied Psychology from October 2015 to July 2019.

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism.

Sarah Foley

School of Applied Psychology

University College Cork

December 2019

This thesis is dedicated to the memory of the residents of Oakfield House, who I had the honour to know and learn from who have since passed away.

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Publications from this Thesis

Peer-Reviewed Journal Articles

Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Thomas Nappey and John McCarthy. 2019. Printer-Pals: Experience-Centered Design to Support Agency for People with Dementia. In 2019 CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2019), May 4–9, 2019, Glasgow, Scotland, UK (Received Honourable Mention Award signifying the top 5% of publications) Doi: 10.1145/3290605.3300634

Sarah Foley, Nadia Pantidi, and John McCarthy. 2019. Care and Design: An Ethnography of Mutual Recognition in the Context of Advanced Dementia. In 2019 CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2019), May 4–9, 2019, Glasgow, Scotland, UK. Doi: 10.1145/3290605.3300840

Sarah Foley, John McCarthy and Nadia Pantidi. 2019. The Struggle for Recognition in Advanced Dementia: Implications for Experience-Centred Design. ACM Transactions in Computer-Human Interaction. 26, 6 Doi: 10.1145/3359594

Sarah Foley, Nadia Pantidi and John McCarthy. Student Engagement in Sensitive Design Contexts: A Case Study in Dementia Care. Under Review CHI' 2020.

Contribution of First Author

The above peer-reviewed journal articles are presented as chapters in this thesis. As the first author of all these papers, I carried out the fieldwork, conducted the qualitative analysis and lead the paper writing and publication process. Co-authors made the following contributions:

Daniel Welsh and Dr Kellie Morrissey: Worked on the design and evaluation of Printer Pals.

Thomas Nappey: Provided technical support for Printer Pals.

Prof John McCarthy and Dr. Nadia Pantidi: As PhD supervisors, they were both involved in discussing and developing ideas, as well as providing feedback on papers.

Abstract

The experience of advanced dementia has been largely excluded from design work in Human-Computer Interaction (HCI), as the experience itself is viewed as 'unreachable' in terms of design engagement. This thesis aims to examine the experience of living with dementia in the care home context, with a view to implementing methods of Experience-Centred Design (ECD) to examine the relational and agentic abilities of people with dementia, particularly in advanced dementia.

In order to examine the experience of advanced dementia and understand the political and social implications of inclusion of people with advanced dementia in design, this thesis draws on the social theory of recognition, a theory which emphasises the need for mutual engagement as a means of developing and sustaining a self-identity. Used as the basis of a design framework, this theory suggests a series of sensibilities for design in this context, which are presented in chapter 2. This framework informs the empirical design work presented in chapters 4, 5 and 6 to examine the needs for reciprocity through design in dementia care, paying particular attention to the ways of engaging with the experience of advanced dementia. The initial ethnography, presented in chapter 4, focuses on the nature of communication, care and participation with people with advanced dementia, with a view to informing recognition-based design work. Findings suggest ways to further support moments of recognition in care and design, such as embodied communication, challenges in recognising the needs of people with advanced dementia and reconfiguring the role of people with advanced dementia in design. Informed by the findings of the ethnography, and with a view to increasing moments of recognition through design, intergenerational design work with student volunteers and residents in care is presented in

chapter 5. Discussed are two case studies; Life Story Box and History Club. In these design projects, students worked with residents to explore their personhood and engaged in the co-design of artefacts which represented the individual and collective life story of the people with dementia. Findings suggest how best to support students and people with dementia in the design process, as well as some of the ethical implications of supporting co-design in this context. The final study culminated in the design and evaluation of 'Printer Pals', a receipt-based media producing technology to increase access to media and encourage social engagement in the care home setting. This iterative design process involved prototype development, evaluation and implementation in collaboration with researchers from Open Lab, Newcastle University. Findings discuss the use of design processes to support agency in care homes, and the role of technology in creating opportunities for positive social engagement and cohesion.

This empirical design work, informed by the theory of recognition and methods of ECD, proposes an approach to designing with and for people with advanced dementia that supports and engages in their agentic social presence. Design work in this context presents an opportunity to position the person with advanced dementia as active in the dialogical process of meaning-making, as well as their own care practices. Reconfiguring the role of people with advanced dementia in relational and social processes, requires careful re-visiting of cultural and social notions of agency and mutuality, and how they have failed to consider the abilities of people with advanced dementia. Design has a central role to play in supporting these abilities, encouraging creative and meaningful care practices in order to honour the needs and rights of the person with dementia to shape a meaningful and connected lived experience.

Chapter 1: Introduction

"A few conclusions become clear when we understand this: that our most cruel failure in how we treat the sick and the aged is the failure to recognise that they have priorities beyond merely being safe and living longer; that the chance to shape one's story is essential to sustaining meaning in life; that we have the opportunity to refashion our institutions, our culture, and our conversations in ways that transform the possibilities for the last chapters of everyone's lives."

— Atul Gawande, Being Mortal: Medicine and What Matters in the End

Dementia has been recognised as a key concern and challenge to health care systems, both locally and globally. Beyond the economic challenge of ensuring care for people with dementia in the increasingly ageing population, the experience of living with dementia highlights our cultural and social understandings of cognition, social contribution and care. In this thesis, I examine the experience of living with dementia in the care home context, with a view to implementing methods of Experience-Centred Design (ECD) to examine the relational and agentic abilities of people with dementia, particularly in advanced dementia. This thesis builds on a body of research which seeks to honour the personhood of the individual with dementia, acknowledging their needs as a person as well as a patient. In these opening pages, I will briefly introduce the field of Human-Computer Interaction in which this body of work is situated, the

current experiences of people living with dementia in Ireland, the care practices which have been established to honour personhood, and my response to these current care practices by focusing on notions of agency, recognition and reciprocity through methods of ECD with people with dementia in care.

Experience-Centred Design and Human-Computer Interaction

This thesis employs and extends methods of Experience-Centred Design for and with people with advanced dementia. ECD methods engage with the lived and felt experience with a view to designing responsive technologies, services and interactions that enrich the dialogical, co-created experiences between the designer and the participant. This approach to design, established by McCarthy and Wright [98] has contributed to research in the third wave of Human-Computer Interaction [15], which aims to examine the experience and consequences of our increasing use of technology in everyday life. As a discipline, HCI has evolved from examining the use of technological systems in the workplace [63], to considering the use and value of technology as a socially practiced activity [7, 36, 132, 136]. ECD as an approach to design has contributed to the involvement of populations and experiences which have traditionally been excluded from the design of technological systems, such as people with dementia [111, 151]. This thesis builds on this work in ECD and HCI

through examining the nature of experience in advanced dementia, and employing design thinking to appropriately respond to this experience.

Living with Dementia in Ireland

According to the latest figures released by the HSE (Health Service Executive - Government Health Authority), approximately 55,000 people are currently living with dementia in Ireland, with this figure set to rise to 113,000 by 2036 [119]. 500,000 people in Ireland have a family member with dementia, signalling both its prevalence in society, and the need to create networks of support for those impacted by the illness. Dementia is an umbrella term, which describes a progressive condition impacting cognitive functioning, memory, language, mood and personality. The causes of dementia include Alzheimer's disease (accounting for 50-70% of dementia), vascular dementia, Lewy body dementia and frontotemporal dementia, but it is also linked to Huntington's disease, traumatic brain injury, and Parkinson's disease [43]. Many people also experience 'mixed dementia', where symptoms of various progressive dementias are reported [119]. The progressive nature of dementia means that while people can live independently in the early stages, they require greater involvement in their care in the later stages, which is associated with severe memory loss, confusion and agitation, frailty, and a reliance on non-verbal communication [25]. A formal diagnosis of dementia requires a series of tests carried out by a medical doctor, including cognitive and neuro-

psychological tests, brain scans, laboratory tests to rule out deficiency or inflammation and psychiatric evaluation to assess whether mental health issues such as depression are contributing to the presenting symptoms [43]. The process of receiving a formal diagnosis is 'the exception rather than the rule', and Cahill et al. estimate that of the 26,000 people living with dementia in their homes, the majority never receive a formal diagnosis [24]. This directly impacts the services and support available to people with dementia and their carers and suggests a severe underestimation of the support which should be provided, as care is largely carried out privately amongst family members and through private care companies.

The experience of dementia varies greatly depending on the stage of dementia, the care system available and the environment in which care is situated. Social and cultural ideas of dementia also influence how people with dementia are positioned within society, often resulting in many retreating from civic and social life [38]. Many people with dementia and their families wish to remain in their home, which for most of us is a place of safety, familiarity and comfort [32]. However, as dementia progresses, the needs of the person with dementia, often paired with concerns for their safety and more frequent hospital visitations, result in a transition into residential care or assistive living facilities. The transition into residential care can present a series of challenges for people with

dementia, as they navigate a new environment, adapt to care schedules, and experience increased intimate and personal care from professional carers [113, 142]. Care homes in Ireland are publicly or privately owned, and while they vary in their resources, are routinely inspected by the Health Information and Quality Authority (HIQA), an independent body set up to assess health and social care services in Ireland. This ensures a standard level of care is met, which responds to the medical, social and psychological needs of those availing of the services.

Historically, dementia has been described in a narrative of 'social death' [133], in which the selfhood of the individual with dementia was said to slip away until the person became a separate entity to their history and experiences. Paired with this, the biomedical understanding of cognitive decline dominated care responses, framing the person with dementia in a process of losing their cognitive abilities (and therefore selfhood), who becomes beyond meaningful reach as their dementia progresses [24]. Towards the end of the 20th century, Tom Kitwood framed this bio-medical approach to dementia care as 'malignant social psychology' which failed to acknowledge and respond to the 'personhood' of the individual with dementia. His subsequent 'Person-Centred Care' (PCC) approach to dementia care, revolutionised both research and practice [79, 81] and has influenced much of the existing approaches to dementia in psychology, gerontology and HCI. PCC emphasises care

practices which seek to honour personhood and acknowledge that a care plan which focuses solely on the physical needs of a patient, such as bathing, feeding and administration of medication, can neglect the psycho-social needs of the person with dementia, particularly their need to belong and exist within social relationships [81]. The PCC approach also acknowledges that carers and loved ones may need support in engaging with personhood in dementia, and promotes reminiscence therapy [101], sensory therapies [74] and outlets for personal expressions such as arts and music [78, 108] as a means of fostering and maintaining personhood. Many scholars have extended this work, calling for a citizenship approach to care [11], the need to look beyond verbal communication to embodied expressions of self-hood [85], and involvement of people with dementia in participatory research [30, 78] to ensure their voices and experiences are central to the dementia narrative and care practices. This thesis responds to many of these care practices through design and has further implications for disciplines beyond HCI, such as nursing, care, and practice.

While the person-centred approach to care has undoubtedly resulted in higher-quality care for people with dementia, many of the relational and cultural consequences of living with dementia prevail. People with dementia report feelings of social loss [23], restricted

opportunities for the maintenance of social identity [23] and a lack of opportunity to engage in meaningful activity [117].In this thesis, I argue that a theory which is so deeply embedded in dementia itself, can overlook some of the fundamental processes that we engage in so as to interact meaningfully and purposefully with each other, such as agency, recognition and reciprocity. To further this argument, this thesis is strongly grounded in the theory of recognition, a social theory which emphasises the vital nature of reciprocal relations in order to develop and maintain a practical social identity. I introduce this theory in the conceptual design framework presented in chapter 2, with a view to examining the role of recognition theory in setting a clearer agenda for ECD approaches to dementia and design. This theory further informs my empirical work and sets a course for HCI research with people with dementia in which their agency and need to be mutually *recognised* through social relationships is central to the design process and outcomes. I respond to these ideas throughout the studies presented in this thesis with a view to examining the role of HCI and design in supporting and engaging people with dementia in reciprocal meaning-making processes.

In Summary, this thesis lies at the intersection of several fields, including the theoretical underpinnings of person-centred care and recognition theory and the design practices of ethnography and ECD. I will discuss these theories and concepts in detail in across the thesis, with

a view to contributing conceptual and empirical findings to each field respectively.

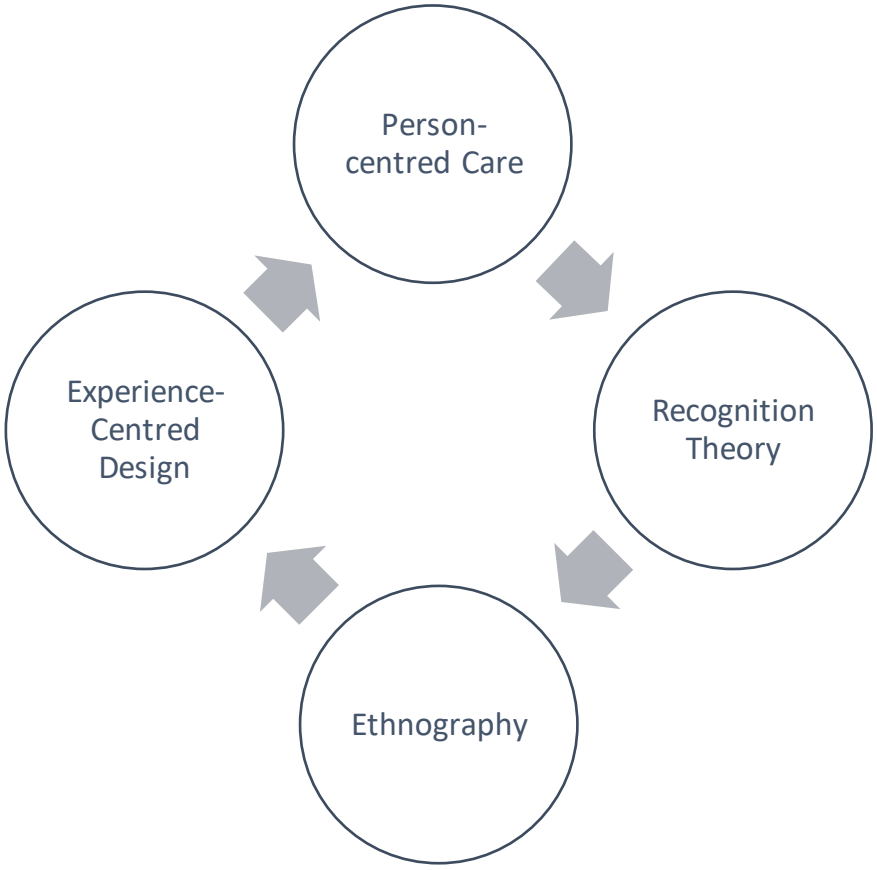


Figure 1: Theoretical and Methodological Positioning

Oakfield House

My experience learning from people with dementia began in November 2014. As an undergraduate psychology student, I was expected to carry out 70 hours of volunteer work as part of the 'Psychology in the Community' module I was taking. Having chosen to do all my previous volunteer work with children, I decided to round out my experience by working with older

adults. I had never been to a care home before. I had little to no experience with older people in general as my grandparents had all passed away before I was born, and truthfully my understanding of old age and ageing hadn't evolved much from the childlike caricature idea of old people as somehow very different to me, a little scary maybe, and with very little chance of our experiences overlapping.

This idea soon changed of course. I was welcomed as a volunteer in Oakfield House, where the staff were eager to show me around, encouraging me to get as involved as I could, and grateful that I would come in to help on a Wednesday afternoon. What struck me immediately was the warmth of the place. The image of a care home as a sombre and silent place where people come to die, was in huge contrast to the colourful, welcoming home that as far as I could see, was full of life. What's more, the residents of the care home, the majority of whom had some form of dementia or cognitive impairment, were mostly friendly, affectionate, humorous people, which frankly surprised me most. I thought I had formed an educated idea of dementia from my undergraduate studies, but it soon seemed that the focus on this decline and deficit left no room to discuss the character that remained and evolved throughout the illness. For some reason I had formed the idea that people with dementia couldn't be present, friendly or caring. Although strangers, the warmth and friendliness of the environment and the people in it was more akin to

the type of care and warmth only expressed in my close family relationships. Many of the residents were in wheelchairs, requiring a level of assistance which resulted in a fast intimacy as we strolled together, they took my hand to thank me or required help manoeuvring around their room. I felt for the first time in my life that I was being very useful and got great satisfaction from this. The hours I spent there felt meaningful, like I was connecting with people on a very human level. There was also a sense of acceptance here, that no matter how differently, slowly or confusedly you navigated the world, that was okay. However, some people's reaction to my volunteer work seemed to suggest that I was 'very good to go' to the care home, that it was somehow selfless of me and that the people there had little to offer in terms of reciprocity. This felt fundamentally wrong. While I couldn't gauge whether the residents of the care home were getting much from my visits, I was certainly benefitting from spending time with them. I've spent the past four years exploring this idea of reciprocity, care and contribution, in a bid to demonstrate the abilities of people with dementia to greatly contribute to and enrich the lives of others.

Five years later I still spend Wednesday afternoon in Oakfield house with the residents. In the meantime, I've conducted an ethnography there, facilitated a student volunteer programme and designed, introduced and evaluated a prototype. During this time, I've worked closely with

many residents, learning of their lives, trying to respond appropriately to the privilege of hearing their stories, and grieving for their inevitable endings. Despite the years of ethnography and the great appreciation for the loss and difficulties that coincide with the liveliness of the home, I'm still constantly struck by the expressions of care, vulnerability, growth and acceptance that I witness there. My time there acts as a weekly reminder to be kinder, more patient and understanding of the wealth of experience of others. In this thesis, I introduce many of these experiences I shared and witnessed with the residents, which I hope contribute to a fuller sense of what it means to live with dementia, and what is possible within this experience, both socially and through design.

Thesis Conception/Overview

Based on my reading of the existing PCC literature and my initial work in the care home, this thesis began with the idea that people with dementia were not being fully acknowledged or supported in their ability to actively contribute to their communities and as people willing and able to engage in care. The traditional emphasis on the medical, biological and cognitive elements of dementia had contributed to this concept of people with dementia as in deficit, whereas the turn to qualitative, experiential methods to capture what it means for a person with dementia to navigate the social world has begun to illuminate this experience. Transitioning

from volunteer to researcher, I started by conducting an ethnography in the care home, spending one day a week as part of the activity team, often accompanying a resident for the day. It was during this time that I aligned my interest more with people with advanced dementia, who had particular needs and ways of communicating, and would push me to consider the extent of what it means to communicate, participate and be included. While I conducted my early fieldwork, I contemplated which social concepts I was trying to capture and support. There were notions of the nature of social identity, the importance of the social construction of meaning-making, the need to highlight agency and 'usefulness' as something that needs further support in dementia care. I felt it was important to acknowledge the inter-subjective experience, giving the experience of the person with dementia a critical theoretical examination and grounding. As mentioned previously, I drew heavily on the social theory of recognition as a guide for my empirical work in this thesis. I introduce this theory fully in Chapter 2, examining the potential of a focus on the inter-subjective need for each other to form and maintain a sense of self. The idea of mutuality is at the core of recognition theory, and is reflected in my design work, which aimed to examine and support mutually beneficial interactions with people with dementia, particularly people with quite advanced dementia. As I began to introduce activities, resources and design explorations into the care home, I examined the role

of technology, media and design to facilitate and acknowledge the role of people with dementia as active contributors, not only to this research, but as members of a community.

Creating Space for Design

My initial understanding of dementia and the potential of HCI methods in this context was informed and influenced by many researchers in the field. While I could see the value of this qualitative work in extending our understanding of dementia, I was drawn to the action orientation of design work and HCI. Experience-Centred Design, established by McCarthy and Wright [98, 99, 155, 157] underlines an approach to design which takes experience as co-constructed and highly contextual, in which we share, remember and relive experience as a process of meaning-making and social connection. ECD has been established within research with people with dementia as an opportunity to both explore and enrich the experience of dementia. This approach was initially appealing to me as it felt like a way to engage further with experience, to bring in resources to the care home, and create an outlet to demonstrate their agency. From a personal perspective, I was also strongly influenced by the work of my PhD colleagues Kellie Morrissey and Mary Galvin, who were finishing up their PhD work in Dementia and HCI as I was beginning mine. Their respectful and insightful approach to the use of ethnography and HCI in the context

of dementia care demonstrated the potential of these kinds of approaches, and I learned so much from them about the importance of capturing experience and always placing the voice of the participants at the core of the research. Further work by Jayne Wallace [151], Anja Thieme [136] Abigail Durrant [39] and Rachel Clarke [26] conveyed the potential of ECD methods in design contexts, which requires a strong relational basis to design work, and an appreciation of the role of designers in creating space for co-constructive, empathetic meaning-making. From this work the role of design in creating space for meaning-making, particularly in contexts which has been largely under-examined in traditional empirical science, is evident. Subsequently, my approach to the design ethnography [72, 125]carried out throughout this doctoral work was informed by my education in psychology and qualitative research methods [42], and the use of design thinking and practices which seek to learn from and respond to the contexts in which they are embedded in order to enrich lived experiences [5, 125]. I extend this work through focusing on the experience of advanced dementia throughout the thesis, which requires careful consideration of how we co-create meaning and extend participation and the role of recognition theory in ECD to further refine the need for mutuality within design dialogues. Through applying recognition theory within methods of ECD, I also examine how restrictive views on cognition, agency and social contribution impact opportunities

for people with dementia to be fully recognised as agentic and caring beings.

While the focus on experience of advanced dementia is a key contribution of this thesis and its theoretical framing, within Oakfield House all residents live together and share social spaces irrespective of their diagnosis. Much of the design work tried to further include people with advanced dementia within the social engagements of the care home, with a view to creating design spaces which were inclusive and attentive to the needs of people with advanced dementia, while also being inviting and enjoyable for all residents who wished to engage. In order to create inclusive and inviting design spaces in Oakfield House, it was important to acknowledge that the needs of people with advanced dementia are very different from those of people in the early to mid-stages of the illness and have largely been neglected in HCI research [129]. Working with people with advanced dementia has led to an engaging and critical examination of what it means to be included in design, and the necessary processes to ensure that the participation of people with advanced dementia is understood, viewed as legitimate and supported in HCI. As is evident in the empirical work of the thesis, the focus on advanced dementia does not mean creating spaces exclusively for people with advanced dementia, but rather creating design processes which are inclusive, in which people at various stages of dementia, and various stages of life, are welcome and

supported. The use of design ethnography in this context has implications for inclusive design, in which we design services and technologies which are sensitive to the needs of people with advanced dementia but avoid separating those experiencing advanced dementia from potentially enriching social interactions.

I outline considerations of the experience of advanced dementia in chapter 4, based on my initial two years of interactions with residents in care, focusing on the need to respond to embodied communication, anchoring communication within the physical world, and extending these considerations to create inviting and inclusive design contexts. As my work within Oakfield house continued, I widened design participation to support inter-generational engagement amongst residents and undergraduate students, to further support moments of mutually beneficial engagement through design (Chapter 5). This work, in which the students and residents worked together to design personalised probes and historically based artefacts, highlighted the potential of the design spaces to encourage moments of mutuality and the co-creation of meaning through design. In terms of examining recognition in this context, the students' account of their experience working with the residents in care highlight the enriching, positive contributions of the participants with dementia. In addition to the relational processes of this student project, practical aspects of how to support design for recognition became

apparent at this stage of the research, such as the potential of media, and the enjoyment of playful -sometimes competitive- conversations which could be supported through engagement with personalised media. These insights were the basis of the final stage of the research, which involved collaboration with colleagues in Open Lab, Newcastle University (Chapter 6). In order to increase opportunities for social engagement with meaningful media and maintain the playful interactions we had witnessed in the student design project, we designed and evaluated 'Printer Pals', a receipt based, media producing device which encourages social interaction based on the interests of the residents of Oakfield House. This design project is the culmination of three years of learning from the residents in care, understanding the abilities of people with dementia and ensuring that they are engaged and part of the design process and evaluation, in which their agency and social contribution is evident and paramount.

This PhD work is rooted in both a theoretical and design approach to understanding what it means to experience dementia in the care home, and the role of design and HCI in responding to this experience. Throughout the following chapters, I detail the experience of dementia in light of theoretical critical groundings, ethnographic findings and design-led interventions, which have implications for practices within HCI such as ECD and Inclusive Design, as well as person-centred approaches in social and health sciences What emerged throughout all of these channels

of examination was an understanding of what it means to reconfigure a person with dementia as active in the process of their own care, and active in the process of the lives of those around them. An approach to care and HCI which acknowledges that people with dementia can deeply impact the practical identity of those around them is an important step in reaffirming what it means to care for and design with people with dementia. Acknowledging the agency and social abilities of people with dementia also requires a re-examination of what facets of personhood we are acknowledging, and the role of HCI and design in recognising and actualising full personhood in dementia care.

Thesis Aims and Objectives

This research is motivated by the following aims:

1. To examine the experience of advanced dementia in order to understand how best to support enriching interpersonal processes which position people with advanced dementia as active contributors to their social world.
2. To examine the role of design and technology to highlight the social contribution of people with advanced dementia and support their social and civic right to be included in design processes, and the wider community.

In order to meet these aims I ask the following questions:

1. What is the interpersonal experience of engaging with people with advanced dementia?
2. How do people with advanced dementia communicate their selfhood and in what ways can we respond to this through design and technology?
3. What implications does the nature of participation in advanced dementia have for wider ECD approaches to design and inclusivity?

Structure of the Thesis

This thesis is presented as a series of publications written for HCI journals and Conference Proceedings. The papers are presented in the order in which the relevant studies were carried out and written, except for the conceptual design framework, which was developed over an extended period of time throughout the PhD work. Below I introduce the content and contribution of each chapter

In chapter 2, I present the publication 'The Struggle for Recognition in Advanced Dementia: Implications for Experience-Centred Design' (under final revisions in TOCHI). This paper introduces a design framework on advanced dementia and design which draws on recognition theory, a social theory detailing the importance of the inter-subjective experience, framing the theoretical positioning of the thesis. The application of recognition theory in design for advanced dementia, as a

means of creating design spaces and outcomes which encourage inter-subjective dialogue with people with advanced dementia, is considered. Current design research with people with dementia is reviewed in terms of recognition theory to present a course for designing with and for people with advanced dementia, considering their fundamental need and right to be recognised. Thoughts and ideas about design in light of this review are presented as considerations for designers in this context, to examine the nuanced presentation of recognition in advanced dementia and the opportunities for recognition to be actualised through design processes. Finally, ECD is extended through examining the nature of dialogue, participation and agency in terms of embodied and non-verbal communication, considering the texture of design in the context of advanced dementia, and situating the intersubjective experience firmly within a social and political struggle for recognition. This design framework was conceptualised during the initial ethnographic work and subsequently guided the rest of the design work presented in chapters 4, 5 and 6. This paper also introduces early ethnographic findings in order to demonstrate how the reader can put the framework into practice, and the type of interactions to expect in the design context of advanced dementia.

Chapter 3 is a methodology chapter. This was considered necessary as the house style of many HCI publications, particularly conference proceedings, expect a succinct method section, too brief to make explicit

the methodology needed to support a PhD. The process of carrying out ethnography in care, the role of ECD, data collection and analysis, as well as the practical ethics and reflectivity involved in the research process are discussed. A reflective piece 'Sitting with Loss' on my experience of the more sensitive and personal aspects of carrying out HCI research in this context is also presented. I present three vignettes from my field work which capture the personal impact of navigating through these interactions with people with advanced dementia, resulting in a greater understanding of my role as a researcher here. I also discuss the personal development that came as a result of placing the inter-personal experience at the core of my research process. The personally engaged nature of this research resulted in my own understanding of what it means to engage with people with dementia in acts of mutual recognition, so as to support recognition further and understand the role of emotional engagement in ECD. I take a social constructionist [21] positioning within the data analysis, which considers knowledge as socially constructed between individuals and their social worlds. This approach to analysis resulted in the positioning of the actions and dialogues with the participants as co-constructive and socially consequential, resulting in an examination of their role in meaning-making processes as legitimate and worthy of a response, both in the moment and through design.

In chapter 4, the paper 'Care and Design: An Ethnography of Mutual Recognition in the Context of Advanced Dementia' (CHI'19) is presented. This paper details the first phase of the ethnography which involved a participant-observer approach to data collection. This initial ethnography involved working closely with people with advanced dementia with a view to understanding mutual recognition in this experience. A thematic analysis of field notes, which detail moments of care, connection and communication between myself and the residents is presented. These findings convey the experience of advanced dementia under the theoretical lens of recognition, conveying the abilities of people with advanced dementia to engage in mutually co-constructive processes. The paper argues for an approach to design for recognition which acknowledges the agency of the person with advanced dementia and presents the types of participation people with advanced dementia engage in, which can be viewed as efforts to give and receive recognition, rather than purely symptomatic of dementia. Building on this position, a series of design considerations are outlined. They seek to acknowledge the person with advanced dementia as vital to the recognition of those around them and call for design to support further incidences of recognition through engaging with the physicality of the environment, acknowledging expressions of care, and recognising the need to expand design networks.

My initial design work is presented in chapter 5 in the publication: 'Student Engagement in Sensitive Design Contexts: A Case Study in Dementia Care (to be submitted to CHI'2020).' This paper details the work I carried out with student volunteers and residents in care as a means of increasing opportunities for mutually beneficial, intergenerational engagement through design projects. Supporting students and participants to engage in design projects which aimed to support mutually-engaged intersubjective processes further demonstrates the abilities of people with dementia to be active and agentic in making positive social contributions to their communities. This paper presents two case studies: Life Story Box and History Club. In these design projects, students worked with residents to explore their personhood, co-designing artefacts which represented the individual and collective life story. Findings from this study suggest the part of design in reconfiguring the role of both the residents in care and the students, the ethical practicalities of supporting these types of projects, as well as the use of media, audio and crafts to extend the exploration of the inter-subjective experience. Through supporting this design work, the case for examining the abilities of people with dementia to continue to contribute to their communities, and the need to ensure that the care home is positioned as a key opportunity for engaging in meaningful community based HCI work is made.

In chapter 6, the paper 'Printer Pals: Experience-Centred Design to Support Agency for People with Dementia (Presented with Honourable Mention at CHI'19) is presented. This paper details the design, implementation and evaluation of a receipt-based media producer that was used to facilitate story-telling, quizzes and musical entertainment in the care home and integrated the findings presented in chapter 4 and 5. The findings focused on the role of the design process and use of the device to detail the various ways in which the residents contributed to the design and evaluation of Printer Pals, the co-creative construction of collective knowledge and understanding, as well as the implications of designing for social connection. Attention is paid to the need for inclusive design environments which are respectful of various kinds of participation in dementia, the role of technology and design in supporting acts of agency through participation and the need for greater access to meaningful media as a means of supporting communication in the care home context. Within the discussion of this paper, I also make the case for bringing the findings of this work, beyond the case of dementia and the care home, to other contexts in which individuals and groups may be restricted in their opportunities for recognition.

Finally, in chapter 7, the over-arching findings of the project, their implications for HCI and design and the use of recognition theory as a guiding theoretical frame throughout the thesis are discussed. Particular

attention is paid to how the empirical work of the project responds to the conceptual framework outlined in chapter 2, the use of the empirical findings to further the argument for inclusive design processes, and the role of design and technology in communities of care. Consideration is given to the relevance of this research to how we design with people with advanced dementia, what the experience captured in this research suggests in terms of extending ideas of personhood in dementia care, and the need for recognition within experience-centred design practice. Further I call for a closer examination of how we position people with dementia in our design work, and how this is reflected in wider cultural understandings of dementia.

Contributions of this Thesis

This thesis presents a strong conceptual argument for the need to create inclusive design environments for people with advanced dementia. The application of the critical social theory of recognition foregrounds the right of people with advanced dementia to belong and the role of design in further highlighting their needs and abilities. The conceptual framework offers a practical guide to designers and researchers in the field, in regard to the practical application of designing for mutuality, belonging and inclusion.

The empirical work presented further extends our understanding of the experience of advanced dementia, which presents new considerations

for design processes in HCI. The experience of advanced dementia has been largely excluded from HCI research and this empirical work is presented to extend a more critical understanding of this experience, with a view to creating more inclusive design processes.

This empirical work also extends ECD by presenting the experience of advanced dementia as a lens to consider agency, intentional communication and subtle participation as legitimate means of shaping experience. Responding to the experience of advanced dementia through the design of technology is shown to enrich inter-personal experiences and extend understanding of participation in design. The introduction of design methods in care contexts extends the opportunity for creative engagement with the experience of people with dementia, resulting in more meaningful engagement with their personhood.

This thesis is not intended as an examination of people with dementia, but rather an examination of the ways in which we respond to people with dementia, through design, care and the provision of resources. Throughout this work I have taken the position that people with dementia are not the problem, but rather reflect our personal and cultural responses to people who are cognitively different. As technology continues to permeate care, the need for understanding how to include the voices of people with dementia in the design process is important now more than ever. This thesis firstly examines the experience of dementia, but then

expands and tests it, in a sensitive and ethically framed understanding of the need we all have to be acknowledged as agentic beings. By ensuring this learning with people with dementia is central to how we design and why we design, HCI can ensure that the technologies which are integrated into care are supportive rather than restrictive and designed to promote social connection and an exploration of what it means to live fully with dementia.

Chapter 2: The Struggle for Recognition in Advanced Dementia: Implications for Experience-Centred Design[1]

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Abstract

Focusing on the person with advanced dementia as a social being presents a new opportunity for Human-Computer Interaction (HCI) and Experience-Centred Design (ECD), opening up design opportunities that appreciate the agency and intentional actions of the person with advanced dementia. If HCI is to shift from the predominantly assistive approach to a focus on experience, a theoretical framing that emphasises the experience of the relational nature of selfhood is needed. In this article, we present recognition theory - a social theory based on an inter-subjectivist account of the struggle for recognition - as a way to extend ECD approaches for advanced dementia. Focusing on people with advanced dementia, we examine recognition as a social and ethical perspective for establishing and maintaining self. We present a framework for design to illuminate

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research with people with advanced dementia, experience-centred engagement and social identity.

Introduction

Design within Human-Computer Interaction (HCI) has moved beyond considering the specific and sometimes very particular functional needs of people with motor, sensory, or cognitive impairments, towards an appreciation of varieties of lived experience and the potential of design and technology to enrich everyday life [90, 120]. Were HCI design for advanced dementia to welcome this social and cultural diversity, as well as being sensitive to clinical diversity, interaction with resulting technologies would put those different kinds of diversities into a creative tension with each other. This could have important implications for the lived experience of people with advanced dementia, including how they are seen by the rest of the population.

Put simply, the point of HCI is to ensure that there is a strong focus on the people who use and live with technology in its design, development and evaluation. It has been appreciated for some time that thinking about those people as users oversimplifies the focus of HCI research. For example, Bannon [7] expressed concern that creating a category of people called 'users' risks limiting our understanding of their abilities, interests, perspectives, values, and so on. In a context in which users are seen in contrast with designers, Bannon worries about the tendency to see them as

naïve. He argues for a view of "the person as an autonomous agent that has the capacity to regulate and coordinate his or her behaviour, rather than simply being a passive element in a human-machine system" [7] (p.206). This proposed re-configuration of the user [95] from passive to active has resulted in a participative and collaborative approach to research in the third wave of HCI, which embraces 'experience' and 'meaning-making' as legitimate sources of knowledge [98]. In design, the perspective that we take on the people who use technology matters because the act of designing any new technology, in many ways, configures the intended users [154], much as the sense designers have of prospective users constrains the design space [122]. If we think of our users as impaired in some specific way, our design is likely to try to compensate for the impairment, configuring the variety of people who might use it in terms of that specific impairment and neglecting their many and varied other qualities.

Our interest is in designing for people with dementia, and in this specific project people with advanced dementia. The inclusion of people with dementia within HCI, as users and potential participants, has relatively recently gained significant and growing interest, as is evident in the growing literature in the ACM library [146], as well as the development of special interest groups within the HCI community [18, 92, 109]. This work calls for a critical response to the experience of dementia

through HCI research which responds to the embodied, relational and psychological aspects of dementia, positioning the person with dementia as active in the research process [90, 96, 97, 111]. As this field continues to grow within the HCI community, it is vital to develop our understanding of the wide-ranging experiences of dementia, including advanced dementia, and the potential of HCI design to contribute in these contexts.

Positioning dementia as a clinical condition or state has resulted in an approach to design which focuses on assistive and medical technology, such as memory aids, safety monitoring and GPS tracking [114, 129]. While these technologies can help with the practicalities of living with dementia, they have less to offer in terms of quality of life and the need for respect and recognition as fully-fledged people. Arguably, they also risk presenting people with dementia to themselves and to the wider community as lacking: always forgetting simple things; always in danger of getting lost; unable to manage in their own homes [16]. The assumption that people cannot do one thing or another can become a self-fulling prophecy that leads to the people themselves and others simply accepting this supposed lack of ability. Similarly, the assumption that loss of selfhood is a neurologically and cognitively-derived inevitability in advanced dementia contributes to a potentially self-fulfilling prophecy, in which the expectation of a lack of agency produces social interaction and research methods that miss the agency that is there [13].

HCI design also has the potential to provoke a re-imagination and reconfiguration of people with advanced dementia, a specific group that have hardly been discussed in HCI [129] until recently [46, 138]. Experiential research in HCI could be used to stimulate discussion about the contribution that people with advanced dementia make to society: the value of their presence in a community to re-framing communal understanding of diversity, ageing, care; their importance to their families; the capacity to lay down stories for future generations; their potential to generate fun, joy and compassion. Design approaches such as Critical Design [8], Feminist HCI [9], and Value Based Design [52], in their different ways, nudge HCI to encourage and engage in the kinds of questioning and new ways of thinking that could enable people with advanced dementia to live more independent and/or richer lives. ECD, with its focus on the dialogical co-creation of meaning has the potential to further examine and enrich the relational aspect of care in the context of advanced dementia.

In this article, our aim is to set a course for further advances toward design practice for people with advanced dementia [45, 138]. Our starting point is that the scope for enriching experience through design is best explored with a focus on the relational context in which a person with advanced dementia lives, as well as the relational context in which people and designers engage. If our ambition for HCI design is not just assistive

technology but enriched experience for people with advanced dementia, then the design focus is likely to be on reconfiguring social relationships which, as we have argued elsewhere [99], is a defining characteristic of participatory projects. Given that relationships with people with advanced dementia are often institutionally managed, for example, through medical gatekeeping in care and state gatekeeping offered through legislation [1], a theoretical and methodological frame that can stretch from intersubjective relations to the politics of exclusion and stigmatisation is needed.

In our work to date, Experience-Centred Design [98, 99, 156] has provided a strong starting point by means of its aim to enrich experience "by giving a voice to those who might otherwise be excluded from design and by creating opportunities for people to enrich their lived experience with and through technology" ([156] p.6). For this article and project, the salience of the social construction of personhood and identity together with the politics of exclusion and inclusion, requires additional clarity about the social processes through which personal agency and capacity are recognised, or indeed misrecognised as we will argue is in the case of people with advanced dementia. Illuminating these processes is a prerequisite for inclusively and sensitively designing with and for people with advanced dementia.

In this paper, we draw on the theory of recognition [3, 64] to ask questions about the nature of design for people with advanced dementia.

Doing so challenges ECD to be even more socially and politically orientated, to recognise the person with advanced dementia as a participant, not only in the design process but also within their relationships, care environments and wider society. We describe in detail the development of the theory in Section 3, which will form the basis of the design framework that follows. As we review the current literature on advanced dementia below, we ask the reader to consider the following questions in relation to recognition: How is the need for mutual engagement supported through existing design practices in HCI? In what sense do the needs of people with advanced dementia challenge typical concepts of participation and engagement? In what ways does the design space approach the political rights of people with advanced dementia to be recognised for their individual merits and sources of personal esteem? We pose these questions now to frame our use of recognition theory to respond to these needs of people with advanced dementia.

In the following sections, we will respond to these questions through 1) discussing the clinical, social and HCI literature on advanced dementia in order to inform discussion of advanced dementia in HCI, 2) introducing recognition theory and what it suggests for advanced dementia and experience-centred design and 3) presenting a conceptual framework that results from the dialogue between ethnographically-informed experience-centred design and recognition theory, which has

been a feature of our work with people with advanced dementia [45, 46]. The framework forms the conceptual and methodological core of the contribution of this article, a means of encouraging and framing design that works with the potential of ECD for advanced dementia to frame a substantive HCI design-led research response to a significant social issue.

Advanced Dementia, the Self and HCI

People with dementia are often discussed as a singular group with a specific set of needs and requirements. However, inclusion in research, in both HCI and other social science fields, has resulted in a more nuanced understanding of the different ways in which dementia progresses at an individual level [25, 85, 88, 90, 105, 106, 147]. The experience of dementia exists along a continuum, and people can experience the symptoms at various stages with different levels of intensity. However, the advanced stages of dementia are very distinct from the early ones, which suggests the possibility that a different set of design considerations and processes may be needed.

Advanced dementia is generally diagnosed using the MMSE (Mini-Mental State Examination), which scores cognitive impairment from 0-30 through a series of questions to assess orientation to time and place, recall, attention, language, repetition, and complex commands such as drawing figures [100]. Anything from 0-9 on the scale is considered severe cognitive impairment and people in the advanced stages of dementia can

sometimes score 0 [2]. Symptoms vary depending on the type of dementia (Alzheimer's [86], Lewy Body [148], vascular [76], frontotemporal lobe [6] and or other more uncommon causes [87]). Advanced dementia is associated with severe memory loss, a 're-occurring need for orientation [25]', confusion, anxiety about their environments and the people around them [147], and sometimes the complete loss of verbal communication skills [106]. For those experiencing dementia in old age, they may also live with multi-morbidities, frailty and increased risk of falling [105]. Yet, within this complex illness, there are also moments of lucidity in which the person demonstrates their ability to reflect, remember, and socially engage [45]. The challenge in advanced dementia care is to respond carefully and sensitively to both the more difficult aspects of dementia and the moments of connection and calm. A focus on the social experiences of advanced dementia begins to address that challenge.

Beyond the cognitive and physical changes, there are often significant social changes in advanced dementia involving a transition into residential care. While this is often to ensure the safety and overall quality of life of the individual, for someone who is disorientated and wary of their environment, [105, 116] the transition to residential care can further remove the person from their sense of self [116]. This may be perpetuated as staff struggle to ensure that their needs as patients are met, with few cues or reminders as to the preferences, personality and previous life-style

of the resident in care [116]. Ethnographic research into the advanced stages of dementia has examined the social behaviours which are typically viewed as confirmation of a loss of selfhood [45], which Kitwood suggests are 'labelling' normal behaviour as symptomatic [80]. Guided by attachment theory, Miesen [104] examined the common experience of parental fixation in the later stages of dementia. Concern for parents was considered as not merely memory loss or disorientation, but as a means of seeking safety and well-being. Framing these occurrences as a deeply rooted need for care and safety rather than symptoms of memory loss, opens up ways we can respond to these kinds of expressions from people with advanced dementia.

To what extent there is a continuation of 'self' in advanced dementia has been questioned, leading to a lack of maintenance of the social identity of the individual [28, 37] . As theorised by many scholars, the need for positive social engagement is crucial to the maintenance of self and social identity [38, 79, 81]. Although there is evidence of persistence of self in advanced dementia [23, 85], memory loss and the confusion it can cause in social settings (e.g. not recognising a family member or responding to a stranger as if they were a family member) means that a sense of fragmentation of self and perceived loss of identity is often enacted more poignantly within close relationships [12, 112]. As spouses and children take on the role of carer, and many decisions

regarding care are considered outside of the autonomous capabilities of the person with advanced dementia, there is a significant shift in the relationship dynamic, one of the key outlets for maintenance of selfhood [57, 112]. Many residents in care find it difficult or refuse to engage in the social activities of the care home, which reduces their opportunities for positive social engagement [25]. As a result of this, social interaction, and one's places in the social world becomes more fractured and unfamiliar. Sabat [123] examined self-manifestation in advanced dementia, clarifying the ways in which we perform, remember and express the self. For the person with advanced dementia, the way the social world responds to the various aspects of self can reaffirm, or erode the self-identity [123]. For example, in a case study of a woman with advanced dementia, Dr. M reported that her social interactions consisted mostly of conversations about dementia, providing little opportunity to express the other facets of self, such as her career as an academic:

'Rather than being confronted constantly with her disabilities in social relationships which confined her to the persona of 'patient', she wanted a 'real relationship' that didn't focus on "Going always to see people to see what's wrong with me". Such a desire is hardly unreasonable. Few of us desire to have relationships with others in which our shortcomings are constantly the main focus of interaction. p.30 [123].'

The social persona of a 'patient' has been strongly associated with people with advanced dementia. As we can see from the testament of Dr. M, a focus on the needs of the 'patient', rather than the full self of the individual, constrains their social identity to one of being 'defective' and 'burdensome' across various societal context such as the family, community and civilian duties [107]. The need to see beyond the persona of the patient and respond positively to their other aspects of the lived experience is an opportunity for design in this context.

Verbal language, which is so closely linked to our ideas of how we communicate our identity, becomes extremely fragmented and limited in advanced dementia [38, 139]. Basting [12] argues that cognition and memory have come to be equated with selfhood in Western culture, and in turn threaten the actualisation of selfhood for the person with advanced dementia [12]. This has led researchers to consider the need for extending selfhood and identity to the body. Kontos [83, 85] extends the personhood approach to care by critically considering the body as a site of selfhood, '*imbued with its own wisdom, intentionality, and purposefulness, separate and distinct from cognition'[85].* Taking an embodied approach to understanding selfhood extends opportunities for the person with advanced dementia to express themselves. While verbalizing memories may be difficult for the person with advanced dementia, their bodily actions and the way they engage with their environments convey

memories of social norms and activities. For example, the following excerpt details the ability to 'show' memories that can no longer be verbalised:

'For instance, when given a bar of soap, washboard and an old shirt, one woman was able to re-enact memories of wash day that she could not describe p.30 [142].'

Honouring embodied selfhood presents an opportunity to not only extend memory and communication but also reconsider how social and political rights translate into mundane care practices. Twigg [142] highlights the body in dementia care as not only a site of physical care, but also as a political site. For example, dressing and personal care are ways of extending and communicating our identity, social status, and personal taste. If the person with advanced dementia can no longer dress themselves, or choose what to wear, there is the potential of further eroding their sense of self, as less careful clothing and personal hygiene practices are viewed as signs of the illness, and elicit a negative response from others [22].

How others respond to the experience of advancing dementia can play a significant role in the way in which people with advanced dementia are viewed and valued within society. In her auto-ethnographic account of her mother's dementia, Janelle Taylor [135] describes how her parents' friends stepped away as her mother's dementia progressed, equating her

inability to remember their names as meaning she was devoid of the ability to care, or engage in social practices of caring. In contrast, Taylor captures her mother's willingness to engage in the social art of conversation, as proof of her ability to care:

'When I tell some small story about something that happened, she murmurs sympathetically. When I express an opinion, she agrees. When we sit together, she attends to my presence, reaches out to me, pats my hand. These communicative practices are, I believe, also practices of caring—my mother cares about smoothness of the back-and-forth flow, takes care to keep it all going, and in doing so she acts in a caring way toward me and other people around her.'p.328 [135]

Taylor's reflection on the dialogical nature of her mother's communication draws attention to her continued care for the flow of conversation and desire to be included in the social world. Often the expressions of people with advanced dementia are labelled as symptoms of the illness rather than a communication of a need to be included and active in their relationships [30, 80]. HCI research into the experience of advanced dementia has the potential to highlight the role of people with advanced dementia as active, engaged participants. However, much HCI design to date is about providing prostheses, aids for memory or communication, in which people with advanced dementia are positioned as users in need of monitoring, assessing and assisting [31, 77, 114]. While

this undoubtedly protects the person with advanced dementia, it does not address their need to maintain and develop their personhood. It may even contribute to the loss of 'self' reported in the social science literature [13, 23, 123].

In contrast, Treadaway, Kenning and colleagues [78, 92, 139, 140] have illuminated the design space for people with advanced dementia by focusing on reciprocal 'in the moment' compassionate design. Their use of crafts, e-textiles and adaptation of the design workshop to ensure that people with advanced dementia are comfortable to express emotion and explore their lived experience, demonstrates how design research and practice can be used to encourage playfulness, tactile engagement with materials and design for positive emotions and memories [138]. Through their co-design process with people with advanced dementia and their carers, Treadaway et al. produced a series of design probes which provide tactile support for the exploration of personhood and positive well-being [46, 93]. The nature of the activities during the design workshops, elicited positive memories and drew on the strengths of the participants. For example, the following activity of making bread together emphasises sensory skills of the people with advanced dementia:

'The feel of the flour in the bowl, the smell of the dough once the water had been added, the warmth experienced during the kneading process all contributed to a feeling of pleasure from the sensory experience. The

kneading process quickly became repetitive and rhythmic as participants stopped chatting and became absorbed in the task. Comments from the participants during the activity highlighted the ways in which the activity stimulated pleasurable memories – some long past. Others commented on how the kneading process was a tacit skill and they were able to continue happily whilst thinking about other things. ([9] P.11)'

Engagement with the tacit, positive and mundane can evoke positive emotion through creative processes and strengthen the relationship between designers and researchers. The intersubjective experience, and how it is co-constructed through social interaction in the design process, is central to our own fieldwork with people with advanced dementia [45, 46]. Through our ethnographic work with people with advanced dementia in residential care, we detailed the subtle yet engaged ways in which people with advanced dementia demonstrate their agency in social interactions [45, 46]. In the following example, we see an interaction between the first author and a resident who needs assistance with her mobility:

'I knocked on her door just as she was leaving the bathroom and she said she'll come down with me now. She's mobile but travels in a wheelchair for safety and comfort. She asked me do I mind if she gets a glass of water before we go. I tell her to take her time, there is no hurry. She pours herself a glass of water and I think about asking does she need me to do it but then

decide not to, as she is clearly able. She offers me a glass, but I tell her I'm fine, I just had my lunch. She says she'll just sit down in her chair to drink it and tells me I should sit down too. I sit on the end of her bed, mostly because I don't want to rush her [45] (p.9).'

Had the researcher taken control of the pace of this interaction, the opportunity for the resident to express and experience their agency may have been missed. Instead we see how the resident engaged in a collaborative process, setting the agenda herself and letting the researcher know what she wanted to do. More crucially, the researcher's attempt to respect the agency of the resident positioned her as an active contributor, shaping both the interaction and their inter-personal engagement. A theoretical unpacking of these types of interactions, in which the actions of the person with advanced dementia are taken as legitimate and consequential in shaping interpersonal relations can illuminate ways to support deliberate actions of the person with dementia in design processes [45].

Research into the experience of advanced dementia highlights both the cognitive and physical changes associated with the illness [106], which are heightened through the quality of social interactions. Considering this insight into the experience of life with advanced dementia and the research on 'self', how can the need for social interactions that are affirming of one's sense of self be more appropriately considered and

supported within the context of dementia care and design? How can people with advanced dementia have opportunities to actively contribute to relationships and wider society, leading to feelings of increased social value? How can these insights become practically embedded within our design processes and outcomes? In order to highlight both the potential of ECD in this space, and the need to view to the person with advanced dementia as active in this process, we will draw on the theory of recognition, a socially and politically oriented approach to social identity formation, as a means of anchoring and extending ECD in this space. Our claim is that a strong appreciation of the mutuality of engagement, which is required to sustain cultural and social identity and diversity – a key need in advanced dementia care – is provided by recognition theory.

Recognition Theory and Experiencing Advanced Dementia Care: A Dialogical Approach

The extracts from Foley et al. [45] and Taylor [135] above illustrate the potential for meaningful dialogue between people with advanced dementia and others. This suggests an alternative approach to designing (and caring) for and with people with advanced dementia that we see as involving the kind of profound recognition between people that is -in practice prosaic- and that keeps meaningful social interaction going and people's senses of them-selves interpersonally real.

"We become full human agents, capable of understanding ourselves, and hence of defining our identity, through our acquisition of rich human languages of expression …, we are introduced to them through interaction with others who matter to us …" ([134]p.32).

Recognising someone involves appreciating that they have certain qualities that you regard positively. As a process, it has both psychological (seeing the qualities) and evaluative characteristics [73]. In contrast, to be misrecognised is failure to receive recognition for these qualities, making it increasingly difficult to have a positive psychological relationship with oneself. In order to combat this misrecognition, those who experience negative social feedback are said to engage in the 'struggle for recognition' [73]. Recognition theory has been used to illuminate the struggle for recognition of many groups, who may experience acts of misrecognition based on aspects of their identity, such as race, gender or disability [51]. The thesis that identity is partly shaped by recognition or misrecognition [134] makes the theory a seminal concept and process in design for advanced dementia. Below we describe the key modes of giving and receiving recognition, with considerations as to how they apply to the experience of advanced dementia.

Mutual recognition (or mutuality) is defined as the 'ideal reciprocal relationship between subjects' [66] and is the central concept of the psychological orientation running through recognition theory. This form

of recognition is expressed through the active process of viewing the 'other' (e.g. the person with advanced dementia) as not only equal to 'self' but essential, in that we come to understand our own intentional behaviour through respecting that of the other. Honneth [64] argues that the self is a 'series of social processes' which is shaped as a result of either receiving recognition or being misrecognised. Honneth draws on the work of social psychologist G.H. Mead [103], using the relationship between mother and child to demonstrate mutual recognition as a basic human drive [64]. The mother and child may not be 'equal' in the sense that the child is dependent on the mother for survival. However both come to realise the other as a social agent, who in turn is capable of forming the social identity of the other [64]. This example has been used to further the Hegelian argument that the struggle for recognition is the 'fundamental struggle' that continues to play out across the lifespan as we interact with, and receive social feedback from others, which in turn constructs our sense of self [73]. For the person with advanced dementia, their care interactions, no matter how well intentioned, may exasperate their struggle for recognition if they are not viewed as an equal agent in the interaction. Failure to view the person with advanced dementia as a source of recognition can also hinder those engaging with them of the opportunity for mutual recognition.

Giving and receiving recognition is a cyclical process, in which both acts are necessary for the other to occur. Most scholars agree that there are four forms of receiving recognition, namely; Elementary Recognition, Respect, Esteem, and through Caring Relationships [73]. The first form, Elementary Recognition, is received through the primary caregiver (e.g. in dementia care) and is essential for the individual to establish a sense of self [65]. Honneth argues that this form of recognition- the interest in socially connecting with another- is present from birth and is 'primary to cognition', in that the need for mutual recognition drives cognitive development ([65], p. 40–44). When considering the experience of a person with advanced dementia, their opportunities to connect socially can re-affirm or deconstruct the various aspects of who they are, and to what extent they are considered a source of recognition for those engaging with them.

If elementary recognition acknowledges the universalism of all people, the second kind of recognition, 'recognition respect', is concerned with the need to respect the 'equal moral standings of persons and their demands' [73]. Failing to consider another as equal in this basic sense is considered a moral injustice, signifying a disturbance of this basic relationship [127]. For the person with advanced dementia, the extent to which their equal moral standing has been questioned has resulted in their experience being under-examined. This highlights the way in which

individuals have different needs that should be recognised, known as the 'recognition of difference' [73]. This recognition of difference combats the grouping effect that occurs when certain minority groups are viewed as a singular unit in their struggle for recognition, when in fact their difference requires recognition rather than deconstruction. Building on this, the third form of receiving recognition is through 'Esteem'. Receiving esteem is based on the individual's or group's particular merits, achievements or contribution to society [134]. Considering the restricted opportunities for people with advanced dementia to take on traditional roles in societal life, we must be mindful of what are deemed 'achievements' and how this may affect individual opportunities to receive recognition. For example, within the structures of care, the person with advanced dementia is often considered a passive recipient of care [107], with little opportunity for them to actively engage and contribute to the development of positive social environments. In Foley's interaction with the resident in care in section 2, recognition in this instance came from both the recognition of the restricted opportunities for the resident to exert her agency, and a desire to respect her acts of agency. Viewing the resident as a co-creator in their dialogue together, offering water, negotiating the pace of the interaction, speaks to the recognition of the resident's contribution and need for esteem. Similarly, active participation of people with advanced

dementia in ECD projects is a moral, social, and perhaps also cognitive achievement to aim for.

Possibly in response to this, the fourth way of receiving recognition- through caring relationships- examines ways to experience recognition for our individual merits, while also receiving unconditional acceptance [64]. This form of recognition is integral to one's sense of self and can provoke individuals and groups to seek further forms of recognition. We see how Taylor's interaction with her mother is rooted in this form of recognition, emphasised by the daughter's (Taylor) appreciation of her mother's 'practices of care' through their dialogue, and the various ways these are communicated. While this form of recognition is psychologically oriented [55], it is important to be aware of the social conditions that can interfere with developing mutuality, for example, forced distance between families due to work commitments, or being separated to receive care, which is often the case with people with advanced dementia. In practice, this may be a challenge for ECD, with the professional distance between designer and participant that many designers are aware of and fight against, further compounded by the cognitive gap between the person with advanced dementia and the designer. Leaning on experience and especially on the dialogics of experience, the inevitability of multiple perspectives and voices, may provide a route to engagement and participation here.

Just as recognition theory examines the importance of achieving recognition, it also highlights the ways in which we may fail to gain recognition, and the ethical implications of this experience [34]. To be misrecognised is to experience disrespect and humiliation. For Honneth, misrecognition results in the sense that one has 'nothing of value to offer…to lack any basis for developing a sense of one's own identity' ([67] p. 16). Considering the restricted opportunities to socially contribute, or be acknowledged for their contribution, people with advanced dementia are vulnerable to both psychological and cultural misrecognition. Through the lens of recognition, theorists have highlighted how certain groups, for example, people of colour, have been misrecognised at a personal and systemic level [51]. Fraser [50] argues that misrecognition is an injustice that has both cultural and economic dimensions, and any form of misrecognition is rooted in 'systemic features of global capitalism' [51]. This is particularly important when we consider the misrecognition of marginalised or vulnerable groups, who have traditionally been given lesser status in society, resulting in cultural disrespect and economic discrimination. The psychological experience of people with advanced dementia is often disrespected through a lack of consideration for this experience in research and policy.

Sensitivity to the key tenets of recognition theory in ECD suggests ways to respond to the experience of advanced dementia through design.

This reciprocal approach to the development of human agency, identity and self, offers hope of design that matters to people with advanced dementia, which may not be available in a purely cognitive or monological model. Throughout the dementia literature, a narrative has emerged of feelings of 'social loss' [13], which is perpetuated by the symptoms of advanced dementia, in which the person is seen as cognitively unreachable, or 'lost' [13]. There is a risk that the person with advanced dementia may be deemed as incapable of mutual recognition, as one cannot be sure that their behaviour is intentional or reciprocal. This lack of recognition suggests that people with advanced dementia are engaged in the struggle for recognition but may be further restricted in this struggle due to a discrediting of their experience. For example, infantailization [70, 124], in which the person with advanced dementia is approached and considered as a child, is often reported in dementia care. This approach restricts the recognition of their lived experience and agency [16]. In our ethnographic work with people with advanced dementia, finding the balance between recognising the person as fully agentic, while also recognising the facets of their illness that they may be unaware of, such as the fact that they can't go home for example, was a key challenge in establishing what the process of recognition involved in this context [45]. While our previous work in this context has presented empirical evidence of the abilities and engagement of people with advanced dementia in

design processes [45, 46, 152], in this paper we set a series of design sensibilities which frame a theoretical contemplation of the experience of advanced dementia with a view to presenting design practices to foster and maintain the social presence of people with advanced dementia. A fuller recognition of the person with advanced dementia will acknowledge their previous versions of self, while also recognising the self of advanced dementia as fully engaged in the process of a struggle for recognition.

Rather than question a person with advanced dementia's ability to give and receive recognition, it may be useful to question our own lack of recognition for people with advanced dementia, and of the ways in which they do demonstrate their ability to recognise others. Taylor [135] questions why other people's willingness to recognise her mother is dependent on her ability to cognitively 'recognise' them in the present, regardless of previous incidences of care, respect and friendship. Applying our understanding of recognition to the experience of advanced dementia can further clarify why relationships, care and research with people with advanced dementia can be challenging. It is also important to question our own need for recognition, and how this shapes the dialogical design practices we engage in. Understanding this, and transcending it to consider the needs of people who can not necessarily give back the care they receive speaks of an approach to recognition that requires nothing in return, but rather is a recognition of the human condition, and our

unconditional need for the 'other' in all stages of our lives. In terms of relationships between designers and people with advanced dementia, it is important to constantly reassess this dynamic, questioning not only what we as designers are bringing to the relationship, but also what we are gaining from this.

In the next section, we return to the questions we asked at the beginning of this paper and discuss some of the practical considerations and reflections required to embed the theory of recognition into experience-centred design with people with advanced dementia, as well as the questions experience-centred design can ask in terms of seeking recognition of the experience of advanced dementia.

Conceptual Framework: Designing for Recognition with People with Advanced Dementia

As we have outlined, the theory of recognition investigates the nature of what it means to be recognised, from broader societal recognition to the personal and intimate recognition that forms the basis of mutually beneficial relationships. Practically underpinning our ethnographic work with recognition theory has further informed our understanding of the experiential aspects of recognition in advanced dementia [45]. Responding to this theory in design practices in HCI can provide guidance for the

types of interactions and care systems we are designing for. If the struggle to be recognised is the 'fundamental struggle', the examination of the experience of advanced dementia through this theoretical lens can clarify the types of social design processes to aim for. In doing this, we do not wish to perpetuate the idea that people with advanced dementia are 'sufferers', but rather to include them within the realm of the universal struggle for recognition [3], as people who are worthy of full recognition through the provision of enriching social environments and resources.

The theory of recognition encompasses many of the sensibilities outlined in ECD [99], giving them philosophical weight, particularly in terms of drawing on the personal and political. In this sense, recognition theory is an ideal to hold our research aims up against, enabling us to ask questions about recognition as a goal of design for advanced dementia and misrecognition as something to be guarded against in processes and outcomes. The theory suggests an approach (designing with recognition) and an outcome (designing to highlight the need for recognition) that could make a difference to the experiences of marginalised and vulnerable people. In the case of advanced dementia, it suggests the need for heightened sensitivity when communicating with participants. With these sensibilities in mind, we present our framework for recognition in ECD with a view to engaging with the practical and practice orientated considerations needed to further the cause for recognition in this context.

Generation of the Design Framework

Three aspects of our experience in designing for care of people with advanced dementia contributed to the development of a design framework: 1) our empirical ethnographic work with people with advanced dementia, 2) our particular appropriation of the theory of recognition, and 3) the existing HCI literature on experience-based approaches to design and dementia. As we engaged in ethnographic work with people with advanced dementia, we concluded that a strong theoretical grounding was needed to both guide our in-situ interactions with people with advanced dementia and to inform our design thinking. The strong intersubjective emphasis in recognition theory, as well as its orientation to social and political selfhood, led to a critical understanding of the person with advanced dementia, seeking recognition through dialogue with those engaged in their care.

Through our ethnographic work with people with advanced dementia [45, 46, 152] we established an understanding of the types of mutually engaged interactions that occur with people with advanced dementia. To aid in the analysis of this work we considered the ideals of recognition against the experiences of people with advanced dementia we had documented. We then examined the existing literature in HCI and dementia, advanced dementia and ECD under the analytic lens of the theory of recognition. We assessed the dementia literature in terms of the

key outlets of recognition, namely: Elementary Recognition, Respect, Esteem and through Caring Relationships [73], focusing particularly on the experiential evidence from research conducted with people with advanced dementia. We questioned what aspects of the theory were apparent in the dementia research, in terms of examples which could be considered recognition in practice, or where recognition theory helped to clarify what kinds of developments were needed in these interactions to achieve full recognition. We also considered the challenges of realizing recognition in this context, and the need to acknowledge certain aspects of advanced dementia, and the current care systems which may appear as barriers to recognition. This resulted in an understanding of the potential to provide support for different opportunities for recognition in this design context, which are reflected in the framework below.

The aim of the design framework is to orient design with and for people with advanced dementia toward those aspects of interaction that signal their abiding sense of self, with a view to embedding them in ECD processes and experientially meaningful outcomes. The four design sensibilities described below were identified in our ethnographic work [45] and other design work in dementia and HCI, [62, 90, 111, 151]. They are intended to guide design practice by heightening sensitivity to elements that could reveal self-in-interaction with people with advanced dementia and/or point toward opportunities for design that would enhance

opportunities for recognising self in future lived experiences of interacting with people with advanced dementia. Conceptually, the four design sensibilities can be considered together as a holistic approach to embedding recognition theory into design practices. In practice however, a heightened awareness of any of them individually or in combination can be productive. Take for example, an interaction from our ethnographic work conveying the communication of the person with advanced dementia. Initially their communication, both embodied and verbal, suggests their confusion and anxiety:

'I brought one lady back from prayers because she was adamant she needed to go to town. She was clearly very anxious, gripping her pants with her hands, rocking back and forward. She kept saying 'they won't know where I am' and I really didn't want to leave her on her own so I said I'd wait with her until 'they' came. I tried to re-direct the conversation to her lovely scarf. She was dressed very well, in a co-ordinated outfit. There was an immediate change about her and she visibly calmed down. She started to run her hands over her scarf, explaining her daughter had got it for her- like all her clothes. I said her daughter must be very stylish and she agreed with me that she was. The nurse came in then and I took her hand to say goodbye, she gave me such a big smile and gripped my hand for a long time. It felt like she was clinging to me for reassurance that we were both here.'

When responding to the communicative actions here, the researcher was able to consider the layers of meaning expressed by the person with advanced dementia. While initially, it was vital to respond to the need for reassurance of safety, finding 'ways in' to meaning, such as the scarf, resulted in a change in the embodied state of the person with dementia, and an expression of care and affection between them and the researcher. Finding opportunities to make meaning together in care homes often requires the researcher to consider the entire interaction as an opportunity for meaningful dialogue, beyond the active 'making' of design work. In this example, while accompanying a resident of the care home to the social space, the researcher has two opportunities for creating moments of personal meaning:

'Before we leave her room I ask if she wants to bring anything from her table. She says she'll bring her phone and a tissue. There's a little toy dog in the tissue box and she feels it, asking me do I like it? She says she's minding it and starts to stroke it. She says her daughter has a dog like this, a Basset Hound. I tell her he's very cute. She gets a tissue from the box and then we head off.'

By ensuring the resident is positioned as an equal partner in this exchange, and taking an opportunity to discuss objects of personal meaning such as the toy dog, we see how moments in which the agency of the person with dementia is expressed and supported are often subtle, but

speak to opportunities to engage in a recognition of the needs and lived experience.

There is an element of critique in emphasising recognition as a salient concept and practice in designing for people with advanced dementia. Its' critical and ethical importance is in the likelihood of absence of recognition or misrecognition of the potential of people with advanced dementia. In many cultures, people with advanced dementia are seen as in the process of losing their cognitive faculties and as increasingly unable to function [12]. Given the importance of recognition for sustaining a person's sense of self, the risk of misrecognition of some categories of people becomes a critical societal and psychological moment. Sustained misrecognition puts generally accepted human rights such as equality and inclusion at risk, doing psychological damage to personhood in the process.

One practical guard against such risks is to find opportunities for recognition and respect of personhood wherever they can be found. Design may be a small part of most people lived experience, but its growing use in the reconfiguration of health and care services [35, 75] makes it an important factor in peoples' experience in hospital and in care when they may not be well. Normalising sensitivity to people's need to be recognised and to experience their own agency would defend against the damage that misrecognition can do to people, especially those whose sense

of self may already be vulnerable. Approaching design as a process of making space for reciprocal interaction between equal, different people [99] who respect each other's agency is a good start.

In presenting our design framework we wish to identify a set of design sensibilities which pragmatically applies the values of recognition through practices seeking to recognise and produce technologies that further highlight the need for recognition in advanced dementia. In order to contextualise the design, we will draw on some of the previous work in HCI which has hints of recognition in practice. We will also use the research on advanced dementia and our fieldwork to clarify the specific needs of people with advanced dementia in this design context. As we demonstrate, existing work in HCI speaks to the some of the values of recognition in terms of 1) being relationship oriented, 2) sensitive consideration of the abilities of people with dementia and 3) designing for connection. In addition, the research outside of HCI into advanced dementia can help illuminate the design context more clearly in terms of the relational and experiential considerations in advanced dementia care, which have implications for the designer/participant interactions in this context. Using the theory of recognition as a guide, we develop the design sensibilities with a view to teasing out the considerations required to design with and for recognition in this space, and the types of outcomes this approach has the potential to develop.

This design framework proposes a series of sensibilities to suggest how designers can craft opportunities for mutual recognition in the design process and the practice of making through:

-Taking the embodied and unique communications of the person with advanced dementia as an opportunity for engaging in dialogical meaning-making.

-Introducing creative design practices within the care home so as to encourage creative, 'in the moment' experiences which foster a sense a belonging.

-Working within a socially complex design context, and adapting and refining design activities in response.

It is intended that these considerations are useful to UX designers, design specialists, and engineers who are interested in the practice of working in advanced dementia in their own design practice. This framework highlights the interconnected sensibilities that identify design processes and outcomes as based in the core values of recognition theory. We present four design sensibilities which together can be considered as an approach to design which reflects the various opportunities, and challenges, in designing with and for recognition in advanced dementia.

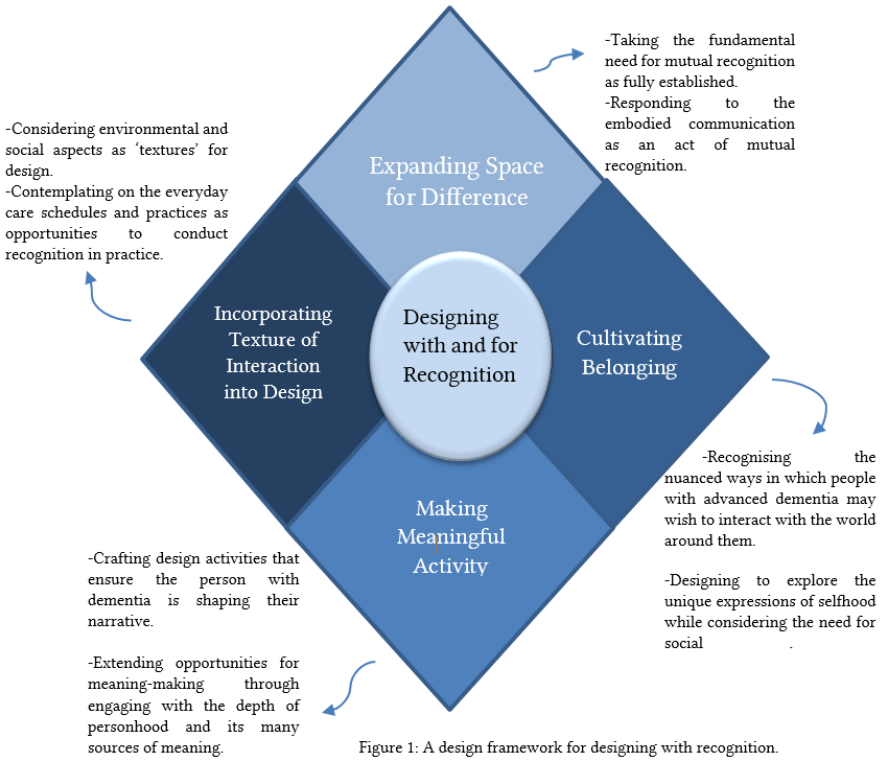


Figure 1: A design framework for designing with recognition.

We do not intend to suggest a practical sequence for designing with and for recognition theory, as the nature of experience in advanced dementia is fluid and ever-changing. Rather this set of sensibilities encompass an approach to design in which designers can return to one or many of the sensibilities as is appropriate at the time. For example, while a design project may start with lots of activities, the person with dementia's needs and preferences may change over the course of the project. Or conversely, design interactions may begin very slowly, with the designer spending time getting to know the person with dementia, their daily patterns and

then introducing design activities in order to expand opportunities for recognition. In the remainder of this section, we unpack the sensibilities presented in the framework to demonstrate how they translate into design practice with and for people with advanced dementia.

Expanding Space for Difference

Taking the design process (and designed artefacts) as an opportunity to promote recognition, the person with advanced dementia should be presumed to be able and entitled to fully participate in the design of their care and of their futures regardless of the ways in which they communicate [107]. This presumption is the starting point when recognition is important in a design process. When communicating with friends, we make sense of their words and actions by assuming that they are meaningfully interacting with us such that what they say or do relates to what we have said or done and vice versa [58]. Without this presumption, no meaningful communication could take place. No matter how distant another person's response seems from our communicative action, the development of shared understanding and mutual recognition can only occur if we assume they are trying to communicate with us, unless there is clear evidence to the contrary [16].

The simple act of presuming that people with advanced dementia may be trying to communicate with others – rather than seeing their

'confusions', 'incoherencies', 'ill-timed laughter or upset' as unreachable cognitive loss [80]– and, like other people, are worthy of the effort that is involved in all communication begins the process of making space by initiating reciprocal interaction and recognition [135].

It is not unusual for designers to work hard to understand the needs and desires of others and respond in design to these needs. We assume that this is going to be challenging but worthy of the effort and, because of that, try all kinds of ways of communicating, from talking about prototypes to telling relatively unconnected stories or making art together to try to find a way in. Designers are used to making space for reciprocal interaction. The challenge is to be sensitive to the agency of people with advanced dementia who may sometimes appear to be lost, treating them as equal agents [16]. A focus on mutual recognition creates opportunities to respond practically to the reported 'social loss' experienced by people with dementia [12]. Designing with people with advanced dementia presents an opportunity in which the respective strengths of all parties, people with advanced dementia, professional and family carers, and designers are recognised and supported to participate. This is not necessarily straightforward to do but, if done, can be dissensual and transformative. In a similar vein to Tim Ingold's [72] argument that anthropology, when seen as a process of learning about cultural practice with and from people (rather than about them) who use what they learn to move forward, is

transformative, so we argue that learning with and from those who take part in the design process can be a co-creative way of moving forward. This will at times change technological imaginaries, including in this case what is socio-technically and culturally possible for people with advanced dementia [99].

There is an example of just such an approach in the ECD projects involving people with dementia, (though not necessarily advanced dementia) which demonstrates the potential of a mutual and relational approach to design in dementia care. Jayne Wallace's extended engagement with Gillian, a person in the early stages of dementia, and John, her husband and main carer, used probes that were designed specifically to get to know Gillian and John and, with them, to explore self and personhood. Wallace et al. [149, 151] describe the design-led enquiry as one of Wallace, Gillian, and John 'making sense of the experience together' (p.2625). Wallace enabled this dialogical engagement in which all three participants recognised each other's perspectives, experience, and values by developing a design process in which it was clear from the start that all three of them decided on and agreed the focus of the project.

In their reflections on this and other projects, Wallace et al. [149] are careful to point out that they are not promoting an alternative methodology to experience-centred design. Rather, a different sensibility to the design methodology and a different way of relating to precepts such

as understanding the user experience and engaging the users in the design process. So also is the case in this paper. The focus on recognition does not imply an alternative to the experience-centred design approach used by Wallace and the other projects we have outlined. Rather a new way of relating to 'knowing' and 'experience' and 'values and feelings' that clearly orients to the co-creation of designed artefacts and co-construction of knowledge that Wallace and colleagues exemplify. One that, for example, is sensitive to the agency of all participants. As we have indicated above and, as Wallace et al. [151] were already clearly sensitive to some years ago, mutual recognition is at the heart of this process:

As relationships are deeply implicated in self, the scope for design of digital technologies to help us construct self, reflect on self and nurture our relationships has a deeper relevance than often credited in HCI. Viewing self as co-constructed and potentially protected by others shows us that in dementia it is not only the self of the person with dementia that is dramatically shifting, but that of the partner/chief-carer also.'' ([151] p. 2624).

While a commitment to establishing a relationship based on trust, and meaningful dialogical engagement is a route to recognition, the advanced stages of dementia are often associated with a change in communication, in which we must further examine the ways dialogical interactions are possible. Dialogical interactions are based on the underlying assumption of

the purposeful intentions of dialogue between individuals, which has partly contributed to a lack of recognition for people with dementia, whose cognitive intentions are often questioned [135]. Take for example an interaction between Carol and Sarah from our ethnographic work, in which their dialogue is based within momentary understanding rather than a shared history or understanding:

"Sit yourself down there", Carol says indicating that I sit beside her. "I will of course", and I pull up a chair. I ask her if she wants to get her nails done. She seems confused by the question so I take her hand and move my fingers over her nails... 'They could do with a paint over' and she doesn't protest so I get the remover and start taking it off. 'This is a lovely room' she says, looking around. She is also taking in the women around her and smiling. Her nails are nearly clean at this stage. 'This is what I like...Perfect Peace'. This makes me smile, what a lovely response. 'What did she say?' the woman beside me asks. So I repeat it. This makes the women around us and the volunteers smile too. I pick up a pink and ask her if she likes that, she nods in approval so I take her hand and start painting. Her hand is gripping mine, which makes it more difficult to paint but I manage. Kate comes back them and gives me a nod as if she's very surprised. 'You're on a winner' she says, 'she'd never let you do that.' She brings out the cakes then that we've made in the morning. 'For me?' Carol asks when she's given one. 'Well you

made them so you deserve one,' I say. 'I did?' She has no recollection of this morning, so I brush it off. 'Is the cake nice?' 'Lovely,' she says" [45].

Rather than further questioning the communicative actions and capabilities of people with advanced dementia, design that is sensitive to the potential for recognition can appreciate the ways in which dialogue plays out in this context and shapes the design space. With a view to listening carefully and acknowledging equally the ways in which the person which advanced dementia listens, we can design artefacts that respond to the dialogical interactions of people with advanced dementia. While the work conducted by Wallace et al. made space for reciprocal interaction, responding practically to advanced dementia in this design space requires a more careful consideration for how we communicate. Designing to support enriched experiences with people with advanced dementia may require an opening up of what is traditionally deemed 'dialogical', to include communications that are embodied [84].

Embodied 'ways of knowing' have been adopted in HCI research as a means of extending concepts of selfhood to include bodily actions and interactions with the physical world as legitimate and worthy of response through interaction design [90, 143]. Paying attention to the embodied actions of people with advanced dementia provides more opportunities to listen, and extends opportunities to engage in this experience [44]. In her ethnography with people with advanced dementia, Kontos captured the

ways in which embodied communication extended their personhood, and opportunities for recognition of each other:

After breakfast Dora was in her wheelchair in a line-up of residents against the wall in the hallway. The resident next to her was crying out, 'nurse, nurse', and then started to weep and repeated the same phrase over and over, 'I want to go home'. Dora reached over and placed her hand gently on top of the resident's forearm. Holding her hand there, she sang Tumbalalayka, a Yiddish lullaby p.834 [83].

In this example, the engagement between the two people with advanced dementia conveys both the need of the person crying out for comfort, and the ability of the other to recognise and attend to this need. We can attend to both these needs in our design processes by ensuring that the person with advanced dementia is positioned as someone engaged in the recognition process, and central to extending the recognition of others. Considering advanced dementia within cultural and communication spheres, the act of listening to the person with advanced dementia, and designing outcomes which encourage active listening, can shift the clinical ideation of people with advanced dementia as being deficit in some sense [81], towards an appreciation for the person expressing their selfhood through social interactions.

Taking an embodied approach to recognition in ECD, sets a course in which researchers can be more open to the ways in which people with

advanced dementia engage in opportunities for mutual recognition. Listening and responding to the embodied communication of people with advanced dementia throughout the research process can better ensure that design processes and outcomes are not based on pre-defined symptomatic management, but rather listening to learn [137] of the experience and creating design outcomes which respond to this, and encourage others to listen - and learn from - the communication of the person with dementia. Mutual recognition in action here is engaging with the embodied tone of expressions such as hand holding, waving or clenching, facial expressions of pleasure or discomfort, and responding with similar non-verbal gestures which ensure the person with advanced dementia feels listened to and comfortable in the design space. Through emphasising and designing for the holistic sensory experience, technology and design can extend dialogical interactions, to include movement, touch, non-verbal communications and facial expressions, thus extending opportunities for recognition in future interactions with those who may need support in their attempts at recognition.

Making Meaningful Activity

One of the strengths of recognition theory is that is encapsulates a holistic view of the outlets in which recognition is possible, and the consequences of misrecognition if we are unsupported in gaining respect

and esteem. We gain recognition through acknowledgement of our various accomplishments and achievements [73], but these can often be forgotten, or unsupported within care practices. In the case of advanced dementia, gaining recognition for one's past achievements, and providing opportunities to continue to demonstrate their abilities are crucial aspects of care that can often be overlooked or underfunded [123]. Meaningful activity, can be viewed as acts of recognition, making meaning together through the communicative process of activities which speak to the achievements and abilities of the person with advanced dementia.

According to Atul Gawande, who has also been influential in forming our approach to designing in advanced dementia, what makes life meaningful is the autonomy "to shape our lives in ways consistent with our character and loyalties" ([56] p.140-141). Recognising this and having a sense of what it means in practice, is a key sensibility in our research framework. Activities are ways of expressing our inner lives in concrete ways. For the person with advanced dementia, activities can provide a platform to communicate their maintenance of self but require practical support in the provision of time, space and resource as well as psychological support in which the person with advanced dementia is positioned as agentic in their actions. Methods of ECD are well suited to explore the meaning behind activities. The nature of examining and responding to the experience of our participants through dialogically

constructed design is an act of making meaning, both physically and psychologically.

Gawande has a very interesting way of unpacking autonomy and meaningfulness in terms of appreciating that people write the stories that make their lives, and particular moments and decision in their lives, meaning-full. Meaningfulness is shaped by our desire "to retain the autonomy–the freedom–to be the authors of our lives" ([56] p.140). And this is because, "life is meaningful because it is a story. A story has a sense of a whole, and its arc is determined by the significant moments, the ones where something happens (p.238)''. Our personal stories, the 'life' we have constructed for ourselves, matter to us. Interventions that cut against this arc are likely to feel uncomfortable or wrong and to unsettle.

The term 'meaningful activity' and what this encapsulates requires careful consideration and exploration, particularly in a context in which people have lost some control of their daily schedules and are restricted to the resources, meals, visiting hours, and staff demands that scaffold life in a care home [45]. Methods of ECD can aid in exploring and designing for meaningful activity, which requires careful consideration of both the interests and capabilities of people with advanced dementia. It is through this dialogical co-creation of meaning that the design activity becomes a source of mutual recognition. As a researcher working towards recognition, ensuring that the participants define what has meaning in

terms of the content and function of a design response, is a way to engage in mutual recognition and create space for meaningful activities through design responses.

The nature of 'activity' and what this means in the design context can also provide opportunities for recognition of the unique contribution of the person with dementia. The process of supporting design activities can foster and support acts of recognition related to esteem and respect in regard to our accomplishments and contributions [73]. Often people with advanced dementia are excluded from much, if not all of the design process, or presented with a finished prototype for deployment purposes [129]. However, the inclusion of the voices of people with advanced dementia is possible at all phases of the design process, in which activities employed by the designers can become opportunities for recognition through collaboration. Branco's approach to participation and 'open design' scaffolds the design activities in a way that allows the person with dementia to engage in a level of activity that they feel comfortable with, without over-compensating or restricting their role in the design process [17]. Through presenting the families with design probes which could be completed and used in whichever ways they saw fit, the design considerations were based on the use of the prototype, in which making together and learning from each other was the goal of the activity. The personalisation of the board games and the nature of the tasks, such as

solving puzzles together and sharing stories of their family history, provided opportunities for collaboration in which the family members and designers could recognise the unique contribution of each individual in completing and using the design probes [17].

To extend this type of activity to advanced dementia, further exploration and commitment to recognising the abilities of the person with advanced dementia is needed. Sabat explored the nature of selfhood in advanced dementia with Dr. M [123], in which she described her frustration at being seen and interacted with as a patient:

The dispositions, the passions, the inclinations, the sense of duty which gave rise to her career as an academic in the first place, are still very much alive within her even though she is moderately to severely afflicted with AD. She wants desperately to be seen as herself – and in this sense, 'herself' is the social persona of 'academic, intellectual, professor, astute, incisive thinker' (p.32).

In this context, DR. M wasn't being recognised for her various achievements and social contribution. While those around her were recognising her needs as a patient, her previous sources of recognition, which held more meaning to her, were being misrecognised. Design processes which encourage people with advanced dementia, and those around them, to engage in meaningful activities which recognise the various aspects of their selfhood, can encourage a more rounded

appreciation for the person with advanced dementia for both previous and present acts of recognition. Designers who take this approach can draw out past experiences, not to merely reminiscence, but as the basis of creating new experiences, and approaching the individual as a wealth of knowledge in their own lives. In the following example from our field work, the first author engages with Jim on the topic of his home town:

I bring him in a map of the county where he's from, and some pictures of the village he lived in that I found online. In Cork, we are about 6 hours away from where he lived but using the map I ask him about some of the towns that were close by to him. 'I'll tell you where that is now…' he says, gesturing out the window. 'You go down the road there, take a left, and keep going on the road for about five miles.' He is about 300kms off, but he was very confident in his directions, and I don't correct him. Maybe these pictures have brought him somewhere else in his mind, and he seems in control there, so I don't want to undermine this. He locates all the buildings of this village for me as if they're just outside, and maybe he is communicating how psychologically close they are to him.

In this example, the use of photographs and maps creates a clearer sense-making process between the participant and researcher. Recognition in this instance comes from the participant defining the meaning of the

activity, supported and legitimatised by the open approach of the researcher. Emphasising the mutual nature of this process, of making meaning together, can produce moments of recognition in which the person with advanced dementia is an active, and central part of this process. Embedding recognition into the design process here involves considering the transient nature of communication and activity for the person with advanced dementia and the need to recognise their future expressions of selfhood as further opportunities for recognition.

Designing for and with people with advanced dementia challenges further our assumptions of the role of the user in design [144]. Making with, learning from, and responding to people with advanced dementia in a way that is sensitive to their needs, but acknowledges their agentive role in the collaborative interactions, can further our understanding of what participation in design means, and how it is pragmatically and ethically carried out in this setting [72]. In terms of recognition, viewing the other as a source of meaning, who shapes and contributes to the meaning-making process through collaborative activities, creates a sense of recognition, highlighting the need for the 'other' in co-creating and understanding of our own sense of self in this context. Designing by making together is not only an important step in terms of recognition in practice, but stretches the boundaries of what design does in this context, and what participation in design practice encompasses.

Cultivating Belonging

The critical and ethical aspects of belonging relate to recognition of difference. It often plays out in the contemporary critical theory literature, including Fraser's critique of Honneth's approach to recognition [50], in terms of cultural and identity differences; specifically, the rights of cultural minorities to recognition, in short to belong "as full partners in social interaction" ([49], p.113). This is a good way to think about belonging with respect to people with advanced dementia too and design processes intended to engage the person with advanced dementia. The critical sensibility is to their need and right to be recognised as belonging to the community and society in which they live and incorporating their difference into this exchange. This is increasingly important in the context of many Western states, that are worrying about and trying to come up with ways of 'dealing with' the growing problem of dementia [38]. In many cases, the response has been institutionalised care, facilitated by medical and communication technologies [114]. Whether in care homes or in their home communities, a challenge for recognition in design for advanced dementia is to be responsive to people's need to belong, while acknowledging that 'belonging' can mean something different for each individual.

As we discussed before, a lack of social resources may cause forced distance between family members and friends, who are often the

predominant source of recognition [51]. In order to create a sense of belonging, in which people with advanced dementia feel connected and recognised, it is worth considering how social engagement is structured within the care environment. In their work, Morrissey et al. [108] highlights that physical proximity within the care context does not equate to connection, and people with dementia should be supported in establishing a sense of belonging with each other [111]. 'Swaytheband' is an example of how ECD can encourage and foster a sense of belonging, as the design was based on the culturally shared interests (such as music) of the participants, with the design outcomes encouraging embodied, social connections. Viewed from the perspective of recognition, this project highlights the nature of belonging in society and the need to encourage and support belonging which moves away from traditional concepts of 'contribution', such as working, and emphasising social engagement and enjoyment, as a legitimate social contribution [49]. McCarthy and Wright [98] emphasis the potential of design to advance the quality of people's experience of both the personal and political systems in which they live, emphasising the moral implications of inclusion:

"It can and should attempt to impact people's lived experience in ways that are socially, politically, and personally meaningful. Viewed in this way, it is a

growth and development of the moral and ethical impulse of PD and user-centered design.'' ([26] p.9).

The emphasis on ethical and moral motivations for inclusivity are echoed within recognition theory [121, 127], calling on societies to reflect and consider the recognition of individuals and groups as a moral right. Drawing together the ethical considerations of recognition theory and the civic inclusivity envisaged through ECD can create space to further question what we owe individuals with advanced dementia in a just and moral society, and how design can respond and aid in this struggle for recognition. Recognition theory has highlighted the ways recognition unfolds at varying levels, from the interpersonal to the systemic. By adopting this theory to frame the experience of advanced dementia, we can draw together the need for mutuality through dialogical interactions, and the ethical and political implications of designing for recognition in this space. This wide examination of the systems and supports needed to ensure recognition takes places, allows for a critical exploration of both dementia care, and the need for inclusive and universal design. As we can see in Morrissey's example, designing for civic inclusion, or recognition for one's social contribution, does not require an overtly civic activity, but rather comes from the sensibility that people with dementia have the right to belong and engage in their social world, in whichever way they feel has meaning. Janelle Taylor [135] details the attempts at belonging her mother

makes, and the enjoyment she appears to get from the simple gestures of recognition:

In a cafe, as we share a scone, Mom and I make what passes for conversation. I've learned to ask only the sort of question that does not require any specific information to answer: "So, things going okay with you these days?" "How's my favourite Mom doing, you doing alright?" I tell her funny little stories about my kids. Sometimes we leaf through a magazine, looking at the pictures and commenting on them. Sometimes we look out the window, and I make general observations that require no specific response. "Looks like spring is coming, look at those leaves coming out on the trees." "Sure are a lot of people out walking around today!" "That guy's hair is really curly." With each exchange Mom smiles at me, beaming affectionately in that familiar, slightly conspiratorial way, as if we are both in on the same joke p.328 [135].

The act of belonging in this account is socially constructed between Taylor and her mother. The art of their conversation, the back and forth, may be pared back, but speaks to their need and ability to connect with each other. Belonging in this context, requires design processes to support the need to belong, and the ability -and right- of people with advanced dementia to belong. When considering the right to belong, and what that means and feels like within the care home environment, it is helpful to apply the critical aspects of recognition, such as Frasers [50], to avoid

designing for 'forced belonging' or over-emphasised similarities within the group of people with advanced dementia. In the struggle for recognition, individuals with similar attributes can be 'grouped' together somewhat superficially in a bid to receive recognition, for example based on race, gender or socio-economic status. In terms of the generalisation of people with dementia, this grouping is both physical (sharing intimate spaces in the care home) and theoretical, through the ways we discuss and plan dementia care within research and policy. The experience of advanced dementia is as varied and multi-faceted as the people who experience the illness. The fact that all cases of dementia are often spoke of as the one experience within research and policy reflects this sentiment of misrecognition, in which people experiencing extremely complex conditions are considered as a singular unit. The role of ECD in this context can highlight the vastness in experience of people with advanced dementia. In designing for belonging, we must first design for difference. By this, we mean considering the individual, and their environment as an opportunity to make connections, express and celebrate their difference, and create space for people to come together in a way that is meaningful for them, while not losing their sense of identity through superficial belonging and physical proximity.

That people with advanced dementia have the right to belong, no matter how they communicate or engage in their social environments should be a

fundamental principle in shaping our care and design practices. However, it is also important to recognise the ways in which people with advanced dementia also foster belonging. The subtle acts of caring for the other, of showing concern, is not lost in advanced dementia [45]. In our design practices, we can highlight the abilities of people with advanced dementia to belong and create space in which others belong through designing for mutual engagement and focusing on the contribution of the person with advanced dementia. In the examples above, we see how Taylors mother was in tune with the needs of those around her, and willing to take part in the social construction of belonging and connecting. Bringing this sentiment into designing for advanced dementia may involve a close consideration of the actions of people with advanced dementia and designing responses which elevate and support their ways of cultivating belonging. This may involve designing for group involvement or technologies which provide opportunities for personally meaningful engagement and can be further refined and developed over time. It is through the recognition of the contribution of people with advanced dementia, and bringing this forward through design practice, that the risk of grouping and misrecognition can be overcome.

Incorporating Texture of Interaction into Design

Many of the projects we have described in this paper contemplate the sensitivities of working with people with dementia, and we wish to highlight them as invaluable examples of how we can further recognise people with advanced dementia through inclusion in the design process and engagement in mutual recognition [90, 111, 151]. In order for this to occur, a number of considerations of the texture of the design process and outcomes are necessary. By texture here, we mean the felt experience of the social interaction entailed throughout the design process or ultimately the felt experience of social interaction with and through any artefacts designed in a project. The texture, and felt experience, of social interaction with a person with advanced dementia is likely to be quite different to interactions with many other people. While that is true in general, one's experience of interacting with any person A is likely to be quite different to my interaction with any person B because of individual differences, interpersonal histories etc., texture of interaction with a person with advanced dementia requires specific attention here for people who may engage in design projects with them in regard to the timing and fluidity of our interactions.

Guidance from The Alzheimer's Society and other similar organisations, as well as a number of academic papers identify patterns that are discernible among populations of people in the later stages of

dementia [105, 106]. People with advanced dementia may have limited speech and therefore are unable to respond verbally to what is said to them. They may not understand what is being said to them, they may repeat a small number of words over and over, or may use words in ways that don't seem to make sense. Above we described the work of responding to others on the basis of a presumption that their previous utterance is an effort to communicate and is central to recognition in this context. So it is with people with advanced dementia. In the following example from our field work, we see how the resident with advanced dementia communicated her friendliness, as well as her caring ability, albeit in a contemporary manner:

'Are you my friend?' Diane asks me as she takes my hand. I assure her that I am as we walk back to her room. It's filled with dolls and teddies, which she minds as if they were her children. Speaking with staff, they explain that they ensure that the dolls are treated as children, bathing them and feeding them. This calms Diane greatly and extends to her respect.

The nature of communication between the researcher and person with advanced dementia can vary from warm, comforting conversations and bodily reactions, such as hand holding and laughter as we see above, but also expressions of frustration, anger and grief through shouting, tears and silence. The recognition of difference is also apparent in this example. The person with advanced dementia expressed her care through looking

after dolls. In responding to this with respect, the staff supported this expression of care. To work together in a design project, as one would with any other participant, the challenge is to try to identify what the person with advanced dementia is trying to get across to us, especially their feelings, and to respond accordingly. If the person seems happy and chatty, smiling with them and talking to them may be a good response. When verbal interaction is difficult, more attention has to be paid to body language, facial gestures, and so on.

Taylor describes the shift that occurred in their relationship when she let her mother set the pace of their interactions. In doing so, she slowed down and came to appreciate momentary life as it presented itself:

'A few days ago we spent a half hour looking out my mother's bedroom window to where a woman sat on the sidewalk outside, next to her baby in its stroller, blowing bubbles. The breeze caught the bubbles and carried them up, whirling and dancing, catching the afternoon light in brief rainbow flashes. It was the kind of thing I would not normally sit and watch—and it was beautiful. A young mother I do not know created a fleeting moment of wonder, and my own aging and impaired mother helped me to see it [135] (p.327).'

In terms of recognition, Taylor's mother contributed to the creation of this moment of calm and beauty that could easily have been lost had Taylor set the agenda of the interaction. Ensuring that the researcher has

the awareness, and willingness to engage in this sort of communication, creates an opportunity for mutual recognition, in which the person with advanced dementia is really listened to, co-creating, and leading the nature of the interaction. This involves respectfully considering the daily routines of care, allowing the person with dementia to set the pace of the interactions, acknowledging their needs beyond that of a research participant, and being willing to allow these considerations to set the tone of the design process. This may involve a 'slowing-down' in terms of the design process, but also allows for time to reflect and consider the whole experience of people with advanced dementia.

Buse and Twigg [22] have closely examined the interactions of care in advanced dementia, particularly focusing on dressing and the multiple layers of meaning created within the act of bathing, picking out clothing and dressing. Consider the following example of a care worker describing her approach to dressing in advanced dementia:

... if you imagine you're getting someone dressed and you can say to them, "Lean forward. Can you put your arm through there and arm through there and just pull it down?" it's a lot quicker than saying to someone, "I've got to put your top on, can you lean forward?" You know; "Ethel, I need to bring your arm through, can you relax your arm, love? Can I bring it through?" and then it's very slow ... and you have to be reassuring and calm.' [22] p.343.

This example shows the complexity of a seemingly simple task, which requires a sensitivity to the needs of the person with advanced dementia in terms of their privacy, choice of clothing, comfort and safety. In this simple interaction, they are layers of identity to recognise and maintain. By taking these 'everyday practices' and examining the layers of meaning within the interactions, ECD can provide an opportunity to creatively consider these practices under the lens of recognition. Examining these practices as potential acts of recognition and designing to respond to the practices which may lack recognition, will ensure a more thoughtful interaction process, guiding the care interactions which can take up the majority of time, such as bathing, clothing and feeding.

Considering the pace and tone of our design outcomes, and the effect they will have on the social environment for the participants can also encourage others to consider more deeply the lived experience of people with advanced dementia. Making recognition the aim of design outcomes speaks to incorporating the struggle for recognition into the underlying ethical values of the texture of ECD, while also encouraging the designer to be aware of the context of the design space. Barry et al., [10] discuss the practical, everyday ethics of design as the 'responsibility of all designers, in a continuing process of reflection on what it means to be value sensitive in design' (p.2710). In the case of people with advanced dementia, being 'value sensitive' incorporates the day-to-day

considerations which we have previously discussed, but also the framing of appropriate design practices within the context of care. For example, designers have the potential to emphasise and produce artefacts of aesthetical beauty and enchantment, but must also be mindful of existing resources, staff workload and functionality within the care environment. An in-depth understanding of the environment, such as a care home, can allow for design and technology to enrich existing practices, and understand the potential ways in which the experience can be recognised and improved in this setting. In terms of recognition in this design context, working with multiple stakeholders in the ecology of care, such as carers, designers and volunteers can further reconfigure design participation, creating an opportunity for mutual recognition amongst people with advanced dementia and those involved in caring with them. While the person with advanced dementia and their particular needs are central to shaping acts of recognition in our design practices, recognising the distinct needs of those engaging in recognition, such as carers, is also fundamental to ensuring recognition takes place. In this sense, creating design processes and contexts which are inclusive and support opportunities to engage in meaningful interactions, can serve a useful purpose within the care environment, which can be mutually and pragmatically meaningful to all those invested in the care of people with advanced dementia.

In ensuring that the person with advanced dementia sets the tone and pace of the design process and finds meaning and belonging in the activities and outcomes, the research is also creating space and time to reflect more richly on the experience of advanced dementia. Designing to enrich, but also to reflect, can raise further questions of the experience of advanced dementia, and how we best respond to our ethical obligation to create more inclusive design processes and outputs. The reflections and contemplations on this experience through methods of ECD can contribute to the broader narrative within HCI that the experience of advanced dementia is worthy of engagement, that the 'user' in the environment is capable and deserving of enriching experiences and technologies. Carrying this sentiment through our research practices moves us forward into a space in which inclusive design is actualised, and recognition is achievable. Incorporating these various textures of interactions into our early engagements with people with advanced dementia allows for a design process and ultimate outcome which considers these interactions as central to meaningful engagement and can encourage others, such as carers and family members, to take similar approaches to their own care interactions.

Our research framework has outlined the manner in which recognition theory can stretch the understanding of the lived experience of people with advanced dementia through design processes. The existing

projects in HCI which have included people in the early stages dementia have outlined some of the opportunities for creative meaning-making process as an avenue for recognition. The additional considerations from research with people with advanced dementia, held against the ideals of recognition theory creates a clearer outline of the types of design processes we should aim for in a bid to create moments and processes of recognition in this sensitive context.

Conclusion

The move towards experiential design practices in HCI creates more socially enriching design processes and outputs in which we are listening to and learning from voices of those traditionally excluded in research and design [120]. The inclusion and contemplation of the experience of advanced dementia requires a reflection on what we consider participation in HCI, and how the 'user' is positioned within this context [7]. As we have discussed, the experience of advanced dementia presents serious considerations about how we as designers create inclusive, sensitive design spaces. Finding the balance between honoring personhood, and acknowledging challenges in communication and relationship sustainability is a significant step in ensuring this experience can be fully explored and enriched through design. A focus on the relational, dialogical nature of interaction is a key starting point.

In this paper, we introduced the theory of recognition as a framework of sensibilities through which we can (i) better understand and support the social needs of people living with advanced dementia, and (ii) extend the potential of ECD which has already been extensively used in aesthetically-oriented, health-related, and community development HCI projects [26, 98, 136, 157], into areas such as advanced dementia where experience can be very difficult to access and the relationship between felt experience and remembering is extremely complex. We propose that a strong appreciation of the mutuality of engagement with people with advanced dementia is an important step in reconfiguring their social presence and contribution in design. We further clarified the fundamental needs of people with advanced dementia, acknowledging that a focus on the illness itself may lead to a disregard for the fundamental need to maintain a sense of self through social relationships. Further still, recognition theory emphasises our ethical obligation to the 'other', requiring design practices and artefacts which enable the other to experience themselves more fully, and promote and encourage mutuality within the ecology of care. A theoretical and methodological framework which expands from the intersubjective to the politics of exclusion can help overcome the ethical gatekeeping [153] that prevents people with advanced dementia being included in design processes. Recognition theory shifts the focus of design for advanced dementia by mutualizing the social

obligations to recognise the relationships that develop between designers and participants. Through emphasising the importance of mutuality, we can better provide design spaces that respond to the unique contribution of people with advanced dementia in our social world, with an awareness of the various ways in which individuals may seek to be recognised. In this sense, the strong emphasis on dialogical responsive design in ECD can be further enhanced through extending the sense of embodied dialogue and the political undertones of our intentional design responses as a means of shaping a rights-based, practical response to the needs of people with advanced dementia.

Our design framework offers a number of sensibilities for researchers in this design process. As we have discussed, many existing projects with people with dementia speak to the need for supporting personhood, increasing a sense of belonging and being a part of the social world [17, 53, 91, 111, 151]. Our framework furthers this critical approach in HCI and dementia research and suggests the practical threads of recognition we can weave into our design practices in order to support mutuality and respond to the struggle for recognition for people with advanced dementia. We respond to the call for a more critical understanding of dementia in HCI research [90, 96, 111, 138] by presenting the experience of advanced dementia with the intention to provide scope for the participation that is possible in this context.

Taking the practice orientated use of recognition theory presented in this framework suggests a way of communicating and designing with people with advanced dementia that positions them in the process of giving and receiving recognition. Starting with the assumption that people with advanced dementia are able and entitled to communicate their need for recognition can result in an opening up of opportunities to be recognised. Acknowledging the various outlets in which people with advanced dementia communicate their needs, and honoring the time it may take to do so, is another key 'way in' to engaging in the process of recognition. In order to acknowledge the role of people with advanced dementia in this mutual engagement, the designer needs to ensure the person with advanced dementia sets the tone and timing of the interaction, is invited to engage in activities that are meaningful to them, and senses that the design space is a place where their expressed emotions are respected and responded to. Creating design processes in which mutuality is central to the design interactions can create outlets for other forms of recognition, in which esteem and respect [73] are extended more fully to the person with advanced dementia. Crafting these opportunities for recognition may be seem mundane at times, but in the back and forth of conversation [135], the sharing of creative ideas [138] and the extension of respect to the other [45], we build the basis of recognition. In addition to the importance of mutuality, through these everyday design practices, we

can engage more critically in the political and social elements of the struggle for recognition, through the creation of inclusive environments, in which the underlying power dynamics are examined and carefully navigated [49]. For the designer, this involves a sharing of decision-making, a care for the welfare of the participate, and a realization that the only route to recognition for both designer and participant is the acknowledgement of the fundamental need for each other. Designing for and with recognition also creates opportunities for designing for difference, in which the experience of advanced dementia is given a depth of understanding, allowing for a multitude of experiences to be recognised and designed for. Taking the considerations of what it means to be recognised into our design spaces sets a course of actions in which the agency of the person with advanced dementia is respected, and their particular needs in terms of recognition are responded to, both intersubjectively and politically.

Designing for and with the sensibilities of recognition in the context of advanced dementia can ensure that this experience is included within the wider cultural and nuanced understandings of what it means to live with dementia and the need to see beyond symptom management and monitoring in technology and design, towards a politically and ethically motivated design space. By engaging in experiential methods with people with advanced dementia, future design research can challenge societal

concepts of what has traditionally been considered worthy of recognition and counteract the historical exclusion of people with advanced dementia in research, and Western society at large. Designing to enrich relationships and ensure that the person with advanced dementia is viewed as fully deserving, (and capable of giving) recognition creates opportunities for socially engaged, politically sensitive dementia care and design. Designing with others invested in recognising the needs of people with advanced dementia, such as carers, and working to ensure greater recognition for their needs in this process is an avenue through which designers can further extend recognition in this context.

HCI and methods of ECD are well positioned to examine the richness of the intersubjective experience, while examining our ethical obligation to ensure people are fully recognised at a subjective and systematic level. In this paper, we introduced the theory of recognition as a means of more closely examining the fundamental need to be recognised, and the potential of design to examine how this is possible for people with advanced dementia. In doing so, we wish to examine more broadly how to extend inclusive design practices, while committing to honoring the fundamental needs of the other to belong and engage positively in their social world. Approaching the design space as an opportunity to give and receive recognition, we can create more sensitive and meaningful design

outcomes, in which enriching the experience of advanced dementia is central to our design process and outcomes.

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Chapter 3: Methodology

As outlined in chapter 2, an ECD process informed by recognition theory requires an approach to design which aims to enrich the intersubjective process, in which the person with dementia is active in the validation of the self-identity of those engaging with them, and in turn the maintenance of their own selfhood. Like other contemporary researchers adopting recognition theory in their work [51, 54] the theoretical underpinnings of recognition theory have informed the philosophical orientation of this thesis [73]. As the act of recognition is a socially-realised phenomenon, a social constructionist approach to data collection and analysis was chosen to understand the construction of recognition in practice, and the role of design in supporting socially realised acts of recognition [21]. Designing to support recognition in advanced dementia presents certain challenges for both design processes and outcomes. If recognition is the aim, a design approach which considers the person with dementia as agentic is crucial. Furthering this, the researchers' role in the process of mutual recognition is paramount, in which they consider all emotional, creative and everyday interactions as holding potential for creating moments of recognition. As discussed in the conceptual framework of chapter 2, the experience of advanced dementia requires careful consideration of what it means to recognise the person with dementia, as we must consider their need for

belonging and agency, but equally acknowledge the context in which they live (the care home) and their needs as patients, some of which they may be unaware of. In order to understand both the potential and realisation of recognition in the context of dementia and design, I adopted a number of methodological approaches within the long-term design ethnography. As outlined in chapters 4, 5, and 6, this project had three phases; an initial participant-observer ethnography, a student co-design project and a design intervention project. Presenting this work as a series of HCI papers resulted in a somewhat concise method section in each paper, which did not allow for a full discussion of the methodological approaches that I present here. While each phase and subsequent paper adopted various core methods, I took a methodological approach throughout, which aimed to examine and support mutual recognition with and for people with dementia. This required a careful examination of the relational interactions, with a view to supporting these moments of recognition further through supportive and generative design projects. In the following chapter I discuss the methodological principles I followed within ethnography, experience-centred design and thematic analysis. I also describe the setting of Oakfield House, the participants, data collection and ethics. As I outline, the methodology allowed for an examination of recognition in practice, but also required a highly reflective and emotionally engaged design process throughout as part of my role in the

process. To give a sense of the intersubjective work involved as part of this research, I present a reflective viewpoint at the end of this chapter, which frames my learning and positioning throughout the project and the process of mutual recognition with the participants.

Design Ethnography

Ethnography involves the study of people's everyday lives in a situated context, with a view to understanding action and intentions as they occur [59]. Usually taking an open exploratory approach to data collection, the researcher observes and engages in the natural habitats of their participants, documenting their observations through a reflective practice in which they are aware of their interpretative lens as a relative 'outsider' and the impact this may have on data collection and analysis [4]. Ethnographers are encouraged to capture the experience as it occurs, with a view to generating data and findings which produce a highly contextual and reflective accounts of the field [42]. More specifically, this thesis engaged in a design ethnography[29, 125] , which upholds the methodological practices of the traditional ethnography, but seeks to critically engage with the elements of everyday practices which are 'important and relevant specifically for the conception, design and development of new products and services '[125].

Ethnographies in dementia care have illuminated our understanding of the rich intersubjective lives of people with dementia in care. My approach was informed by many ethnographers in the field, whose interactions and reflections on the experience of dementia convey a complex, challenging but thoroughly human experience [53, 83, 104, 108]. For example, the work of Kontos [83] highlights the use of embodied communication to maintain and extend selfhood, while Miesen examines the phenomenon of parental fixation, presenting it as an expression of the need for comfort and care [104]. These ethnographies encourage us to re-examine our understanding of dementia to better respond to the expressions of selfhood. Within HCI, design ethnographies have demonstrated the importance of focusing on experience, and the ways in which technologies can further mediate meaningful interactions. Morrissey's approach examined the role of crafts, music and movement as a means of socially engaging [108]. From her initial observations, she considered the potential of design to enrich these social practices further, based on an embedded understanding of the context for design and the experience of the participants. Similarly, Galvin's approach to understanding the complexity of the carer-cared for relationship dynamic allowed for a sensitive re-configuration of these roles through design [53]. Building on this approach, the need for an embedded understanding of the context allowed for both a trust in the design process from the perspective

of the residents and staff, as well as a pragmatic understanding of the appropriate ways to introduce and support the use of technologies.

The initial ethnographic approach sought to understand, interact with and support the experiences of the residents, with a view to understanding what was meaningful to them, and the potential of designing with recognition in mind to further support meaningful social experiences. At first, I took a 'participant-observer' role in the care home, essentially continuing with the types of activities I did as a volunteer but working more closely with the residents who were experiencing advanced dementia. The participant-observer role in ethnography requires the researcher to become engaged and active in the field as a member of the community [42] while taking notes, examining and reflecting on their experiences as a means of data collection. Ingold [72] describes the nature of this form of data collection as thoroughly embedded in the process in which it is trying to understand:

'For participant observation is absolutely not a technique of data collection. Quite to the contrary, it is enshrined in an ontological commitment that renders the very idea of data collection unthinkable. This commitment, by no means confined to anthropology, lies in the recognition that we owe our very being to the world we seek to know. Participant Observation is a way of knowing from the inside.' [72]

Taking this approach to learning from the participants, and engaging in recognition with them, required careful considerations of the positioning of myself as the researcher, and the people with dementia I was engaging with. The positioning of the person with dementia as an agentic, engaged and respected participant is central to the methodology of this research. Agency in this sense, is acknowledging the intentional and deliberate behaviours of others, in which 'the subjective self becomes a social self' [20]. That people with dementia have agency is a relatively new channel of thought [16], despite the fact that Kitwood considers agency fundamental to well-being and personhood [79]. Boyle argues that while the traditional concepts of agency are contested in dementia, people with dementia demonstrate creative capacity for agency through purposeful action and emotion. Throughout my fieldwork, and latterly informed by the fundamental importance of recognition as discussed in the previous chapter, I considered the agency of the person with dementia as a concept to be respected, understood and supported. Rather than considering the person with dementia as a passive recipient of care, I came to understand the ways in which their interactions shaped and contributed, not only to their own care, but to the care and well-being of those around them. This concept of positioning the person with dementia as central to their own care interactions was further cemented through the work of Mol [107], who calls for an acknowledgement of the various

contributions from social actors, particularly the 'patient' in ensuring quality care is delivered. While Mol uses people with diabetes as her example, people with dementia are often further removed from their care practices and seen to oppose or challenge the well-intentioned attempts to ensure they are safe and cared for. Taking the position that the person with dementia is invested in their own well-being requires an appropriate response to the behaviours that have been deemed 'challenging' [131] such as wandering, attempting to leave the care home, speaking about deceased family members as if they were alive and being upset or agitated. Rather than seeing these behaviours as symptomatic, I tried to respond to the underlying need for recognition, to listen and to make the space comfortable and safe for the person with dementia. Responding to these behaviours as emotional and creative expressions of agency [16] resulted in further opportunities for examining and reflecting on the process of mutual recognition [64] in this context, as while communication may be fractured, there is an acknowledgement of the intention to become a social self through this communicative behaviour. As I discuss in Chapter 4, this approach to design ethnography resulted in findings which present the actions of people with dementia as intentional, and key to the recognition process. While the initial data informed the subsequent design work, it also presents evidence of the abilities of people with dementia to engage in mutual, caring interactions which highlight their agency and need to

interact meaningfully. It also embedded my role as a design ethnographer in the care context, meaning I could work closely with collaborators at later stages in the design process, informing them of the design context from both a contextual and psychological background. I discuss the process of data collection during this stage of the research in more detail in the 'Data Collection' section of this chapter.

Experience-Centred Design

While my design research was strongly influenced by the contextual understanding of the experiences at Oakfield house, this practice of design involved engaging in ECD [98, 99]. As discussed in chapter 2, ECD engages with the felt and emotional life, much of which has now become supported, or disrupted, by technology. This approach to design states that we co-construct experience through engaging in dialogue with one another. Experience can only be understood within context, and the role of technology is dependent on the action and intention of those engaging with it. Design processes which support participants to engage, reflect and examine their lived experience has the potential to enrich this experience through the design of technologies which support aesthetic and emotionally felt co-creation of meaning [157]. Taking a ECD approach involves the designer engaging with this experience fully, embedding their own experience and reflections within the design process, and responding

in empathetic and emotional dialogue through the design process [5]. As discussed in Chapter 2, The ECD approach to design complemented the theory of recognition, which also emphasises the co-constructive process of identity maintenance [73]. Extending processes of ECD to highlight the politics of inclusion, and the rights of people with dementia to be supported in the struggle for recognition suggests a strong emphasis on experience, and an equally strong response. While I have discussed this approach thoroughly in chapter 2, the pragmatics of the design process here involved drawing on the established understanding of the lived experience, the 'ways in' to co-constructive dialogical processes, and the reflective nature of listening and responding through design. Previous work in ECD such as Thieme's work with women in psychiatric hospitals [136] Wallace's design work with people with dementia [151] and Durrant's design work with people who have retired [39] demonstrates the use of design processes to creatively explore the lived experience of the individual, as well as the sensitivity and reflection on the part of the researcher as integral to this research. Further, the introduction of technologies in contexts which are devoid of meaningful engagements with technologies offers further opportunities for civic and social inclusion. I discuss methods of ECD I adopted in more detail in the Data Collection section below.

Setting

The empirical work of this PhD research took place in Oakfield House. Built in 2011, the Community Nursing Unit has four wards: Oak, Sycamore, Cedar and Willow. The two blocks of wards are connected with glass walls, with the reception on the ground floor and the atrium on the second floor. A mural is painted on the wall in the reception. It is of a huge tree with a combination of the four leaves of the wards. There are also photos of the residents and staff, with welcome signs, on the walls. Overall, it's a very welcoming place, with homely touches added such as: a table and mirror, sofa with cushions, coffee table etc. The wards consist of mostly private rooms with private bathrooms. There is one room for four people in each ward, as well as a twin room. One of the wards is designated for the young chronic sick. These residents are all under 65, most of whom have an acquired brain injury. The rest of the wards are occupied by older residents. Staff report that 80% of residents are living with cognitive impairment/dementia. Each ward is square, with a closed garden in the middle and has a living room, a communal dining area and visiting space. There are lots of photographs on the walls, as well as art from the residents and commissioned murals from volunteer artists. The corridors also have nooks, to stop and sit, which have been decorated with scenic stickers to give the appearance of looking out to sea or the countryside.



Figure 1: A mural in Oakfield House

The structure itself has a lot of floor to ceiling windows in all the corridors, maximising the light. The building is surrounded by gardens that are well maintained and the front of the building has views of some of the most striking buildings in the city, including the new council buildings and the old psychiatric hospitals. It is also directly in the flight path of incoming planes landing at Cork Airport, which adds to the activity on view.

Spaces of Note

The following areas described are where the activities take place in the care home and the majority of field notes were taken in these spaces:

The Atrium: Located above the reception, this is the largest space in the Unit and is where most of the activities and social get-togethers take place. It has floor to ceiling windows and also connects the two upstairs wards so there is a lot of foot-fall. There are two big tables for the residents to sit around, usually when we are doing activities. The front wall is lined with sofas. There are two dressers, with tea cups and pots that are similar to ones found in the home. The room has a reminiscence corner, currently displaying items from the war of independence to mark 1916. There is a gallery wall of art done by the residents. There are also plants growing, which are tended to by the residents and staff.

The Sensory Garden: Located to the back of the Atrium on the second level balcony, the sensory garden has slowly been developed by staff and residents over the years. It is lined with potted plants and hanging baskets. There is an herb garden and they also grow potatoes in painted tires. Some of the concrete tiles have also been painted and there are decorated stones on the ground that the residents make during art. The garden is used during the warmer days or as a more private meeting space for families when they visit.

The Therapeutic Kitchen: The kitchen is used for breakfast club once a week when the residents prepare their own breakfast and eat together. It is also used for baking and cooking classes. One wall is lined with the kitchen counters and the rest of the space is occupied by two tables,

dressers, sofas, chairs and wall art. These additions make the kitchen homelier.

The Sensory room: This room is used for individual sessions with people with advanced dementia. The room is softly light, with textured walls that the individual is encouraged to differentiate between. Soft music can also be played and different soft materials are used as part of the sensory experience.

The Church: While this space is not built as a traditional church, it is furnished with Catholic symbols and has an altar and tabernacle at the top of the room. The residents meet here for prayers twice a week and for all intents, it's treated as a church and considered a holy and special place in the care home. When not in use, the altar is partitioned off to create a social space called 'the café' where residents and guests can sit and make tea and coffee for themselves.

In addition to these spaces, I also visited residents in their rooms if they spent most of their time in bed. The rooms are warm and painted in pastel colours. Residents are encouraged to decorate them with their own furniture to make them feel homelier, but all have hospital beds, assistive showering facilities and storage. Most of the residents put up pictures, photographs and cards, not dissimilar to a student's dorm room. This is encouraged to honour the personhood of the residents, some of whom also

have their photo on the door, either a present day one or from a different stage in their lives.

Participants

Over the course of the PhD, I have worked with many residents, staff and students who have shaped my understanding and contributed greatly to this work. Below I describe these participants, the nature of our work together and their inclusion in data collection.

Residents of Oakfield House

As I transitioned from volunteer to researcher in the first year of my PhD, staff were supportive in ensuring I had a full understanding of the experience of dementia and encouraged me to work on 'Life Story Books' with residents in the more advanced stages of the illness, who were less likely to engage in the communal activities. Life Story Work [101] is a well-established activity based in the person-centred approach to care practices. I worked with 11 residents in total on Life Story books, which involved them telling me stories about their lives and producing a book which captured this to present back to them and their families. This initial work typically involved me working with a resident until the book was complete, however some residents died before completion of the project. Due to the personal nature of the stories shared, these Life Story projects were not part of data collection and so do not feature in the thesis.

However, from this work I gained an understanding of the nature of advanced dementia, the ways in which relationship building can be fractured, the reality of memory loss and confusion as well as the humour, care and ease which also existed within these interactions. Many of these residents feature in the ethnographic notes as I began to collect data, and many of the design considerations were made with them in mind. Newer residents with advanced dementia who also came to live in the care home feature later in the project. These residents were actively involved in the Life Story Box, History Club and Printer Pals design phases, in which their input and participation was central to the design process and evaluation. They also feature heavily in the reflective viewpoint presented later in this chapter and informed much of my understanding of what recognition in practice is, and my role as a researcher in this process.

Throughout this PhD research, I worked as part of the activity team, who run the daily recreational activities for the residents. These activities include art, music, films, beauty therapy, bingo, knitting and seasonal trips. These activities are attended by a core group of ladies, none of whom have received a diagnosis of dementia (6-7 residents over the years). Other residents are more fluid to the group, particularly those with dementia or who experience bouts of physical illness. These residents have played an integral role in the social scene of the care home and were involved in the design and evaluation of Printer Pals, in which we aimed to

create sessions which spoke to the varied interests and abilities of the residents, rather than creating groups for advanced dementia. They have also been a huge source of care, friendship and entertainment to me throughout this project and have shaped my understanding of what it means to live in residential care, and the importance of supporting notions of agency, social contribution and care in this context.

Staff

While the staff were never the focus of this research, they played an integral part in the work. The care home management, ward nurses and care assistants were supportive of this research and could see the need for further social support for the residents. In conversation with them and through observation, I got a clear sense of their genuine care for the residents and learned from them the practical elements of assisting people into wheelchairs, helping residents with their meals and being attuned to the needs of the residents at all times. I have huge respect for the staff of Oakfield House; they do immense work with restricted resources and extend care to every resident, family member, volunteer and pet that comes in.

Activity Co-ordinators

From the initial volunteer work right through the PhD process, I worked closely and under the guidance of the activities team. The team has evolved over the years, with each member demonstrating an enthusiasm

for care, fun and purpose on behalf of the residents. The lead member of the team, Kathleen has been a constant source of support and encouragement throughout this PhD and she features heavily in the field work as 'Kate'. Her commitment to the residents, her unfailing determination to support and understand the 'person' in her care and her innate understanding of what fun, laughter and joy can bring to care has influenced me more than any other facet of this work. Her support of this research and of me personally during this project, has been the key to any progress I have made. As a mentor and a friend, she has shaped the approach to this research, and made me more determined to capture the experience of the residents as fully-fledged individuals who deserve care, resources and fun.

Students

As part of the design intervention to increase opportunities for social engagement, I set up a student volunteer programme for social science students in the care home. Over three years, I have worked with 10 student volunteers who hugely contributed to this research. All students were in final year and were undertaking the module 'psychology in the community', requiring them to carry out 70 hours of volunteer work over the course of the year. The students were involved in the case studies I describe in Chapter 5, in which they engaged with the residents to create design artefacts to celebrate the personhood of the resident, and reflect the

relationship formed between the residents and students. Their insight and creativity helped to further my understanding of the potential of supporting recognition in this context, and the role of younger people as key figures in the dementia ecology of care.

Collaborators

Finally, the design of Printer Pals was conducted in collaboration with colleagues in Open Lab, Newcastle University. Daniel Welsh, under the supervision and guidance of Dr. Kellie Morrissey helped to design and introduce a technology into the care home that spoke to the three years of findings and considerations I presented to them. As a psychologist and an ethnographer, I worked closely with Daniel and Kellie to communicate the specific design requirements and considerations for how we could engage sensitively in design in this space. This collaborative work included numerous skype conversations, and a research visit to Open Lab, Newcastle University, where I worked in their makerspace with Daniel and Thomas Nappey to help build the first prototype of Printer Pals. Daniel was involved with the fieldwork and visited Oakfield House during the design phase and prototype testing to provide technical support and observe the use of Printer Pals before the final re-design phase. His technical knowledge, as well as his sensitivity to the context of dementia care, made this process very enjoyable, and I'm sure added to the

enthusiasm of the residents towards Printer Pals when it was implemented.

Ethics

Ethical approval was sought and achieved by the School of Applied Psychology Ethics Committee in December 2015. We sought further formal permission from the care home staff, management and HSE prior to initiating the project. It was agreed that field notes were the most suitable form of data collection in order to protect the anonymity of the residents. As such no visual or audio recordings took place. In line with the Mental Capacity Act [1], which defines ethical decision making when working with vulnerable populations such as people with dementia, family members were consulted and made aware of the nature of the research and proxy consent was sought. The participation of family members was very helpful and encouraging as they brought in photographs or shared stories about their family, particularly for the intergenerational design work with the students.

While the formal ethical consent process was a key initial concern, the everyday ethics of working with people with dementia and designing a research programme that is sensitive to their wide range of abilities and needs was a constantly evolving and reassessed aspect of the research. As discussed by Barry et al. [10] practical ethics needs to be used to inform the design of the research, such as the everyday decision-making process

and navigating power dynamics within design interactions and research. Each aspect of the study design was evaluated based on supporting agency for people with dementia, with a view to engaging in processes of recognition and avoiding misrecognition in this process. I drew heavily on the theory of recognition to inform my decision making and found viewing the project and interactions through this lens to be ethically informative. I also worked through any decisions with my advisory team.

The Mental Capacity Act [1, 69] draws particular attention to the importance of ensuring people with dementia are informed and supported when making decisions. Due to the nature of dementia, this required a weekly reminder of the nature of the work we were doing, and a moment by moment assessment of the well-being of the resident, their needs and enjoyment of the process. Staff, family members and residents assessed it as a low-risk activity, as the activities were based around increased opportunities for social engagement with no serious clinical implications for the residents. I was careful to assess the needs of the residents, particularly when engaging in the student design projects and consulted the residents themselves, as well as staff as to how best respond to their particular needs. Staff outlined some potential residents, they were invited to engage in the project and their family members or next-of-kin would be consulted.

The duty of care to the participants was my main concern throughout this project. This included both the residents and the students, whose interactions overlapped and co-created a shared experience. Students were given orientation before starting, spoke with staff and were shown a video to demonstrate the idea of 'personhood' in dementia care. I facilitated all the sessions with the students, and held debrief sessions after every week. In terms of the residents, I constantly monitored their state of being, and responded through verbal and embodied communication based on their needs. Residents were never expected to engage in the activities if they were not feeling well or sociable, and as I had established early in the ethnography, the students came to understand the fractured nature of participation as a common and reoccurring aspect of research in this area and were very respectful towards this.

Navigating power dynamics and expectations was a further consideration throughout the project. In accordance with the theory of recognition, supporting people with dementia to be positioned as equal agentic beings with the potential to socially contribute was the conceptual thread running through this work. For this to be practically implicated, it required the person with dementia to take the lead in our interactions, and receiving a response which legitimised their actions. Within the care context, there was a need to navigate expectations of my availability to work with the residents, as well as the time-scale of the students' work.

While the nature of the design projects I introduced were complementary to the existing activities scheduled for the residents in care, we slowly expanded the group from working with selected residents, to widening participation in order to grasp the appropriate level of questioning, challenging and introducing technologies into this context.

Data Collection

Data was collected throughout the thesis through participant observation and subsequent creation of field notes. This approach, rather than recording audio or visual data, was agreed upon as part of the ethics negotiation with the School of Applied Psychology ethics committee and HSE (Health Service Executive) management in the care home. As the nature of data collected evolved throughout the research, I present here three phases of data collection and what they involved.

Phase One- Ethnography

During the initial fieldwork, data was collected to capture the interactions, setting and daily events of the care home (See Appendix for sample field notes). The initial Participant-Observer [42] approach involved me engaging in the activities with the residents, whether that was baking with them, arts and crafts or bringing them from activities back to their rooms. At first I narrated the entire day in chronological order, capturing as much detail as possible [4]. This included the activities I took part in, my

interactions with staff and residents, my observations and reactions to moments I felt were particularly striking. As the work continued and my research questions became more refined, my writing pattern changed, to focus on particular moments or interactions that spoke to notions of recognition, agency and co-creation. I captured small notes throughout the day, but felt it was inappropriate to take notes while talking to residents. Instead I noted the events of the day (usually on my phone on the bus home) and would then write fuller impressions of the day once I got home. Sometimes, if there was a particularly difficult incident (such as death of the resident or an upsetting interaction) I would return to my field notes a few days later, to reflect further on the experience and consider how my reaction in the moment related to notions of recognition. During this phase of data collection, I was thoroughly embedded in the interactions I was trying to understand, which required close analysis of my own experience and how it informed the data I was collecting. This phase of data collection formed the basis of my understanding of recognition in practice, which was used to develop the design framework presented in chapter 2. The resulting design considerations presented in the design framework were used to guide data collection for the remaining phases of the research.

Phase Two- Student Design Project

As the research evolved and I began to introduce design methods as part of my work at Oakfield House, the nature of data collection evolved with the aim of responding to the sensibilities outlined in the design framework, such as making meaningful activities, paying attention to the texture of interactions, and expanding space for embodied and different ways of communicating While the data from this phase continued to be based in my understanding and reaction to events of the care home, my role in the context changed from participant observer to a facilitator, as I supported and reflected on the interactions between the undergraduate students who were now engaged in the research, and the residents who participated in these projects. I conducted interviews with the students to capture their reflections on their experience working with the residents (see appendix II). Data collection was also used to examine the role of the materials and resources I was introducing into the design context, such as crafts, photographs, maps, reminiscence items and more personalised content for residents. At this stage, I also began to introduce technologies such as iPads and mobile devices to present digital media to the participants and examined the organic way in which students would use their phones to find pictures for the residents. As I was interested in the process of mutual recognition, the field notes reflect the relational dynamics between the students and residents and capture the development of the students'

understanding of what it means to live with dementia, as well as the residents' expressions of agency and care in response to the students. The use of media to mediate conversation was a key finding of this stage of data collection, but field notes also capture the reluctance of residents to interact with the technology we had, such as smart phones and iPads. This barrier to accessing media, as well as its potential to anchor meaning-making between the residents and students, were key considerations carried through this phase of data collection.

Phase Three- Printer Pals

During the final design phase, data was collected to inform the design and evaluation of Printer Pals. This involved collaborative work with colleagues in Open Lab, Newcastle University, who visited the care home several times to get a sense of the context and aid with the evaluation and deployment. Initially we discussed the data from previous student design work about the use of physical objects and materials which worked to aid communication, such as paper and audio. We also use the previous data to consider the potential barriers to technology, such as a lack of Wifi and an aversion to touch screen technology. This informed the prototype building and ensured the technology was successfully integrated into the context. Figure 2. below depicts this stage of data collection.

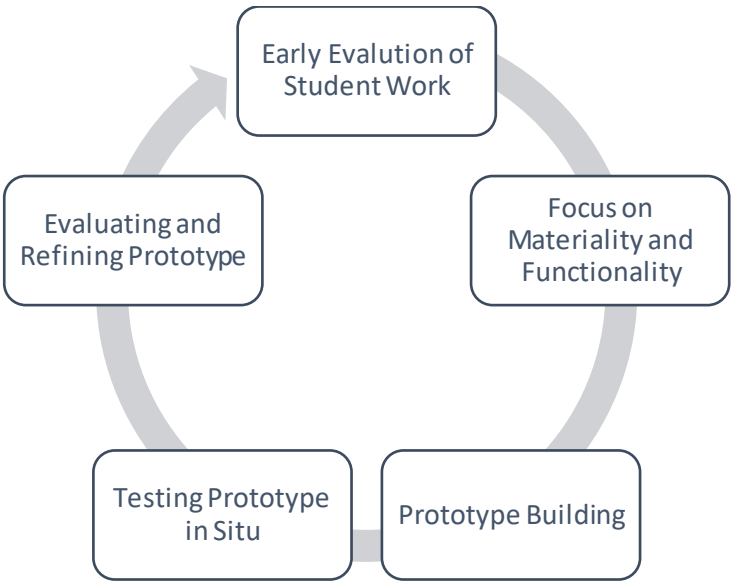


Figure 2. Design Stages of Printer Pals

My field notes from this phase detail the concerns I had around translating my previous findings to design work, the initial prototyping phase and the evaluation and use of Printer Pals. During the evaluation, I was particularly interested in the social interactions that evolved around the use of Printer Pals and the participation of people with advanced dementia, capturing their responses to the media produced and the other residents engaged in the activities.

Thematic Analysis

As recognition theory was the core theoretical framing of this thesis, I chose Thematic Analysis as a method of analysing my field work to allow for a theory driven approach to data analysis. Braun and Clarke [19]

emphasis the openness of Thematic Analysis, as the method is 'not wedded to any pre-existing theoretical framework' and therefore allows for a detailed examination of the instances of recognition theory through the data analysis.

Based on my understanding of recognition theory and ECD, I took a social constructionist approach to the data, in which the actions of the participants were viewed as intentional and socially consequential. Social Constructionism considers knowledge and experience of phenomenon as socially created and is the epistemological basis of several postmodernist theoretical and conceptual frameworks, such as symbolic interactionism [14], narrative [126] and discursive approaches to qualitative analysis [40]. The advent of the technological age and the role of technology in the configuration of mutual recognition, suggests the need for findings of this study to be interpreted through a socially constructed lens. Rather than question the legitimacy of the action of the participants, I took their words and meaning as socially constructed and consequential. This aligned with the concept of recognition, in which recognition is socially co-created, whether on a micro-level between individuals, or systemically within social structures and political policies. Similarly, McCarthy and Wright highlight the co-constructive nature of experience, in which individuals are active in their dialogue with each other, coming from a place of lived experience, and further shaping this experience in their interactions [98].

The use of thematic analysis allowed for an approach to analysis which was open to theoretical interpretation. In accordance with the practice of analysis outlined by Braun and Clarke (REF), analysis involved: 1) the transcription of fieldnotes, 2) line-by-line coding of the data, 3) examining patterns across codes and 4) constructing themes and subthemes from the data. While the theory of recognition informed the data analysis throughout, its use in the thematic analysis is more prominent in chapter 4, in which each theme is overtly related back to some form of recognition. Examples of coding is presented in appendix III.

Data was analysed chronologically based on the three phases of data collection described in the previous section. Analysis involved reading, re-reading, coding, generating themes and was conducted iteratively. This resulted in a latent, theoretical analytical approach. The findings of this analysis are presented in chapters 4, 5 and 6.

Reflectivity

As previously discussed, both the participant-observer and ECD approaches require an interpersonal response from the researcher, whose experience is embedded within the findings of the empirical research and subsequent design outcomes. Reflective practice is fundamental to ethnography, and allows for the researcher to critically assess their role in the research in terms of positioning others, advancing the work and

portraying a clear and practical research output [128]. This reflective approach was further utilised in the data analysis phase, in which I critically analysed my reflections and field notes to examine the incidence of recognition in practice. While the reflective practice had clear academic merits, it also helped with my personal development throughout this work, particularly in terms of sense-making around the illness, loss and grief involved in working with people with dementia. Intertwined in the data is a lot of my personal reactions, thoughts and emotions in anticipation of or response to the fieldwork. Sometimes if an incident was particularly upsetting, I would take longer to process the situation, giving myself time to think about my emotional response and intellectual understanding of the interactions. Reflectivity is an integral part of the ethnographic and ECD process [82], and due to my interest in the intersubjective process of recognition, I paid particular attention to the interpersonal processes and the impact of my interactions with the residents on my internal state. Taking a reflective viewpoint throughout the process I could examine my own positioning in this context, such as my growing affinity for the staff, the attachment to and subsequent loss of certain residents, and the responsibility I felt in introducing students into a context which was certain to cause some form of upset. Below I present a reflective piece that frames my personal understanding of my role as the research progressed, and the nature of mutual recognition in this context. I present this work to

give a sense of the emotional response which was central to my understanding of recognition in practice, and also key to my 'unlearning' of what it means to live with dementia, and the potential of design in this space. 'Sitting with Loss' as presented below, also documents the development of my emotional understanding and responses to the research, much of which was aided by my support system, but also my theoretical understanding of recognition theory.

Reflective Viewpoint- Sitting with Loss

In this section, I introduce three interactions with residents which shaped my reflective viewpoint and my understanding of my role as a researcher in this context.

Sitting with Christy

I go to sit beside him and shake his hand. He looks a bit wary, as he rightly should do. He mentions the pictures I used to show him, so I think that's what he expects today too, which is great. I show him the picture book that we've put together with all the historical pictures of Cork that we used to talk around. He takes the book in his lap and starts to turn the pages. He comments on almost all the pictures, ranging from churches, shop fronts, to political figures. He talks a lot about the politics of Ireland, which comes at the end of the book. He tells us that his brother died in India, fighting with

the British. He talks about all the families and friends that were divided, he seems dejected by this, as is natural. When the pictures come to an end, he goes back to the start. When it stops on the pictures of the old tenements of Cork, the pictures of the young children who lived there makes him very emotional. 'They had nothing,' he says. A tear falls from his eye then, and he takes a handkerchief from his pocket to wipe it away. I get a fright, I didn't want to upset him. I stoop down low and take his hand, telling him it's okay. 'I'm sorry' he says…. 'There's no need to be sorry at all' I reassure him. 'Just makes me sad, to think of them.' He's emotional response has taken me aback. I know he's a reserved man, but he continues to keep hold of my hand, as we talk through the way things were back then. Maybe these scenes remind him of his own experience, but I'm really touched by his compassion to the suffering of others.

Holding his hand as he cried for the people in the photographs, or his own memories, or something else entirely, I wasn't uncomfortable with his visible sadness. Rather I was struck by his empathy, by his tears for the situation for others, a suffering that no longer existed except in his memory. The concept of empathy, a distinct psychological experience based on the imagined lives of others, is rarely associated with people with dementia. And yet, Christy's display of empathy, the openness of it was generally quite rare. Through his display of empathy, and on reflection of the moment afterwards, I was forced to reconsider his experiences. His

dementia didn't make him more distant from the world. Rather, he was very connected, very moved by the lives of others. And I owed it to him to acknowledge this. But to acknowledge it I had to also acknowledge more fully his own pain, whether for himself or others, was also very real.

Sitting with Maureen

I go to talk to Maureen. She's another resident who Kate thinks would be good to spend time with. She's awake eating biscuits and drinking tea, but is lying in her bed. I ask her how she is. She doesn't know me, but smiles. 'Good' she says. She looks directly at me 'Any chance of getting home?' she asks. 'Where's home Maureen?' I ask cheerfully. She rattles off her address, ready for anyone who might bring her I suppose. I hear North Cork city. I have pictures of Shandon on my iPad and I ask her does she know it. 'That's beautiful' she says. I then show her Grand Parade. 'That's beautiful,' she says again. Maybe she's forgotten, but she doesn't ask again about going home, we just chat about what's on TV. It's the Bill or something. I ask her if she likes it, it's very dramatic. She looks at me and we both laugh. Will I change it? The next channel has something older looking on it. 'That's much better' she remarks. I think it must look more familiar to her. What do you like to watch? 'The Waltons,' she answers immediately.

No matter the distraction, or moment of enjoyment I could create, I couldn't bring Maureen home. She spent most of her time confused but could repeat her address no problem. I was happy when I could

successfully distract her, show her the places she missed, but at the same time knew that distraction was all it really was. Her longing to go home never went away. I could sit with her, watch TV, chat and go home, but she never could. Within these interactions, I was keenly aware of how much I could really do here, and how much I had to accept as beyond my ability. At times, this region beyond ability seemed to minimise any progress I had made. There was so much I couldn't do to help, except accepting this and in some way moving beyond it to figure out how I was useful here.

Sitting with Nancy

I sit beside her, take her hand and ask her how she is. There's a musician coming in to play us some music. She says she doesn't know where she is. I'm unsure if she means where she is in the nursing home, or where she is in relation to home. I try to distract her by telling her we're going to listen to some music for the afternoon. This doesn't seem to make much of a difference to her, but when the music starts she is quiet, holding my hand all the while. As the musician continues, Nancy starts to get restless, rocking forward in her chair, sometimes jerking her whole body as if she's getting a fright every few minutes. She starts muttering, which I realise are prayers to God, Jesus, Mary and Joseph to help her. Every time a song finishes she asks me if it's nearly over, sometimes asking the musician to 'please stop' in a helpless bid to get out of here. I find this really distressing because I know how polite, kind

natured and shy she used to act, and for her to shout out in distress is so far removed from how she existed when I first met her. She asks me could she phone 'them' maybe, I tell her they can ring from the ward, that they know where she is, her tea will be on soon. All the usual phrases to try to make someone feel reassured. But none of it works for more than a minute. She asks me if I know where she needs to go, maybe I could bring her? Somewhere out in the city. She mentions a street; I tell her I know where that is. This does reassure her. 'Will we tell them we have to leave early?' she asks hopeful. I hate to do it, but I tell her we can't just leave, but we can see what we can do in a few minutes. I try to bring her attention back to the music, probably trying to distract her and myself. Because this I can't fix.

Out of all the residents, I've known Nancy the longest, since I started volunteering as an undergraduate. When I started, I didn't realise she had dementia. She was shy, in almost a childlike way that I found really endearing. That you could live your whole life and never lose that childlike modesty. She was easy to talk to, always asking about my studies, for my family. She was gentle too, and very grateful for any assistance I gave her. When I started my PhD, I sat down with the staff nurse to discuss who I could work with and her name came up. I was surprised, I didn't realise she had dementia. Further, I learned that she had been through things in her life that were really upsetting. For some reason, learning about this, and thinking about how kind she is, how I had

assumed her life must have been to make her so kind, upset me even more. I found it hard to hold these two ideas of a person together. As her dementia progressed, she retreated, and although I had worked with many people with dementia at this stage, and understood the patterns of the illness, it somehow took me by surprise. I had to acknowledge my grief for her, that the feeling of loss was personal. I wasn't sure I was entitled to these feelings, and it took some time to acknowledge it. My inability to help her, to find some solution that brought her some sense of ease through her anxiety was pointless at this stage. And again, but perhaps more than ever, I found this difficult to accept.

Sitting with Grief

Throughout my work with people with dementia, I was always keenly aware I was going through a deeply personal learning process beyond learning how to do academic research. The only real conclusion I had come to was I was distinctly aware of my failings; of the narrow sense of improvement I could offer to the people I worked with. I was, at first, somewhat uncertain about my role in this process, and the role of my grief for my participants, or my right to it. But eventually, I came to acknowledge that I cared for my participants, and my grief for them was as real as it was vital. This learning came into sharp focus for me last Christmas when my aunt died suddenly. She wasn't ill, or old or confused. No one questioned her role in her family, she was very much central and

vital. And then one day she had the flu, and slipped away. It was, and still is, a huge shock. She had minded me as a child, and for the first time in my life, I was experiencing grief that was unquestionably my own to feel. When I went back home for the funeral, I shared that grief with my family, and many times people who passed through the wake told me I needed to mind my mother now, that I should be strong for her. Had I not spent the last four years trying to understand the role of loss and grief in my research, I would have found this proposition daunting, and would have struggled to figure out what this means. But as I welcomed people to the wake, made hundreds of cups of tea for people who had come to pay their respects, and held my mother's hand as we followed the coffin into the church, I remembered my participants and what they had taught me. Through them I learned that your own grief and pain doesn't have to stop you supporting others through theirs. That the pain of other people doesn't take away from your own. And the moments in which there is nothing that can be done except to sit with someone and share in that suffering together is perhaps the most important moments of connection we can achieve.

I learned this through my participants, and in a way they impacted my life, my relationship with everyone I love and care for in a way I perhaps don't fully comprehend yet. I'm not sure how this will shape the

researcher I become. But I do know that I learned something very important here, and for the I am grateful.

Summary

In this chapter I discussed the methodological approach of this research, detailing the positioning of the person with dementia as agentic and in dialogue with those around them, as well as the underlying assumptions of ethnography, ECD and thematic analysis. I also presented the pragmatic approach to recognition in practice through methods of ethnography and ECD and described the setting, participants and methods of analysis involved in the empirical work, which resulted in a multifaceted approach to understanding and presenting the experience of dementia in a relational context. Through introducing methods of design into this context, the nature of the experience I captured was expanded to include interactions with media and technology. This allowed for data which presented a highly collaborative and participatory view of the actions of people with dementia, and the role of design methods in heightening notions of agency and contribution in the care home context. In the following chapters, I present the papers detailing the three phases of the design ethnography. These papers are presented as conference proceedings in the ACM style, and detail the individual literature and methods which influenced the three research phases, as well as presenting individual findings and implications, which I draw together in the discussion chapte

Chapter 4: Care and Design: An Ethnography of Mutual Recognition in the Context of Dementia Care[2]

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Abstract

While there have been considerable developments in designing for dementia within HCI, there is still a lack of empirical understanding of the experience of people with advanced dementia and the ways in which design can support and enrich their lives. In this paper, we present our findings from a long-term ethnographic study, which aimed to gain an understanding of their lived experience and inform design practices for and with people with advanced dementia in residential care. We present our findings using the social theory of recognition as an analytic lens to account for recognition in practice and its challenges in care and research. We discuss how we, as the HCI community, can pragmatically engage with people with advanced dementia and propose a set of considerations for those who wish to design for and with the values of recognition theory to promote collaboration, agency and social identity in advanced dementia care.

CCS CONCEPTS

• Human-centered computing ~ Field work.

[2] This Paper was presented as part of the Proceedings of the CHI Conference on Human Factors in Computing Systems (CHI'2019).

KEYWORDS

Dementia; Ethnography; Recognition Theory; Experience-Centred Design

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Introduction

The field of HCI has recently seen a growing interest in dementia research, which has served to highlight the importance of responding to the psycho-social needs of people with dementia to the extent of nudging approaches to care and design from the predominantly medical model towards a person-centred care model. Such work has stressed the importance of social connection [110], creative expressions of personhood [151], and maintaining meaningful relationships [53] as ways of enriching the experience of dementia. Further, this shift has motivated the inclusion of people with dementia in research practices, which in the case of HCI research, has resulted in design outputs that enrich the lives of those living with dementia and expand our understanding of how to better design for life with dementia [17, 91, 108, 151].

However, there is still a dearth of HCI research for people with advanced dementia [61, 129]. The experience of advanced dementia is associated with increased agitation, severe memory loss and physical

frailty [106] which sets significant research challenges. So far, HCI research for advanced dementia has largely focused on interventions that support aspects of physical care such as safety monitoring, and symptom management [71, 94]. While these design interventions undoubtedly create a better quality of care for people with dementia, we suggest that in order to design for meaningful social interaction for people with advanced dementia there is a need to better understand the lived experience of advanced dementia and to foreground the importance of such persons as fully belonging and deserving of social inclusion. Recent work has demonstrated the appropriateness of Experience-Centered Design (ECD) [98] for people with dementia [53, 111, 151], as a means of developing and implementing enriching technologies within care contexts.

In this paper, we draw on ECD and report on a long-term ethnography in a residential care facility with people with advanced dementia. We introduce Recognition Theory, which posits the need for mutually beneficial engagement as a means of maintaining a sense of self [64]. We examine the role of design research with people with advanced dementia through the critical lens of Recognition Theory, and detail previous ethnographic and experience-centred design work, which has informed our practice. Our findings contribute detailed examples of how recognition was enacted through the interactions between people with advanced dementia and the researcher. Our analysis positions the person with

advanced dementia as an agentive being capable of and requiring and offering recognition for their social contribution within the care context. Finally, we present a set of design considerations for researchers carrying out design work with people with advanced dementia, for example, attending to the nature of engagement, an awareness of the context of care, and the challenges of designing in this space. Our design considerations are developed with a view to furthering inclusive design practices in HCI.

Related Work

Our research is situated in the space of understanding and designing for lived experience in dementia care and the social theory of recognition. Below we review existing work in this space which has taken an ethnographic or long-term approach to exploring this complex experience.

HCI Research and Dementia

A growing interest in dementia research in the last few years has resulted in a more nuanced understanding of the place of technology and design in creating spaces which are safer, accessible and experiential for people with dementia [62, 90, 93, 111, 114, 152]. An appreciation for experience, as established by McCarthy and Wright [99, 156], has motivated ethnographies in dementia care where the researcher engages in dialogical interactions with their participants, contemplating the nature of the

experience of belongingness and practices design through the co-creation of meaning with the other, as the ECD approach emphasises. For example, Morrissey's ethnographic work [108] focused on the use of music to bring people with dementia together, expressing both their shared interest in traditional music and dance, and the need for social connection amongst them. Morrissey et al. [111], have detailed the use of ECD in designing for dementia as a 'way in' to the experience, drawing on an appreciation of the embodied ways in which people with dementia connect and express their need for belonging in the care environment. Their work informed the design of 'Swaytheband', an interactive baton which encourages people with dementia to hold hands and sway together to music, highlighting the role of design in encouraging meaning-making and embodied connections in dementia care. Similarly, the ethnographic work of Lazar et al. [91] with people with dementia in care engaged with the existing practice of art therapy to design enhancing technologies which aimed to support the agency of the person with dementia. This design ethnography resulted in the deployment of a photo-sharing tool, in which the person with dementia can share their artwork with family and friends as a means of expressing their creativity and social engagement [90].

Ethnography in this space has also considered the relational aspects between people with dementia and their carers [42, 130] and showcased an in-depth understanding of the relationships of care, leading

to the design of sensitive and meaningful interventions. In her long-term ethnographic work, Galvin et al. [53] engaged with people with dementia and their carers in the home, exploring the nature of the relationships between carers and their family members, presenting examples of the complexity of the relationship dynamic between the carer and cared-for, as well as the role of ECD in creating space for reflection and engagement within these relational interactions. Galvin et al. [53] showed how the person with dementia is often positioned in a more passive role in the relationship, as the carer takes on more household tasks, financial decision-making and care planning [118]. Galvin's design response to remedy the above imbalance, the 'Digital Story Cube' a photo-sorting application, aimed to reconfigure the relationship of care, creating an opportunity for the person with dementia to take the lead in engaging with and teaching others how to use the application. Wallace et al. [151], also examined the nature of relationships between couples in her extensive work with Gillian and John, a couple who were coming to terms with Gillian's recent diagnosis with dementia. Long-term engagement with the couple resulted in the design of digital jewellery that represented aspects of Gillian's interests and invited others to engage and reflect on Gillian's 'personhood' rather than focusing on her diagnosis [151]. The work between Wallace and the couple established a sense of trust between them, resulting in richer and more evocative design outcomes.

It is evident from the above that there is a growing body of HCI research in dementia care that has advanced our understanding of the lived experience of people with dementia and informed meaningful design interventions. However, HCI has yet to fully develop and integrate the experience of advanced dementia into its research agenda. Our work wishes to address this by taking on an ethnographic approach to gain a deeper understanding of the lived experience of people with advanced dementia living in care.

Advanced Dementia and the Care Home

The experience of dementia is a complex, multifaceted condition, and it is important to acknowledge the various causes and symptoms of dementia, and how they affect cognitive, social and civic aspects of people's lives. The experience of advanced dementia is associated with severe memory loss, increased agitation and confusion, as well as mobility issues and more frequent hospital visitation [106]. As dementia progresses, many people move into assisted living or residential care, requiring more assistance with personal and physical care. The nature of advanced dementia, paired with the new environment of a care home can result in difficult transitions for people with dementia and their families, in which the relationship dynamics within families and between people with dementia and professional carers can shift. This in turn can often result in the person with dementia being positioned as the person 'in need' of care rather than

a person with agentic abilities [38]. The personal experience of living with advanced dementia has been traditionally excluded from research in HCI and in general [129], creating a lacuna in the understanding of how to best implement and design for more social interventions. Our work is particularly interested in the psychological and social lives of people with advanced dementia, how they participate in their social worlds and shape relationships with others. We are also interested in how technologies and design practices can potentially enrich the lives of people with advanced dementia, helping to view the person with dementia as a fully-fledged participant, who is shaping social relationships. In this respect, we have applied the social theory of recognition as an analytic lens throughout this project as a means of critically understanding the fundamental need to be recognised within our relationships and the wider social context.

Social Theory of Recognition

As mentioned earlier, this work draws on the social theory of recognition as an analytical lens that guides our ethnography with people with advanced dementia. We have previously proposed [under review] a conceptual framework of recognition for design research, which aims to support experience-centred engagements between designers and people with advanced dementia and impact their lived experience and social identity. In this section, we provide a brief introduction to the social theory of recognition that has guided our analysis.

The theory of recognition has its foundations in the works of Hegel, Fichte, Rousseau, and Ricoeur, and continues to be developed by contemporary theorists [50, 64]. Being 'recognised' as an individual involves receiving positive social regard from others, which in turn reaffirms (aspects of) one's identity. Thus, the importance of mutuality in the realization of the self, based on the necessity of the 'other' in providing social feedback [103] is emphasised. Mutual recognition, in which both individuals engage in reciprocal intersubjective engagement, is considered the basis of ideal recognition. Building from the concept of mutual recognition, recognition theory contributes four potential outlets of receiving recognition, namely; elementary recognition, respect, esteem and through caring relationships. The first type, elementary recognition speaks to our fundamental need to be accepted by those around us, i.e. 'others' as a means of establishing an identity. This elementary need to be recognised is present from birth and shapes our interactions and need for others. Secondly, seeking respect involves being recognised for our equal moral standings within society. In contrast, we gain 'esteem' through our role within society and various achievements, such as our occupation, and the provision of resources which recognise our needs, such as health care and education [3, 64]. Lastly, as these types of recognition are not guaranteed or realised within many societal structures, we turn to caring relationships within family and intimate relationships as a means of receiving and

reciprocating recognition. Researchers have examined the struggle for recognition within the wider societal context, such as social work [54], and the various barriers to receiving recognition. These barriers may manifest as discrimination against aspects of one's identity, such as gender or race [50], or through lack of access to education, health care and employment. Failure to be recognised by others, or society, results in misrecognition. In this sense, there are moral and political implications of not recognising difference, in which individuals may not receive adequate recognition and resources to acquire a high quality of life.

For the individual with advanced dementia, the need, and ability, to engage in mutual recognition may be questioned, due to a presumed cognitive inability or indifference to maintaining and developing social inclusion within their care ecology [135].

As we discussed earlier, the person-centred approach to care, as introduced by Kitwood [79, 81] has encouraged a transformation in dementia care and HCI in which the person with dementia is given the status of personhood through various care and design practices. This approach has resulted in an examination of the nature of embodied selfhood [84], identity maintenance [123] and the need for acknowledging the individual with dementia within relational dynamics [115]. This work has been adopted within HCI to ensure the lived experience of the person with dementia is central to how we design. Though a distinct body of

work, recognition theory further highlights the role of people with advanced dementia as not only being worthy of their personhood but rather vital to the identity maintenance of those around them, of actively co-constructing meaning, as well as having the right to be recognised through the provision of resources which speak to their need for respect and esteem. By applying the theory of recognition to our empirical ethnographic findings we can gain insight into the nature of recognition for people with advanced dementia, and the ways recognition can be supported through design. In this sense, the theory provides a clear standard to design for, and a relational, social and civic justification to do so.

Method

This paper reports on the first phase of a long-term design ethnography, which took place in Oakfield House, a state-funded residential care unit. An ethnographic participant-observer approach was chosen as it offers the opportunity to immerse oneself in the daily activities, the lived experience of the other, to build rapport with the residents and staff, gain unique insights into their feelings and concerns and become a key figure in the ecology of care [42]. The use of ethnography in this work focused on producing detailed accounts of the situated interactions that took place between the researcher, the staff and residents of the care facility. These

accounts were analytically informed by the social theory of recognition [34, 54]. In the following sections, we provide a short description of the setting and the methodological approach followed as part of the data collection and analysis.

Oakfield House

Oakfield House is a State-funded residential unit providing care for people with dementia and end of life care. The purpose-built modern building is home to 85 residents, the majority of whom have received a diagnosis of dementia or cognitive impairment (est. 80% of residents). The unit provides private, double or 4 bed rooms, with communal dining halls, lounges and garden areas. The ethnographic work took place one day a week over a period of two years (September 2015-Septmeber 2017) in which the primary researcher assisted with the daily activities of the residential home. These activities included music sessions, arts and crafts, prayers, baking, gardening, beauty therapies, as well as games and quizzes. These activities typically took place in larger communal spaces, such as the therapeutic kitchen, purpose built for use by the residents, or a larger central hall (see figure 1), which is used for group activities. During this time, the researcher also engaged with residents on an individual basis to carry out 'Life Story Work', a common form of reminiscence therapy which encourages people with dementia to share their memories, documenting them as part of a person-centred approach to care [101].



Figure 1: The main communal room in Oakfield House, displaying some of the art work by the residents.

Methodological Approach

As mentioned earlier, an ethnographic participant-observer approach was chosen as it offers the opportunity to immerse oneself in the daily activities of the care home, providing a unique insight into the lived experience of the care of people with advanced dementia. Field notes were taken of the observation of the day-to-day activities including the researcher's conversations with the carers and the residents; these were taken during the session and expanded on after the events [41]. The field notes reflect the engagement of the researcher in shadowing daily activities and conversations with the residents, as well as the response of the researcher in reflection of the interactions. The collected data was analysed using thematic analysis as it allows for an open interpretation of the data while also incorporating theory as an interpretive lens [19]. Drawing on previous ethnographic work which has applied theory as a means of further analysing and understanding the experience of dementia [104, 130], we applied the theory of recognition [50, 64, 135] to the data by

adopting a theory driven, thematic analysis [19]. The analysis resulted in the construction of three main themes, namely; moments of recognition; conflicts of recognition, and recognition of agency, with sub-themes highlighting further the nuanced occurrences and challenges of recognition in dementia care. In the following section, we present our analytic findings in detail.

Analysis

In this section we present the key findings from our ethnographic work through the analytic lens of the theory of recognition. These encapsulate recognition in practice within residential care, as well as the unique challenges and considerations in the struggle for recognition for people with advanced dementia. Our analysis also highlights that people with advanced dementia are capable of engaging with others in collaborative interactions, which speaks to their need and ability to express their agency through various relationships and activities within the care environment. We present the insights into the nature of recognition with people with advanced dementia with a view to constructing more inclusive design spaces.

Moments of Recognition

Within this theme, we present recognition in action as it occurred within our everyday interactions with people with advanced dementia and

staff members in the care home. These moments of recognition, sometimes mundane and sometimes unique in their daily expression and manifestation took the form of embodied recognition, and expressions of care. Each sub-theme highlights the subtle ways in which moments of recognition occur for people with advanced dementia, and how responding to those can heighten a sense of mutual recognition.

Embodied Recognition

The central concept of recognition is the need to give and receive basic recognition and care from those around us [65]. This form of recognition is often associated with caring relationships and based on the understanding that every individual has the right to receive care and acknowledgement of their fundamental need for others as a means of establishing a sense of self [103]. In our ethnography, people with advanced dementia recognised others and communicated that recognition, albeit in more embodied ways. Our ethnographic work highlights the use of touch, gaze and comfort from physical objects as ways that people with advanced dementia recognise the other as a source of human contact, comfort and reassurance and communicate their need for recognition.

In the following excerpt, the researcher encounters Maura for the first time. The researcher recognises Maura's anxiety through her non-verbal behaviour, the gripping of pants and rocking, and responds to her need of

reassurance, creating a moment of common understanding between two strangers:

'She was clearly very anxious, gripping her pants with her hands, rocking back and forward. She kept saying 'they won't know where I am' and I really didn't want to leave her on her own so I said I'd wait with her until 'they' came. I tried to re-direct the conversation to her lovely scarf. She was dressed very well, in a coordinated outfit. There was an immediate change about her and she visibly calmed down. She started to run her hands over her scarf, explaining her daughter had brought it for her, like all her clothes. I said her daughter must be very stylish and she agreed with me that she was. The nurse came in then and I took her hand to say goodbye, she gave me such a big smile and gripped my hand for a long time. It felt like she was clinging to me for reassurance that we were both here.'

Maura in the excerpt above, is able to seek out and acknowledge the researcher, despite knowing nothing of her personal attributes or status and the researcher is equally able to recognise and respond to Maura. A unique opportunity is then created for both parties to experience comfort and reassurance from each other. While the resident displays feelings of reassurance and trust in the presence of the researcher, the researcher also experiences and conveys her own understanding of the need for comforting human contact. In responding to the needs of Maura, the

researcher validates the experience, co-constructing an understanding of reality between them within the interaction.

Paying attention to the subtle embodied expressions of people with advanced dementia, who are often restricted in their physical movement, allows for greater recognition of their needs. In this excerpt, the resident expresses discomfort and confusion both verbally and physically. While the verbal communication between the researcher and resident does little to achieve an understanding of what is needed, the physical interaction through touch and attentive behaviour provides comfort and resolution:

Suddenly she starts to pull her blankets off her, asking me to help. 'I'm too hot' she says. She pulls them off and her legs are so thin. I'm too hot, I can't breathe. I ask her would she like to open the window. She says she would. Once I sit back down again, she says she can't breathe. I'm watching her closely and she is breathing normally, but also holding her hands up, reaching out for something. 'I'm dying' she says repeatedly. 'No you're not.' I try to reassure her. I take her hand and she strokes mine gently. Her fingers are so thin. She might be dying; how would I know? She starts to run her fingers over my watch. She asks me what time it is. 'Three'. 'I'll be dead by four' she tells me. Does she believe this? Is it correct? She seems physically relaxed once I have her hand. She says I'm very good to sit with her. I wonder does she think this is her death bed? After a while, she says her legs are sore,

could I help her move them. 'If I could just stand up' she states. Her legs have been badly ulcerated and crossed over each other. I uncross them gently and she makes a sound that expresses some relief. She seems better now. I put the covers back over her. She's more relaxed and seems to be restful. I'm still afraid she might die right here. But she doesn't. Once she's sleepy enough to be relaxed I leave her.

Responding to the non-verbal communicative cues and embodied actions of people with advanced dementia provides more opportunities for listening and recognising each other. The importance of touch is further reiterated when considering other physical and cognitive challenges such as hearing loss or visual impairment. This embodied recognition reiterates Honneth's [64] concept of mutual recognition by extending the ways in which mutual understanding is achieved through bodily communication. In this respect, embodied recognition opens new opportunities for designing for and with people with advanced dementia, which will be further discussed in the final section of the paper.

Recognition of Other

The ability to give recognition to others is closely associated with cognitive capability and has therefore been questioned for people with advanced dementia [135]. In addition, their ability to contribute to relationships and engage in mutual recognition has been overlooked. In contrast, our ethnographic work showed that people with advanced

dementia can demonstrate their concern and care for others, whether that be concern for family members, other residents or staff, thus are fully capable of engaging in the process of (mutual) recognition. Often, and in the example below, the person with dementia expresses concern for their family members, such as parents, who have passed away, as if they are still alive [104]. Such expressions of concern are routinely treated as mere memory loss, but considering those from a recognition lens, reframes them to expressions of concern and care towards another person. Patricia's expression of concern for her mother who she had cared for throughout her lifetime, illustrates her capacity to recognise others and their needs:

'Patricia is brought in. She is always dressed immaculately. The minute she is set down at the table she says she has to be off, her mother won't know where she is. Staff -and some residents- try to reassure her. The only thing that seems to calm her is to hear that they've called her mother, who told her to enjoy herself. She mentions her mother is 'a kind of a nervous person you know.'

By extending concern for family members and visitors, the residents demonstrate their ability to recognise, consider and care for others, a key element of mutual recognition [64]. Considering such expressions of care from the person with advanced dementia as a form of recognition and not merely memory loss, frames a different understanding of people with

advanced dementia, their capability of recognising others and contributing to a caring social environment.

Through the analysis of these interactions with people with advanced dementia, we can see how responding to their embodied, emotive expressions, based on an understanding of an underlying respect and need for the other, creates moments of recognition which are often poignant, meaningful and caring.

Conflicts of Recognition

Ideally, for moments of mutual recognition to occur, two individuals need to acknowledge, respect and respond to each other's presence and contribution [66]. However, due to the nature of advanced dementia, the person can have a very different concept of reality, fragmented impressions of others and may express concerns or requests that are difficult, or impossible, to respond to. Equally, from a carer's point of view, concerns for the safety, comfort and ultimate well-being of people with advanced dementia can result in tensions of recognition. The contested area between the duty to provide care for people living with multi-morbidities (such as people with advanced dementia) and respecting their expressed requests, was part of our everyday interactions in the care home and raised questions about the nature of recognition in carrying out research within this space. The following theme presents and discusses

some of the everyday interactions that challenged the concept of mutual recognition during this ethnography.

Considering Safety

For people with advanced dementia, their physical care paired with an increased anxiety and confusion about their surroundings can result in conflicts of needs, in which the physical safety of the residents is often considered more pressing than recognising their wants. For example, the following interaction demonstrates the use of compromise and false promises as a means of distracting and comforting a resident requesting to leave the care home. To go along with her request would recognise her wants, but it would also mean disregarding her vulnerable position and potentially endanger her:

'One lady was brought out by a nurse to ask when the bus was going. The nurse was trying to reassure her but also distract her. She was told the bus wouldn't be up until 7- and they'd come to get her. They were very patient with her. She looks visibly anxious, clutching her money in her hand. It's hard to know what you could do there except go along with it?

'White lies' and false promises in dementia care [33] are often used as a means of protecting and, as such, they are difficult to dismiss. For instance, as in the above excerpt, to bring a person with advanced dementia to the bus stop would disregard their basic need for safety. However, equally it

can be argued that white lies undermine the cognitive capabilities resulting in misrecognition of their individual experience and unique needs [50].

An awareness of the potential harm which people with advanced dementia may be to themselves can also result in conflicts of recognition which the carer or researcher must acknowledge and carefully consider their response. In the following interaction, the researcher's understanding of the potential risk of falling forces her to disregard (and misrecognise) the requests of the resident Mary:

'I tried to reassure Mary that the nurses know where she is, and they will come and get her if they need her, but she can only be calmed down for about two minutes before saying again that she needs to leave. She keeps trying to stand up and taking the break off her wheelchair. At this stage, I'm really worried that she'll end up hurting herself and try to gently get her to sit back down, placing my hand on her arm and her shoulder to reassure her.'

This interaction highlights a contested space for recognition, as one questions which aspects of the person (their desire to leave or their safety) should be recognised. Another facet of the above tension that needs to be considered, involves recognition of the illness and respecting the confines which people with advanced dementia may be unaware of. With regards to recognition, this moves away from moments of clear reciprocal respect for

the other person, towards a consideration that one's knowledge, and respect for the person's illness is also in need of recognition at times, and may outweigh their requests to engage in activities that are potentially very harmful. In this sense, there are layers of recognition required, only some of which are possible to adequately respond to.

Acknowledging Misrecognition

Due to the nature of the illness, the person with advanced dementia can have fragmented or intermittent impressions of others. This poses significant challenges for carers and researchers alike as they must acknowledge and cope with misrecognition as part of their recognition of the illness. Having to re-introduce oneself or disregard previous encounters creates a unique dynamic in the development and sustaining of the relationship/rapport between the researcher and the resident and further challenges consent as part of the research partnership. It can result in contested moments as the researcher can assume a position within the care ecology, which the person with advanced dementia cannot draw on to construct an understanding of the relationship:

'I feel awkward as Brid hasn't said anything. I try to be friendly and start a conversation. 'Brid I've brought you some music' and start to play it. She looks up at me then 'Who says you can be in here?' she asks me. 'I just came to say hello,' I reply, trying to stay light, and change the mood. 'It's the same thing, people always looking at me, like an animal in a zoo.' 'I'm sick of it.' I

say to her that it must be really hard. 'I don't want you in here' she says, her voice rising 'GET OUT, GET OUT NOW.' 'Okay Brid, I'll go so, leave you in peace.' I get up and say goodbye, trying to remain calm and not react.'

Confusion and agitation can also manifest on the part of the person with advanced dementia and alleviating those is often not possible despite the researcher's best intentions as can been seen both in the excerpt above and below. In the following example, we present an interaction where the researcher was unable to comfort Sheila, a resident with advanced dementia, highlighting how it is equally important to recognise our sometimes limited response repertories:

Today Sheila is very adamant she needs to leave...As the musician continues, Sheila starts to get restless, rocking forward in her chair, sometimes jerking her whole body as if she's getting a fright every few minutes. She starts muttering, which I realise are prayers to God, Jesus, Mary and Joseph to help her. Every time a song finishes she asks me if it's nearly over, sometimes asking the musician to 'please stop' in a helpless bid to get out of here...Usually I think of distractions and little white lies as kindness, but today I really feel awful that I had to lie to her, that I couldn't do anything to reassure her. It's only afterwards when thinking about it that I realise that maybe all along I've been waiting for some idea, some trick that will relieve

this kind of suffering for people in the advanced stages, with this lady in particular in mind. And I think that maybe I need to let go of the idea that I can make this situation any better.'

Within these interactions, we can see that while carrying out research in this context is well-intentioned, it may not always be an appropriate time, or in the best interest of the well-being of the resident. Considering recognition, and how it can be adopted within a research approach, it is important to respect the needs of the participant in that time and space, while also acknowledging the emotional impact that attempts to establish mutual recognition may have on the researcher when interactions are not fruitfully engaging. In both cases above, mutual recognition did not occur, as neither individual could respond positively to the other. However, it is important to recognise this as an element of advanced dementia, in which seamless, reciprocal engagement is not always possible.

Within this theme we presented a number of interactions in which the researcher's responses did little to satisfy or assure the residents in their distress, and could be viewed as a failure in terms of mutual recognition [50]. This contested area in dementia care and design offers some important insights into the aspects of the person with dementia that we cannot recognise, highlighting further the importance of recognising people with advanced dementia in our design practices when it is possible.

Recognition through Agency

Key facets of recognition such as respect and esteem [55] results from a person's role or contribution to the social world, for example by means of their job or civic duty [51]. For people living with advanced dementia, their right to work or contribute through civic engagement is often the first significant role that they lose [38] and this lack of opportunity to contribute continues as the illness progresses, and the need for physical care increases. However, our recognition-theory informed ethnography showed that it is possible for people with advanced dementia to play an active role in the lives of others and in turn be recognised for doing so, thus gaining esteem and respect. This was possible through structured activities that respect their sense of agency within the care home and through engaging in everyday collaborative acts with people with advanced dementia.

Respecting Agency through Activities

In our fieldwork the organised activities in the care home were seen as opportunities for fostering meaningful social relationships between residents, staff and volunteers, and supporting the residents to draw on their capabilities for social contribution. In the following excerpt, the group activity of baking a cake, which is carefully crafted to accommodate the interests and talents of each group member, is seen to create

opportunities for each member of the group to express their agentic capabilities while working together:

'Once things started to get going and everyone had jobs to do, the mood changed and the chat became lighter and people were joking around. I find their humour funny and often surprising, although I shouldn't at this stage. They're making fun of each other, in an affectionate way. They joked again about the time they made biscuits that were rock hard. 'We never laughed so hard' one lady remarked repeatedly. I was really relieved to sense that the mood had picked up, mostly because I didn't want the residents to feel anger or frustration towards Kate, who is clearly trying her best on her own.'

The above extract highlights how supporting the agency and capabilities of the residents can be challenging, when striking the balance between accommodating everyone in the group to feel useful/occupied, while also ensuring those who need extra support receive it, all the while working towards a common goal (making the cake). As expressed by the residents, being unoccupied can cause frustration, highlighting further the barriers to contributing, such as moving about to get the utensils and ingredients. However, once adequately supported, working together creates space for inside jokes, working patterns and common understandings, creating group cohesion. In such organised activities, agency can be clearly supported through the ways in which the tasks are put together, while also considering how to recognise the contribution of

each individual as a means of extending respect and esteem for their achievements. In terms of recognition, supporting the contribution of the residents is an important aspect of realising mutuality.

Collaborative Acts

Approaching interactions with the residents in care as opportunities for collaboration, and with recognition for their need and ability to exert (a sense of) agency can result in dialogical incidences, in which the person with advanced dementia shapes and leads the interactions, in a moment by moment exchange between individuals who respect the agency of the other. In the following two examples, we see the subtle ways in which the person with dementia leads the activities or how conversation allows for expression of their sense of agency. In the first excerpt, the resident is setting the pace of the interaction between her and the researcher:

'I knocked on her door just as she was leaving the bathroom and she said she'll come down with me now. She's mobile but travels in a wheelchair for safety and comfort. She asked me do I mind if she gets a glass of water before we go. I tell her to take her time, there is no hurry. She pours herself a glass of water and I think about asking does she need me to do it but then decide not to, as she is clearly able. She offers me a glass too but I tell her I'm fine, I just had my lunch. She says she'll just sit down in her chair to drink it and tells

me I should sit down too. I sit on the end of her bed, mostly because I don't want to rush her.'

The opportunities to recognise the agency of people with advanced dementia are often subtle, but nonetheless can show respect for the individual, resulting in collaborative, dialogical acts in which both individuals recognise each other and work together. In this example, the resident's setting the pace of the activity supports both her needs as a patient, and a recognition of one's need for agency, and contribution to the social world. Moments of true collaboration, in which both individuals are working towards a common goal and exerting their agency in respect to the other are somewhat rare, but nevertheless possible, within the advanced stages of dementia. The following example showcases how an understanding was established through small acts of collaboration, building up to a moment where the researcher and Carol engaged in the act of painting her nails, a common, but often challenging, act of care. As highlighted by staff members, the success of this collaboration was not common or guaranteed with Carol, and can be attributed to the building up of morale and understanding through respectful interactions:

'Sit yourself down there' Carol says indicating that I sit beside her. 'I will of course', and I pull up a chair. I ask her if she wants to get her nails done. She seems confused by the question so I take her hand and move my fingers

over her nails… 'They could do with a paint over' and she doesn't protest so I get the remover and start taking it off. 'This is a lovely room' she says, looking around. She is also taking in the women around her and smiling. Her nails are nearly clean at this stage. 'This is what I like…Perfect Peace'. This makes me smile, what a lovely response. 'What did she say?' the woman beside me asks. So I repeat it. This makes the women around us and the volunteers smile too. I pick up a pink and ask her if she likes that, she nods in approval so I take her hand and start painting. Her hand is gripping mine, which makes it more difficult to paint but I manage. Kate comes back them and gives me a nod as if she's very surprised. 'You're on a winner' she says, 'she'd never let you do that.' She brings out the cakes then that we've made in the morning. 'For me?' Carol asks when she's given one. 'Well you made them so you deserve one,' I say. 'I did?' She has no recollection of this morning, so I brush it off. 'Is the cake nice?' 'Lovely,' she says.'

This interaction highlights the ways in which successful collaboration and understanding between the resident and researcher is not based purely on memory of previous interactions, but rather moment-by-moment negotiation through collaboration, allowing the person with dementia to decide on the nature of the engagement, which in this case results in an 'opening up' in the interaction and more successful mutual recognition.

The importance of respecting one's needs as an agentic being, beyond that of a patient with dementia is integral to the overall quality of care provided for people with advanced dementia. Our ethnographic work has shown that there are opportunities to recognise the contribution of people with advanced dementia within their social world and as part of residential care while at the same time attending to their basic needs for safety and physical care. This may require extending our understanding of what we traditionally consider 'contribution' [51] and considering the ways in which people with advanced dementia contribute to their social worlds, building on this within our approaches to interactions and design of interactions in HCI.

Design Considerations

Our findings provide insight into the experience of advanced dementia and the nature of recognition in practice within the care home context. It is evident that advanced dementia is a multifaceted, complex experience, which does not consist solely of the symptoms associated with the disease, but many expressions of the need to belong and engage. This ethnography and the moral commitments entailed in Recognition Theory suggest an alternative approach to designing for and with people with advanced dementia. For example, approaching their gestures, and their talk about people long since gone as efforts to communicate and make meaningful

contact with the other can be considered opportunities for recognition [30]. The communicative actions of people with advanced dementia are easy to dismiss as cognitive or interpersonal failings. But what would their world be like if we –as moral beings and HCI practitioners– instead accepted their gestures at face value, as attempts to communicate and make meaning. This is the methodological and practical starting point of an approach to designing for recognition that this ethnography suggests.

Design practices in HCI that look out for and pay attention to these gestures could support embodied, communicative forms of mutual recognition. Designing with someone who finds it difficult to communicate their feelings, preferences and state of mind but who keeps on trying, deserves a meaningful response, both intersubjective and through design. The challenge is for us to find ways of responding which are supportive and enriching, while acknowledging the difficulties faced by people with advanced dementia. The theory of recognition provides us with a clear goal to hold our design processes and outcomes against.

Drawing on the social theory of recognition as practice in the day-to-day interactions with people with advanced dementia has highlighted many potential opportunities for further recognising the experience of advanced dementia as well as designing for such moments of recognition. However, this requires a certain extension of the role of the researcher that is more akin to that of a carer. It was our experience that establishing

mutual recognition can be both difficult and intense, as the nature of interaction is often fractured and dependent on the pragmatic needs of security and reassurance, but is nonetheless possible.

The aim when designing for recognition in advanced dementia is finding design responses which enable the boundaries of experience to be tested and stretched. In order to achieve this, we must reflect on our role within this design space, our motivations -and restrictions- in realising recognition with and for the person with advanced dementia. For example, when engaging with people with advanced dementia, there can be an instinctive reaction to try to distract them when they need something that is unobtainable, such as going home, calling family members who have passed away, or helping them onto their feet so they can walk. Often, we try to distract, not in a way that is disrespectful, but as a means of alleviating the discomfort. However, it is important to admit on reflection, that the need to alleviate our own discomfort in the face of suffering can also play a role in how we interact with people with advanced dementia, and how we design for them as potential users. We must question our motivation for design, and the potential consequences of our outputs in failing to respond to and recognise the experiences we have observed. A failure to acknowledge this can be considered misrecognition, as it does not appreciate the lived experience of the person with advanced dementia. However, misrecognition in this context is complex, as we are restricted in

responding to the requests of people with advanced dementia, both practically and ethically. Within HCI, we can explore more specifically the practical risks of recognition and the subtle difference between recognising an able person who may not be as able as recognition signifies (e.g. allowing a blind person to walk into the road), as opposed to misrecognising them as unable, so never trying anything and letting them fade away socially and phenomenologically. For people with advanced dementia to be fully recognised, we must accept their vulnerability and suffering, and respond to the creative, emotive communication they offer us.

From a HCI perspective, the ability to respond through inclusive design practices presents opportunities to increase recognition in this context. One inclusive design response would be to focus on creating environments that enable people with advanced dementia to better participate, be heard and listened to. Designing inclusive environments rather than prosthetic environments will ensure that there is a space in which other kinds of communication are available to you and in which I can recognise your creativity and you can recognise mine. In deriving and presenting our findings under the critical lens of recognition theory, we highlight the ways in which people with advanced dementia express and respond to the need to be recognised.

Our findings echo previous work in dementia and HCI which has highlighted the nature of embodied expressions of selfhood [108], the need to support relationships [53], and the potential of design to support agency [91] but our analysis and findings are also different in ways to what those other approaches offer. By focusing on the experience of advanced dementia, we wish to encourage greater engagement with this experience, as well as argue for their inclusion in design and research. This requires an in-depth examination and acceptance of some of the more difficult aspects of dementia, while focusing on the opportunities to engage in design practices which recognise people with advanced dementia as capable of making social contribution, as well as our ethical obligation to ensure their experience is included within universal design outcomes.

Implications for Design

As discussed earlier, the need for physical and medical care that is central to the experience of advanced dementia can often result in overlooking the importance of recognition for one's agency in the context of care for people with advanced dementia. Respecting the other, and taking their actions as legitimate expressions of their agency, is a key component of ensuring recognition occurs, and can be supported through design interventions. The theory of recognition offers important conceptual arguments for the need for recognition within wider societal

context – and we have also argued for its value within experience-centred design for dementia care [under review]. Continuing with this work, the current ethnography has provided detailed accounts of recognition in practice as well as a set of pragmatic pointers in the form of considerations for those who wish to design for and with the values of recognition theory. These are presented below.

The Person with Dementia as a Source of Recognition

When designing in the context of advanced dementia for and with the values of recognition, it is important to keep in mind that the person with advanced dementia is a primary source of recognition, often expressed in tacit ways. Existing design interventions in advanced dementia care have primarily emphasised symptom management and monitoring [114]. We argue that this can result in a lack of opportunities for the person with dementia to be viewed as a source of recognition for those around them, an integral aspect of achieving mutuality and recognition [135]. Our analysis highlights various incidences in which the participants expressed concern and care for others, which can be drawn on as a source of recognition. Such expressions of care need to be supported and will support the person with dementia to engage in mutual acts of recognition. People with advanced dementia often express the desire or need to be part of a social environment [135], to engage in collaborative action [139], and the co-creation of experience [84, 101]. Including them in design processes

will create space for this kind of mutual recognition, with a particular focus on their role in the recognition process [64].

Anchoring Collaboration and Sense-Making in the Physical World.

As shown in our work, moments of (mutual) recognition, and meaning co-creation were supported through anchoring collaborative actions and sense-making in the physical world. For example, the use of tangible objects with personal meaning, such as the woman and her scarf, are 'ways in' to establishing mutual recognition. It is also worth noting that being involved in a conversation, whatever the content of it may be, can create a sense of belonging in which the person with dementia is recognised for their basic need for belonging and social contribution [64], a key component of establishing recognition. In terms of design, using tools or probes, a common design practice [139], to encourage and anchor the conversation in advanced dementia creates opportunities for mutual recognition to occur. As shown in our analysis, embodied communication [84] is also a strength of people with advanced dementia. Design outcomes and processes which support non-verbal cues such as the use of touch, gaze and physical objects, can encourage a sense of basic recognition of the need to belong within social groups.

Designing for Agency

Our analysis offers insight into the subtle ways in which people with advanced dementia can express their agency; through acts of collaboration,

ability to participate in group activities, and expressions of their needs and preferences. Recognition Theory emphasises the need to contribute to one's social world, and the ways in which traditional forms of contribution, such as the ability to work and engage in civic activities have been an important source of recognition for many individuals in care [50]. Design interventions and in particular co-design processes that take the agency of the person with advanced dementia as fully established, can create opportunities for people with advanced dementia to express their capabilities and knowledge and collaborate with others. Design spaces can support acts of recognition of this agency, through the provision of materials, exploration of the interests of the person, considering all expressions of participation as worthwhile and supporting them to engage in whichever way they wish to. At the same time, such design efforts must also acknowledge that their agency can be different (depending on wheelchairs for mobility, being confined to the care home and the resources of this context, living within a routine of set care activities) as well as the physical and psychological aspects of the lived experience, such as arthritis, impaired vision and hearing as well as an increased need for rest and reassurance and consider appropriate ways to address such limitations. Design responses should be sensitive to this, but also encourage gentle pushing of the boundaries of what has been typically considered the capabilities of people with advanced dementia as a means

of exerting their agency in an environment in which they are largely restricted. In finding the balance between recognising these different aspects of the individual, we get closer to full recognition.

Broadening Design Participation/Membership

Recognition theory emphasises the role of caring relationships as a source of recognition throughout our lives. For people living with advanced dementia and those closely invested in their care, it is important to acknowledge the need for support in continuing to recognise the person with dementia within their new lived experience. Design interventions can support this by widening the ecology of care to include, for example, family members, community volunteers and staff. This can encourage them to view the person with advanced dementia in a different position, as an equal agent and source of knowledge, care and recognition for others. Basing design processes on the lived experience of people with advanced dementia may require working with family members and friends, which is also an opportunity to increase recognition and encourage reflection on previous acts of recognition from the person with advanced dementia [135], which can often be forgotten while families re-configure their relationships. While it is important not to replace the person with dementia with their family member as the source of knowledge or conversation, encouraging participation amongst family members and staff is a key opportunity for mutual recognition [65]. Setting up inclusive

design processes helps counteract the idea of grouping people with advanced dementia together as the 'other' [50] and instead positions them as a valued member of a community. Having one-on-one conversations, being a member of a social group, exchanging stories and listening to each other are often considered to be beyond the realm of interest of people with advanced dementia, which can lead to misrecognition of their experience [64]. HCI research can provide opportunities for recognition for all involved in the process, encouraging an engagement with the lived experiences of the person in care, which can be shared with others, and used as the basis of mutual recognition and design.

Conclusion

In this paper, we presented our application of recognition theory to the experience of people with advanced dementia, with a view to increasing sensitive engagement within design processes. We underline the basis of a HCI approach which seeks to honour the need for recognition as a fundamental right, and the potential of design spaces to encourage engagement with people with advanced dementia. Our findings convey the embodied, mutual interactions which are possible in advanced dementia care. Applying these findings to design practices and outcomes frames a design process which supports the agency of people with advanced dementia, creating social inclusion within design spaces.

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Chapter 5: Student Engagement in Sensitive Design Contexts: A Case Study in Dementia Care[3]

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Abstract

There is a growing body of HCI work that seeks to understand and enhance the lived experience of people with dementia. The majority of this work involves researchers working alongside people with dementia and their carers, focusing on the design project outcomes. In order to enrich the social context of this design work, we have explored broadening participation to include student volunteers. To encourage mutually engaging and empathetic experiences in this design context, careful consideration of how to support both students and people with dementia was needed. In this paper, we present two case studies of design projects between students and people with dementia. Our findings detail the students' empathetic learning process and explain the use of design processes to reconfigure the role of the residents in the care context. We

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discuss the project learning outcomes as well as practical and ethical considerations to support mutual engagement in sensitive design contexts.

Author Keywords

Dementia; Intergenerational Engagement; Co-Design; Experience-centred design.

ACM Classification Keywords

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

Introduction

Dementia is a neuro-degenerative disease which results in a progressive decline in cognitive functioning. The experience of dementia can vary greatly, depending on the cause [60] and the stage of dementia the person is experiencing [106]. Many people experience a change in cognitive functioning, as memory, decision making and abstract thinking can be affected. The nature of dementia and the social structures which have been developed to care for those living with the condition often result in the reduction of social opportunities to engage in the community [118]. Design processes that support positive relational experiences can provide opportunities for creative expressions of selfhood in dementia care [91, 140, 150]. Broadening design participation to include student volunteers has the potential to increase positive social engagement in this context. Bringing students and people with dementia together to explore creative expressions of personhood, while building inter-personal skills, may result in important personal development for all those involved. Within these

design processes, striking the balance between supporting the agency of both parties, and scaffolding the design process in a way that is mutually engaging, requires careful consideration.

In recent years, HCI has begun to consider the role of design in healthcare, as a process which can bring meaning [136], foster empathy [93] and help establish enriching relationships [150] in otherwise clinical settings. The role of this work in 'reconfiguring the user' [144] has positioned the user in the design context as a person with a rich lived experience, who has the potential to add meaning to the design process and the right to express their agentic abilities within this context [90]. The turn to experience [98] has resulted in an examination of not only how the user engages with technology and design, but also the positioning of the design experience itself as a meaningful activity. In this paper we present two design case studies that brought together people with dementia in residential care and volunteer university students: 'Life Story Box' and 'History Club'. In this project, we aimed to reconfigure the role of the residents in care, as respected experts capable of engaging in mutually beneficial relationships. Our findings identify some of the key considerations when supporting individuals throughout the design process, and the types of mutually beneficial relationships which develop within this context. We conclude with reflections on how to support design processes with populations that are typically considered vulnerable in research settings. We also discuss

the sensitive issues which arise when designing in this context and their implications for HCI, such as the ethical implications of beginning and ending projects, the role of the researcher in facilitation, and the value of examining student engagement in the dementia ecology of care.

Background and Related Work

Recent work in HCI and dementia has explored the design process as a means of creating inclusive environments in a research field which has traditionally positioned the person with dementia as 'passive' or unable to contribute to the design process [129]. In this section, we first present recent work in design and dementia, which has focused on design processes as an opportunity to explore and evolve the relational aspects of care. We then present a small but growing body of work in HCI that seeks to broaden design participation.

Dementia and Design

The inclusion of people with dementia in research processes requires careful consideration of the experience of the person with dementia, as well as navigating the various barriers to including people with dementia in research, such as policy [1] gate-keeping and participant burden [61]. Where design research is possible, it has the potential to create open, creative processes which allow for the exploration of what it means to live

with dementia and how relationships can be fostered and nurtured through this process.

Many design projects take a person-centred approach to their research, which has been heavily influenced by Kitwood's work on the importance of honouring the personhood of the individual with dementia, seeing beyond the illness to create socially orientated approaches to care and design [79, 81]. Building on person-centred care in HCI, the work of Wallace et al. [151] reports on designing artefacts to explore the personhood of the individual with dementia, while also examining the empathetic relational dynamic which evolved as the design process continued. Lazar et al. [91] also examined the role of co-creative relationships, between art therapists and people with dementia in residential care, to explore the use of technology in this context to further engage and support the creative process. Fostering and supporting relationships was central to the work of Morrissey et al. [111], who examined the use of 'Swaytheband' to encourage people with dementia to enjoy music sessions together. These projects highlight the use of design to support relationships between people with dementia and those engaged in their care.

Designing for emotion and connection is a route to further understanding the experience of dementia. In their work, Treadaway and Kenning [138] explore the use of exploratory co-design processes to improve well-being

for people in the advanced stages of dementia [78, 138, 139]. The inclusion of people with advanced dementia in creative processes, such as working with e-textiles [139], crafts [78] and baking [141] highlights the design process as an opportunity for well-being 'in the moment' and designing for positive emotions [140]. Introducing design projects into contexts such as residential care with people with dementia, requires an approach which supports meaningful engagement, while being sensitive to the needs of the participants [93]. Many projects in HCI have shown an appreciation for empathy as a path to enriching design [149, 155], in which the experience of the participant is fully considered and responded to positively. Due to the nature of dementia, Foley et al. [45] argue that empathy may not go far enough, as we first need to recognise the person with dementia as an agentic being, capable of engaging in mutually beneficial relationships [45]. Recognising the person with dementia as an active contributor to their social world and expanding design participation may be a route to examining these social processes further.

Expanding Design Participation

Creating design processes which encourage better communication with people with dementia has resulted in an increase in the design of artefacts which are open to enhancement, manipulation and personalisation [17, 62, 152]. Branco et al. [17] took an 'open design' approach to creating probes

and board games to encourage communication and fun amongst families. By including people with dementia and their families in the design processes and encouraging them to continue to adapt the design after to match their changing needs as a family, this project conveys the importance of 'design after design' as a means of supporting the creativity and ability of the person with dementia [17].

While research often focuses on the dyad of the person with dementia and their primary carer, recent work in HCI has examined the experience of volunteer caregivers as key members in the ecology of care [47, 48]. Foong et al. [47, 48] positioned volunteers as central to enhancing the quality of care for people with dementia, by designing an interactive system to integrate volunteer caregivers' knowledge of the daily experience of the person they were caring for into their medical records. Supporting volunteers in this context can enhance care practices and broaden the opportunity for positive social interactions. Considering the needs of younger people within the dementia care context, further widens the care ecology. In their work, McNaney et al. [102] examined the role of younger people in dementia care and the potential of technology to support communication. Building on this work, Welsh et al. [152] designed 'Ticket-to-Talk', a smart phone application used to support intergenerational engagement by encouraging younger people to set up digital profiles for the person with dementia, which held their favourite photographs, music

and films. This work highlighted the role of younger people in systems of care, and the potential to extend the use of technology as a meaningful resource for people with dementia.

While a theoretical understanding of social processes such as empathy and agency is important to critically examine and design for lived experience, it is perhaps just as vital to examine how these incidences of empathy and mutuality unfold practically, between people who are not particularly concerned with the theory behind human experience, but instead are very much engaged in the process itself. Through supporting people with dementia and students to engage in design processes which aim to foster empathy and support agency through mutually engaging design work, we can examine the practical and inter-personal outcomes of these kinds of projects. In this work, we considered the complexity of navigating and supporting these relationship processes, while aiming to set up design processes which 1) supported mutual engagement and learning and 2) explored the need to 're-configure' the positioning of the person with dementia, with a view to recognising their agency. This mutually beneficial experience, in which both students and people with dementia are supported to engage in personal development through interacting with each other, is central to our design agenda. If adequately supported, it can result in enriching design experiences which broaden participation for

people with dementia through mutual recognition of each other's worth between them and the student volunteers.

Method

This paper builds on our previous work involving a two-year ethnography in the state-funded residential care unit 'Oakfield House'. As part of the present project, we recruited eight student volunteers to engage in design projects with the residents, with the aim of enhancing the social opportunities in the care home. In the following section, we describe the setting, participants and design approach of our study.

Setting

This project took place over the course of 18 months in 'Oakfield House' a residential care unit which is home to approximately 90 people, many of whom are living with mild cognitive impairment or a form of dementia (approx. 80%). In the first phase of this research, the first author carried out an ethnographic study, taking part in the activities in the care home, such as art and crafts, music sessions, day trips and Life Story Work [101]. The findings from this phase of ethnography recommended a 'broadening of design participation' as a means of ensuring the residents had more opportunities to engage in enriching social encounters. In response, we recruited undergraduate students who were undertaking a 'psychology in

the community' module, which required them to spend 70 hours volunteering over the course of two semesters.

Participants

We worked with 8 students over the course of 18 months, three in the first year and five in the second. The students were all undergraduate psychology students, who were considered co-researchers and co-designers throughout the project. The students worked with residents who had received a diagnosis of dementia and who staff felt would enjoy and benefit from more social engagement. In the table below we present the residents we worked with and their diagnosis.

Table 1. Residents taking part in the study and their diagnosis of dementia (pseudonyms have been appointed).

Participant	**Diagnosis**	**Case Study**
May	Advanced Dementia	Life Story Box
Maeve	Lewy-Body Dementia	Life Story Box
Charlie	Dementia	History Club
John	Mild-cognitive Impairment	History Club
Marcus	Parkinson's Disease	History Club

Joseph	Multiple Sclerosis	History Club

Ethics

Ethics was sought and approved by the School of Applied Psychology Ethics Board and the management of the care home. We also consulted with the residents and their family members about the nature of the project and it was explained to them that they could stop taking part in the project at any stage. Obtaining consent from people with dementia is a contested issue and we were sensitive to the need to continuously assess the needs of the resident each week. The nature of participation in this project, in which two groups of potentially vulnerable people were encouraged to engage meaningfully, required an application of practical ethics throughout the design process [10]. In this respect, the role of the lead researcher was key in ensuring the project progressed ethically. We will discuss these ethical considerations in detail in later sections.

Findings

In this section we present the findings of our thematic analysis, which detail the experience of the design process and reflections on the work carried out. The constructed themes and sub-themes detail the relationships developed through the design projects, and the resulting enhanced empathy and agency for those involved.

Case Study One: Life Story Boxes

This project involved three students working closely with residents, visiting on a weekly basis over the course of two semesters. The Life Story Boxes were created by the students and residents to represent the life of the resident, taking physical form through the design of personalised artefacts (see figure 1). This approach was informed by the common form of 'Life Story Work' which is used in dementia care as a type of reminiscence therapy, but is usually presented in the form of a book [101]. The aim of the boxes was to encourage others to engage in the stories of the residents, aided by physical probes such as maps, photos, vanity items, postcards and quotes. The students worked with the residents to design and craft the Life Story Boxes, curating the content of the box over time by bringing in probes which represented the conversations they were having with the residents. The Life Story Boxes also represented the relationship forged between the students and the residents, and contained photographs of the students, documenting the new friendships. This element of the boxes was chosen to indicate that the focus was not only on the past experiences, but represented present and future possibilities of developing meaningful relationships in the care home. As a result of this work, the students and residents formed a close working relationship, which shaped both their understanding of dementia, and provided a valuable learning experience. The following themes were constructed to detail this

experience; Forming new understandings through relationships; Empathy through design; Navigating roles; and Researchers in practice.



Figure 1: Examples of the Life Story Box

Forming new understanding through relationships

Through their engagement with the residents, the students gained insight into the nature of dementia and the capabilities of people with dementia. The students developed a new understanding of what dementia is and how it is experienced, often in contrast to their academic studies of the '*concrete…disorder*'. In the following excerpt, one of the students reflects on how their previous understanding of dementia didn't allow for the fluidity of the experience:

'I didn't have any experience about dementia beforehand. I mean I knew what it was, from books, and we had that module last year…and we

went through dementia and it was like 'oh it's all concrete'. It's all like funnelled into one...disorder. Whereas then you come in here and it's like, everyone is completely different in the way that they act and some days they're bad, some days they're good... some days you could see they have dementia and then other days you're like 'don't see what's wrong with them whatsoever.'

As the students' empathy developed, they were able to discern between the 'good' and 'bad' days for residents. They could see that life in the care home had some of the rhythms of life experienced elsewhere and that people with dementia had days in which they wanted to get involved in the project and other days when they didn't. Their sensitivity toward this and their growing ability to recognise the will of the person with dementia, although sometimes slowing progress of the project, led to more important outcomes in terms of the students and people with dementia being able to see each other as fully fledged people, engaged in something that could be meaningful to both. It opened up the space for an enhanced appreciation of the social capabilities of people with dementia and for developing friendships in this context. The nature of the relationship developed over the course of the project from tentative encounters to open friendliness and concern for each other. At first the students found themselves surprised that the residents would remember them each week and also their ability to communicate clearly:

'Yeah I can't think of any moments that really stuck out, just there was, a few. Maeve said 'Oh how is the psychology going', and it was strange, not strange, but I was surprised that she remembered cause even like, when I talk to someone else, like an older adult in my life, who doesn't have dementia, they wouldn't even remember that, they'd be like 'Oh what course are you doing again?' and she remembered and then, I remember another time too, …. You know Maeve seemed very aware of her, feelings or something, like I remember her saying 'oh I put up a bright face but there's dark clouds behind' or something and I remember thinking that was very, I don't know, just very self-aware.'

The students expressed their surprise at the abilities of the residents at times, particularly when their memory and self-reflection proved to be strong, which contrasted with the students' idea of what dementia involved. The careful language of the student here, in not wanting to label the residents' abilities, conveys a compassion towards the experience of the resident, and a willingness to admit their misunderstandings or prejudice when it came to previous ideas of what people with dementia are capable of. While the students met with the residents once a week, they quickly established an appreciation for the time together, and the personality of the residents. The fondness between the residents and the students grew as the project progressed, as both the

residents and students used familial terms to describe their relationship with each other:

'I was thinking when we were listening, you'd be so lucky if he was your Grandad.'

'*Maeve said to the nurse that came in she had adopted the girls. They loved this, thought it was such a nice thing to say. She asked them to write down their names so she could tell her daughter about them*.'

In these examples, comparing the developing relationships to family indicates a growing fondness and mutually positive relationship between the residents and students. Maeves' request to write down the names of the students to share with her family suggests her investment in the relationship.

This theme conveys how the development of personal relationships between the students and residents resulted in a more nuanced and compassionate understanding of what it means to live with dementia. It also highlights the development of students' understanding of the complexity of the experience and the project, making it possible to engage in mutually beneficial interactions with the residents.

Empathy through design

As a result of learning about the lives of the residents, the students developed a sense of empathy for both the illness they were experiencing and the way in which the label of dementia can cloud the other facets of the individual. In wanting to engage and find common ground with the residents, the students became sensitive to the confined experiences of the residents in care, resulting in recognition of their agency, and how it can become stifled in their current situation:

'You know, May talked about not being able to clean, or cook and boil the kettle or whatever. And even for people outside having dementia, not having that freedom is kind of like, even talking about the weather, is difficult when they haven't been outside. Yeah May would say like 'It's cold today' and we'd say 'Oh it's actually getting sunny there.' And how and I was explaining 'oh it's spring' and how the daffodils are growing and like you just don't get to see that here. We can just leave and you know, she can't. She's basically stuck there and... it was another moment that struck me actually, when we showed her a black and white picture of a bicycle and she got so excited and so happy, I think her exact words were, ' This is the best thing I've ever seen.' (Laughs) Just cause (sic) she hadn't seen a bicycle in so long, or like the way we can look up anywhere in the world, you can look up anything on the internet and see so many things, whereas, you're just in that room and see the same objects, the same people.'

In an attempt to find common ground with the residents, the students reflected on their everyday lives, and the ways in which they were restricted, such as not going outside or being able to offer tea to their guests. In this we see a growing empathy for the experience of the residents, and an appreciation for the mundane yet purposeful everyday activities that the student took for granted. This helped the students establish their role, in providing resources to the residents as a means of responding to their interests, such as bringing in a photo of a bicycle, and use the design sessions to explore the interests of the residents. In turn, the recognition of the resident's desire to more actively contribute in the care context (offering tea, being enthusiastic about the project) led to a working relationship that was mutually engaging. The dynamic which evolved here resulted in a mutual recognition of the role of the students and residents, and their potential to work together to enrich the design process.

The students also took on an advocacy role for people with dementia as they were adamant of the need to engage with people with dementia as 'normal people' and wished others would consider the feelings and emotions of the person with dementia as legitimate. They were distressed on behalf of the residents in many cases. In the following example, the first author describes the need for the 'Do Not Resuscitate (DNR)' forms in the resident's medical notes:

'We were talking about the DNR forms that the residents have to fill out- They are always in the first page of their medical notes. I explained that it's not something you'd have time to rummage for. The students thought that it was sad most of them had them. I said it was because most people in here are dying. 'But they're living here' Orla said and she was adamant, which made me stop myself. These students have only been here three weeks at this stage and they already see the residents as living, valued people, who aren't finished with life yet.'

This excerpt provides an example of the fresh insight into the lived and felt life of the resident that the students brought. In clinical settings, the presence of illness and death can become almost banal, and those working in the setting (such as the first author in this example) can become used to these occurrences. However, the students' fresh perspective and their certainty that the residents were very much still living, acts as a reminder of the importance of supporting these types of interactions in care. As a result of establishing the active role the residents were playing in the positive design process, the students were concerned at the idea that the person with dementia was viewed as a 'subject' in research. In the following field notes, we see an example of the students getting frustrated at the language used by a staff member to describe the resident they were working with:

'The nurse said to her that she was our project-no she isn't!' They seemed really annoyed by this as they didn't want her to think that.'

The students' reaction shows a protectiveness over both the resident and the relationship that had formed through this process. The idea that the resident was a 'project' removes their personhood and contribution from the process, suggesting they were an object of study rather than an active participant. The students positioned the resident as an active contributor in their relationship, distancing from the idea that they were an object to be studied, but instead were mutually engaged in shaping the relationship dynamic and direction of the project.

Navigating Roles

Alongside their expressed concern and care, the students were also aware of their role as co-researchers and struggled with how to balance their investment in the project and the person. Students' weekly visits resulted in building a strong bond with the residents over time. This also led to upset and disappointment on the part of the students if sometimes the residents were indisposed due to feeling unwell or having a visitor. The students discussed this growing attachment with the residents with a concern for its implications to the project and themselves, as illustrated in the following excerpt:

Lucy mentioned that she was sad that she couldn't see her (May was asleep). 'I'm worried I'm getting too attached,' she stated nervously. 'It's

better than not being attached to anything.' Eve replied. I could see Lucy considering this...and she agreed.'

While concern for attachment may be due to the understanding of the confined time of the project, the students were also conflicted in their role as researchers, and didn't want the residents to think they were studying them. The need for an exploration of the experience of the resident in order to design the Life Story Boxes resulted in a fondness for the resident, but also a more sensitive awareness of their illness. Channelling this into the design of the Life Story Boxes helped the students and residents to work through this exploration in a creative process between equals. In the example below, we see how they were reluctant to be viewed in a clinical capacity as 'psychologists' in fear it would re-position the resident's idea of them:

'The girls mention that Maeve asked what they studied and they were afraid to say psychology in case she thought they were studying her. Because Maeve is wary of other clinician staff they don't want to put themselves in a similar category.'

Establishing roles in a design process needs careful consideration around power dynamics, particularly when some of the residents have issues with memory, or are wary of the idea of research. In this sense, the use of physical objects, such as crafts made to represent the residents' interests, acted as a reflection of the type of activities they were engaging

in together and helped to re-orientate the residents and students in their role as co-creators. In navigating this, they came to understand that they were there in a research capacity, but deeply engaged in the experience and care of their participants. This resulted in a meaningful experience, in which both parties benefited. Here one of the students describes their perception of the project being mutually beneficial:

'Yeah any time I've ever, after we chat with May, I always go to Lucy, 'Oh that was so good.' and you know, it's always positive feeling you get out of it. No matter what, and I feel like it goes both ways. When we leave May I feel like she has enjoyed talking to us as much as we've enjoyed talking to her you know? And it's just a good feeling.'

In their actions and reflections on the 'Life Story Box' project, the students highlighted an openness to learning, as well as offering a fresh, empathetic thought process when considering the lived experience of the residents. In the following field notes, the actions of Maeve convey her investment in the project, perhaps even surpassing her son's expectations of her ability to engage mutually with the students and the Life Story Box:

'The students were nervous to go in as Maeve's son was visiting. So I went in first. Maeve recognised us immediately. 'Oh Hello' she said. The girls' picture has been added to her wall, alongside the photos of her family. 'You've made the wall of fame' her son tells the girls. Maeve has curlers in her hair and jokes she was getting ready for them. She asks if there back in

college yet, how they've been. As an aside her son says 'she a bit…' and gestures to his head. But she seems in good form. The girls open the box and show Maeve what's inside. They show her the framed picture of a local sea-side town, and she points to her son. Again he starts to say she's confused. But she recognises it as where he lives. 'She'll be telling me all about this tomorrow' he says.

In this example, the social engagement with the students, and her interaction with the photograph provide Maeve with an opportunity to demonstrate her ability to engage in mutually beneficial interactions, widening the scope of communication between her and her son. The addition of the photograph of the students to the wall conveys Maeves' fondness for them, which is also demonstrated in her questions to the students. Her actions here are in contrast to her son's suggestion that she will be confused, positioning her in a more capable role than he expects of her. The new relationships formed between the residents and students may act as a reminder for family and staff of the residents' ability to develop and maintain meaningful connections, furthering recognition of their potential in the care context.

Through their investment in the project, both the students and residents engaged in a positive social exchange, in which care for one another provided an opportunity to refine their interpersonal skills. Recognising the roles the residents were willing to take, we reconfigured

the social nature of the second project to reflect their active contributions more widely.

Case Study Two: History Club

In this second project, building on the individual work carried out with the Life Story Boxes, we were eager to create group activities, which encouraged conversation and highlighted the capabilities of the residents to discuss more serious topics. Whereas the Life Story Box work supported the development of empathic relationships, in the History Club study, we were interested in created opportunities for residents' expertise and voices to be used and recognised. We set up a 'History Club' to encourage conversation about the history of the city, in which the residents would share their memories and teach the students about the city. The name 'History Club' was chosen to avoid the negative association with 'Reminiscence Therapy' in the care home, which was viewed as an activity for those who need help with their memory. Instead, we aimed to create an activity in which people were free to share, or listen, to the stories which connected and divided the residents, such as history, politics and current affairs. The History Club was run over the course of 14 months on a weekly basis with 5 students, with family members, other volunteers and staff. The research team brought in historical pictures, maps, audio clips and videos to support and inspire conversation. Based on the stories of the residents, the students then worked to collect and refine a collection of

photographs in a scrap book which represented the collective lived experience of the residents and the stories they had shared. During the final months of the History Club, the sessions sometimes took on a competitive nature, and we created a series of quiz cards based on the stories shared and knowledge of the residents.

The following themes detail the experience of the students and residents and the type of activities that took place in this case study: Sharing Knowledge; Taking Initiative and; Finding Value in Learning.

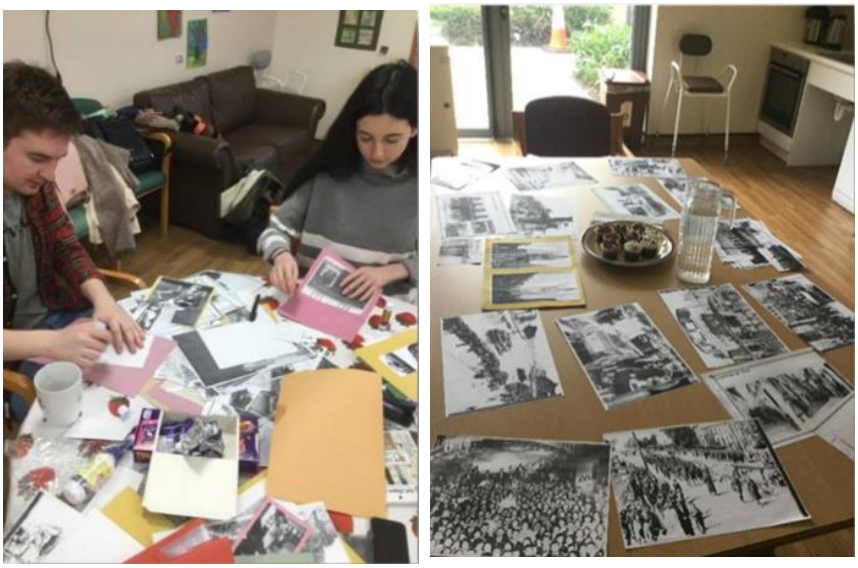


Figure 2: Examples of the History Club

Sharing Knowledge

From the initial session, it was evident that the History Club was an opportunity for residents to engage intellectually on a level that they hadn't previously in the care context. The old photographs depicted various scenes, people and buildings that shaped the 20th century in Cork City. Some photos resonated with the residents more than others, giving them the opportunity to share their stories or knowledge of particular events, such as the following example of a resident who was usually very quiet talking about a famous ambush:

'A conversation starts about Michael Collins (A political figure in the Irish fight for Independence 1890-1922), and I ask the lady beside me if she likes him. 'Yes,' she nods. She's been very quiet up to know but she starts to tell us that her husband's cousins heard the shots that killed him. Kate asks where he was killed. 'Béal na Bláth' she answers correctly. I pull up a picture of it and she confirms that it's the place, nodding her head. She becomes the person we turn to when someone gives an opinion on Michael Collins. I'm surprised at this, because during other activities she seems not to keep up with what's happening, but here in this conversation, she has become the expert.'

By providing the photographs, this resident had the opportunity to communicate her knowledge on a very particular topic and becomes the expert in the social group. This resulted in a re-configuration of her role,

from passive to active contributor, allowing for a recognition of her intellectual ability. In the following example, we see how the support of the photographs, along with the audience, inspired one of the residents to speak about his views on the political history of Ireland:

'Sitting around the table with the pictures laid out in front of us, Charlie leads the conversation. We spoke mostly about things that have changed in the last hundred years, from the railway, to the way our country was run. Charlie spoke of the 1800s and how the British changed our country. He was passionate about this and spoke of the strategies of the British, to divide and conquer. All this came from Charlie, and he went from one topic to the next without much input from the rest of us, such as the 1916 Rising and political figures of the time.'

In this example, the resident expressed his opinions and showcased his vast knowledge of the history of Ireland. Providing the space to express these opinions creates moments in which the person with dementia is positioned as an expert, teaching the students of times gone by in the city that they all share. This design process resulted in a re-configuration of the resident, with their agentic abilities becoming more apparent as they led the conversations. Reflecting on the process, one of the students discussed his amazement at what he had learned from the residents during the Club:

'Yeah definitely, I think like some of the stuff, like chatting to Charlie. He knew so much about the history, so much stuff he'd tell you, And you're just like 'What?!' I don't know how he...I couldn't retain that much information. He comes out with all this stuff about the roads and people and places.'

The student's perception of what it means to live with dementia was further contested by the residents' wealth of knowledge when it came to history. The recognition of the abilities of the resident expanded the empathy of the student, positioning Charlie as someone to not merely empathise with, but greatly admire. Merging these two dissensual concepts together formed a new understanding for the student of the capabilities of someone with dementia, and their potential to contribute to the learning experience of others. From the perspective of the residents, the opportunity to intellectually engage and teach the students demonstrated, perhaps to themselves, their carers and peers as well the students, their ability to positively contribute to these interactions.

Socially Connecting

The History Club provided an opportunity for the residents to connect through conversations that spoke to their common interests. In the example below, two residents who share a bedroom but hadn't had much previous engagement, converse for the first time:

'Charlie spots his wife coming in so he says he better be off. I offer to bring him up. The girls say goodbye to him and he says he'll see them next time. He greets his wife and the three of us head back to his room. As we pass the entrance, the wife of his roommate is leaving. She stops with us and says to Charlie 'I never knew that you could talk so much.' She's laughing as she says it but it strikes me. Is this true? The two men share the same bedroom.'

This example is a reminder that the close proximity in which many residents find themselves living in care does not mean there are opportunities to engage socially or discuss common interests. Providing space in which these explorations are encouraged can help foster friendships and recognition of the similarities amongst the residents.

As some weeks the History Club was attended by lots of residents, with various capabilities and interests, the need for group work and light-hearted fun became more important. In these sessions, the students and residents became 'team members', working together to figure out the names or details of the photographs:

'We were all sitting around the table and I passed around the photos. I notice the students are more confident in introducing themselves, shaking the hand of the participant and telling them their name. Kate comes around then and takes up one of the pictures of an actor. 'Okay now' she gets the attention of everyone. Ten points for the person who can tell me who this is.' This causes some of the residents to shout out, trying to make out who it is. No one

knows straight away but eventually one of the residents shouts out 'Katherine Hepburn!' 'Yes, well done!' This turns into a bit of a game then, with Kate holding up different pictures and the residents shouting out who they are. Everyone is laughing and shouting out. Some people are quieter, but cheer and clap with the group when someone gets it right.

The use of quizzes, and questioning is often considered unfair territory in dementia care. However, this nature of questioning positioned the residents as capable of engaging in the role of team member, contributing to the collective enjoyment of the group. The mixing of students and residents created a fun and equal group dynamic, as the students were not experts on the topics either.

Within this theme, we see the opportunity to support agency for the person with dementia, and the importance of creating resources and space for the exploration of the interests of the residents, which they are clearly ready and willing to take given the opportunity.

Taking Initiative

While the initial sessions were facilitated by the first author and staff, the students and residents took on a more prominent role as they became more confident in the ways to communicate most effectively with each other. This resulted in the main researcher stepping back, and allowing the students and residents to take the lead in the interactions:

'John is talking to two of the students and they're asking him about soccer, and where he played. He doesn't need much prompting, and talks about lots of different stories, telling jokes. He has everyone laughing. He tells the story of how he sang in the opera house the night before it burned down. I have a picture of it and pull it out. He jokes 'I lit the place up with my voice.' Everyone laughs, including the residents. The other two men are more quiet. But the students make sure to include them asking questions and listening to what they answer, often repeating it so as to create an understanding between them. I really notice this week that they seem more confident in asking questions, sorting through pictures and listening to the residents. They congratulate the residents on the boccia tournament that they had won last week. Suddenly John stands up 'I'll be back,' he says and shuffles away. We look at each other in confusion. A few minutes later he come back and sits back down. 'Now, no messing around here.' He takes a gold medal out of his pocket and holds it up for us to see. 'I have to hide it from the grandkids, they're after it.' He passes it to the students and they all admire it, congratulating him again. 'I'm watching it,' he jokes, making sure it comes back to him.'

Here we see how the resident is expressing his agency in the interactions with the students, telling them stories, bringing in meaningful objects for them to look at and leading the conversation. In turn the students created an atmosphere in which the agency of the resident was

encouraged, providing him with an outlet where his actions were positively received. The growing mutuality that developed provided a basis of engagement which allowed both residents and students to exert agency, growing in social confidence and stepping into a new role in the care context.

As students and residents began to refine the content of the History Club, the contribution of both groups resulted in the provision of more resources from the students, and important topics of conversation from the residents:

'The students had sent me photos and images that spoke to the topics of conversation from last week, which I had printed. The men exchanged stories of growing up in Cork and where they lived. They also talked about the current homelessness crisis and Asylum Seekers. These are serious topics that affect our society, but I've never heard them discussed in the care home before.'

As the conversations evolved, the students and residents found commonality in discussing societal issues which are often not discussed in general care practices, but speak to the abilities of both groups to discuss political topics. For the person with dementia, their ability to show empathy is also apparent here, as they show concern for their fellow citizens.

The enthusiasm shown by the residents and their families for the History Club gave a certain confidence to the students, which resulted in the continued growth of the Club. The feedback from the residents acted as a source of inspiration for the students giving them a sense of purpose and the determination to provide materials and space for the project. This is illustrated in the following example from one of the students:

'It's literally just a matter of sitting down and thinking about, you know the idea of the city history, was a great idea and then, ideas spread from that and it's kinda (sic) led by the people who are there. I think if we had had the first day and it hadn't gone well... But they were already invested in it so we automatically went away and got more stuff for it and just built on top of that. So basically everything we did was based on what they gave back to us.'

Here the student discusses their motivation for further developing the group, in which the interests of the residents inspired the content and motivated their work. In this theme, we see the development of a more confident role for the students, which created a supportive and enjoyable environment for the residents to exert their agency.

Finding Value in Learning

The students' enjoyment of the project, and the meaning they found in it, was attributed to feeling valued and purposeful as co-researchers. When

asked about their experience, the students discussed the importance of feeling valued as key players in the care home, and the purpose that they found through this type of learning:

'Even when we came in the first day and they were very positive about the whole thing. Cause when we were going in first I kind of felt like we were... not a burden, that we were just volunteering and that was it. But they were really invested in it, they like sat us down and said we really want you to be here, that made a huge difference.'

By setting an initial meeting with management, the students felt welcomed by the care home staff, and were more certain of the potential of their role there. The students understood that social engagement was valued by staff, and in a sense they were fulfilling a role that staff wished they could do themselves. The students also discussed the ways in which the work had impacted them. One student spoke about his mother noticing his enthusiasm for the project:

'Like I said it to my Mam there when we first started and I was telling her about your work and what we were doing and she goes 'Jeez you sound really passionate about it.' Yeah I really enjoy it. You go up and it's not two hours of work, you know, the two and three hours, definitely overwhelmingly positive.'

Distinguishing the project from work suggests that it was considered a pleasurable experience, in which the students found a refreshing break from traditional learning structures. The different model of learning, in which social and creative skills were encouraged, provided an outlet for active, responsive engagement, in which the student could find purpose.

From this project, the residents and students carved out a new role for themselves in the ecology of care. From the residents' perspective they were viewed as experts, with knowledge and stories to share beyond their role as a patient in care. The students in turn came to better understand their potential in this space, taking responsibility for the development of the relationships, and learning to contemplate and consider the experience of dementia with new applied knowledge.

Discussion

The aim of this work was to support mutually beneficial relationships during the design process by broadening participation to include student volunteers. Our findings detail the learning process of the students, which resulted in a more compassionate and nuanced understanding of dementia, and an outlet in which the residents were capable of demonstrating their ability to positively contribute to the design process. The residents and students engaged in a process of knowledge and social exchange, re-

configuring the role of the residents, not just in the care home, but also in the community. The residents became a source of knowledge, compassion and care for the students, who in turn grew to appreciate and facilitate the design space in which both groups grew in confidence and agency.

Through this work it became evident that engaging in design processes with people with dementia requires a sensitivity to their illness, but also a willingness to look beyond this, and support the agency of the individual to engage in social processes [45, 46]. As is evident in the findings, this can result in mutually beneficial social engagements in which care, intellect and agency are supported and exchanged. In HCI, design processes have already illuminated the benefits of being positioned as someone actively co-creating a positive social environment [45, 93, 151, 155]. While recent work [48, 102, 152] has begun to explore the potential of technology to support volunteer engagement, our findings suggest that the design process itself can support enriching social engagement through broadening participation. Our findings also extend this existing work showcasing that design processes can move towards a reconfiguration of the role of the person with dementia, highlighting their natural caring abilities and intellectual interests [144]. Expanding design participation in this care context to include students, creates opportunities to expand the means of communication [85] and expressions of personhood [151, 157], which in turn supports the agency and mutual recognition of both groups

[45]. Bringing these two groups together in co-creative design processes also showcases design as a key element of contemporary care practices.

The two projects presented here provided the students with a safe learning environment in which their inter-personal skills could be fostered and refined. While it was an opportunity for them to learn, they also brought a fresh perspective to this ecology of care, in which honoring the personhood of the residents was firmly at the center of their work. This fresh perspective can be highly beneficial particularly for clinical professionals, researchers and family, as it can challenge established practices and give insight to new opportunities for moments of connection and care. Often students and residents are positioned as those in need of educating or care, but our work challenged this stereotypical view and showcased how it is possible to reconfigure traditional roles and highlight the agentic contributions brought by both groups. However, this requires an examination of one's role in the process, and being open to learning from participants rather than about them.

Design Considerations

Taking part in design projects with vulnerable populations has implications for how our students experience and consider other groups, breaking down psychological barriers, and thus creating more inclusive design agendas. While the open, participative nature of this project was

pivotal to its success, there are important aspects of these types of projects which require careful planning. In this section, we consider the sensitive issues of doing research and designing with populations that are typically deemed 'vulnerable'. Especially for early career researchers, working closely with groups who give insight into a different way of communicating and being in the world provides greater awareness of how to design and research in a manner that is inclusive. Encouraging this type of experiential learning can provide students with the skills to build empathy and respect for the lived experience of others, thus creating more socially engaged design work.

Managing Expectations and Ensuring Well-being

In terms of ethical research practices, the everyday practices of care needed to conduct research with two groups of potentially vulnerable participants requires careful consideration. It is one thing to be labelled a 'vulnerable participant' [1], and another to explore the vulnerability that is at the core of how we establish empathy and support agency [10]. If our design processes have the potential to evoke this kind of vulnerability, an ethical approach to design is needed. Ultimately the well-being of both parties is pivotal to the success of this process and should inform any decision made about the progress of the project [10].

Navigating the dynamics between the participants, staff and institutions in order to maintain ethical integrity requires setting expectations between all those involved, ensuring that each stakeholder feels comfortable with the process and is not at risk of being exploited in some way. From the perspective of the students, this means ensuring they feel safe and respected as co-researchers, while the well-being of the participants with dementia is not compromised. For example, design projects such as ours are often given a certain time-scale for completion, as well as inevitable endings of the participation of students due to their studies concluding, or the illness or death of the resident. Considering the ending of the project from its beginning is a crucial step in ensuring a sensitive approach to the research process. In our project, the students quickly learned of the fractured nature of participation, that some weeks would be different to others, based on the needs of the residents. We were conscious that the students may be upset at times, particularly if residents passed away. Ensuring that the students feel supported by the main researcher through de-briefing sessions was an important element of research planning.

We were also aware that the students were fulfilling a distinct need for increased social engagement for the residents, who may be confused as to why the sessions were no longer taking place. The semi-structured nature of the project, which ultimately resulted in the celebratory

presentation of the designed artefacts, helped to clearly mark the ending of the project, leaving behind an artefact to continue to be used [17]. From the perspective of the staff, their facilitation of the design work came from an appreciation of the social opportunities for the residents, but also their need for research-led evaluation of their care systems. Ensuring that the findings are translated into useful resources which may contribute to the provision of resources for people with dementia can ensure that the institutions are benefitting practically from engaging in the design process.

Supporting Co-Design with Vulnerable Participants

The examination of the role of the students in this design process, highlighted both their innate ability to engage as co-designers and also provided a wealth of insight into the design process. Co-design projects that encourage an exploration of the lived experience of vulnerable participants are a complex endeavor, logistically and emotionally. A key consideration is how to initiate and facilitate them. The role of the lead author in this project changed over the course of the project, as reflected in the findings. At first, there was considerable input in terms of facilitating sessions, engaging with students in dementia training, and structuring the nature of the activities. However, as the students' confidence grew, the researcher took a step back, acting more as a mentor to provide encouragement and resources. Examining how to navigate this transition is a key step in the design process. The researcher ultimately has

a duty of care to both the students and residents, and their involvement as a mentor rather than designer can provide this support, as well as the opportunity for critical evaluation of the process. Ensuring the sustainability of these design opportunities requires a more permanent infrastructure between designers and care systems. Setting up a strong link between research institutes and the contexts in which we design, can help to create more permanent relationships between two institutions, which will organically adapt and re-orientate over time, but nonetheless is always open to supporting each other.

Conclusion

In conclusion, this paper describes the enriching social engagement which can be supported through design processes in dementia care. Our findings convey the nature of mutually engaged learning, and the ways in which design can reconfigure roles in clinical and educational settings. We suggest that careful planning of design projects, in which the abilities of both groups of participants are supported, provides a solid base for ensuring that students are key figures in broadening design participation in dementia care.

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Chapter 6: Printer Pals: Experience-Centred Design to Support Agency for People with Dementia[4]

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Abstract

Whereas there have been significant improvements in the quality of care provided for people with dementia, limited attention to the importance for people with dementia being enabled to make positive social contributions within care home contexts can restrict their sense of agency. In this paper we describe the design and deployment of 'Printer Pals' a receipt-based print media device, which encourages social contribution and agency within a care home environment. The design followed a two-year ethnography, from which the need for highlighting participation and supporting agency for residents within the care home became clear. The

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residents' use of Printer Pals mediated participation in a number of different ways, such as engaging with the technology itself, offering shared experiences and participating in co-constructive and meaningful ways, each of which is discussed. We conclude with a series of design consideration to support agentic and caring interactions through inclusive design practices.

CCS CONCEPTS

• Human-centered computing ~User studies

KEYWORDS

Dementia; Person-centered Care; Media and Technology; Experience-centered Design.

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Introduction

In order to appropriately respond to the needs of the increasingly ageing population, dementia has recently received growing attention within HCI [92, 109], examining the potential of design to enrich the lived experience of people with dementia, their carers and the wider care ecology through designing for experience and social connection. However, people with dementia, particularly those in the later stages of the illness, are often

presented as disinterested [146] or unable to engage with design processes and technological outcomes [129].

Within the care home environment, opportunities for people with dementia to express their agency and make social contributions are often restricted, as they are positioned as 'passive' patients in need of care [107] whose contribution is conceptualised within a narrative of loss and compensation [1, 129]. This can result in people with dementia experiencing significant 'loss of self' [12]. A lack of opportunity to take an active role in the care environment can increase this experience of loss of self. Designing to support the person with dementia to express their sense of agency and ability to participate within design practices has the potential to address this issue.

In this paper, we present findings from the design and deployment of 'Printer Pals', a receipt-based media generating technology that is used to encourage social agency amongst people with dementia and their peers within a care home environment. The design of 'Printer Pals' was informed by a three-year ethnography that examined the nature of communication, participation and the potential of media, such as stories and photos, in supporting agency for people in the advanced stages of dementia in care homes. The final few months of this ethnography, which focused on the potential of media to support social engagement and agency, contributed directly to the design of Printer Pals.

The paper provides a detailed account of how people with dementia engaged with Printer Pals and what their engagement demonstrates about the potential of technology to support social identity in people with dementia. Specific findings include their easy engagement with the materiality of technology, a surprise in light of the general assumption that older people tend not to be interested in technology, as well as their willingness to engage in playful, challenging and topical questioning using Printer Pals. The contribution of this research is two-fold. Firstly, we extend McCarthy and Wright's experience-centred design [99] approach by highlighting the experiences of people with advanced dementia, a particularly challenging setting for HCI research. Secondly, we present a series of design considerations when working with and for people with dementia, including the broader implications of our findings for inclusive design practices and outcomes.

Background and Related Work

Whereas design responses to dementia have in the past largely focused on cognitive assistance, safety monitoring, and assessment [114], in recent years HCI has explored dementia as a social, cultural and interpersonal experience, reflecting the social constructs of dementia and the potential to enrich this experience through design practices and outcomes. In this

section we discuss previous work in HCI that has informed the current project.

Dementia and HCI

Dementia is a multi-faceted, complex illness which is predominately associated with changes and decline in cognitive functions such as memory, executive functioning, communication, planning and decision-making [106]. In addition to the cognitive aspects of dementia, considering the experience of dementia within social and cultural contexts (e.g. how a diagnosis can result in negative social consequences) is also very important [12]. The close association between cognitive ability and selfhood within Western culture has resulted in the construction of dementia as an experience of 'deficit' and 'passivity' [12, 38, 112, 135], as people with dementia report a loss of selfhood due to lack of opportunities to engage in their social world [23].

In response to this, a socio-psychological approach to dementia care has been developed, which aims to understand and support the 'personhood' of people with dementia, and acknowledges their need for engagement, respect and agency [81]. This person-centred approach to care has been adopted within experience-based methods of designing with and for people with dementia in HCI, resulting in an exploration of the ways in which people with dementia experience their social worlds, and how supportive technologies can enrich interactions [93, 150]. The

Experience-Centred Design (ECD) approach, as established by McCarthy and Wright [99, 156, 157], examines the iterative, dialogical construction of experience and the place of design in enriching this experience, and has contributed to the growing inclusion of people with dementia in research [111]. The work of Wallace et al. [151]was foundational in applying the concept of personhood and dementia in ECD. Wallace's engagement with a couple, Gillian and John explored the potential of design, in this case digital jewellery, to represent the lived experience of Gillian, and the aspects of their lives that were meaningful to them [151].

The potential of technology to extend, maintain and celebrate personhood has been explored in several recent projects. Lazar et al. [91], highlight the opportunity to support agency using technology, through the design of a photo sharing tool, in which the person with dementia can creatively express themselves through art therapy and share their creations with their family and friends. Hodge et al. [62] have explored the use of Virtual Reality to recreate meaningful places for people with dementia. Through creating immersive opportunities in which the person with dementia can engage in new experiences, Hodge et al., also contest the idea that people with dementia are opposed to engaging with technologies, framing experiences with technology as shared social engagements:

'Our workshops have indicated that…short, playful VR experiences can be shared even in an ad-hoc basis with friends and family, and people can discuss what they are experiencing even while they are experiencing it' [56].

Similarly, the experience of the person with dementia is central to the design and use of 'Ticket to Talk', an application developed by Welsh et al. [152], which encourages intergenerational engagement, based around a series of probes and the curation of media specifically tailored for the person with dementia. Within these design approaches, there is a space for what Branco et al. [17], describe as 'Open Design' and 'Design after Design' in which the technologies are used to hold, display and engage the experiences of people with dementia, and in doing so, provide an opportunity for others to engage more meaningfully with the person with dementia.

The Care Home and Social Agency

As people with dementia transition into care, many of their previous roles within their families and wider communities come to an end. This can often result in them being seen as 'patients' who depend on staff to attend to their physical care [107]. Within a care home setting, it may be taken for granted that the physical proximity in which staff and residents work results in a natural development of friendships and close relationships. However, much of the conversation and daily activity of the care home is focused on physical care, such as bathing, eating and assisting residents in

their wheelchairs [142]. The nature of the environment, shared spaces and staff demands can mean there is little time and few resources to support people with dementia to engage more actively to maintain and develop their social identity. HCI has explored the potential of designing for this space to encourage more social connection and engagement within the care environment.

Wallace et al. [150] were commissioned to design and install 'Tales of I', an interactive display consisting of a traditional dresser that held decorative globes representing different topics for reminiscence, which when placed on top of a retro-fit television, would play a short film to encourage discussion between residents and staff or family members. The use of images and media within shared spaces was also central to 'Photostroller', an interactive photo-display tool which was placed in a care home to encourage conversation and playful, ludic experiences inspired by the media [11]. This work highlighted the use of media as an anchor for connecting and engaging with each other. In designing for connecting and belonging, Morrissey et al. [111], explored the embodied nature of connecting and communicating, in which people with dementia express their ability and need to engage in social activities through music and dance. In supporting people with dementia to move and connect through the design of 'Swaytheband', an interactive baton that changes colour as it is moved to the beat of music, Morrissey highlighted the

nuanced ways in which people with dementia engage and participate in their social environment, as well as the legitimacy of embodied selfhood as a means of maintaining social identities [111].

The design and implementation of Printer Pals is the final outcome of a larger project which examined the experience of people with dementia living in residential care and the potential of design processes to enrich this experience. The first phase of the project involved an ethnography in a state-funded residential care unit, in which the first author engaged with people in the advanced stages of dementia with a view to understanding the nature of mutual engagement, supporting agency and introducing appropriate technologies into the care environment. The findings of this ethnography suggested that people with dementia often express care, and a willingness to interact with those around them through subtle embodied actions and expressions. One of the key aims of the project is to encourage social participation with people with more advanced dementia, to ensure that they can engage meaningfully in the social aspects of the care home. In order to examine those subtle engagements more closely, we engaged student volunteers to participate in activities in which the residents and students were mutually supported by each other to learn from and teach each other. As described in the next section, the work with the student volunteers was the basis of the design of Printer Pals.

Method

Setting

To support people with dementia to take on a more active role in the care home, we engaged with student volunteers to set up a 'History Club' in which the residents would share their stories and memories from growing up, supported by historical photographs which were provided by the research team. We chose to name the sessions 'History Club' to encourage intergenerational engagement and facilitate social and political discussion. This positioned the person with dementia as an expert who discussed in the political and historical events which shaped society. Discussions often took on a competitive and playful nature, as participants guessed famous cultural and political figures in the photographs. This led us to reflect on how to ensure access to photographs for people with dementia that was more personal and open to interpretation. However, the potential for introducing media and personalised content was restricted by lack of Wi-Fi in the care home and residents' reluctance to use touchscreens (e.g. tablets) as the interface would often change when the resident wished to point out something on the screen. Therefore, media had to be printed and shared with residents, slowing down the ways in which we could respond to their interests and opinion. The initial design of Printer Pals aimed to further support and enrich these activities.

Ethics

Ethical approval was sought and received from the University Ethics Board, as well as from management of the care home. To respect the privacy of the residents and their families, it was agreed that only research field notes would be taken, and no form of aural or visual recordings would be used. The first author conducted weekly introductions of the nature of the activities to the residents, constantly ensuring they were comfortable with the current activity, and could choose to leave at any stage if they wished. The sensitive nature of obtaining consent from people with dementia has been well legislated [1], and the research team considered the everyday ethics of each part of the research process, from initial observations, to design workshops, in ensuring that residents felt safe, informed and comfortable with the nature of engagement.

Study Design and Analytic Approach

Data collection for the design and implementation of Printer Pals took place over the course of eight months, from January to August 2018. We carried out iterative sessions and evaluations, once a week over this period, to introduce our early ideations, prototype and refined models for interaction and critique with the residents and staff. Each session was typically attended by approximately 10-14 residents, 2-3 volunteers and 2 staff members. As stated previously, field notes were taken during sessions and expanded upon

after the workshops [42]. The research team examined both the nature of residents' participation, as well as the pragmatic considerations of designing and introducing media and technology to the environment.

In our setting, like in most care homes, residents living together have varied diagnoses and abilities. The aim of the project was to encourage people with advanced dementia (who may be non-verbal, have severe memory loss and different ways of communicating) to mix socially with others in earlier stages and exert their social agency during the Printer Pals sessions. The residents who took part in the sessions had various diagnosis (see below) associated with different types of participation. The symptoms of dementia can vary depending of the type of dementia [6] that the individual has and the stage of dementia they are experiencing [105]. For example, someone in the early stages of dementia can often live independently, experiencing at times some memory issues or confusion [6]. In contrast advanced dementia is associated with severe memory loss, agitation and a dependency on non-verbal communication [106]. We viewed all these types of participation as valid, paying particular attention to the participation of people with advanced dementia, which is often not fully captured in research.

Table 1. Diagnosis of residents and nature of participation.

No. of Residents	Diagnosis	Nature of Participation
4	Mild Cognitive Impairment	Sharing stories, telling jokes, singing.
5	Dementia	Answering questions, giving opinions, singing and dancing.
5	Advanced Dementia	Non-verbal participation, spontaneous singing and moving, listening.

We adopted a thematic analysis [19] approach to data analysis of the field notes, which involved initial coding, interpretation of the content, and generation of themes and sub-themes based on this analysis, informing both the second iteration of the design, and the analysis of the nature of participation and curation of media to reflect the engagement of the residents. We conducted a bottom-up, latent analysis in which we were interested in examining the experience of engaging with Printer Pals and the types of interactions which occurred amongst the residents. We took a constructionist approach to the analysis, in which meaning was socially constructed by the participants through their engagement with each other and their environment [19]. This approach served to further emphasise the ability of the residents to construct meaning and experience, which has been traditionally questioned within research and dementia [118].

Design

The aim of Printer Pals is to ease facilitation of interactive group activities, while simultaneously challenging perceptions of the abilities and agency of people with dementia. In its first iteration, Printer Pals was a media-centred print-based quiz in the form of a Raspberry Pi, receipt printer, and speaker enclosed in a laser cut cardboard cylinder (see figure 1).



Figure 1: A Printer Pals Receipt and the Original Prototype

Group sessions with Printer Pals took the form of a quiz, following a familiar format taken from the previous history club that researchers conducted in the care home. We chose the names of the activities with staff, volunteers and residents to encourage fun social engagement. By positioning the person with dementia as an expert we aimed to highlight what participants offered in this social context. Printer Pals was kept in the public space in the care home and was brought to host quizzes and storytelling for the residents. In these sessions, Printer Pals would print tasks for the group to complete. Before sessions, volunteers would use a web interface to create and upload tasks to Printer Pals, such as songs with

instructions to guess the artist, images of famous faces, riddles, and jokes. Tasks could also be a question asking the residents to share their opinions or preferences. Volunteers would then print these in the group session using the web interface, choosing which task to print next in a way that naturally followed the group discussion around the tasks.

Printer Pals was iteratively developed over two deployments through an experience-centred design approach [98]. This process was heavily influenced from our understanding of the residents from our previous ethnography, which was implemented into the design. For example, the printer forces a slow interaction as the group waits for a task to print, affording everyone the chance to participate. It was also important that the activity should leave something behind, so that those who have played will have a physical cue to remind them of the recent activity. We chose a familiar medium of receipts to deliver tasks, as almost everyone has experience with receipts and they encourage people to take and keep them. The design also accounted for limitations presented by the care home setting, such as a lack of internet access. Observations from the previous ethnography influenced our decision for the initial prototype to have both a robust and inexpensive aesthetic and haptic qualities. We hoped this design choice would encourage physical interaction with the artefact.

Deployment

1st Deployment

The first iteration of Printer Pals had a rough cardboard housing, with a largely exposed receipt printer. It had a solid body, with a camera embedded into the lid of the device. This camera would be used to scan QR codes printed onto tasks, forcing the device to reprint a task should a resident wish to keep it for themselves. This camera was removed before the first deployment in consideration of the staff's reactions to a camera being introduced in a group activity. As such the internal components were left exposed. Printer Pals was used in the initial deployment as a "Quiz-Master", which would ask questions of the groups, instead of a volunteer asking questions themselves. Residents would gather around Printer Pals, as researchers printed tasks for the group to complete. Many of these tasks were themed on historical facts of the local area, following on from a previous history club reminiscence activity that residents were already familiar with. Tasks also extended to more general pop culture, such as guessing famous faces, along with more challenging jokes and riddles. Residents responded well to Printer Pals, particularly enjoying the famous faces, riddles, and jokes. We observed some of the residents keeping the receipts to show family members when they next visited. Residents noticed the exposed components of Printer Pals and reacted excitedly, asking

questions about what they were and expressing their desire to have a computer, having never had one when they were younger.



Figure 2: The Final Three Printer Pals

2nd Deployment

Printer Pals was redesigned for a second deployment, using the observations and feedback we had collected from the residents (see figure 2). The key changes were the ability to interact with the internal components of the device, different aesthetic and haptic qualities, such as polished and rough textures, as well as a means of manipulating the volume to ease participation for those who are hard of hearing.

Adding a method of interacting with the components stems from the serendipitous interaction where residents noticed the internal components. In response the body of the redesign was broken down into three stages, which residents could assemble themselves with the help of a volunteer, allowing them to see exactly how the core components fit together.

The material of the devices was also important, as we would often observe residents rubbing the device because of the roughness of the cardboard. We also noted many different responses to the receipt paper, some people would keep and preserve them, whereas others would discard them at the end of each session. We wanted to explore whether a more refined and expensive looking device would encourage residents to keep the receipts, rather than discard them. In response we designed three new devices. The first was an improved cardboard version, keeping an aesthetic robustness to encourage physical interaction. We created a more refined 3D printed plastic version, rendered in bright colors that matched the residents' communal space. And lastly, a polished metal version. We felt it was important the higher quality versions seemed as if they belonged in the communal space to encourage ownership and familiarity of the device and support further interaction with it. All of these kept the three stage build process.

Findings

The following themes describe moments of interaction with Printer Pals, and the conversations and activities that came about because of the media content of the tool. To explore the ways in which interaction with Printer Pals supported and encouraged agentic interaction, we present the following themes: At Home with Technology; Co-Constructing Knowledge

and Experience; and Levels of Participation. Within these themes we examine the nature of participation and how people with dementia contribute to their social environment, often taking the lead and building on each other's experiences to create new shared experiences. Pseudonyms are used throughout for the purpose of privacy.

At Home with Technology

Throughout the sessions, the ways in which technology and media have been embedded into the lives of the residents became more and more apparent. Printer Pals and the content it created resulted in people with dementia exploring the physicality of technology, the nature of engagement with media, as well as the opportunity to express their agency, sharing experiences and opinions.

Appropriating Content

Conversations within the sessions were often tied into and enhanced by the media content of Printer Pals. In the following example, the session was loosely themed around relationships and romance. One of the residents began to talk about the dance halls that they used to attend. The researcher then prompted this further with some dance music content on Printer Pals:

I asked them would they have danced to something like this...and played the Blue Danube waltz. Some people swayed along. Over the song

playing, one lady said she preferred Irish music. Another gave an example of an Irish song she had danced to, so I pulled that up on YouTube. At this stage I had my Laptop, phone and iPad on the table. 'They are just lovely things to have' one lady remarked. I said I was very lucky to have them. The Irish music got a few 'Whoops' and claps as the residents moved to the music.

The content provided by the researcher was appropriated by the residents in their own individual ways, as they preferred Irish dance music to the classical waltzes. In this way, the residents shaped and contributed to the content so that it was more suitable for their tastes, while expanding the content of Printer Pals. The use of additional pieces of technology throughout the initial sessions garnered interest from some residents, who admired and engaged with the electronic devices, something which is not often captured or considered as appropriate within a care environment.

Ownership and Enjoyment

Engaging with the technology throughout the sessions, as well as in conversations around the nature of technology within their own experiences, highlighted an ease of interacting with technology and media, which contributed to the successful deployment of Printer Pals (PP). In the following example, the researcher introduced the final design prototype to the residents, demonstrating the ways in which their recommendations had been included in the device. One resident conveys her surprise at Printer Pals:

I moved back to make sure they could see Printer Pals plugged in. 'Now do you remember when David (Pseudonym) was over to visit and he made the printer?' 'Oh yes' some of them nodded, smiling. 'Well he's made you three new ones, based on the things you thought would improve them, like making the volume louder and the outside prettier,' I explained. I picked it up then, showing it to them. 'He made that' one lady asked, astonished. 'It's just marvelous, I love the gadgets,' another remarked. I showed them where the speaker was, and the printer, and Kate said 'I think it's just marvelous.'

Including the residents from the initial paper sessions, and prototyping, to the final phase ensured that Printer Pals' use and physicality was tailored to them. It also created an understanding and ownership over the device which helped with Printer Pals being used more comfortably than other technologies such as tablets and laptops. Similarly, the researcher explained the mechanisms used to build the device in the lab, all the while reiterating that the adaptations were based on the inputs of the residents and their use of the previous versions of the prototype:

We introduced the new PP, and they commented very enthusiastically about the color. David explained how he made it, 3D printing, sanding, painting. We showed them the inside parts, they thought I was breaking it as I took it apart. Surprisingly they remarked parts like the speaker and board were 'Cute' or 'Dotey' especially when Kate compares it to her speaker, which is much bigger. They all laughed at this.

The description of the technical aspects of Printer Pals as objects that are 'cute' or 'dotey' (an Irish term for cute or disarming) highlights the residents' excitement and willingness to engage with the mechanics of the device. We were eager to show the residents what Printer Pals consisted of, to create a sense of understanding and inclusion in the process, while also challenging the assumptions that older people, and people with dementia are unable or disinterested in engaging with technology.

Bringing People Together with Technology

Prompted by Printer Pals, we asked the residents to reflect on their use of technology and how this has changed over time. When talking about how interactions with technology have changed, they explained and demonstrated the ways in which they used to adapt television viewing to make it colour:

'So how has technology changed since you were a child?' As a follow up I asked, 'do you remember getting a television or phone in your house?' There was a consensual vocal response, in which a lot of residents said 'Yes' and nodded…One lady said how they had one of the first televisions on their street, and people used to be looking at in through the window. People laughed at this. Kate pointed to the flat-screen TV hanging on the wall. 'And they would be about half the size of that one.' 'And in black and white,' another responded. Then another lady offered that they use to hold up

coloured plastic, from a bottle of 'Lucozade' to their eyes to make it look coloured. Everyone laughed at this, as she was gesturing with her hands as to how they would peer out through the plastic. Kate got up then and started to look around at the shelves. She took a tin of sweets down and brought them back to the table. She began to pass them around to everyone. 'Look' she said, as she took the rappers off an orange and red sweets, holding the rappers up to her eyes. Everyone laughed and those with wrappers copied her, remarking that everything was purple, or yellow and swapping wrappers around.

Here, the residents discuss the nature of their interaction with technology, in which they adapted and manipulated their use of devices to improve them after use. Technology use was described as a communal activity, which attracted neighbors and families together. In a similar way, Printer Pals mirrored this type of interaction with technology, as it is open to sharing experiences and adaptation after use. This familiarity with technology was further explored as some of the residents took an interest in the way in which Printer Pals was enacted, making connections between the actions of the researcher on her laptop and the resulting printed receipt:

The woman sitting beside me is very interested in my laptop screen, and watches as I scroll up and down looking for songs to play. She then turns to the printer pals and says 'it's coming out look' and so I rip it off and give it

to her. She looks it up and down, holding it the way you would scan a receipt to make sure it's all correct.

This woman engaged in a sense-making process in which connections were made between the devices and the output of the device. The engagement and close examination of the receipt paper, mirrors that of how one would examine a receipt having purchased something in a shop. The mundanity of the paper, and the understanding of how cheap it is, encouraged the residents to engage more closely.

In this theme the interaction with Printer Pals demonstrates a familiarity when engaging with technology in this manner. The positive engagement with the device, as well as displaying an interest in the mechanics of the design demonstrate the use of technology in creating social connections through communal activities and interests. Involving the residents in the design process from the initial stages, ensured that the mechanics of the device were not over-simplified or hidden, resulting in an ownership over Printer Pals and its use.

Co-Creating Knowledge and Experience

The introduction of Printer Pals, and the nature of interactions facilitated around it, provided an opportunity for the residents to contribute their own experiences and opinions to the group. However, it was the ways in which understanding, and knowledge was co-created within the sessions that highlighted the agentic contribution of each individual, resulting in a

process of sense-making together. In the following theme, we examine the nature of collaboration and co-creation amongst the residents as a means of examining the function of the Printer Pals sessions, highlighting the various social contributions of the residents.

Sharing Experiences

Printer Pals sessions offered the residents opportunities to share memories and experiences from their lives that were important to them. For example, a question printed from the Printer Pals asking, 'Have you ever been married, what are your memories from the day?' prompted the residents to share their happy memories together:

'Happiest day of my life.' One lady stated straight away. 'It was just brilliant.' I asked her more about the details, what she wore, where she was married, the wedding guests. She spoke of one guest in particular, who she worked with, who died a few years later. Everyone was quiet as she spoke. Another lady told us about her wedding day, and how her wedding cake collapsed. She laughed as she told the story, she repeated it a few times and lots of people laughed along with her.

In the telling and sharing of these important milestones of their lives, the residents offer both an insight into their lived experiences before coming into the care home, but also connect and compare these experiences as a way of sharing common interests and memories. In listening to the stories of others, the residents create space for sharing and

connecting with the story of others, while also reflecting on memories of their own. Weaving together their own stories into a new, shared experience creates opportunities for more meaningful engagement.

Taking the Lead

Printer Pals inspired conversation amongst the residents, allowing them to take control of sessions through engaging in content which resonated with them. In the following example, a resident enters the session mid-way through a conversation in which we asked about people's favourite meal:

Another man rolls up to the table, situating himself in front of me between two ladies. Kate asks him. He replies, 'I'd have to think about it'. But then asks straight away 'Did anyone ever make crab apple jam?' 'Hmm, no I don't think I have,' Kate says. You'd need lots of sugar.' She turned to another lady 'Did you ever make jam?' 'Oh yes' she nods vigorously. 'Blackberry, gooseberry' she replies animated. 'Wow' Kate responds. 'There's nothing like jam and bread' I say. 'Did you make your own bread too?' She nods again. 'Four girls and one boy' she says, as if explaining her reason for baking. I had never heard her talk so much and later Kate remarked to me 'You wouldn't get that kind of response from her normally you see.'

In taking the original question produced by Printer Pals, and re-interpreting it to take the lead in a conversation, the resident demonstrated their ability to shape and contribute to the nature of the conversation. In this instance, the simple question evolved into something

much more specific, which created a more detailed memory to be shared by another resident who would normally remain silent. Through the evolving nature of the conversation, the residents created their own meaning from the topic.

Through the exploration of different types of media using Printer Pals, the residents took the lead in creating their own content, some of which was unfamiliar to the staff and researchers. In the following example, the presentation of a song which is not well received, prompts an important contribution from one of the residents:

The next song is from a musical, kind of Motown in style. But only Kate sings along, and I don't think they like it. 'These are all old songs?' one lady asked me. 'See I wouldn't remember them; I only know the ones since I came in here.' Which I had never thought of before. 'What songs would you like?' I ask her, and Kate also encourages'. What's your favourite? The lady thinks for a long time, 'My favourite….' she says. 'At the end of a perfect day.' I had never heard of it, but the other residents seem familiar with it. She repeats some of the lyrics. 'I learned it in school and sang it at a singing contest when I was about nine or ten.' I type some of the lyrics into google. Kate reads out some of the lyrics, and the lady confirms that's the one, continuing to say them. Two of the other residents chime in too. I find the song on YouTube and they listen closely, leaning into my phone as it plays. They sing along, remembering the song. It's a lovely song about being

thankful for the day and going to sleep in peace. When they're finished I give them a clap, and those who were singing smile. I'll add this to the playlist for next week.

In terms of the co-construction of knowledge and experience, the residents pieced together what they knew about the song, and in response the researchers produced the media online. The fact that the song was only known by the residents highlights their ability to take the lead in creating content that was meaningful to them. Referring to the fact the older songs were less familiar to her, the resident highlighted the use of more general popular music as void of meaning within this session.

Challenging Ability and Perceptions

Based on some of the initial sessions which were more competitive in nature, we also added more challenging questions, riddles and jokes to Printer Pals. In the following example, the residents were originally challenged by the riddle, but the transfer of knowledge created an opportunity to take the lead in challenging others:

I read it out to them. 'I travel around the world but stay in one corner, what am I?' I repeated it on request, and the residents began to shout out answers. We all complimented them on their guesses and gave them some hints; that it was small, and cheap and there would be more around at Christmas. One lady got close with a post-card so we told her she was the closest. Eventually one person a lady got it right and shouted out 'Stamp.' We

all gave her a cheer. She said she thought that was very clever. I give her the receipts and tell her to quiz the staff on the war. 'Sure I have two from before' she says referring to earlier sessions. From then, anytime a new person comes in she asks them the question. One man rolls in in his wheelchair and she tells him she has a question. 'He'll get it, he's a genius' the women beside me says. 'It's simple' the woman with the receipt tells him. Kathleen says 'You're only saying that because you know it now' and everyone laughs. The man gets in very fast. 'A stamp,' he says. Everyone gives him a cheer. He smiles at everyone. *A few minutes later the manager of the care home comes up to talk to Kate. Before she goes, the lady tells her to come here, she has a question. 'See will you get this now, he got it in two seconds.' 'I'm very proud of myself there now,' he says and he looks it. The manager takes a few guesses and eventually she gets it too. They give her a cheer as well.*

In challenging the residents with this type of riddle, we wanted to highlight their ability and willingness to engage in fun, competitive activities. As is the nature with riddles, no one was expected to know the answer, and were congratulated enthusiastically if they guessed correctly. The residents and staff worked to piece together the clues, meaning the manner of questioning didn't put anyone under pressure. Once the riddle had been answered, the residents then challenged, and helped new residents and staff to answer the riddle, which re-configured them as the source of knowledge rather Printer Pals.

Throughout this theme, we have illustrated the ways in which the sessions were led, re-constructed and shared by the residents, with Printer Pals acting as a prompt to encourage creative interpretation and engagement with each other. The nature of the activity, and the curation of meaningful media over time highlights the positive social contribution made by the residents as well as their ability to exert their agency as part of the wider group participation.

Levels of Participation

Many residents engaged in the session with various levels of participation, depending on their preferences and abilities. In the following theme, we examine the different ways in which people interacted throughout the sessions, with a view to considering various types of participation as worthy of acknowledgement and widening the scope of participation.

Communicating Care Through Object Interactions

The way residents chose to engage with Printer Pals, materials and topics varied throughout the sessions and highlighted the spectrum of ways in which the residents could express their agency. In the following example, we see how a resident, Jim, makes sense of the needs of those around him and attempts to ensure that another resident was included in the session:

Seated to my right is a man who has advanced dementia. He spent a lot of the time sorting and arranging the receipts, which calms him down. A

lady comes in late, she really enjoys the sessions. She is left at the back, behind a row of wheelchairs. Jim tries to pass her a receipt, so much so he set off his alarm. He gestures to the people in front of her to pass her back the paper. I get up and say I'll help her to move in, bringing her around beside Jim and I. He then passes her on all the receipts he had gathered, and they smiled at each other.

While the nature of Jim's engagement, in sorting through the receipts on the table may seem solitary, his concern for the resident who is physically excluded from the group, as well as his determination to ensure she is provided with materials, in this case receipts, highlights his awareness of the social needs of those around him and the willingness to engage when needed. Helping, sorting and ensuring that others have materials are various ways in which Jim makes sense of the social environment around him, as well as expresses his agency in the care home setting.

Subtle Participation

While some residents were more vocal in the answering of questions and sharing of experiences, for others engagement was subtler and in direct response to a particular form of questioning from Printer Pals. In the following example, we see how one song caught the attention of a resident, and prompted her from quiet to more active participation:

May is usually very quiet and non-responsive. When a country music song came on there was immediately a change about her. She announced the name of the singer and started mouthing the words. She started to smile and brought her hands together, swaying them along with the music. I had never seen her so animated. I looked over to Carmel to see her smiling and we caught each other's eye as she gestures towards her. She continues to sing and sway along to the music until it stops. I smile at her and she smiles back. As soon as the song is over she resumes her usual position. But for a moment she was completely engrossed in this song.

The reaction of the resident to one particular song during the entire session demonstrates the ways in which individuals who may appear to be disengaged and non-responsive are paying attention and quietly participating. Within this example, there is evidence of embodied responses to the song, further strengthening the resident's participation. Similarly, in another example, we see a subtler embodied response to a song, conveying a sense of engagement and enjoyment from the music:

During the next song, an old musical, one lady who is very quiet (advanced dementia) moves her hands with the music, making patterns in the air as if she's dancing. She doesn't speak, but the movement is purposeful, engaging with the music. Once the music stops, she lays her hand back into her lap.

In presenting this example, we wish to highlight the changing nature of participation in advanced dementia. While considering engagement within the session, this resident offers a simple dance, which expresses both her presence in the group, as well as her enjoyment of the music. This highlights the ability to continue to socially contribute within the advanced stages of dementia, as well as the need to reconsider what we deem as successful levels of participation within sessions.

In this theme, the varying nature of participation, as well as the value of each type of engagement from the residents was examined. Through these examples, we argue that the nature of participation within the sessions, whether directed towards Printer Pals or carried out by the residents organically, highlights the nuanced ways in which agency and social contribution are performed in this space. The use of media to support and encourage acts of agency point to open design spaces in which the use and adaptation after design is possible.

Discussion

Our findings provide insight into the nature of interaction with technology for people with dementia, and the use of Printer Pals to mediate and support opportunities to express social agency through the co-construction of new experiences, in which the person with dementia takes the lead in shaping conversations and content. The device itself created

excitement, inclusion and a sense of ownership, in which the residents were encouraged to share their experiences. The way in which Printer Pals printed and played content added a playful element to the sessions and the impartiality of Printer Pals relieved social pressure, as no one was being asked a direct question. Residents were welcome to engage in whatever way they chose. We held to the sensibilities outlined by McCarthy and Wright [98] and examined the use of technology to support participants' agency, in a context which is often void of technologies aiming to enrich social experiences. Carrying out ECD with people with dementia further developed our understanding of the nature of experience and social agency, and the ways in which technology can support this through sensitive design practices. In terms of expanding the current practices within experience-centred design for dementia, our findings highlight the willingness of people with dementia to be questioned, challenged and involved in conversations, and engage with the process of designing and using technology. In light of our findings, and previous work in HCI and dementia, we offer the following considerations for designing in this space with and for people with dementia. We also suggest the ways in which learning from people with dementia can be transferred into broader, more inclusive design practices.

Challenging Negative Perceptions of Technology for People with Dementia

Within HCI, there has been a narrative surrounding the use of technology with older individuals and within care homes as problematic and unsuitable [146]. While there needs to be critical consideration of the use and purpose of technology in care homes, the perception that older people and people with dementia are unfamiliar with, or averse to technology can prevent them from engaging and enjoying socially enriching technologies. As demonstrated in our findings, the residents have lived with technology for most of their lives. They have an interest and willingness to engage in the physicality and mechanics of Printer Pals, as well as enjoying the content together, as was common with more traditional entertainment technologies such as television. While the technology itself was aesthetically novel, the receipts and media were familiar. Through their involvement in design processes and evaluation, people with dementia challenged the perception that they cannot enjoy technology and showcased that they can create more suitable high-quality technologies to become part of the care home environment and care practices [144, 146]. Involving people with dementia in design can help ensure that ageing and mental health are supported and celebrated through the design of technologies, which echoes the wider positive ageing movement [7].

Reconsidering Agentic Behaviors and Social Contribution.

The nature of everyday life in a care home can be restrictive in terms of practicing one's agency and making what is traditionally considered positive social contributions. The ways in which people with dementia, especially advanced dementia, are considered passive [23, 107], or unable to make positive social contributions may be due to a narrow sense of what activities, such as paid work, are considered contributions in Western society [51]. In examining the subtle ways in which the residents expressed care for each other, such as offering stories and sharing social experiences, design processes and outcomes can further examine what is deemed as a worthy contribution, and in doing so support the agentic abilities of the person with advanced dementia. By considering agency in terms of caring, emotional responses to those around them, we can shift the debate away from whether people with dementia have agency, and towards best understanding how to support them in expressing their agency with experienced-based technology. The work of our volunteers in this setting was vital to supporting the content creation and scaffolding the sessions, but it also ensured more opportunities for social contribution from the residents. By incorporating a critical approach to understanding agency as a socially realised ability, we can design technologies which support the playful, caring and emotional elements of agency for people with dementia.

Inclusivity and Accessibility

Throughout our study, we aimed to examine and implement accessible design which was sensitive to the various abilities of the residents. While we were able to incorporate many of these considerations into the final design of Printer Pals, others became more apparent at the later stages of the evaluation. For example, while the volume can now be adjusted significantly on the device, staff recommended an in-ear audio stream for residents who might be distracted by other sounds within the environment.

Finding the balance between aesthetics and functionality was a concern from the beginning of the project, as many residents were reluctant to engage directly with certain types of technology used by the research team, specifically those with touch screen technology. Through introducing Printer Pals first in cardboard, and then encased in robust materials in the final evaluation, the residents felt more comfortable engaging with the technology itself, and the printed receipts. The iterative nature of the design process ensured that the residents were included and consulted within each stage of the project, creating space for people with dementia to have a direct input into the technology that was built. Supporting appropriate inclusion for people in the later stages of dementia within design processes can result not only in more enriching technologies, but also furthers our understanding of how to best support

and include people with advanced dementia in HCI research [19] which calls for participatory approaches to design and dementia.

The nature of some of the activities, riddles, and quizzes challenge the perceived capabilities of people with dementia [118]. While we are sensitive to the nature of questioning, to position people with dementia as 'beyond' being challenged in this way can be equally insensitive. Presenting these challenges and quizzes to a group ensured that no one was directly challenged, but also gave the residents the opportunity to be part of a team. The fact that the questions were presented by Printer Pals, rather than the researcher or staff directly, changed the nature of questioning, as the questions were delivered by a third-party object, which was sometimes challenging, but always playful in nature. We were particularly eager to ensure that people with advanced dementia were included in the social activity, and considered their participation, whether it was listening, smiling, singing or dancing, valued participation and feedback. Through inclusive design practices, we can challenge the perceptions of people with advanced dementia as incapable of engaging with playful and fun activities, opening the space for design in dementia which encourages fun, social connection and competition. Designing for competition, playfulness and emotion can create a broader outlook on the nature of life with dementia, extending the possible aspects of the lived experience to capture within experience-centred design [93].

The Use of Technology to Encourage Social Connection

While it is important to consider the unique experience of dementia in how we design, what we learn from people with dementia can be translated into more universal design practices. Designing for dementia requires a careful consideration of social environments and dynamics, and how to support opportunities for social agency. Printer Pals was used in this context as a way of bringing a group of strangers together, to create a sense of understanding and belonging in an environment in which few choose to live. Many people find themselves in similar social contexts, such as hospitals, temporary accommodations, work places [16, 28] etc. in which social connections need support to be established and maintained. As is the case of designing for dementia, a focus on technological solutions for the more obvious challenges facing the individual can overlook the social and cultural consequences for those living in socially restrictive environments. In this context, Printer Pals was an opportunity to listen to each other, laugh together and build cohesion as a group. In designing technology to bring people together and co-construct meaning, we can examine what this means for individuals within their social environment, broadening the scope of designing for social belonging.

Conclusion

In this paper, we presented the findings from the design, implementation and evaluation of Printer Pals, as a means of exploring and supporting the

agentic social contributions of people with dementia in the care home environment. Through our findings, it is evident that people with dementia play an active and engaged role within the care home and can be further supported in their agentic abilities through the inclusion in design processes and outcomes which provide opportunities for further participation.

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Chapter 7: Discussion

Summary of the Findings

In its earliest conception, this PhD research set out to examine the experience of dementia, using ethnographic methods, with a view to designing a technological intervention for social engagement. It evolved into a critical examination of the nature of intersubjective dialogues and their role in developing and sustaining social presence and identity. While this research is still very much rooted in experiences of people living with dementia, attention to deeply meaningful, often subtle moments that can be categorised as 'caring moments' between people with dementia in the care home, between them and the staff, and between all of them and the researchers, position the thesis as about care and the role of design in evaluating and promoting these caring moments.

The aims and objectives outlined at the beginning of this thesis set a course for this research which sought to 1. Examine the interpersonal experience of advanced dementia and 2. To examine the role of design to draw attention to the social contribution of people with advanced dementia. In order to examine this, I asked the following questions:

-What is the inter personal experience of engaging with people with advanced dementia?

-How do people with advanced dementia communicate their selfhood and in what ways can we respond to this through design and technology?
-What implications does the nature of participation in advanced dementia have for wider ECD approaches to design and inclusivity?
Throughout the course of the research these questions, which began as separate threads of understanding, merged into an exploration of the role of design and design thinking in the context of enriching communication with and for people with dementia in care. Through initially seeking to understand the experience of advanced dementia in context, the role of design and its potential to enrich this experience was slowly introduced to add further opportunity for engaging critically with this experience. What emerged from this was an understanding of how people with advanced dementia engage meaningfully within design spaces, and the role of design in creatively contemplating and responding to the experience of advanced dementia.

Within a HCI field which emphasises participation and experience-based design practices, this work with people with dementia tested the boundaries of what is considered meaningful participation and social engagement [61, 93, 111], challenging research design to deeply examine the ways in which we engage in dialogue with people with advanced dementia [85, 98]. Adapting and responding to the needs of people with advanced dementia as research participants sheds further light on some of

the more rigid views on cognition [135], agency [16] and contribution [12]. These concepts, which have traditionally led to the exclusion of people with advanced dementia from both design and society, had to be re-examined to ensure that the 'ways of being' expressed by people with dementia are thoroughly incorporated into our understandings of human experience, and into the manner in which we explore and support active participation in generative and ethical design practices in HCI. In this chapter, I discuss the body of knowledge generated across this PhD, stating the contribution of this thesis to the field of HCI and the questions this body of work raises in regard to the future of dementia care and the role of HCI and technology in the advancement of care.

Key Findings and Contributions:

This thesis contributes knowledge across several fields, most notably HCI. However, this work also demonstrated the role of HCI and design in care contexts, which has implications for caring professions such as nursing and social work. My positioning as a psychologist in this research context allowed me to examine the design process as inherently relational, which also resulted in the design itself as a means to examine how we construct meaning through communication and activity. Below I present the key findings and contributions of this thesis, which I then discuss in the remaining sections of this chapter:

1. The design framework demonstrates the need for consideration of how we seek recognition for our lived experience, and the implications of designing for recognition with people with advanced dementia. The design sensibilities have been considered throughout the empirical work of this thesis, the framework is also a contribution to wider HCI practices.

2.The detailed accounts of interactions with people with advanced dementia demonstrate the various ways they communicate their ability and willingness to participate with social world.

3. The attempt to engage in the act of recognition with people with advanced dementia presents a re-examination of notions of agency, care and communication as legitimate no matter the expression, and the need to respond to such attempts in order to experience mutual recognition.

4. The introduction of design and creative methods of meaning-making into the care context promotes activities which seek to demonstrate and support recognition in care. This work demonstrates the ethical and social value of design work in opening up space for explorations of personhood.

5.The introduction and use of technology and design methods which seeks to support meaningful social activity, such as printer pals, promotes inclusive design that demonstrates the role of technology and design in supporting people with dementia to socially contribute to their social contexts.

In the remining sections, I discuss the implications of this doctoral research in relation to the aims and objectives of this thesis. I also consider the implications of this work in terms of future research and the limitations of the work presented.

Examining the Dialogical Experience of Advanced Dementia

In the opening chapters of this thesis, the current state of dementia care in Ireland [119], the move towards person-centred approaches to care [79, 81], and the current understanding of advanced dementia regarding opportunities for design [78, 138] were described. It is clear from all of that work that people with dementia, particularly advanced dementia, are positioned as passive in the process of their own care [118] and have been largely excluded from research and design processes [129]. While many advances have been made to expand the understanding of what it means to live with dementia and the social consequences of this experience [11, 104, 123], facets of the medical model still prevail, resulting in a response to dementia which is concerned with cognitive decline, monitoring, risk assessment and symptom management [77, 114]. This thesis is situated in the body of research concerned with the potential of experiential design work with people with dementia, such as the work of Wallace [151], Lazar [90], Morrissey [111], Treadaway and Kenning [141], amongst others [17, 61, 78], who convey the need for careful, creative approaches to participatory work with people with dementia. One of the aims of this research was to generate relational understandings of advanced dementia, drawing on the theory of recognition to guide the findings. One of the original contributions of this project is the focus on advanced dementia,

along with the insights derived from working with people with advanced dementia using experiential design processes.

This thesis presented a series of examples in which the purposeful actions of the person with advanced dementia were carefully examined in terms of dialogical meaning-making. Findings from chapter 4 demonstrate the subtle yet engaged nature of dialogue, in which the person with dementia is situated as central in the on-going meaning-making process. This does not always appear as a coherent, sequential interaction, but rather acknowledges that the person with dementia is in the process of continuous sense-making, and responding appropriately to this requires a range of dialogue that extends to non-verbal, embodied cues. As we see in the example with Maura, expanding the dialogical repertoire to the embodied actions of the person with dementia results in being better equipped to respond:

Suddenly she starts to pull her blankets off her, asking me to help. 'I'm too hot' she says...I'm too hot, I can't breathe. I ask her would she like to open the window. She says she would. Once I sit back down again, she says she can't breathe. I'm watching her closely and she is breathing normally, but also holding her hands up, reaching out for something. 'I'm dying' she says repeatedly. 'No you're not.' I try to reassure her. I take her hand and she strokes mine gently. Her fingers are so thin. She might be dying; how would I know? She starts to run her fingers over my watch. She asks me what time it

is. 'Three'. 'I'll be dead by four' she tells me. Does she believe this? Is it correct? She seems physically relaxed once I have her hand. She says I'm very good to sit with her…'If I could just stand up' she states. Her legs have been badly ulcerated and crossed over each other. I uncross them gently and she makes a sound that expresses some relief. She seems better now. I put the covers back over her. She's more relaxed and seems to be restful. I'm still afraid she might die right here. But she doesn't. Once she's sleepy enough to be relaxed I leave her. (Chapter 4)

The dialogue here is an opportunity to engage in processes which seek out and honour the agency of the person with advanced dementia. While Maura at this time was not actually dying, her words (and more so her actions) communicated a discomfort and unease that required careful attending to. Response in this context meant engaging in a dialogue which is deliberate and carefully crafted so as to support the agency and purposeful actions of the person with dementia.

The social and embodied communications that encompass interactions with people with advanced dementia presented a challenge for design research to engage reflectively with these interactions. In the design framework presented in chapter 2, and the subsequent papers in chapters 4, 5 and 6, the focus of analysis is on intimate interactions with people with advanced dementia, and reflections on their social lives, their ways of communicating and the need to really listen and respond to

expressions of selfhood as a means of intersubjective enrichment. The experiences of care and relationship development with people with dementia contributes to a more active and empathetic grounding of what it means to live with advanced dementia. Societal and emotional understandings of dementia as a 'social death' or 'the long goodbye' [133] remove the personhood of the individual with dementia from the narrative, as their social presence and contribution is assumed to have ended. This thesis counteracts this narrative through presenting interactions with people with advanced dementia as relational and socially consequential, in which the person with advanced dementia is positioned in the process of seeking and giving recognition in their social exchanges. This acknowledgement of the active role of the person with dementia, regardless of how they communicate, is the starting point for greater critical and relational design responses to personhood.

The examination of the relational aspects of dementia care became more explicit through the analytic grounding in recognition theory and set a course for this thesis to examine the complexity of what it means to engage in acts of recognition with and for people with advanced dementia. As discussed in chapter 2, the social theory of recognition examines our fundamental need to be recognised as a means of developing and maintaining a practical social identity [73]. The implications of the struggle for recognition extend from our interpersonal relationships to the

provision of resources and opportunities within society [51]. The critical approach to the experience of dementia presented in this thesis firstly highlighted the way our exchanges with people with dementia, both interpersonally and culturally [38], have failed to respond to their need to be actively engaged in the process of developing and maintaining a practical social identity [64]. Engaging with the experience of advanced dementia while taking recognition as a fundamental right, required a re-examination and reconfiguration of the role of people with dementia. Drawing from Honneth's concept of mutual recognition [68] within the empirical work, the need to honour the agentic behaviour of the person with dementia, while also demonstrating their impact on the development of the social experiences of those around them, including my own, was highlighted. In presenting this work across the thesis I demonstrate how our response to people with advanced dementia is a key consideration for how recognition unfolds in practice [25, 105]. The dialogue is an opportunity to engage in the ongoing sense-making process, keeping the fundamental struggle for recognition active. Throughout the field notes the opportunities to attend to agency in this context may be subtle, but nonetheless suggest a respect for the needs of the residents to play an active role in the ongoing dialogue they *are* engaged in. Take for example the interaction with Nancy presented in Chapter 4:

I knocked on her door just as she was leaving the bathroom and she said she'll come down with me now. She asked me do I mind if she gets a glass of water before we go. I tell her to take her time, there is no hurry. She pours herself a glass of water and I think about asking does she need me to do it but then decide not to, as she is clearly able. She offers me a glass too but I tell her I'm fine, I just had my lunch. She says she'll just sit down in her chair to drink it and tells me I should sit down too. I sit on the end of her bed, mostly because I don't want to rush her. (Chapter 4)

Paying attention to non-verbal behaviour, as demonstrated in the field work, not only acknowledges the embodied selfhood of the person with dementia [85], but provides opportunities for moments of caring interactions that are reciprocal. As a researcher, positioning the person with dementia as active in the process of meaning-making resulted in an examination of recognition in practice and the emotional and psychological implications of engaging in this process. How we respond, both in the moment and through design depends on our willingness to communicate with people with dementia, to engage in the subtle, often non-verbal -and sometimes uncomfortable- ways they communicate with us. This work echoes Craig's sentiment [30] that rather than considering dementia in terms of cognitive decline, it is more inclusive to treat it as a communication issue, in which the person with dementia is trying to communicate with the various resources and skills available to them, if

only the rest of us could see it. In light of the emphasis on reciprocity and mutuality presented in this thesis, it is evident that this communication warrants a meaningful dialogical response, both in the moment and through design. Ensuring that people with dementia are acknowledged for shaping the experiences of others requires a dedication to extending our own communication repertories, while also taking a reflective approach to examining the consequences of engaging in acts of recognition with a person with dementia. I presented my reflective positioning in chapters 3 and 4 particularly, to give a sense of the complexity of these interactions and an insight into the emotional and psychological challenges of these interactions, particularly when the person with dementia expresses frustrations and confusions which are difficult to respond to. Similar to Taylors' use of recognition theory to explore her relationship with her mother [135], adopting recognition theory in this context resulted in a critical examination of the interactions of care, which range from pleasant and mundane to distressing. Throughout the thesis I presented a number of vignettes from the field work which demonstrate the limitations of my response to the concerns of the person with dementia, and the emotional aftermath of feeling I had failed them in some sense. Navigating these interactions is difficult both personally and in a design research sense. Nonetheless, a dedication to constantly evaluating the capacity of emotional and research responses in these interactions is the only route to

ensuring we develop relational exchanges which are respectful and transformative for the person with dementia. I present these personal and practical difficulties to convey the complexity of the experience, the light and shade, the possibilities and restrictions in responding meaningfully to this experience, both interpersonally and through design. It is not a seamless space for research and if HCI research is to excel in this context, more open and honest discussions are needed about these challenges. This is perhaps one of the main outputs of this thesis; that the stilted, uncomfortable, sometimes funny but always poignant interactions in advanced dementia are well within the realm of human experience, and therefore worth designing for. In giving these experiences theoretical weighting and psychologically and emotionally meaningful responses, we not only acknowledge the struggle for recognition for people with advanced dementia (as outlined in chapter 2), but can turn the focus back outwards, to examine more closely how the experience of advanced dementia reflects our own ideas of self-identity and preservation as designers and researchers, the weight we place on narrow-minded cognitive and social contribution and the systems of care we as a society have put in place to respond the needs of people with dementia. That people with dementia are fundamentally worthy of recognition should not be an unusual stance to take, but at times it seems that the majority of the theoretical and empirical work of this thesis was trying to prove this point.

Moving beyond this argument and taking it for granted that people with dementia are deserving and capable social actors, we can focus further on building services *with* people with advanced dementia, ensuring their rights to be recognised are implemented into the care practices they are engaged in.

This thesis offers insight into the relational exchanges that are possible, and vital, with people with advanced dementia in order to sustain their self-identity. Positioning the person with dementia as active in the process of seeking and giving recognition, regardless of how subtle this action may seem in the moment, is a strong advance in the move towards a relational and embodied understanding of personhood, both in the context of dementia and beyond. In responding to the everyday care interactions that hold potential for meaningful and co-constructive engagement, we extend the possibilities for design and care.

The role of design in reconfiguring participation in dementia care

While examining the experience of advanced dementia was a key aim of this work, of the second aim was to apply this understanding to support re-configuring the role of the person with dementia, both in relational and design dialogues. Reconfiguring participation so as to explore the potential roles available to the person with dementia requires us to consider them as equal yet different partners in dialogue, and often taking our cues and tone from their purposeful actions. As demonstrated in the below interaction

with Carol, this approach to re-configuring participation results in more fruitful and collaborative dialogical interactions.

'Sit yourself down there,' Carol says indicating that I sit beside her. 'I will of course', and I pull up a chair. I ask her if she wants to get her nails done... 'They could do with a paint over' and she doesn't protest so I get the remover and start taking it off. 'This is a lovely room,' she says, looking around...I pick up a pink and ask her if she likes that, she nods in approval so I take her hand and start painting. Her hand is gripping mine, which makes it more difficult to paint but I manage. Kate comes back then and gives me a nod as if she's very surprised. 'You're on a winner' she says, 'she'd never let you do that.' She brings out the cakes then that we've made in the morning. 'For me?' Carol asks when she's given one. 'Well you made them so you deserve one,' I say. 'I did?' She has no recollection of this morning, so I brush it off. 'Is the cake nice?' 'Lovely,' she says. (Chapter 4)

This moment between myself and Carol is a poignant yet reassuring insight into the nature of dialogue and collaboration with the person with advanced dementia. In the absence of short-term memory remains an innate understanding of the back and forth of these caring exchanges, and the potential for collaborative actions which highlight the role of the person with dementia. Transitioning from these everyday interactions, such as painting nails, into design practices which seek to further enrich everyday care practices, requires an approach to

interactions which is open to the re-configuration of the role of the designer and the role of technology as much as the person with dementia.

According to Suchman [132], if agency is to be adequately acknowledged as a socially realised concept, then HCI research must consider '*boundaries between persons and machines to be discursively and materially enacted rather than naturally effected and to be available, for better and worse and with greater and lesser resistances, for refiguring' [132].* The interactions between researcher, participant and the technologies presented in this thesis (such as Printer Pals) reconfigured both the nature of dialogue with the person with dementia and the use of technology to engage further in the process of meaning-making.

Reconfiguration here is not an attempt at blatant equality amongst researchers, participants and machines, but rather a nuanced process in which those engaged in co-creative meaning-making are viewed as equal but different, echoing the sentiment outlined by McCarthy and Wright on dialogue in design [99]. While it is important to re-configure the user [7, 132, 144] so that the participant feels supported and confident in their role in shaping the process, in this context successful design collaboration requires the researcher to also re-configure themselves, and to somewhat restrict their own agency to ensure the person with dementia is taking the lead. Sometimes this will mean abstaining from planned activities, rescheduling and re-evaluation that temporarily requires misrecognising

our own needs as researchers in order to attune to those of our participants. As demonstrated in the reflective viewpoint in chapter 3, configuring my own role in the design process required a deeply reflective approach to the research. This work demonstrates the ways in which agency is also dependent on dialogue and that mutual recognition is not wholly positive to experience, but rather an acknowledgement of the deep impact of others on our sense of self. In terms of ECD, an aesthetic appreciation for these complex exchanges which shape our experiences, our sense of agency and ultimate recognition, require an examination of both the enriching and concerning elements of interactions.

The design activities introduced in this project elevated the roles of the people with dementia, configuring them as experts and mentors in their lived experience. As noted in the History Club field work, the activities carved out a new role for Charlie, who shared his historical and political opinions, appearing very confident in doing so as he grew into the role:

'*Sitting around the table with the pictures laid out in front of us, Charlie leads the conversation. We spoke mostly about things that have changed in the last hundred years, from the railway, to the way our country was run. Charlie spoke of the 1800s and how the British changed our country. He was passionate about this and spoke of the strategies of the British, to divide and conquer. All this came from Charlie, and he went from one topic*

to the next without much input from the rest of us, such as the 1916 Rising and political figures of the time. (Chapter 5)

Here Charlie demonstrates the potential of extending spaces for belonging in which previous experiences are shared and re-defined in the design and care context. The reconfiguration of the role of people with dementia requires supportive, inclusive and creative spaces in which they are positioned as an active, complex and worthy individual, whose interactions shape the technology that we are implementing into care communities and practices. The role of materials and technology, which became central to interactions in the student project as well as Printer Pals, further demonstrated the need to consider agency as socially realised within our interactions with both each other and the technological materials which support these interactions. According to Suchman this approach to agency situates our ability to re-configure as socially constructed and realised:

'The point in the end is not to assign agency either to persons or to things but to identify the materialisation of subjects, objects, and the relations between them as an effect, more and less durable and contestable, of ongoing sociomaterial practices.' [132]

The introduction of technologies such as Printer Pals engaged staff and residents to consider the role of media and technology in creating more active scheduled activities in the care home, through the provision of

resources which speak to their individual differences and lived experiences. These types of activities, particularly when new listeners are invited into these spaces, such as visitors and volunteers, re-positions the person with dementia as a story-teller with a wealth of experience and as someone with particular taste and style. Designing processes and technologies which encourage this type of dialogical sharing of experiences allow for personhood to be further recognised, and the role of people with dementia in their own communities of care to be reconfigured as active and meaningful.

Design in Communities of Care

The examination of the experience of people with dementia and the subsequent reconfiguration of relationships through design activities are in practice acts of care, in which the concern is first and foremost the improvement of the care of the person with dementia. This thesis presents care and design in context. Care, similar to agency, is presented as a socially realised interaction, in which the person with dementia is positioned as active in both their own care, and that of those engaging with them. This, according to Mol [107] is a key distinction in the movement towards more logical and meaningful care interactions. If design is to extend care and dialogue with people with dementia, situated knowledge generation is required. In this thesis, design activities were created to extend dialogue within an existing care practice. In order to

ensure these practices were ethically and practically appropriate, learning from and within the context through ethnographic methods was crucial. This resulted in both a successful expansion of creative design methods, but also an understanding of how to navigate and consider the care context in which we design.

Learning with and from people with dementia in this thesis required being embedded in their environment. I became a member of the care community, and part of the very context I was trying to examine. As Tim Ingold states [72], learning in context is transformative for the researcher, in which insight becomes lived experience, and knowledge generation thereafter:

'What we might call 'research' or even fieldwork is in truth a protracted masterclass in which the novice gradually learns to see things, and to hear and feel them too, in the ways his or her mentors do.'

My mentors in this context were the residents and staff of Oakfield House. Learning from them and with them in an active research process resulted in the generation of findings which reflect both '*what life is like and what it could be'* [72]. This, according to Ingold, is the aim of design research [72]. Designing in context requires both an understanding of life as lived, and of the challenges and opportunities if we are to expand the lived experience through design. As is evident in this work, which echoes many previous HCI projects in care homes [78, 111, 150], to design in the

dementia care context requires careful navigation of the various relational and social complexities that inevitably arise in a context which is home to some, workplace to others and in which serious and difficult care is being carried out every day, often under restricted conditions [22, 89, 111]. The empirical work presented in this thesis demonstrates the challenges in supporting notions of agency and reciprocity in socially restrictive circumstances, where many residents are confined to wheelchairs and care schedules, with few outlets for the expressions of selfhood which previously shaped their life narrative. As noted in the following field notes detailing the History Club activities, social connection and engagement are not necessarily organically developed:

Charlie spots his wife coming in so he says he better be off. I offer to bring him up. The girls say goodbye to him and he says he'll see them next time. He greets his wife and the three of us head back to his room. As we pass the entrance, the wife of his roommate is leaving. She stops with us and says to Charlie 'I never knew that you could talk so much.' She's laughing as she says it but it strikes me. Is this true? The two men are in the same bedroom. (Chapter 5)

In learning from the people with dementia in regard to their shared and individual interests, there were opportunities to facilitate design processes resulting in the transfer of their knowledge into design activities and outcomes, further supporting agency and social contribution in this

setting. The framework for design and subsequent field work presented throughout this thesis offers insight into the everyday rhythms and routines of life in the care home, which largely revolve around meal times, bathing, dressing and medical administration. The challenge for designers in this context is to attune and adapt to these everyday schedules, to find space and time for appropriate research activities. In learning from the existing care practices, the designer is better equipped to respond to the textures of the context and ensure design processes and subsequent outcomes (such as Printer Pals) are both sensitive and generative within their context.

In terms of my practical role in the care home and as a member of this community, my biggest initial and sustaining contribution from the perspective of the staff was most likely my presence, as a helping hand to engage with residents in need of assistance or attention. Learning from them as I navigated this environment, I quickly understood the need and necessity to be useful, and it was never an option to sit and observe while others worked to ensure the safety and comfort of the residents, both personally and ethically. Over time staff and residents began to engage more with the design work and it transitioned from individual work to more group-based activities, based on the feed-back from residents and their families of their positive experiences of the research activities. The slowing down involved in this project, which is in great contrast to the

growing trends of rapid ethnography, weekend workshops and limited research time schedules, was central to the trust and relationships built during this project. I acknowledge the time span of a PhD is perhaps a rare opportunity for this long-term engagement, but it does suggest a sense of timing that allows people with dementia to set the agenda, research design, and planning as an ethical practice. It also suggests the many roles the researcher may assume in this role, as a designer, volunteer and friend. Being comfortable with these roles, and seeing them as part of the process, is central to establishing fruitful design relations. While these facets of design research are not accounted for in many research or service design funding cycles, making these insights central to our empirical work can aid in setting new ethical standards for design research.

The students' involvement added another layer to this design work, as well extending communities of care and design in Oakfield House. This phase of the project provided further evidence of the contribution of the participants with dementia in the development of positive and formative relationships. They were both active contributors to design communities and mentors to the students, who in turn learned from their engagement with the people with dementia and developed a facet of their own social identity which was related to responsibility and civic engagement.

In his reflections on this work, one of the students Owen describes the response of the participants with dementia to the design activities as strong motivation to engage in the projects:

'It's literally just a matter of sitting down and thinking about, you know the idea of the city history, was a great idea and then, ideas spread from that and it's kinda (sic) led by the people who are there. I think if we had had the first day and it hadn't gone well... But they were already invested in it so we automatically went away and got more stuff for it and just built on top of that. So basically everything we did was based on what they gave back to us.'

This response from Owen details his own sense of mutual recognition in action, in which he was forming and refining his own practical social identity based on the social feedback of the residents he was engaging. The nature of mutual recognition evident in the student project demonstrates the use of design to support the development of social identities, in which the dialogue through design results in reciprocal and more engaged members of the community.

Students continue to work within Oakfield House as volunteers, and one of the major practical successes of the PhD research was building strong links between the School of Applied Psychology and the care home in which students are supported to engage in volunteer programmes. This means that the care home residents continue to work on design projects

such as the Life Story Boxes and History Club presented in chapter 5. As these projects involve low-tech activities, staff feel more comfortable supporting and extending these activities in the care home, which evolve based on new residents and their interests. Embedding participatory design activities into the everyday care schedules of the care home results in creative explorations of personhood for the residents, particularly new residents, which indicates an interest in their lived experience as well as an acknowledgement of their continued role in their community. 'Handing over' participatory methods to the community of care results in further adaptation and simulation of these activities into the communities we are aiming to improve. This concept of how we 'give design away' to communities of care, and the sensitivities and considerations required to do this, as outlined in chapter 5, presents a strong contribution to fields beyond HCI, such as nursing and social care. Integrating creative methods which speak to the strengths and interests of people with dementia, as well as their need to be recognised, can be integrated into care schedules, but only if staff and communities of practice are supported in doing so. Working with staff to understand the resources and potential available to them, is a crucial step in embedding design into care. Suggestions for future work to support this include wider dissemination of these findings outside of HCI publications, as well as working with community groups to expand understandings of the nature of engagements.

While engaging in research processes within communities of care produces numerous worthwhile outputs in terms of knowledge generation, community development and research progress, ensuring community partners are informed and engaged about their involvement in the project requires careful relationship building based on trust at an interpersonal and institutional level. For example, the initial enthusiasm and support for the project was less about the prospect of implementing technology and design but more so that it engaged in research set in a university, which brought a level of respect and esteem with it, which in itself is an act of broader recognition which design research can implement. This understanding was the basis of the working relationship, which drew two institutions together in a growing collaboration that benefitted both communities. The staff and residents engaged with the ideas I presented, which for them was also an opportunity for the provision of further materials, resources, time and money that a university-based project involved. These practical resources were a pragmatic exchange for the space I was given to generate knowledge, in which both parties were benefitting from the research relationship. This signified the desire for resources on one hand, but also the interest and value placed on technologies in communities of care. The status placed on this work undoubtedly supported the progression of the research I was carrying out, but also spoke to the responsibility of the research team to ethically carry

out projects, particularly in settings which are eager to engage with larger research institutes. In this regard, setting careful expectations down from the beginning ensures both institutions have an understanding of what the research process entails.

One aspect that was not as prominent in the empirical work is the complexity of the social lives of the care home. The dynamics between residents, staff and families often reflect the frustrations of the resident who wants to go home, the sadness of the child whose parent no longer remembers their name, and the stress of staff working within a care system that is stretched to capacity. In this sense, the role of the researcher is often to engage in contemplative and creative work that others simply do not have time or capacity for, both practically and emotionally. While it is easy to engage in the practice of mutual recognition once a week as a researcher invested in the process, the everyday care practices and schedules do not always prioritise such activities. Relationships between family members, friends and professional carers has been examined within much research [12, 53, 135]. Examining these relationship dynamics, based on the current understanding of the potential of recognition theory in this context, would create more nuanced understanding of their implication for supporting mutual recognition further. Coming from a place of acknowledging the practical complexity of caring, researchers are better

situated to sensitively engage in supporting carers and families to consider what recognition means for them in this context.

Communities of care require support and resources, both materially and psychologically in order to expand their caring repertoires through design and HCI. While it is easy to be critical of services, care systems and a society ill-equipped to cater to the needs of people with dementia, the relational and psychological responses which may be the ultimate cause of a traditional lack of understanding and resources for care and dementia require sympathetic and nuanced responses. Practically this involves responding with designs and resources which support and often make visual the contributions of the person with dementia in their own care interactions. While the design and implementation of technology was central to the findings and trajectory of this research, the impact of the process itself is the strongest remaining practical output. What sustains beyond the prototype is the continued work towards ensuring working and fruitful communities of care, in which research institutes are directly working with the care community, who feel confident in ensuring they are listened to as equal partners in knowledge generation. These working relationships can sustain opportunities for design spaces to grow and develop into more generative design relationships, in which those directly engaged in the systems of care we are trying to improve are central to the development of the research agenda.

Everyday Ethics and Design in Context

Engaging with communities of care requires careful ethical planning and continuous assessment of the research process [10], beyond the formal research ethics and assessments associated with research with people with dementia. Barry et al.'s 'Virtue Ethics' [10] approach to HCI research outlines the need for practical, everyday ethics to guide the design process. Fundamentally this involves supporting people with dementia and ensuring their safety and well-being are central to research processes and outcomes. Ethical decision making must also consider the experiences of others who are closely invested in the well-being of the person with dementia [22, 101], while also engaging in their own sense-making process in regard to what this experience means for them. This research presented a number of everyday ethical decisions concerning: the involvement of people with dementia in the project, the engagement with the students who were contained to short term projects, and the deployment of a prototype that required a certain level of computer skills to maintain and repair. Navigating these challenges required careful consideration of the well-being of the person with dementia, both in the moment and over the course of the project. The needs of the research team (both myself and the students) also required consideration, as de-briefing was often necessary after particularly difficult times, such as the death of a resident. On these

cases, staff were very emotionally supportive, and over time I learned how to extend my own coping strategies into practical support for students in this context. In regard to ethical practice, the role of the designer here is to seek out support for themselves, whether professionally or socially, so that they are equipped to support other members of the design community, ensuring the well-being of the individual members is maintained and elevated.

Translating the experiences of the people with dementia and the environment of the care home into a suitable design prototype was also challenging, particularly considering the range of interests and abilities of the residents and demands on staff which did not allow for constant maintenance of Printer Pals or overseeing student engagement. The introduction of technologies and design methods resulted in higher expectations in regard to what I could offer as a researcher in this setting. Making plans for ethical beginnings and endings of these projects, and the continued support of all those involved, is therefore integral to research design and implementation. In this work, this involved setting clear expectations about the duration of the projects, a slower retreat from my role in the care home, organising social events to celebrate the end of projects, and ensuring staff of Oakfield House felt the avenues of communication were constantly open. Considering these ethical concerns from research initiation to completion requires the researcher to be

dedicated to 'everyday ethics' and allowing this to guide the design process.

The thesis presented the application of a theory that is inherently ethical in nature. In attempting to follow the guidance of recognition theory, the research methodology required many instances in which the quality of the experience of the participant was questioned. This resulted in a methodology that was slow and considered, and ultimately ethical in nature. The application of recognition theory in this work further guided the everyday ethics of the project. The ethnographic design work created opportunities for the critical application of recognition theory throughout the research, which informed both practical and theoretical advances in the thesis. For example, considering the various expectations set in the research, such as the person with dementia who may enjoy the social engagement, the staff who expect increasing engagement with a wider range of residents, and research collaborators and funding partners who expect certain outputs, can be difficult to navigate. While balancing all these expectations is undoubtedly challenging, returning to the fundamental aim of recognition ensures the everyday ethical decisions are steered by a strong appreciation for mutuality, agency and care. Orientating designers and participants to the nature of recognition in practice and how our everyday interactions hold potential for mutual recognition within communities of care, further informs practical ethics

values with HCI and design practice. Making time and space for recognition through design requires research teams to implement recognition as a core aim and priority within design practice, and encourage research institutes and funding bodies to respect this as an integral part of research ethics implementation.

Experience-Centred Design and Expanding Dialogues

Approaches to design and care intersect in ECD, which seeks to engage in life as felt in order to enrich this experience for participants. This essentially involves caring for the participant, albeit with a heightened sense of the role of dialogue and aesthetics in our everyday interactions. This thesis brought together caring practices associated with the care home, and ECD methods which seek to develop and deliver meaningful engagement and dialogue supported by technology.

Much of the design implications and considerations outlined in the discussion sections of chapters 4, 5 and 6 indicate a move towards inclusive design processes and the implications for this design research beyond the context of dementia care. For example, the Printer Pals project described in chapter 6 suggests the use of design processes to encourage and support social cohesion in settings which may be somewhat devoid of meaningful communal opportunities. The open platform approach used in Printer Pals presents an opportunity to build a repertoire (in this case of meaningful media) which is representative of the collective group

experiences. These design approaches are applicable to other settings in which social cohesion needs support, such as community groups, work places or temporary accommodations. Similarly, the student design project outlined considerations which are relevant for many design settings, in which two or more distinct groups of people, who have various needs and expectations, are supported in creative processes as a means of fostering a new sense of belonging as a group. Pullin [120] suggests that it is the design itself which further excludes people from engaging in meaningful interactions with technology in everyday life [27, 120]. Engaging in participative processes which are responsive to the needs of participants, and in turn encourage creative and inclusive design processes, will ensure that technology is designed to extend experience for people who use it rather than serve as further restriction to their participation in everyday life.

The aesthetics of technology in this context demonstrates the need to carefully consider the requirements and use of technology in an environment. The design and use of Printer Pals allowed for the examination of technology as a means of supporting agency through participation and content creation. This required careful consideration of the nuanced expressions of agency in this setting. Examining how to support the agency of people with dementia raises important questions for Experience-Centred Design. At times, navigating the needs and interests of

the various participants presented contested spaces for the equal expressions of agency amongst the residents. While they were in dialogue with me as a researcher seeking to support their agency, they were also in dialogue with each other, and responding to their shared environment as a means of constructing meaning. In this sense, agency is not a seamless interaction in which everyone acknowledges and respects the agency of the other.

The aesthetic quality of the interaction with Printer Pals engaged the participants in a caring exchange which was mediated by technology. The activities it facilitated encouraged a sense of shared space to engage in unexplored avenues of connection, both in regard to technology and their abilities to engage with it. The movements of Mary in reaction to a song played by Printer Pals demonstrates purposeful engagement with the technology:

During the next song, an old musical, one lady who is very quiet (advanced dementia) moves her hands with the music, making patterns in the air as if she's dancing. She doesn't speak, but the movement is purposeful, engaging with the music. Once the music stops, she lays her hand back into her lap. (Chapter 6)

The expressions of agency within this project may appear subtle at times, but in the response to a song they enjoyed, piecing together a story to share and keeping hold of a receipt to show their grandchild, the

residents demonstrated the creative and relational aspects of their selfhood. Taking a design approach which seeks to honour agency, while acknowledging the everyday decisions and interactions which restrict all of our agency to an extent, is a practical starting point to ECD processes. As technology continues to pervade into care practices, design processes which seek to support agency throughout the design and subsequent technological outputs will ensure that the role of technology is to support exchanges that acknowledge agency, and subsequently recognition, as a movement in care and design. As Mol suggests, technology and care are not opposing ideas - or at least they don't have to be [107]. Technology can be designed, implemented and used as a tool to enrich care interactions. From technologies which seek to enchant [99], to interactions which support more seamless physical care, technology has a central role to play in ensuring that care is viewed as a process in which individuals work towards a shared goal of high-quality care.

Much of ECD theory and practice encourages an approach to experience which suggests a contemplative engagement with the everyday interactions which shape our understanding of the world we live in, and the role of technology in enhancing, enchanting and enriching these experiences [98, 156, 157]. This approach to design is particularly appropriate for examining the experiences on the fringes of what is considered as enriching, such as the experience of advanced dementia.

Generating knowledge within dialogical co-creative methods of ECD, requires the researcher to engage in contemplative interpretations of experience. McCarthy and Wright outline the four threads of experience as 'compositional, emotional, sensual and spatiotemporal'[156]. While these sensibilities are present in exchanges with people with dementia, building up a shared sense of meaningful experience with a person with dementia further stretches the boundaries of what is considered experience. Dialogical exchanges are extremely fluid in the processes of sense-making with a person with dementia, and we cannot rely on previous shared experiences as a means of co-constructive meaning-making. Instead, experiences and stories are presented and re-presented, dialogue is fractured, confusing and often distressing. There is also a distinct imbalance in the underlying assumptions which hold shared experiences together. While my experiences as the researcher and understanding of my role were based on the memories of previous dialogue between myself and the person with dementia, the person I am engaging with may have no previous memories to situate our exchange. Honouring the need to re-negotiate and orientate the intersubjective exchanges under the assumption that this is a new exchange for the person with dementia is a central consideration for design as a research activity in this context. Dialogical interactions must further contemplate the nature of shared experiences, and the role of memories in shaping

dialogue. Taking the assumption of memories out of the dialogue requires the researcher to examine the moment by moment co-creation of meaning in sharper detail. Design as a research approach here presents an opportunity to engage in the complexity and certain tension of dialogue with people with dementia in a creative manner, diffusing these complexities into design responses.

The use of ECD in this thesis allowed for a contemplative and creative response to the experience of dementia and life in the care home. Carrying out design work with and for people with dementia requires the researcher to examine their own practical social identity and how it is shaped and enriched by their participants. These interactions which were the basis of knowledge generation and design present an extended understanding of dialogue in ECD, which is based in momentary, embodied expressions which seek to acknowledge the agency of the person with dementia.

Conceptually Framing the Design Experience in Advanced Dementia

The biggest challenge -and subsequently the most exciting outcome- of this work was the use of recognition theory to theoretically examine and practically support the struggle for recognition for and with people with advanced dementia using methods of ECD. The use of recognition theory in ECD with people with advanced dementia resulted in an elevated

understanding of dialogical practices in design, and guided these dialogical practices in regard to supporting intimate exchanges of mutual recognition while situating these practices within a wider social and political context. The framework suggests several options for implementing aspects of recognition theory into the design practice, particularly mutual recognition. Recognition in practice requires the researcher to extend the act of recognition to their participant and acknowledge the dialogical nature of their mutual recognition of each other. Beyond that, design methods are an opportunity to explore further the need we have to be recognised, and to make clearer the varied ways in which we communicate this need, whether that is embodied, socially or culturally. Taking the notions of mutuality, respect and esteem as outlets for identity maintenance holds designer and design accountable for whether or not we are engaging in recognition with and for our participants, and has the potential to guide dialogical richness and political awareness within ECD practice. The use of this theory in the development of the design framework presented in chapter 2 set clear challenges and opportunities for this work to critically engage in experiences of mutual recognition with people with advanced dementia and resulted in a recognition of the complexity and richness of these experiences. In a design context which has rightly been described as challenging [61] and in which we still debate the capabilities - and rights - of people with advanced dementia, the

introduction of recognition theory makes clearer what design here can and should be. While it may be difficult to respond completely to the needs outlined in the theory of recognition, it is ultimately a response to strive for. It holds the human need for belonging and acknowledgement as central to the design response. The introduction of this framework into HCI is intended to communicate the value of recognition to designers, UX researchers, and engineers, who seek to apply human-centered, relational approaches to design. Engaging with the framework can help guide researchers to critically consider their role in practicing recognition, and their positionality as a person engaged in the process of recognition.

At its core, this is a design orientated thesis, which sought to contemplate and creatively respond to the experience of dementia through the design of enriching, socially-orientated technologies. Engaging in participative, experience-based methods resulted in an approach to design which relied on co-constructive dialogues as a means of knowledge generation, in a context in which communication and meaning is questioned and largely unexamined [135]. Introducing the concept of recognition, particularly mutual recognition, into ECD design practices, resulted in an exciting opportunity for ECD to refine what it means to engage in dialogue, why it is vital to maintain a social identity, and the various paths to recognition available within design practice. Taking mutual recognition as the guide throughout this thesis ensured a

commitment to understanding what it means to extend the emotional, psychological and practical threads of recognition through and with design. The sensibilities outlined in the design framework of chapter 2 were carried through and tested throughout this design work, ensuring a practical understanding of mutual recognition in context. For example, the evaluation of Printer Pals demonstrated the capabilities of Jim regarding his process of giving mutual recognition:

'Seated to my right is a man who has advanced dementia. He spent a lot of the time sorting and arranging the receipts, which calms him down. A lady comes in late, she really enjoys the sessions. She is left at the back, behind a row of wheelchairs. Jim tries to pass her a receipt, so much so he set off his alarm. He gestures to the people in front of her to pass her back the paper. I get up and say I'll help her to move in, bringing her around beside Jim and I. He then passes her on all the receipts he had gathered, and they smiled at each other.' (Chapter 6)

The focus on mutual recognition in the analysis of this thesis, resulted in the types of exchanges, which would traditionally be viewed as 'challenging behaviours' to demonstrate the potential of recognition theory in HCI and design to highlight the process of mutual recognition with people with advanced dementia. The implementation of the concept of recognition into how and why we design sets a clear path for designers and research, in which we constantly seek to recognise the fundamental

and universal struggle for recognition. While the theory has the potential to be applied to many exciting research topics in HCI, applying it to the experience of advanced dementia tested both the theory itself, and the experience-based design practices we have introduced as a HCI community into dementia care.

The design research presented in the empirical of chapters 4, 5 and 6 speaks to the sensibilities set out in the design framework in chapter 2. In responding to the call to design with and for recognition in this context, the empirical design work outlines the means through which we support these processes. For example, the design framework set an agenda which encouraged 'making meaning in activity'. In response, the engagement with the student design project (Chapter 5) and the personalised content creation facilitated by Printer Pals (Chapter 6) supported design activities that encouraged meaningful conversation and interactions with media to engage with the lived history and personhood of the person with dementia. I outlined the concept of 'incorporating textures of interaction into design' as an approach which considered timing, tone and the intentional actions of the person with dementia as key considerations for design. I explored this notion of texture as a relational process more thoroughly in the initial ethnography (Chapter 4), conveying the complex yet reciprocal nature in which communication with people with advanced dementia is possible. Through designing processes which speak to the

need for increased outlets for creative expressions, the research cultivated belonging, ensuring inclusive design cultures throughout the process. For example, the student design project supported a widening of design participation and created a design community that drew on the creative abilities of participants to anchor relationship development. And finally, throughout the empirical work, I highlighted the incidences in which attuning and responding to the embodied communication of people with dementia is an opportunity to engage in mutual recognition in the moment, while also embedding this into the design process through introducing materials to support communication. Responding to the framework throughout the design work encouraged a careful and sensitive approach to design, in which the need to support acts of recognition was central to each momentary and pragmatic decision. As demonstrated in the empirical work, responding to all facets of recognition theory may not be possible at once, but it does suggest an approach to design and HCI in sensitive contexts which seeks to honour and support recognition in creating opportunities for a heightened and enriching intersubjective experiences.

Introducing recognition theory into the field of HCI and ECD more specifically, has the potential to aid in the ethical and relational framing of design projects, which many researcher struggle with in regard to how we engage and support vulnerable populations in sensitive contexts [5, 97,

145]. As demonstrated in this work, injecting recognition theory into design work does not eradicate challenges and dilemmas for designers entirely. We may still struggle with how to support participants and engage in personally difficult mutuality. What is does make very clear is *why* we need to engage in the struggle for recognition within design practices and how to hold our work accountable for furthering this struggle for our participants. The theory allows us to tease out and critically consider the facets of the personal, social and political injustices that can seem overwhelming when working with individuals and groups who have been misrecognised. Navigating these challenges with the understanding and appreciation of recognition and how we all, to some extent, are engaged in that struggle makes space for greater empathy and clearer social impact in design and HCI.

Limitations

While this research strove to examine and reconfigure both the role of design and the experience of advanced dementia, upon reflection there are a number of areas that could benefit from further consideration in the future research in this area.

The framework presented in chapter 2 set a course for design that aimed to support incidences of recognition, engaging in reciprocal processes with people with advanced dementia. As the framework paper states, its use does not suggest a structure for design processes, but rather captures the kinds of interactions to expect and make space for in this design context. Presenting the subsequent design responses as publication which warranted new contributions and could not draw explicitly on an unpublished framework presented a challenge in this research. While the subsequent design outcomes aimed to respond the framework as much as possible, further examination of the use of the framework would allow for more critical engagement with its use in sensitive design contexts. For example, a design response which focuses more on the embodied nature of non-verbal communication would allow for 'expanding space for difference.' A design response which examined more individual ideas of what belonging means in care would expand notions of 'cultivating belonging' for those who prefer solitary activities.

On reflection, the methods employed in this research presented a particular lens that made it impossible to capture the complete and varied experiences of the wider care ecology, such as families and professional carers. For example, although I did broaden design participation through the student design project, this design work could have gone further towards supporting families to engage in creative design processes.

The aim of this research was to engage in the relatively underexamined experience of advanced dementia in care, so as to understand the potential of design to respond to the social needs of this group. This research is intended to open up this design space and demonstrate the potential of contemplating and responding meaningfully to the experience of advanced dementia. While much more research is required to fully consider the nuances and potential of recognition theory in HCI, the presented work is both a response to the research that has already presented the potential of design in this context, and an extension of the experience of dementia into a thoroughly universal design space, calling for the experience of advanced dementia to be considered in terms of the act of recognition. As suggested in the next section, this approach to design proposes a strong methodological contribution to HCI.

Extending design and Methodological Contribution to HCI

As the focus of this work was the design process rather than the product, the thesis contributes several methodological considerations for HCI, which are applicable both within and beyond the context of Advanced Dementia.

Contemplating and responding to the experience of advanced dementia expands our understanding of this experience, while incorporating it more fully into notions of the lived experience. Methodologically, ECD allowed for a creative and dialogical engagement with the experience of advanced dementia [98]. In examining the experience of advanced dementia using these methods, the notion of 'experience' as is commonly understood requires a re-examination. Considering the ways in which a person with dementia communicates as opportunities for agentic and relational behaviour sheds new light on this design context, which has been predominately medicalized [1, 77, 86, 106]. Responding to the various attempts to communicate made by the person with advanced dementia suggests an inevitable reconfiguration of their role, from passive patient to active contributor. It is the role of design to ensure this reconfiguration is reflected in the types of design processes and subsequent technologies we produce.

Extending beyond the context of dementia care, this work presents a number of considerations for designers in HCI. Working with people requires a dedication to understanding and responding to their lived experience in a way that enriches it. As in the case of advanced dementia, considering embodied, relational and reciprocal aspects of the lived experience can guide the designer in widening the design response. A general critique of dementia technologies is that they may infantilize the person with dementia [124], or act as memory prosthetics [89]. While it is imperative to avoid such design responses, considering the need for recognition within wider design practices suggests the need to design for connection and meaningful communication. Applying this design perspective to other groups who may be considered vulnerable or require social support presents opportunities to engage in new understandings of the role of design in engaging with recognition. For example, considering the role of embodiment, designing for meaningful activity and cultivating a sense of belonging by supporting creative design interactions with people who experience misrecognition in some form, whether relational or systematic, can begin to address this misrecognition through establishing a basis of understanding through design.

In terms of the design process employed in this work, in order to respond appropriately to the experience of advanced dementia in the care context, it was important to engage in long-term relationship building so as to incorporate the needs of the individuals and their context into the design response. Design

processes which aim to engage in a similar process can capture the universal elements of design which allow for inclusive engagement with technologies. Establishing the considerations required to ensure that design and technology is responsive to various abilities (in this case sensory and communication changes due to dementia) can make wider impact in contexts which have been left on the fringes of technological innovation. This methodological approach undoubtedly requires more time, but ultimately produces design processes and outcomes which are rooted in notions of what it means to design with and for recognition.

Conclusion

This thesis presented the experiences and contributions of people with dementia in design processes which sought to seek out and honour opportunities for recognition. Framing the experience of dementia and the subsequent design response in the critical theory of recognition presents a course for design in HCI to engage in the struggle for recognition and respond with design processes and technologies which support acts of recognition, agency and care.

This thesis contributes both empirical and theoretical advances in understanding the experience of advanced dementia, and the role of ECD in ensuring people with dementia are engaged in reciprocal design dialogues. Engaging in the process of mutual recognition with the person with dementia requires an investment in their social identity and the acknowledgement of the practical and psychological ways in which we have traditionally misrecognised this experience as beyond the realm of

meaningful social contribution. The theoretical framework informed by recognition theory suggests the role of the designer in sensitive contexts, such as a care home, to pay attention and respond to the embodied and subtle yet active ways in which people with dementia engage in mutual recognition. The caring interactions outlined in chapter 4, presented groundwork for HCI and design researchers to draw on these types of interactions as the basis of meaningful design work. The subsequent design processes introduced in chapters 5 and 6 demonstrated the use of design to heighten experiences of mutual recognition, making space to explore and acknowledge the various ways in which people with dementia contribute to our communities of care and design. The use of design processes, in which the person with dementia is actively engaged in meaning-making, content creation and mutuality, demonstrates their abilities to exert their agentic, caring abilities, and the role of design in making time and space for these social exchanges. The design outcomes of this work speak to the need to create technologies which encourage explorations of what it means to participate in dementia care, and how technologies can encourage further engagement with the re-configuring of the person with dementia as an active contributor and agent for mutual recognition.

Creating opportunities for recognition through design requires a dedication to seeking out and responding to the various ways in which

participants engage in acts of recognition. Future HCI research which considers recognition as a fundamental element of the design process and response has the potential to engage critically in what it means to seek and gain recognition in today's society. While the theory of recognition is rooted is established philosophy, the advent of the technological age presents both opportunities and risks for individuals and groups seeking recognition. HCI can and should play a central role in ensuring that technology is designed to consider the varied ways of interacting in the world and the need to be recognised within relationships, communities, as a civic right.

As the role of technology in care systems continues to grow [98, 107], design has a central role to play in ensuring these technologies reflect an approach to care which creates meaning and supports the person with dementia to continue to shape this meaning and the narrative of their own lives. Acknowledging that people with dementia shape the narrative of design and their role in realising mutual recognition for those investing in their care, is an important starting point through which we can design and care for each other in the most vulnerable times of life.

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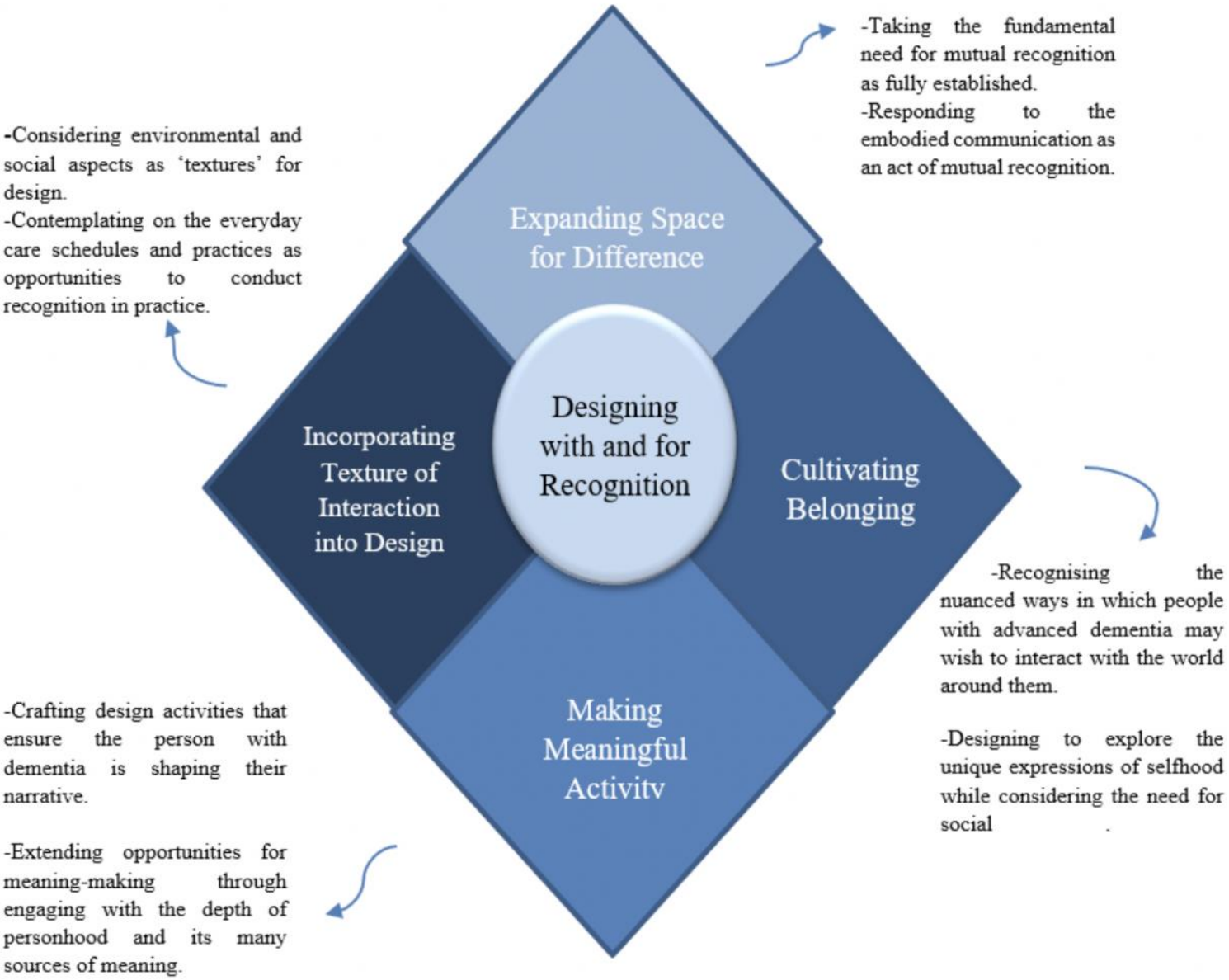
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Appendix I - Design Framework (Chapter 2)



Appendix II- Early Field Notes (Chapter 4)

Abbreviated Terms Used:

Rs =Residents

AD = Alzheimer's Disease/Dementia

K= Activities Co-ordinator

14/07/2016

I came in today for baking but I felt a bit of a tension when I got in. Things were running behind schedule and some of the residents were giving out, which change the normal mood of the place. K. had to run out to get eggs so I was there with the residents trying to pick up the mood. When she got back she was delighted to see me, more so out of relief that she wasn't on her own for the day. She apologised to everyone for being late, I could tell she was flustered by the look she gave me a few times. Once things started to get going and everyone had jobs to do, the mood change and the chat became lighter and people were joking around. I find their humour funny and often surprising, although I shouldn't at this stage. They're making fun of each other, in an affectionate way. They joked again about the time they made biscuits that were rock hard. 'We never laughed so hard' one lady remarked repeatedly.' I was really relieved to sense that the mood had

picked up. I feel it in my chest at the slightest indication of tension between people and maybe I was relieved not to feel that anymore, but I mostly didn't want the Residents to feel anger or frustration towards K., who is clearly trying her best on her own to do the work of at least three people.

After everyone had been brought back for dinner, K. asked would I like to help out with lunch, which initially made me feel nervous, because it seemed liked primary care, which I'm not used to doing. She brought me down to the dining hall and everyone was sitting around eating. Some were assisted by nurses, others were sitting with family members and the rest were eating independently. The nurse introduced me to everyone at the table. There were two daughter of residents, one lady and G., the man I would help. I knew of G. but I had never spoke to him. When he came in initially, they thought about me doing life story work with him. He had been in the army his whole life, had circumnavigated Ireland in a boat by himself and had written a book about it. Knowing this already, I was really very curious and impressed by this man. He must have seen so much in his lifetime. I was also aware of a paper I had just read on an ethnography in a care home where it was reported that when feeding the residents, staff would stand above the residents and have their own conversations while ignoring the Rs. This meal didn't feel like this though. I made sure to ask G. if the food was okay and when he was ready to finish he let me know

and we got into a rhythm that was comfortable. He was reassuring me that he was well able to eat the biscuits afterwards on his own and he offered me some too but I reassured him I would get my own and he should have them. There were two daughters feeding their Dads at the same table and the nurse was joking with them that they will be getting uniforms soon. They were really lovely, asking me questions. I always notice a slight change in family members once they know I'm doing a PhD in dementia care. They talk more, especially if it's their parents and they are really interested in what I'm doing. Watching the daughters feed their Dads made me think of my own Dad and how it would feel if we were in that position. Honestly I can't imagine it because I don't like to think of my Dad needing that much help, how it would go against everything he is as a person. Just as they probably couldn't imagine this role reversal when they were growing up. I'm always struck by how people manage to be happy and friendly. The women were chatting away about an up-coming wedding in the family and how the Father was coming to it and was looking forward to it. I really admired them, for their hands-on approach to caring for their parents, even while they were in care. I hope that they find some comfort in knowing that they are doing all they can because it can't be easy for them.

Three separate incidents with different Residents

In the afternoon, after prayers the ladies were knitting while the men played cards (very gendered activities, but they are popular). I sat beside a lady with advanced AD. While everyone else was content to knit and chat, she was really anxious, saying she had to go back, 'they' won't know where she is. I tried to reassure her that the nurses know where she is, and they will come and get her if they need her but she can only be calmed down for about 2 minutes before saying again that she needs to leave. She keeps trying to stand up and taking the break off her wheelchair. At this stage, I'm really worried that she'll end up hurting herself and try to gently get her to sit back down, placing my hand on her arm and her shoulder to reassure her. The ladies around us ask why we can't just bring her back but K. explains that it's better for her to be distracted instead because if she's put into bed she'll get even more anxious. Eventually she was brought back to her room and honestly I felt relieved because I was scared something would happen to her, and frustrated that I couldn't help to reassure her for more than a few minutes. About ten minutes later, a nurse returned with her again, saying she had wanted to come back. It's really hard to know what to do here, and it's pretty upsetting to experience someone's unsolvable distress.

I brought one lady back from prayers because she was adamant she needed to go to town. She was clearly very anxious, gripping her pants

with her hands, rocking back and forward. She kept saying 'they won't know where I am' and I really didn't want to leave her on her own so I said I'd wait with her until 'they' came. I tried to re-direct the conversation to her lovely scarf. She was dressed very well, in a co-ordinated outfit. There was an immediate change about her and she visibly calmed down. She started to run her hands over her scarf, explaining her daughter had got it for her- like all her clothes. I said her daughter must be very stylish and she agreed with me that she was. The nurse came in then and I took her hand to say goodbye, she gave me such a big smile and gripped my hand for a long time. It felt like she was clinging to me for reassurance that we were both here.

I was asked to go see if M. a new Rs. would like to come down for prayers. When I asked a nurse on the ward his response was 'She wouldn't come for me, but you can try.' I didn't really know what to expect from her when I got there but obviously she had changed her mind and was following the rest of the Rs down. This lady is tiny; she doesn't reach my shoulder. But unlike most of the residents, she's very mobile and can walk anywhere but like to take your hand as you walk. Once we got down to the church, she told me she had to go back up, they would be expecting her. I wasn't sure who 'they' were, but she seemed really worried that they wouldn't know where she was so we walked back to her room and she told me she would wait here. She thanked me for bringing her back. This

seems to happen again and again with different Rs. They're worried about people missing them, not knowing where they are.

18/08/2016.

After lunch I came back to bring down people who wanted to go to prayers. There was plenty of help today so it didn't take much time. I went up to get N. I knocked on her door just as she was leaving the bathroom and she said she'll come down with me now. She's mobile but travels in a wheelchair for safety and comfort. She asked me do I mind if she gets a glass of water before we go. I tell her to take her time, there is no hurry. She pours herself a glass of water and I think about asking does she need me to do it but then decide not to, as she is clearly able. She offers me a glass too but I tell her I'm fine, I just had my lunch. She says she'll just sit down in her chair to drink it and tells me I should sit down too. I sit on the end of her bed, mostly because I don't want to rush her. The leaving cert results are out today and she mentions it. She tells me she's been praying for all of them and I ask her if she anyone in her family was getting results. She says no, they're all too old or too young. We talk about how it's too stressful these days, with the points being so high for everything. She says it's awful for people who aren't good in school and whose parents mightn't have been good. They'll be good at other things she says, they just have to try it. 'No point in doing something that you don't want to do.' I agree with her, saying there's loads of options other than college

you could do. She puts down her water and I get her the walker which she uses as support to get to the wheelchair. She takes a banana out of the bag in the walker, deciding it doesn't need to be there and I bring the wheelchair up to her, making sure the brakes are on and the foot rest is pushed away. I'm always conscious of the foot rests as the residents seem to be scared that they will hurt themselves with them. N says I'm a great girl to be coming in here, as she tells me every week. I say I love coming in, it's much better than studying. She says 'well yes, but the studying is the thing that will get you where you need to go.' By the time we get there most people are down already. N asks me not to put her near the top because 'you'd have to talk to the priest and you'd be thinking of what to say.' I make sure she sits in her usual spot, beside her friend. N is a shy lady, very modest and I've become really fond of her, she kind of reminds me of my Mam. When we do art she sometimes asks me to sit beside her and help her and is always undermining her work and saying mine is lovely even though they're the very same.

I sit by the side for prayers, hoping the priest won't ask me to read. He does sometimes, and I don't mind but I don't want to get the biblical terms wrong in front of such a religious crowd. K plays music before prayers and then the priest welcomes everyone, especially the new faces. There is a new resident who is the talk of the home because she's 95, and 'can do everything for herself'. She doesn't look 95, and is dressed very

well. I'm not religious but I usually enjoy the prayers as it's relaxing in between the two activities. In the middle of prayers, there is suddenly movement behind me. One of the Rs who is fully mobile and sharp has got up to try and convince a man trying to get out of his wheelchair to sit back down. It's probably one of the most anxious times, when for some reason, a resident decides that they want to leave and try to get up. Although I've never seen it happen, for someone to fall out of their chair can be really dangerous and upsetting. K notices and goes down to the men, telling the man standing the she'll sit with R, the man in the wheelchair. She gets a chair, sits down beside him and takes his hand in both of hers and whispers something to him. This calms down R and he relaxes back into his chair. The priest has been continuing Mass throughout this, as he is used to disruptions. When it is time for communion, K gets up to help the priest, telling him who should receive communion. She gets my attention and asks me to sit where she was beside R. 'Just take his hand he'll be grand' she mouths over at me. I make my way over, sit down and say hello, taking Rs hand, asking him is he okay. He doesn't respond verbally, but he grasps my hand tightly and we sit there in silence as the priest gives out communion. Sometime he reaches forward a little and scratches and his leg with his other hand. When it's our turn to get communion I don't want to have to let go of his hand and disrupt him so I receive communion on my tongue, which I find really weird but I get over it. K

gives him a thumbs up as she walks by and he smiles back at her. Every now and then her will look around him and say something but I can't understand what he is saying and he doesn't seem like he's trying to communicate directly to me. Once mass is over, K announces that there will be music by a Brazilian musician, if anyone would like to come up to the Atrium to listen. After this, people start moving and more nurses come in to help push the wheelchair. A nurse tells me she will bring R up and I rub his shoulder and tell him I'll see him soon. He looks at me, doesn't say anything but seems relaxed enough. K asks will I bring a lady upstairs to her room, she doesn't want to go to the music. There are loads of people in the lift on the way up, chatting about the music. This concert is out of the regular schedule and there were a lot more Rs than usual in the Atrium so there's more excitement than usual. I ask the lady, A, if she still wants to go back to her room, just in case she had changed her mind but she says she does. When we get the the ward, I ask the nurses at the station where A's room is and they both say I can leave her with them so I put her chair facing into the desk so she sees the nurses. She tells me thanks and I tell her to take care. At this stage, everyone is up in the Atrium and the singer and her boyfriend, who is helping her, are set up at the top of the room. The residents are in lines, the way a concert hall would be set out, and I think this is nice, it feels like we're at a concert. I sit down in an empty seat between two Residents.

K hushes everyone, even though it's never fully silent here, someone will always be talking. She welcomes the singer, tells everyone she's from Brazil and is going to play guitar and sing songs for the afternoon. The singer introduced herself and tells everyone she's going to sing songs in English and Portuguese and that her English is not so good but she hopes they will help her. Her boyfriend is the son of one of the volunteers, and he's recording her session. She starts singing 'Dream a little dream' and it's really very beautiful and soothing. The Rs are mostly silent for her and some of the volunteers and staff and looking around and nodding in approval of the singer. When she's finished, she gets an applause, with people commenting amongst themselves that is was lovely. She moves on to a song in Portuguese that she explains is famous around the world and I recognise it. During the song, I realise the man I was sitting with in Mass R, is in front of me and is leaning forward in his chair again. I get up and kneel down beside him to get him to sit back down, and he does. K sees me and gestures that I sit beside him so I grab an empty chair and pull it up beside him and take his hand again and he calms for a while. The singer is getting a very warm reception after each song and people begin singing along when she sings Hallelujah by Leonard Cohen. R claps at the end of each song too, sometimes for longer than everyone else, his movement is very rigid. After a while he started to scratch at his head and face, and I wondered if this was out of anxiety, because I

sometimes do the same thing when I'm anxious. After a while he stopped this and started biting one of his nails. He would bite it and the look at it and start biting again. I was worried he was hurting himself so I got up and got him a tissue to wipe his nail, which he did and then handed me back the tissue. He examined the nail, biting it until it was pointed in the middle and started to scratch his face around his eye and his head with the nail he had been biting. It was as if he was sharpening it up and it was distressing to watch if I'm being honest, like he was self-harming. I tried to distract him and rubbed his back, trying to sooth him in some way. He stopped with the scratching and I was really relieved, but I doubt it had much to do with me, he just decided to stop. He then started reaching forward, as if trying to grasp at something, but there was nothing there. He wasn't being disruptive or verbal, he seemed confused but not frustrated really. All the while, the singer continued. She was really interactive with the Rs and chatted in between songs which I think is really important. If she messed up she would start again, which I also thought was nice and authentic. When the singer was on her encore song (she sang for about 30 minutes in total) a woman came into the Atrium and came up to where R and I were sitting. She seemed surprised to see him. 'Hello Dad' she said, rubbing his shoulders and giving him a hug. He didn't really respond to her, but he didn't pull away either. We exchanged smiles and she said she was delighted to see him out, and I got the sense it

wasn't a usual occurrence, as she repeated this to him a few times. I told her he had been down to prayers as well and she said it was great to see him out of his room. She seemed genuinely relieved for him. I felt for her because her Dad didn't show her any more sign of recognition than he had me, a total stranger. I can't imagine how difficult that must be and I don't think any amount of research can take away the pain felt by family members when their loved ones don't remember them. I told her we were just finishing up and that she could take her Dad back to his room if she wanted. She said she would. The whole situation just seemed really hopeless to me. I could sit with him and feel content as long as he seemed relaxed and safe. I don't expect a response because he doesn't know me. But for his daughter, that same response must be so much harder.

The singer received a huge applause at the end and K said she is welcome back anytime, it's an open invitation. She said she could learn some Irish songs but K insisted that no, it was nice for everyone to learn about different cultures. People started to move then, I started chatting to the ladies around me, asking if they enjoyed it and they all agreed it was lovely. It felt like we had just been to a concert and I felt like it was proper entertainment, someone it was a privilege to watch, not just a method of passing the time. A lady asked me if I would bring her back so I did. This lady is really well liked and gives you the warmest smile but her health has deteriorated a lot since I first met her and now she's in a permanent

wheelchair that has been packed with extra cushions. It looks comfortable but she must be in a lot of pain. When we get to her room another Rs is coming out of it. 'Was just getting the paper' he explains, waving it at us. I like that they pass around the paper, like we would at home. They must also trust each other because she didn't seem to mind at all that he had been in her room. I set up the lady by the window and brought her table around to her, making sure she had everything she needed. The window was open causing a breeze so I asked did she want it closed but she said to leave it. Once I got back most people had been brought back to their rooms and K was sweeping up the floor. We remarked that it was a lovely afternoon, the Rs really seemed to enjoy it. She also said, that she had been meaning to say it to me the Manager here had emailed her about an upcoming advocates meeting. They needed an impartial person to go and K thought that I would be suitable 'caused you'd know' she says. She said it'd be interesting for my research too. I said I'd be delighted to go and I was genuinely chuffed that they consider me as a knowledgeable person within here and they would trust me with this responsibility. We also talk about the possibility of training me up to do Sonas, which is one on one sensory therapy for PWD. She said we'll talk about it all when I get back but she'd like to get going on it. We chat for a while about Europe and holidays and she says she'll leave me go and I head off to catch the bus. As

usual, I'm in a really good mood leaving, like I've done a good day's work that actually made a difference of some sort.

28/07/2017

Got in today, everyone has started baking already. They've decided to start earlier so that tidying up can be done by the Residents. I get a lot of compliments from the ladies, probably because I'm wearing a dress which is strange I suppose. They ask me where I got my clothes making cupcakes today, they've got a new cupcake maker. Everyone seems in good spirits and I get stuck in giving out aprons and hats. Two girls from Cedar are here, and they both seem to be very alert. The youngest Rs (29 recently) smiles at me. She's always very dressed up, her family keep her hair dyed blonde and her outfits are always put together. I'm running around the place trying to make sure everyone has something to do. J is back today and although he's a Rs, he is a huge help. M- who I usually help is here and she is in great form. We've established a real comradery I feel. She has become a lot more vocal lately as well and I wonder how that is? She has limited use of her hands but she's got the hang of it today. 'now we're going' she repeats, smiling at me. A nurse brings in another lady the, who I know will need extra help too so I decide to divide my time between the two women. C- has dementia and I know that since she got new glasses her symptoms have improved- they can't believe it really but I think this kind of thing should really be checked. This is the kind of thing that makes

me so frustrated. I'm curious to see is there a change in C- the last time I talked to her she was a bit hostile- and seemed suspicious of everything. I remember feeling uncomfortable with her because she seemed paranoid. But today she's very different. She takes my hand when I say hello. I give her an apron and hat. She's looking over at the women across the way from her and they say hello. She's commenting on how happy they seem- and she's delighted to be here she says. I ask her would she like to whisk some eggs. She takes it and moves the fork around the glass, but doesn't really accomplish anything in terms of whisking. I'm watching her carefully and eventually she stops and says she'll have to go back; they'll be waiting for her. I tell her that if she sticks around she will get some cake and she eyes my suspiciously but then smiles. She says her mam makes lovely cakes. 'does she?' I ask. It's clear her Mam is still alive to her. 'What does she make?' 'Everything' she says. Talking about her Mam has made her forget she needs to go. When she asks again after a few minutes, I tell her I'll bring her up before lunch. 'I've had my lunch already,' she says. 'Oh really, what did you have?' 'I don't remember, she says. 'Sure that's alright too, it's not important.' 'If it was important I would remember,' she replies. This makes me smile because it's true. What does it really matter if someone can't remember what they had for dinner? She remembers her mam. When she asks again to go back, she needs to go to Shandon street, where she grew up. 'That's a huge hill, I say. 'It's not, she

argues. 'it's great exercise anyway'. She smiles at me then. I'm trying to weigh out ingredients for everyone but want to keep an eye on her. She asks another lady if she knows where her mam is. The lady is very kind and patient-'I don't know where my own mother is love,' she replies. Which mightn't be the response that C is looking for but it's meant kindly. Some of the cakes are out of the oven, K breaks up little bits and hands them out. 'They're hot now,' she reminds people. When she gives some to C- I say to her, 'see I told you there'd be cake if you stayed down here.' C smiles at this, and K gives me a knowing nod. C breaks off some of her cake and gives it to and I thank her. There's only a tiny bit of cake so this is really generous. She starts talking about her Mam making cakes again. 'What kind of cakes did she make?' 'Oh everything, we were ruined.' 'That's no harm either though,' I say and she agrees. I know she got new glasses so I ask her about them. 'She doesn't understand what I'm saying.' 'I'm a bit deaf' she shouts, so I ask her again, pointing to her glasses, saying they're lovely. 'Are they,' she asks?

It's time to wash up so some of the residents want to help. One lady has taken it on as her duty, so she asks me to bring her over to the sink, where she'll dry up for one of the men who is washing. He's another one who is very helpful. I often see him looking at the younger residents and I know he has a lot of empathy for them because we've talked about it before. He

considers himself very lucky I know. He's always joking around with them as well; he brings life to the place.

After the place has been cleaned, N asks me to bring her up. She likes things done on time- and people tend to them for her- maybe because she'll vocalise that she's unhappy more than others. So I always bring her up first. She's always very lovely and today is no exception. I ask her how her feet are, because they've been sore and she's wearing slippers today. We talk about that for a while. She tells me about a man who used to work here who came to see her during the week. He has moved jobs but I can tell she was delighted that he came in to visit her especially. She tells me about his children, they're grown up and in University. 'You must be busy with College too' she says. I tell her I'm teaching later. 'Oh really, teaching? She clarifies. She seems impressed, which is lovely. I ask her does she want to go to the dining room or her room. 'My room, I'll go back on the walker.' I think she likes to walk when she can. I park her beside the bathroom and get her the walker. She compliments my dress, I tell her it's warm which is the main thing for me. Once she's up from her chair I move it over to the sink. She thanks me again and again, asking will I be back. 'I'll be in after dinner.' 'Alright darling, thank you Sarah, see you later.'

When I get back down to the kitchen- C is still there- 'Now' K signals to me to bring her up. 'I promised I'd bring you back and now I will' – She

smiles at this. 'Will you help me stand up?' she asks. 'Sure we'll go in the chair' I tell her. She's not too pleased I can tell, but she doesn't object really. On the way out she asks me where we are going. 'Upstairs,' I tell her, but upstairs isn't somewhere that means anything to her I don't think. As we walk past the door she asks me is it raining. 'Not yet, look at those clouds coming in though.' As we pass by the windows she says ' Oh yes, I know this place, I like this.' But when we get to the lift she says she won't get in that thing. 'Bring me up this way.' So I obliged and bring her into a nook by the window. She wants to go outside then, but I know we shouldn't so I tell her they'll be waiting for her in her room for lunch. She doesn't believe me I think. I turn us around, hoping that this time she'll be okay. Luckily there are two ladies waiting for it too, and I take the chance that this will distract her and it does. She gets in without any hesitation. When we get out, into the Atrium, she recognises it and says 'Oh yes.' Once we get to her ward the nurse says she will take her.

After lunch there's going to be beauty, cards and boccia. There's the tournament coming up next week, so they need to practice. Up in the Atrium, there's only two TY students and two residents who can get there independently. They ask me where everyone is. 'I'll have to go get them I say.' First I have to move the tables into the middle of the room, and the others girls help me. I can tell they seem uncertain still, they're only here two weeks, so I try to be extra friendly. When the tables are moved I go

down to Oak to see who wants to go. N is resting when I pop in but she wakes up straight away- 'Oh hello love'- 'I'll be down, I'll walk myself.' 'Take your time, no hurry.' I say I better go down to check does NL want to go down- 'You better,' she jokes. NL is ready too so I help her into her chair too. One of the legs is unstable so I try fix it and it works. When I'm in the one of the nurses comes in asking do we need help. I don't think I do, I've done this hundreds of times at this stage, but I let him because I've never been trained so maybe I'm doing it wrong. He asks me if I'm a student nurse. 'No I'm a volunteer, I'm doing research'. He's faster (less gentle) than I would be, but Nl doesn't seem to mind, so maybe I'm overly cautious about it. We set off then, and when we get there, most of the residents are sitting around the table. I go to get C, see if she's up for the activities. She's sitting at the nurses' station, reading the paper- I wonder if she's actually reading it or if it was just given to her. When she sees me, I ask her how she is, would she like to come to get her nails done. She says she won't. She's feeling low, she doesn't feel well, she can get out of it. She asks me then what I did to my hair. I think she must be thinking of someone else, and my hair is confusing her. I say I didn't do anything with it, didn't even brush it. I have a long necklace on and this get her attention. She takes hold of it and says its beautiful. I tell her I got it for my birthday. She has a firm grip on it and I'm a little bit anxious that she'll try pull it off. I ask her again if she wants to go and she says she will now, but she

needs to tell the nurse. The nurse is chatting with another women, and when C gets her attention she says. 'I need to say, I need to say…. I'm not feeling well' 'Are you not well' the nurse repeats back. The nurse looks to me saying 'We were thinking that we will try with the Boccia in a while.' C seems happy with this decision so I tell her I might see her later, I'm just next door.

When I get back in the men are sitting around the smaller table playing cards and the women are ready to knit and get their nails done. K has brought up the beauty crate and is trimming nails. P(who is blind) asks me what her nails are like. I tell her they could do with being painted again. She's very independent so when I have the nail varnish remover ready, she does it herself, asking me if they're all done after a while. N is on the other side of me so K asks me if I'll file her nails with this electric filler. I joke with N that I'll try not to hurt her (It's not really a joke, I've never used one before). I take her hand and make sure she's okay and she assures me she is. Since I've learned about N's medical history my fondness for her has increased and it astounds me further how lovely and kind she is.

The nurse then wheels in C- she must have changed her mind about coming out. I move around the table to say hello to her. 'Sit yourself down there' she says indicating that I sit beside her. 'I will of course', and I pull up a chair. I ask her if she wants to get her nails done. She seems confused by the question so I take her hand and move my fingers over her nails.

They're painted but it seems like they were done a long time ago. 'My niece' is all she says, as an explanation for why they are painted. 'They could do with a paint over' and she doesn't protest so I get the remover and start taking it off. 'This is a lovely room' she says, looking around. She is also taking in the women around her and smiling. Her nails are nearly clean at this stage. 'This is what I like……Perfect Peace'. This makes me smile, what a lovely response. 'What did she say?' the woman beside me asks. So I repeat it. This makes the women around us and the volunteers smile too. I get the feeling it's a very poignant moment. I bring out the bag of nail varnish then, asking her which she likes. There's pink, and a horrible green which I joke about with the girl beside me, saying we could try this one. I pick up a pink and ask her if she likes that, she nods in approval so I take her hand and start painting. Her hand is gripping mine, which makes it more difficult to paint but I manage. K comes back them and gives me a nod as if she's very surprised. 'You're on a winner she says, she'd never let you do that.' I'm delighted to hear this, as if I've made a break through. It's a very relaxed atmosphere. K brings out the cakes then that we've made in the morning. 'For me?' C asks when she's given one. 'Well you made them so you deserve one' I say. 'I did?' She has no recollection of this morning, so I brush it off. 'Is the cake nice?' 'Lovely,' she says. K tells every that C used to be a music teacher and plays the piano. She also gestures towards the keyboard in the corner. 'She might

play for you.' 'Do you play piano, would you play for me?' I haven't played in years she insists. I ask her again, but she whispers 'not with all these people here.' So I don't push it. I might try again some time to bring the keyboard to her room. It'd be amazing.

After the cakes are eaten, we clear the floor and get ready for Boccia. I've never seen it being played before but I know they really enjoy it. The two teams sit on either end of the room and a white ball is placed in the middle on the floor. Everyone is given a ball. They're heavy but small. The aim of the game is to use the ramp to get as close to the white ball as possible. It's basically bowls (I think?) but the ramp makes it easy for people in wheelchairs. The ramp is made of what looks like a pipe sawn in half mounted on a blank of wood on wheels. It's simple but very effective from a design point of view. You just have to push it along from one person to the next. The game gets going and it's actually really fun. The teams cheer for each other, egg each other on. I help with C when it's her turn because I'm sitting beside her like she asked me too. She's the only person in the room with severe dementia, and the other residents are aware of this, they cheer her on more than anyone. She's actually really good and is delighted with herself, smiling all the time. The game goes on for about half an hour, they take it very seriously, and are competitive about it. But more than anything it's really enjoyable and I think it's to see the men and women enjoying something together.

Appendix III- Interview with Student Volunteers

(Chapter 5)

S = Sarah

O= Owen (Student)

E= Emer (Student)

S: Okay, are we ready?

So, when you think back about, what your perceptions maybe of dementia were before you came here, did you have any particular ideas of what that meant and do you think that's changed since your experience here?

E: Yeah, Well I think anything I knew about dementia, em like, from psychology anyway was like the biological stuff and like symptoms and like I never met anyone with dementia and my kind of perception of it was like basically, that it was just memory loss or pure memory like, an extreme form of that. And one thing I was kind of conscience of when we started talking to Mary was that, you know, we'd go in one week and then she mightn't know who we are, and like we'd have to explain who we are and she might be afraid of us. Not afraid you know but not knowing who we are and that might intimidate her. Whereas, I found it surprising that from every week she remembered who we are and like she remembered details about us and like the conversations we had had. I think I was like,

when we used to be chatting away and she'd say something, about, maybe us doing psychology, or something we'd talk about last week, I was kind of surprised at like, what she said? And then I felt kind bad for like being surprised and I didn't give her enough credit like? Am yeah, so I think how it changed.

O: I'd be the same. I didn't have any experience about dementia beforehand, I mean I knew it was, form Textbook, and we had that module last year, do you remember… EH I think did it? It was all about like different diseases

S: Oh yeah Abnormal is it?

O: Yeah Abnormal and we went through dementia in that and it was like 'oh it's all concrete' well not concrete, it's kind of flexible but they have *this* wrong with their memory, *this* wrong with their functioning

E; Yeah, *this, this, this,*

O; It's all like funnelled into one…disorder. Whereas then you come in here and it's like, everyone is completely different in the way that they act and like, some days they're bad, some days they're good…and it's not…like some days you could see they have dementia and then other days you're like 'don't see what's wrong with them whatsoever.'

E: Yeah Yeah,

O: It's just all very flexible, it's just completely different to what you learn about.

S: Yeah cause I think when we learn about it's like, this one way street almost, that you just kind of get worse and worse as you go along,

E: Yeah

S: But it's clearly not like that really.

E: There's like certain symptoms that like you have to have, to have dementia, and then, like that's it, whereas you know, as O said, some people some days, you might think 'there's nothing, they don't have dementia. Like there's nothing *wrong* with them I suppose. Like they just seem completely, like the dementia just isn't there…

O; It kind of lures you into a false sense of security as well.

E: It does yea

O: *you* forget they have dementia, well, I would. Many times I've forgotten, and be chatting away to like C or someone and just, don't realise. Which is good as well I suppose, its better than coming in and saying, 'oh have to deal with this, have to deal with that' and you're not really dealing with anything, you're just, you know, talking.

E: Yeah

S: That's very true. And like, is there any moment in particular that ye can think back on, that you're like 'this kind of has stuck with me for any reason or is there any?

E: well I definitely think the video, I know that was like the first day and all, and that's probably like, but I just found that ten minutes was like changes completely how you think about it. And I think she was dead right to show us that and anything that happens out of that… nearly everything that happens in here you can base on that ten-minute video. Even when we went into your one, can't remember her name, R?

S: Yeah

O: DO you remember that day and she…wasn't in the best of form (laughs)

S: Yeah

O; And she kind of went off on one, but like then even after your like, you have to see what she's seeing, and that really stuck with me that, whole episode kinda thing. And like that was the worst that we, well that I saw.

S; Yeah well, that was probably the worst that I had ever seen, and I was kind of conscience then that I had brought you into it, but then I was, I was actually talking to John Mac about it and he was saying that, because in my head at that time, afterwards I was quite taken aback by it and I was like 'Oh well it's her disease it's not her', 'She didn't mean it personally, like don't take it personally' , whereas ye were like 'That's exactly what

the lady in the video was saying like do you know? It has come from somewhere, and he was like, 'yeah Sarah it's because you acted with sympathy, whereas the students reacted with empathy,

O: Yeah

S: But there's a difference there and like, I feel like that really taught me something as well. Because you know when you're in here all the time, you almost have to come up with

O: Tell yourself

S: Or Like you have to get thicker skin, but then when ye come in and you take them 'As they are' , it's really important.

O: That was even the first week or the second week was it?

E: I think it was the first week? Oh sorry, the video or the?

O: Oh no, with R.

E: Oh Yeah

E: Yeah but it was definitely like, one of the most, like it was, quite intimidating at the time but it was definitely the most, worthwhile things to experience, in that, it shows you exactly, the worst parts of it.

S: Yeah that's very true

E: And it's like, yeah that did stick with me big time.

S: Yeah

E: Yeah I can't think of any moments that really stuck out, just there was, a few, like I said before, when am, Mary said 'Oh how is the psychology doing, or something, and I just it was strange, not strange, but I was surprised that she remembered like cause even like, when I talked to maybe, someone else, like an older adult in my life, who doesn't have dementia, they wouldn't even remember that, they'd be like 'Oh what course are you doing' and she remembered and then, I remember another time too, it was just. You know m seemed very aware of her like, feelings or something, like I remember her saying 'oh I put up a bright face but there's dark clouds behind' or something and I remember thinking that was very like, am, I don't know, just very self-aware.

S: It's poetic almost

E: Yeah, it was like poetic, and then she was explaining another, em, some incident that happened, about she was getting ready for breakfast and the nurse was very rushed with her, or something and then she went to explain, like she said this herself, she was like 'Oh when I look back on that later,' and she thought 'Oh that wasn't right, the nurse shouldn't have, been rushing me, that wasn't nice and I just thought that was interesting

in that, after it happened she thought to herself and like reflected back on that morning, like, I just thought that awareness was interesting and how she was able to describe it as well. Maybe it comes back to how like just didn't expect her to say those things, maybe I came in with like this 'mind' that 'okay, you know, I didn't give them much credit, and then I was surprised when they were able to these things. I think that was my attitude when I came in, not really expecting anything.

O: Yeah that awareness is definitely a huge thing, do you remember when we were in with, and she was like, she said something about being starred at like an animal in a zoo, or something, and I was like "Jesus, they obviously like, that really does, like they are actual people, as opposed to like, someone with dementia.

S: Who you have to work around almost. Yeah I think there is a danger that people are like 'yeah they won't remember it, they won't know what's going on.

O: Oh they 100% do like. Like they might not remember one day but it's there.

S: And like something stays like, always, like the emotion

O: That's definitely the big thing that you learn, was they, it's not like you tell them one thing and then instantly you leave the room and all that's gone.

E & S: Yeah Yeah

O: Start afresh. Everything you say, it's the same as just talking to a normal person.

S: yeah because when I go home then like, you know, my aunts or even my parents like, when I listen to their conversations, like they do repeat themselves ALL the time and I think

O: Everyone does sure

S: Everyone does yeah, and we're like 'I can't remember what I was saying, I don't know what, you know?

E&O: Yeah

S: And I think we expect dementia to be this extreme, different kind of behaviour but it's not.

O: it's more of the fact that, they're all elderly people do you know? You know your Granny at home or something, she forgets somethings and

some days, they're in not great shape, some days they're in great shape and they're chatting away, it's like

S: Yeah

O: I honestly didn't see that much of a difference between people in here, compared to my grandmother, and she's one of the most lively people I know.

E&S: Yeah

S: Yeah it's funny, I think maybe like when you think of someone who's ill, you know everyone in here is ill, you kind of…

O: you there's automatically the thought of them as being, something wrong.

S: Emmmmm

S: Yeah so, This is my last question, but if there's anything else you want to say. Do you think there's anything that you've learn, not just in terms of dementia, or like sickness, from people that you've talked to, in terms of your own, life or like is anything going to stick with ye?

E: I just thought, it taught me to like, treat people like all, this sounds like corny but like, all the same, in the fact that like, they're not just people

with dementia, they're people. I think like the whole autonomy thing really got to me. Like a lot of them are stuck in here. and like they don't get any choice on anything and it's like. Like everything is done for them and you can see a lot of people hate that. Even with like JM, I know he's not the most, like, down the line out of all of them, but he does, he makes a point of doing everything for himself like.

S: Yeah it's like this, what he can do.

O: I think they should definitely make that more of a thing like, you know like those dementia villages and that kind of stuff, where they all, it's all...what's the word. When they make it important for them to?

E: Prioritise?

O; yeah, kind of like that. When they prioritise little small individual tasks they can do and just keep for themselves, keep their independence and their autonomy, it just makes a huge difference.

S: Yeah cause I suppose there is a tendency if someone is frail or sick, 'oh I'll do everything for you. 'But I think, we need to kind of think about what's important for us, like you wouldn't want to feel like 'Oh I can't do anything for myself'.

O: Even the thing with Mary, like how she wanted to do her hair and like, and she wants to do her makeup and her jewellery and stuff.

E: Yeah

O: And like you should us a study before about someone, 'just let them do their nails, or something.'

S: Yeah

O: And I was like, that just makes a huge difference.

S: Yeah like their personal, I suppose identity? And trying to maintain that as much as possible.

E: Yeah Especially that kind of brings me back to another moment when I was saying there about how the nurse, M was describing how the nurse was rushing her to get out to get to breakfast and then Mary said that she hadn't even buttoned her blouse properly, and brushed her hair and like, when she was talking you could see how that really upset her, that like she wasn't like, you know, dressed nicely and her hair wasn't like and that's important to her, like her appearance and presenting herself and then she was saying how another nurse at breakfast then brushed her hair for her and she thought that was really nice. And that, that's her thing, how she looks is important to her so like, you know, as you said, prioritising those

things and the other point you said there about, them kind of being stuck, like not even, being stuck here. You know, Mary talked about like, not beng able to like clean, or cook and boil the kettle or whatever. And even for people outside having dementia, not having that freedom is kind of like, even like talking about the weather and stuff is, difficult to talk about that when they haven't been outside.

S; I always think yeah.

E: Yeah like M would say like 'It's cold today' and we'd say 'Oh it's actually getting sunny there and how and I was explaining how oh it's spring and how flowers are lovely and how the daffodils are growing and like you just don't get to see that like, we can just leave and you know, she can't. She's basically stuck there and, there's something else she said, em, it was another moment that struck me actually, when we showed her a picture of, you know when we were doing the memory box, and we printed off a black and white picture of the bicycle and we showed that to her and like she got so excited and so happy and like i think her exact words were, ' This is the best thing I've ever seen.' (Laughs) Just cause she hadn't seen Just cause she hadn't seen a bike in so long like, or like the way we can look up anywhere in the world, you can look up anything on the internet and like see so many things, whereas, your just in that room and see the same objects, the same people, you know like?

S: Yeah

E: Everyday, so yeah it's just interesting like, yeah even just without having dementia, just being in the same place and the same things and not knowing, not being able to go home or whatever is just struck me.

S: It must be so hard.

O: I think another big thing I'll probably take forward is like the fact that like, theory of psychology compared to what it actually is...it's just not the same like. you know like, that essay we have to do for this, you know the reflective thing?

S: Yeah

O: They emphasises that the theory is completely different, and you're gonna have set backs in her you just do not have, like when your studying for an exam, you know what I mean?

S: Yeah

O: You could probably apply that to pretty much everything. For our course, definitely. There's no way everything in psychological theory is gonna be the same as what you experience when you're working, it's just not going to happen.

S: Yeah they're totally different ways of learning. Yeah and I suppose what you said there reminded me of something I wanted to ask. Cause from perspective, ye guys were coming in and I wanted ye to have a good experience in here. But there are things, like set backs that you just cant forsee I suppose. You things like someone might be sick or asleep (laughter).

E&O: Yeah, (laughter)

S: So when ye look back on it are those the kind of things you remember.

O: I definitely had an overwhelmingly positive view of it.

E; Yeah same.

O: The whole experience, even like, I just loved those classes, even with the lads from Headstrong who came down, they clearly enjoyed, and like they don't have dementia. I really do think it's such a worthwhile thing to do. and i think the, even at the very start you were saying, if it goes well you could make it a thing between the college and here, I just think it's a no brainer really- like it makes no sense not to do it. It helps everyone. You like it's such a good thing for us to have, there's not a lot of people who would have this much work done with people, properly done.

S: Yeah, it shows initiative as well, i think when you're in the mind set of volunteering or whatever, I think we forget that people don't. And even if you're going for a job, it could be really random job, like they'll see 'Oh you volunteer in a nursing home, that's different.'

O: I don't even think of it as volunteering though, most of the time.

E: Yeah, no I wouldn't either.

O It's not a chore to come up here like.

E: Yeah like I think of it like, I just think of it as Me and Lucy visiting Mary and it's like a chat, you know?

O: I think that another thing, I think whenever you tell people you're working in the nursing home, they're like 'oh it must awful.' It's really not at all.

S: Yeah I get that all the time.

O: Like I said it to my Mam there when we first started and I was telling her about your work and what we were doing and she goes 'Jeez you sound really passionate about it.' Yeah I really enjoy it like. You go up and it's not two hours of work, you know, the two and three hours, definitely overwhelmingly positive.

E: Yeah Cause like any time I've ever, after we chat with Mary, I always go to Louise, 'Oh that was so good.' and like, you know, you'd never come of there being like that, it's always positive feeling you get out of it. Em yeah. No matter what, and I feel like it goes both ways. When we leave Mary I feel like she has enjoyed talking to us as much as we've enjoyed talking to her you know? and it's just a good feeling.

O: It's basically the whole crux and your thing isn't it, how it's not just one way?

S: Yeah with people with dementia, there's this sense that it's all up to the carer to do everything for them and there's no sense that people with dementia give back I think? And even if it's anger, even if it's a bad thing, they still make a difference in the room that they're in you know?

E: Yeah..yeah.

O: Yeah definitely, I think like some of the stuff, like chatting to Mary or Chatting to Chris. Chris knew so much about the history, so much stuff he'd tell you, And you're just like 'What?!' I don't know how he, I couldn't retain that much information. It's like, he comes out with all this stuff about the roads and people and places.

S: Yeah cause I remember I brought him up after the first day and one of the nurses was just like to him 'Oh did you learn loads about Cork?' and I

was like 'No, he taught us about it'. You kind of have to remember that they can take an active role in the activity as well.

O: I think as well, you know the way you have the specialised box and the more general one, I think that's just a really good idea. Getting a load of general ones and then making them more specific.

S: Yeah you can kind of change.

O: Cause like Chris has a general interest in history or, John Has an interest in football, do you I think it makes a big difference.

S: Is there anything else? I think we covered a lot.

S: Yeah so I suppose for me, I wanted, not only ye to get a good positive experience out of it but to create the understanding that it's possible. Like you said people are always like to me 'Jeez that must be so hard, and like yeah like sometimes it is, sometimes you do see upsetting things.

O: I'd say it's one to every ten positive things. That's what I just think people would really benefit from it, our course especially. If you had, just with this community module if you had, three people a year up to do it. Even when we were starting, they had no set places to go. They just tell you to just go find your own places. But if you just gave people the option

you know like. It's easier for everyone really. And I'd say Cathy would love it as well to have proper people up here every year.

S: Yeah cause ye will be gone next year and I'll be going eventually as well. I think it's really important, it's not just the people, you need to set a structure between UCC and here.

O: Even when we came in the first day and they were, I think that struck me as well that they were very positive about the whole thing. Cause when we were going in first I kind of felt like we were being, not a burden, that we were just volunteering and that was it. But they were really invested in it, they like sat us down and said we really want you to be here, that made a huge difference.

E: I think it's like you said before, they just don't have the time, to you know chat to people or like on individual basis or set up the group. They don't really have the time to be doing that. so if you set up something that, was kind of organised and that could be done.

S; And like the stuff is so simple, we take for granted I think, that we can just look things up, even you know the lady I gave her a picture of the church, and She was like, 'Oh My Goodness' and was nearly falling over. And you know, that was so simple like, but it's having the time to think of those things is really important.

E: It's literally just a matter of sitting down and thinking about, you know the idea of Cork history, was like a great idea and like then, idea spread from that and it's kinda lead by the people who are there. Cause i think if we had had the first day and it hadn't gone well, they had been like 'Oh it was grand or whatever.' But they were already invested in it so we automatically went away and got more stuff for it and just built on top of that. So basically everything we did was based on what they gave back to us.

S: That's the way it should be I think, but I think there's ideal and then we have the day to day reality as well.

E: Yeah the practical elements.

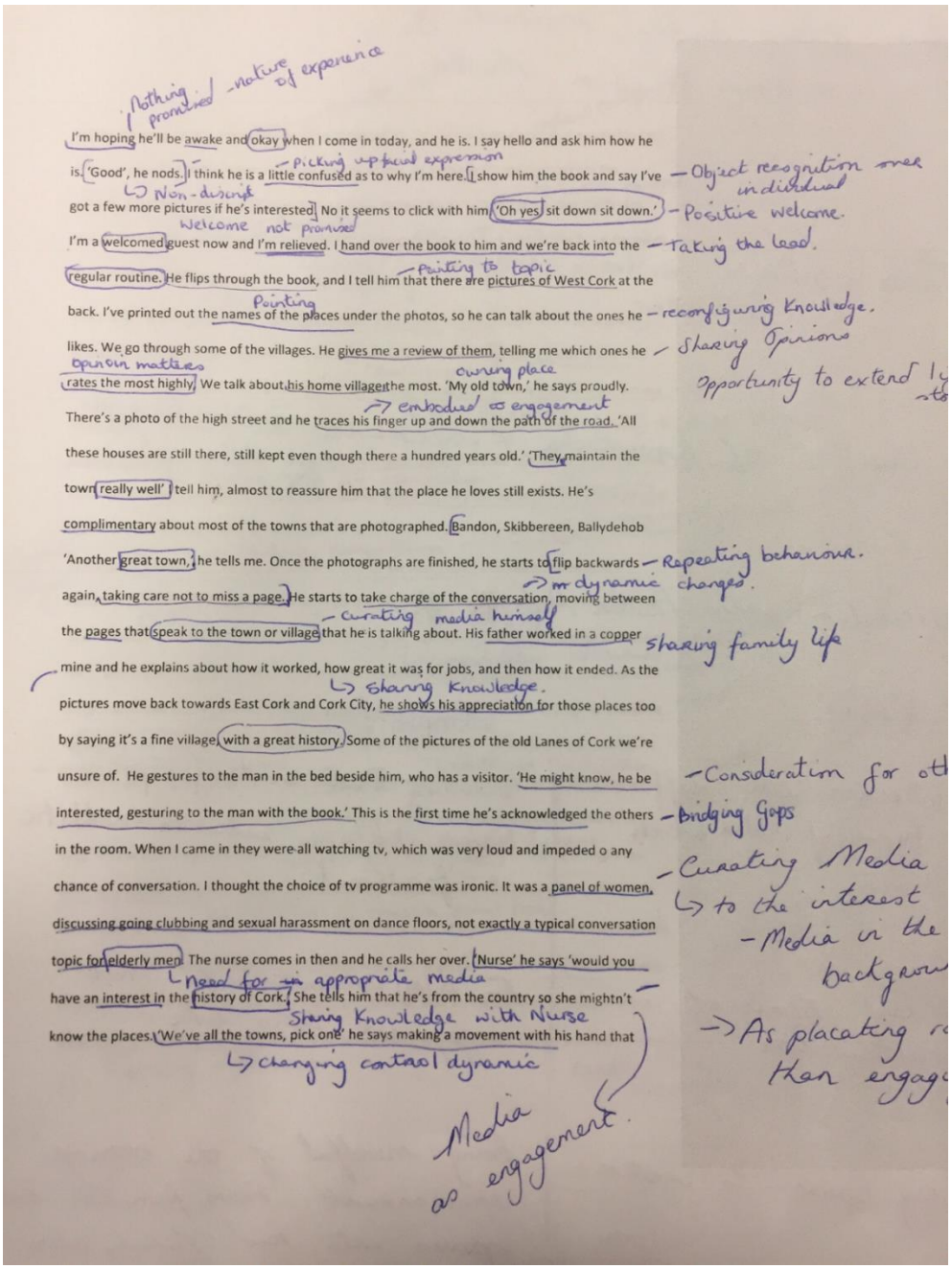
O: Yeah when people are asleep or sick.

S: Yeah well that's part of their life as well I think, so you have to.

O: And we're only come up here once a week as well like, it's not like we have hours upon hours to deal with them, not deal with them, that sounds awful, but you know.

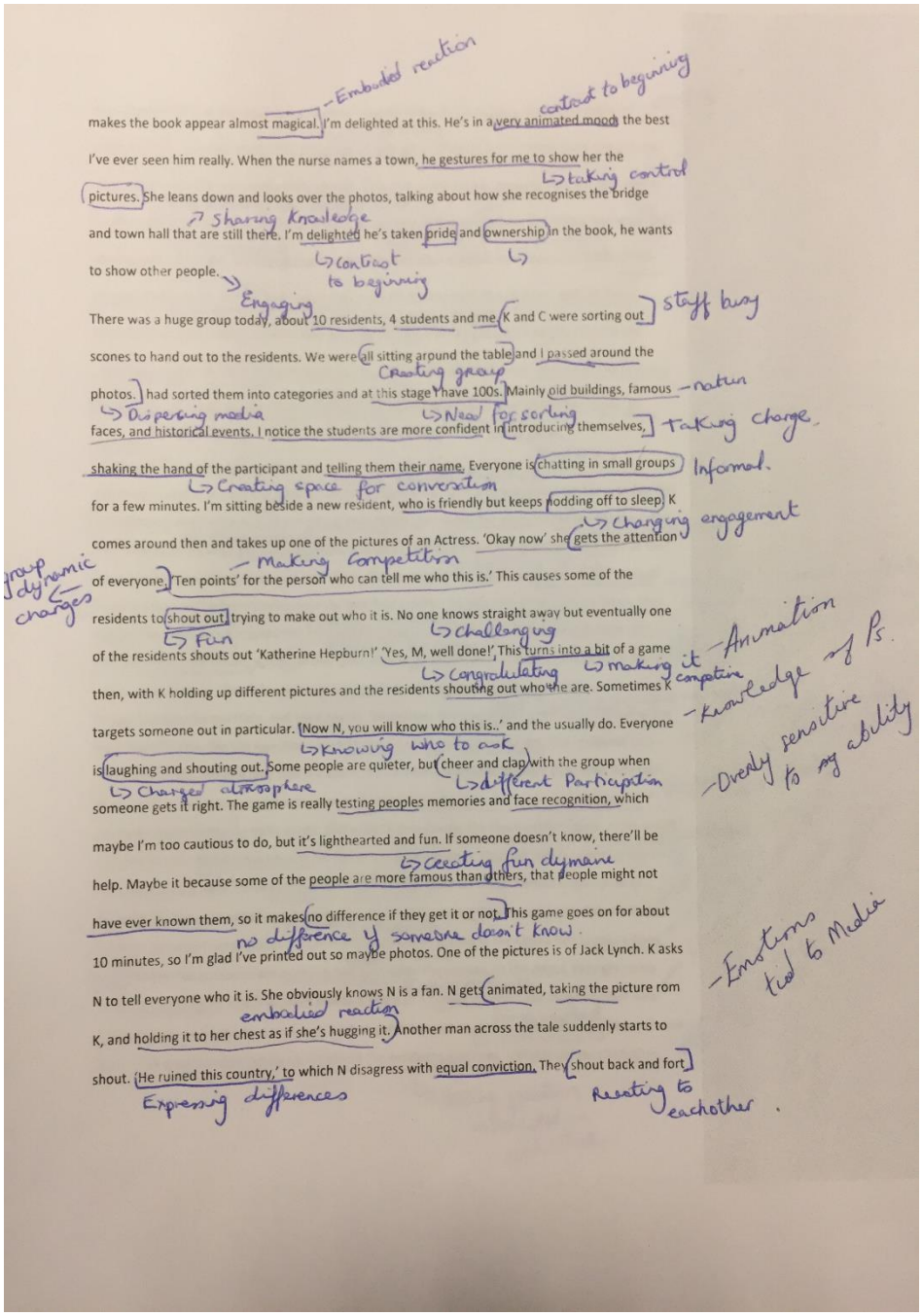
S: No I know what you mean. Like if you were here all day everyday you'd see so much.

Appendix IV-Printer Pals Coding (Chapter 6)



I'm hoping he'll be awake and okay when I come in today, and he is. I say hello and ask him how he is. 'Good', he nods. I think he is a little confused as to why I'm here. I show him the book and say I've got a few more pictures if he's interested. No it seems to click with him 'Oh yes sit down sit down.' I'm a welcomed guest now and I'm relieved. I hand over the book to him and we're back into the regular routine. He flips through the book, and I tell him that there are pictures of West Cork at the back. I've printed out the names of the places under the photos, so he can talk about the ones he likes. We go through some of the villages. He gives me a review of them, telling me which ones he rates the most highly. We talk about his home village the most. 'My old town,' he says proudly. There's a photo of the high street and he traces his finger up and down the path of the road. 'All these houses are still there, still kept even though there a hundred years old.' 'They maintain the town really well' I tell him, almost to reassure him that the place he loves still exists. He's complimentary about most of the towns that are photographed. Bandon, Skibbereen, Ballydehob 'Another great town,' he tells me. Once the photographs are finished, he starts to flip backwards again, taking care not to miss a page. He starts to take charge of the conversation, moving between the pages that speak to the town or village that he is talking about. His father worked in a copper mine and he explains about how it worked, how great it was for jobs, and then how it ended. As the pictures move back towards East Cork and Cork City, he shows his appreciation for those places too by saying it's a fine village, with a great history. Some of the pictures of the old Lanes of Cork we're unsure of. He gestures to the man in the bed beside him, who has a visitor. 'He might know, he be interested, gesturing to the man with the book.' This is the first time he's acknowledged the others in the room. When I came in they were all watching tv, which was very loud and impeded o any chance of conversation. I thought the choice of tv programme was ironic. It was a panel of women, discussing going clubbing and sexual harassment on dance floors, not exactly a typical conversation topic for elderly men. The nurse comes in then and he calls her over. 'Nurse' he says 'would you have an interest in the history of Cork.' She tells him that he's from the country so she mightn't know the places. 'We've all the towns, pick one' he says making a movement with his hand that

Nothing promised - nature of experience
Picking up facial expression
↳ Non-discript
Welcome not promised
Pointing to topic
Pointing
opinion matters
owning place
→ embodied ∞ engagement
Repeating behaviour.
→ dynamic changes.
curating media himself
sharing family life
↳ Sharing Knowledge.
Bridging Gaps
Curating Media
↳ to the interest
Need for appropriate media
Sharing Knowledge with Nurse
↳ changing control dynamic
Media as engagement.
Object recognition over individual
Positive welcome.
Taking the lead.
reconfiguring knowledge.
Sharing Opinions
Opportunity to extend
Consideration for oth
Media in the
→ As placating
than engag



makes the book appear almost magical. I'm delighted at this. He's in a very animated mood the best

I've ever seen him really. When the nurse names a town, he gestures for me to show her the

pictures. She leans down and looks over the photos, talking about how she recognises the bridge

and town hall that are still there. I'm delighted he's taken pride and ownership in the book, he wants

to show other people.

There was a huge group today, about 10 residents, 4 students and me. K and C were sorting out

scones to hand out to the residents. We were all sitting around the table and I passed around the

photos. I had sorted them into categories and at this stage I have 100s. Mainly old buildings, famous

faces, and historical events. I notice the students are more confident in introducing themselves,

shaking the hand of the participant and telling them their name. Everyone is chatting in small groups

for a few minutes. I'm sitting beside a new resident, who is friendly but keeps nodding off to sleep. K

comes around then and takes up one of the pictures of an Actress. 'Okay now' she gets the attention

of everyone. 'Ten points' for the person who can tell me who this is.' This causes some of the

residents to shout out trying to make out who it is. No one knows straight away but eventually one

of the residents shouts out 'Katherine Hepburn!' 'Yes, M, well done!' This turns into a bit of a game

then, with K holding up different pictures and the residents shouting out who she are. Sometimes K

targets someone out in particular. 'Now N, you will know who this is..' and the usually do. Everyone

is laughing and shouting out. Some people are quieter, but cheer and clap with the group when

someone gets it right. The game is really testing peoples memories and face recognition, which

maybe I'm too cautious to do, but it's lighthearted and fun. If someone doesn't know, there'll be

help. Maybe it because some of the people are more famous than others, that people might not

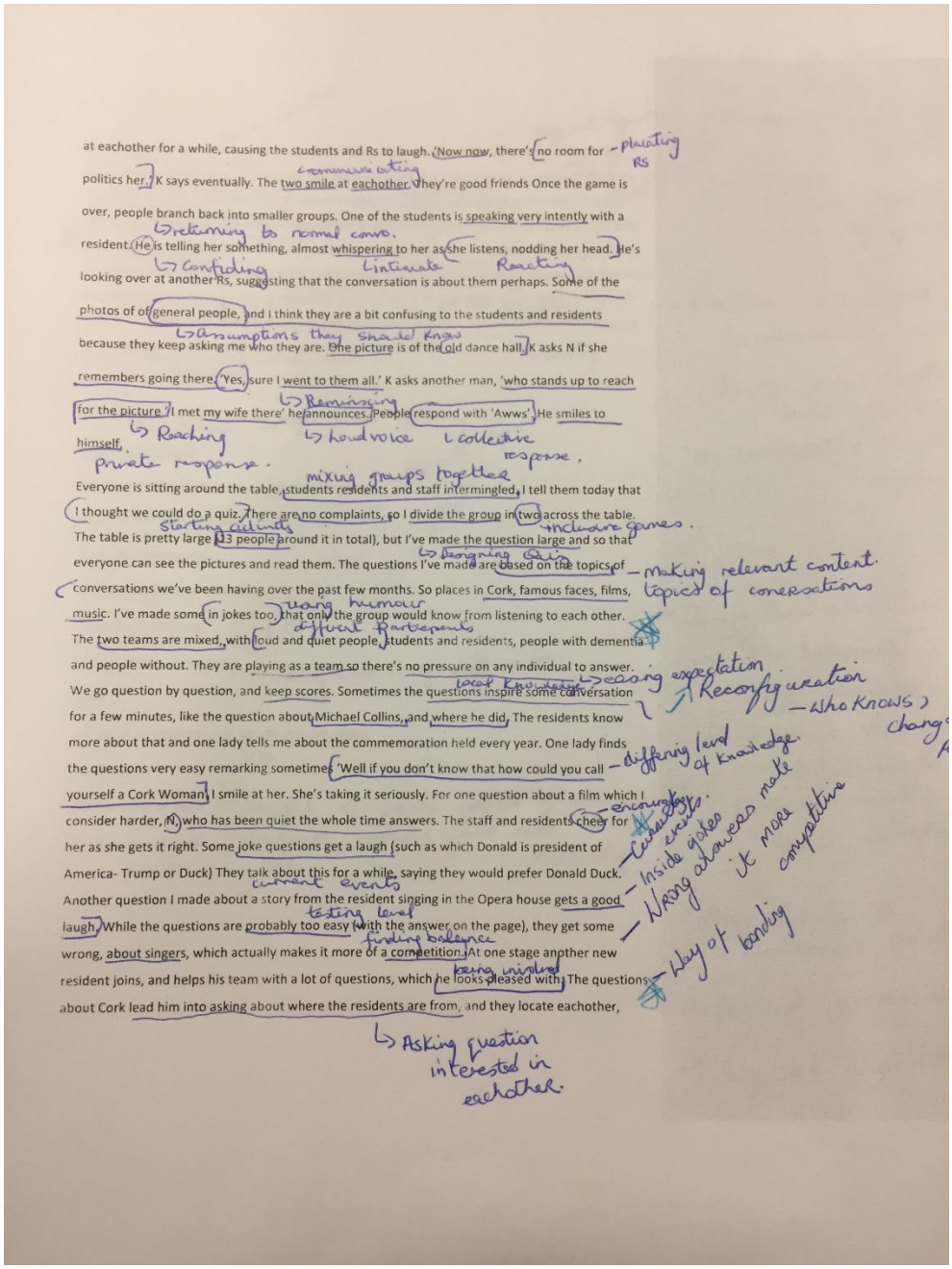
have ever known them, so it makes no difference if they get it or not. This game goes on for about

10 minutes, so I'm glad I've printed out so maybe photos. One of the pictures is of Jack Lynch. K asks

N to tell everyone who it is. She obviously knows N is a fan. N gets animated, taking the picture rom

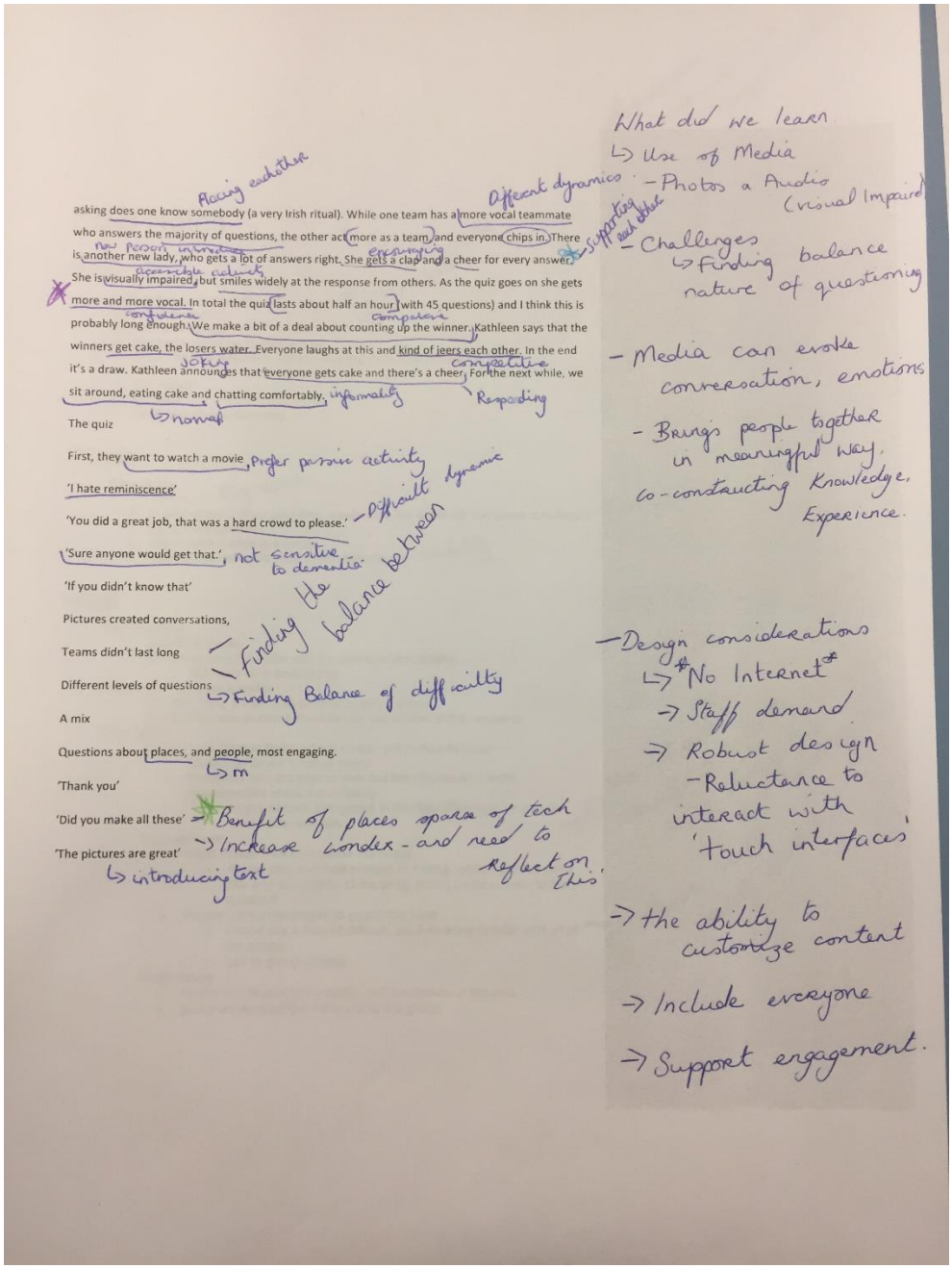
K, and holding it to her chest as if she's hugging it. Another man across the tale suddenly starts to

shout. 'He ruined this country,' to which N disagrress with equal conviction. They shout back and fort



at eachother for a while, causing the students and Rs to laugh. 'Now now, there's no room for politics her,' K says eventually. The two smile at eachother. They're good friends Once the game is over, people branch back into smaller groups. One of the students is speaking very intently with a resident. He is telling her something, almost whispering to her as she listens, nodding her head. He's looking over at another Rs, suggesting that the conversation is about them perhaps. Some of the photos of of general people, and I think they are a bit confusing to the students and residents because they keep asking me who they are. One picture is of the old dance hall. K asks N if she remembers going there. 'Yes, sure I went to them all.' K asks another man, 'who stands up to reach for the picture.' I met my wife there' he announces. People respond with 'Awws'. He smiles to himself.

Everyone is sitting around the table, students residents and staff intermingled. I tell them today that I thought we could do a quiz. There are no complaints, so I divide the group in two across the table. The table is pretty large (13 people around it in total), but I've made the question large and so that everyone can see the pictures and read them. The questions I've made are based on the topics of conversations we've been having over the past few months. So places in Cork, famous faces, films, music. I've made some in jokes too, that only the group would know from listening to each other. The two teams are mixed, with loud and quiet people, students and residents, people with dementia and people without. They are playing as a team so there's no pressure on any individual to answer. We go question by question, and keep scores. Sometimes the questions inspire some conversation for a few minutes, like the question about Michael Collins, and where he did. The residents know more about that and one lady tells me about the commemoration held every year. One lady finds the questions very easy remarking sometimes 'Well if you don't know that how could you call yourself a Cork Woman'. I smile at her. She's taking it seriously. For one question about a film which I consider harder, N who has been quiet the whole time answers. The staff and residents cheer for her as she gets it right. Some joke questions get a laugh (such as which Donald is president of America- Trump or Duck) They talk about this for a while, saying they would prefer Donald Duck. Another question I made about a story from the resident singing in the Opera house gets a good laugh. While the questions are probably too easy (with the answer on the page), they get some wrong, about singers, which actually makes it more of a competition. At one stage another new resident joins, and helps his team with a lot of questions, which he looks pleased with. The questions about Cork lead him into asking about where the residents are from, and they locate eachother,



asking does one know somebody (a very Irish ritual). While one team has a more vocal teammate who answers the majority of questions, the other acts more as a team, and everyone chips in. There is another new lady, who gets a lot of answers right. She gets a clap and a cheer for every answer. She is visually impaired, but smiles widely at the response from others. As the quiz goes on she gets more and more vocal. In total the quiz lasts about half an hour (with 45 questions) and I think this is probably long enough. We make a bit of a deal about counting up the winner. Kathleen says that the winners get cake, the losers water. Everyone laughs at this and kind of jeers each other. In the end it's a draw. Kathleen announces that everyone gets cake and there's a cheer. For the next while, we sit around, eating cake and chatting comfortably.

The quiz

First, they want to watch a movie

'I hate reminiscence'

'You did a great job, that was a hard crowd to please.'

'Sure anyone would get that.'

'If you didn't know that'

Pictures created conversations,

Teams didn't last long

Different levels of questions

A mix

Questions about places, and people, most engaging.

'Thank you'

'Did you make all these'

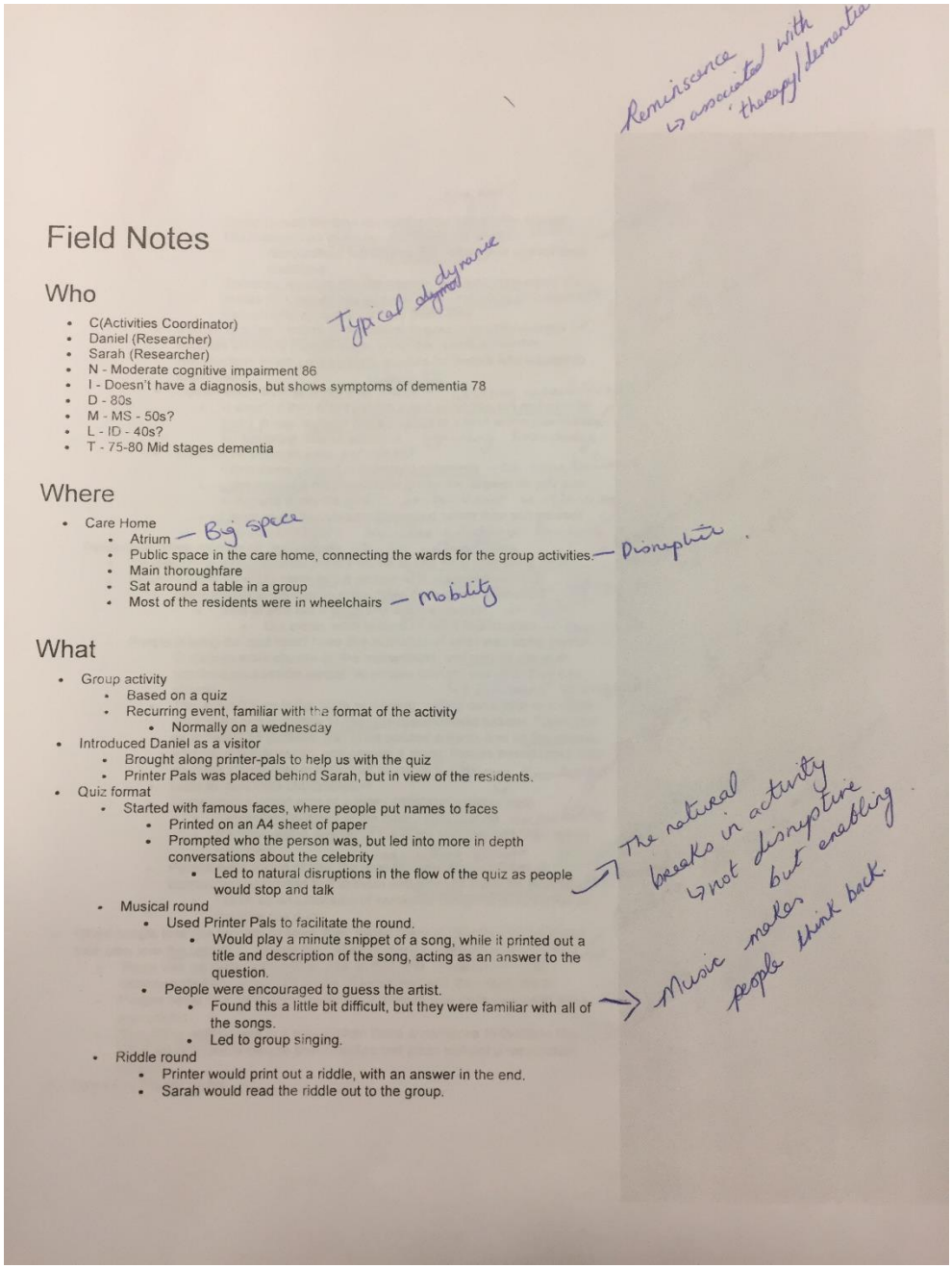
'The pictures are great'

What did we learn

↳ Use of Media

- Photos & Audio (visual Impaired)
- Challenges
  ↳ Finding balance nature of questioning
- Media can evoke conversation, emotions
- Brings people together in meaningful way, co-constructing Knowledge, Experience.

- Design considerations
  ↳ *No Internet*
  → Staff demand
  → Robust design
  - Reluctance to interact with 'touch interfaces'
  → the ability to customize content
  → Include everyone
  → Support engagement.



Reminiscence
↳ associated with therapy/dementia

Field Notes

Who

Typical dynamic

- C(Activities Coordinator)
- Daniel (Researcher)
- Sarah (Researcher)
- N - Moderate cognitive impairment 86
- I - Doesn't have a diagnosis, but shows symptoms of dementia 78
- D - 80s
- M - MS - 50s?
- L - ID - 40s?
- T - 75-80 Mid stages dementia

Where

- Care Home
  - Atrium — Big space
  - Public space in the care home, connecting the wards for the group activities. — Disruptive
  - Main thoroughfare
  - Sat around a table in a group
  - Most of the residents were in wheelchairs — mobility

What

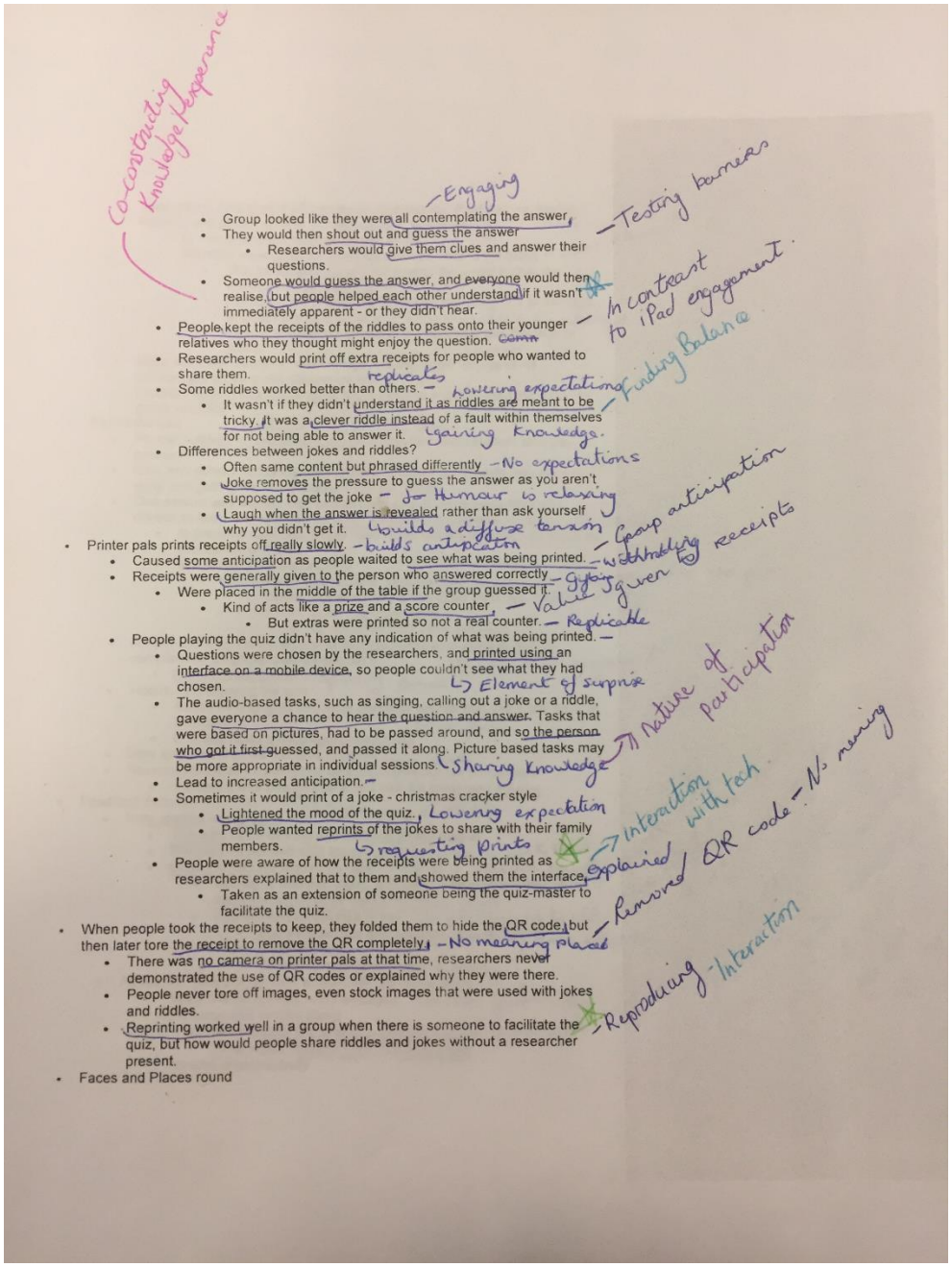
- Group activity
  - Based on a quiz
  - Recurring event, familiar with the format of the activity
    - Normally on a wednesday
- Introduced Daniel as a visitor
  - Brought along printer-pals to help us with the quiz
  - Printer Pals was placed behind Sarah, but in view of the residents.
- Quiz format
  - Started with famous faces, where people put names to faces
    - Printed on an A4 sheet of paper
    - Prompted who the person was, but led into more in depth conversations about the celebrity
      - Led to natural disruptions in the flow of the quiz as people would stop and talk

→ The natural breaks in activity ↳ not disruptive but enabling

  - Musical round
    - Used Printer Pals to facilitate the round.
      - Would play a minute snippet of a song, while it printed out a title and description of the song, acting as an answer to the question.
    - People were encouraged to guess the artist.
      - Found this a little bit difficult, but they were familiar with all of the songs.
      - Led to group singing.

→ Music makes people think back.

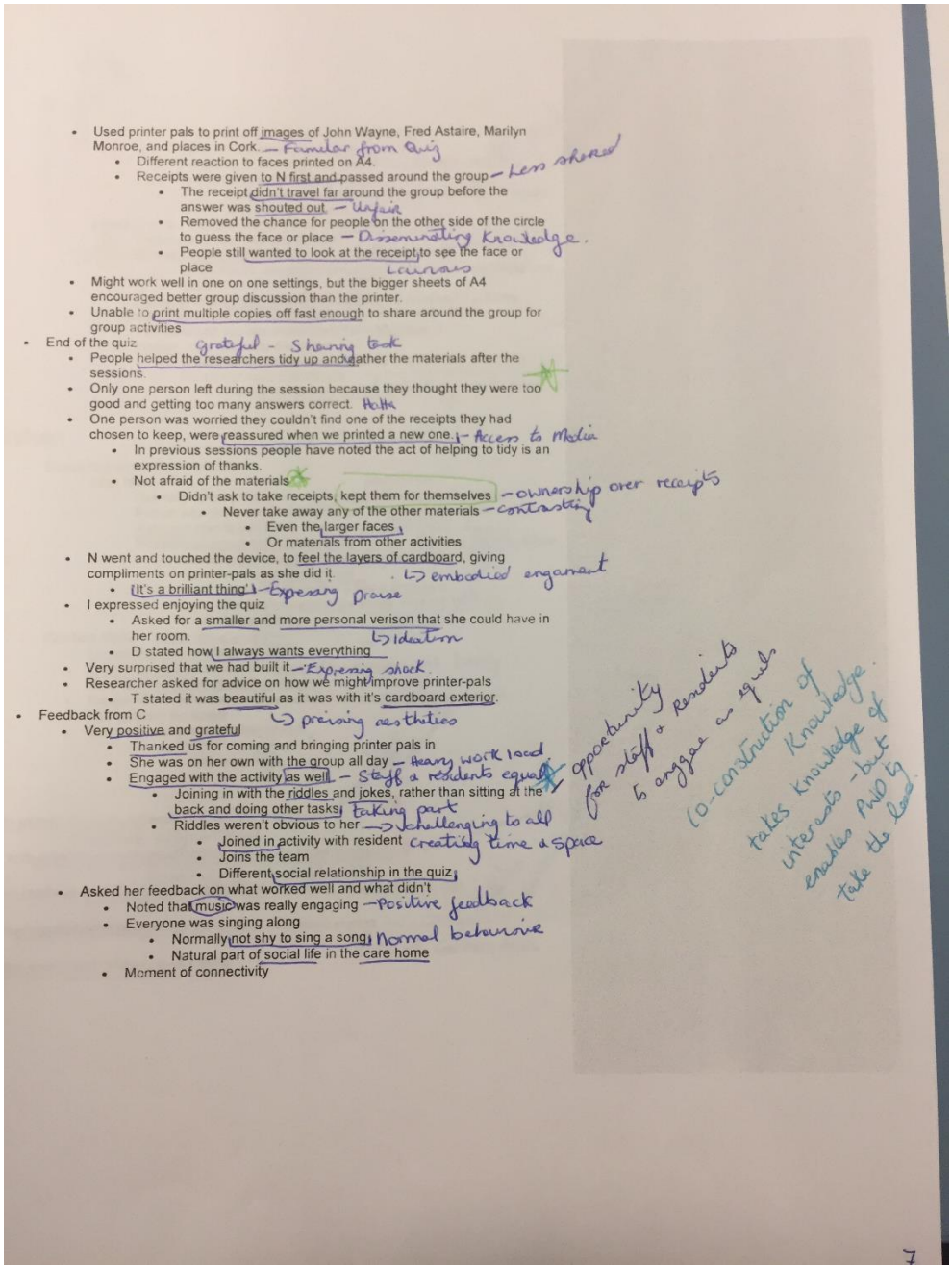
  - Riddle round
    - Printer would print out a riddle, with an answer in the end.
    - Sarah would read the riddle out to the group.



Co-constructing Knowledge/Experience

- Group looked like they were all contemplating the answer, – Engaging
- They would then shout out and guess the answer – Testing learners
  - Researchers would give them clues and answer their questions.
- Someone would guess the answer, and everyone would then realise (but people helped each other understand if it wasn't immediately apparent - or they didn't hear.
- People kept the receipts of the riddles to pass onto their younger relatives who they thought might enjoy the question. comm – In contrast to iPad engagement.
- Researchers would print off extra receipts for people who wanted to share them. replicates
- Some riddles worked better than others. – Lowering expectations – Finding Balance
  - It wasn't if they didn't understand it as riddles are meant to be tricky, it was a clever riddle instead of a fault within themselves for not being able to answer it. Gaining Knowledge.
- Differences between jokes and riddles?
  - Often same content but phrased differently – No expectations
  - Joke removes the pressure to guess the answer as you aren't supposed to get the joke – Jo Humour is relaxing
  - Laugh when the answer is revealed rather than ask yourself why you didn't get it. Builds a diffuse tension – Group anticipation

- Printer pals prints receipts off really slowly. – builds anticipation – withholding receipts
  - Caused some anticipation as people waited to see what was being printed.
  - Receipts were generally given to the person who answered correctly – Going given to
    - Were placed in the middle of the table if the group guessed it.
      - Kind of acts like a prize and a score counter, – Value
        - But extras were printed so not a real counter. – Replicable
  - People playing the quiz didn't have any indication of what was being printed. –
    - Questions were chosen by the researchers, and printed using an interface on a mobile device, so people couldn't see what they had chosen. ↳ Element of surprise
    - The audio-based tasks, such as singing, calling out a joke or a riddle, gave everyone a chance to hear the question and answer. Tasks that were based on pictures, had to be passed around, and so the person who got it first guessed, and passed it along. Picture based tasks may be more appropriate in individual sessions. ↳ Sharing Knowledge – Nature of participation
    - Lead to increased anticipation. –
    - Sometimes it would print of a joke - christmas cracker style
      - Lightened the mood of the quiz, Lowering expectation
      - People wanted reprints of the jokes to share with their family members. ↳ requesting prints
    - People were aware of how the receipts were being printed as researchers explained that to them and showed them the interface. – Interaction with tech
      - Taken as an extension of someone being the quiz-master to facilitate the quiz.
- When people took the receipts to keep, they folded them to hide the QR code, but then later tore the receipt to remove the QR completely. – No meaning placed – Removed/Explained QR code – No meaning
  - There was no camera on printer pals at that time, researchers never demonstrated the use of QR codes or explained why they were there.
  - People never tore off images, even stock images that were used with jokes and riddles.
  - Reprinting worked well in a group when there is someone to facilitate the quiz, but how would people share riddles and jokes without a researcher present. – Reproducing Interaction
- Faces and Places round

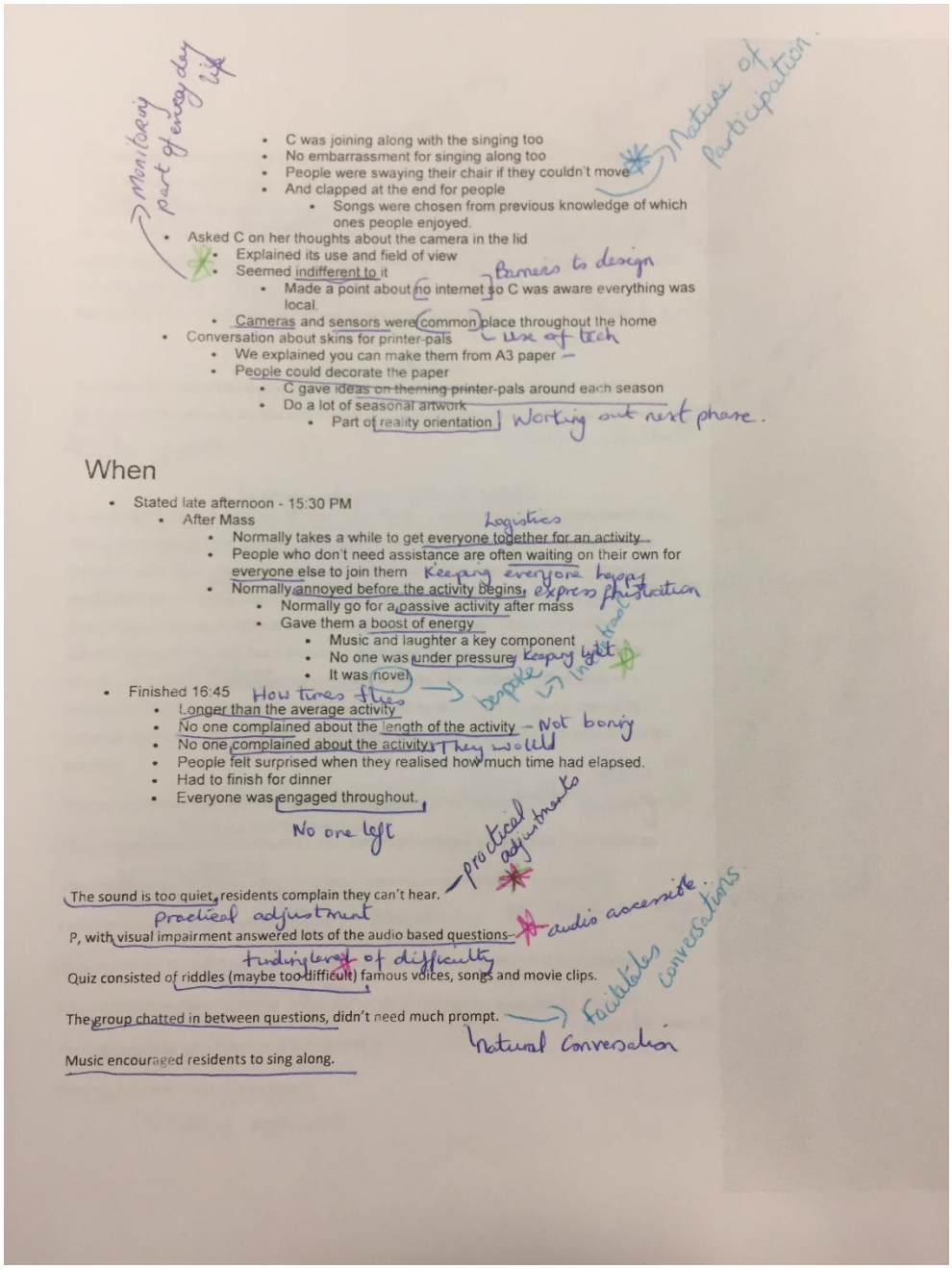


- Used printer pals to print off images of John Wayne, Fred Astaire, Marilyn Monroe, and places in Cork. — Familiar from Quiz
  - Different reaction to faces printed on A4.
  - Receipts were given to N first and passed around the group — Less shared
    - The receipt didn't travel far around the group before the answer was shouted out — Unfair
    - Removed the chance for people on the other side of the circle to guess the face or place — Disseminating Knowledge.
    - People still wanted to look at the receipt to see the face or place Learners
  - Might work well in one on one settings, but the bigger sheets of A4 encouraged better group discussion than the printer.
  - Unable to print multiple copies off fast enough to share around the group for group activities
- End of the quiz grateful - Sharing task
  - People helped the researchers tidy up and gather the materials after the sessions.
  - Only one person left during the session because they thought they were too good and getting too many answers correct. Hubris
  - One person was worried they couldn't find one of the receipts they had chosen to keep, were reassured when we printed a new one. - Access to Media
    - In previous sessions people have noted the act of helping to tidy is an expression of thanks.
    - Not afraid of the materials
      - Didn't ask to take receipts, kept them for themselves — ownership over receipts
        - Never take away any of the other materials — contrasting
          - Even the larger faces
          - Or materials from other activities
  - N went and touched the device, to feel the layers of cardboard, giving compliments on printer-pals as she did it. ↳ embodied engagement
    - 'It's a brilliant thing' — Expressing praise
  - I expressed enjoying the quiz
    - Asked for a smaller and more personal verison that she could have in her room. ↳ Ideation
    - D stated how I always wants everything
  - Very surprised that we had built it — Expressing shock
  - Researcher asked for advice on how we might improve printer-pals
    - T stated it was beautiful as it was with it's cardboard exterior. ↳ praising aesthetics
- Feedback from C
  - Very positive and grateful
    - Thanked us for coming and bringing printer pals in
    - She was on her own with the group all day — Heavy workload
    - Engaged with the activity as well — Staff & residents equal
      - Joining in with the riddles and jokes, rather than sitting at the back and doing other tasks; Taking part
      - Riddles weren't obvious to her — ↳ challenging to all
        - Joined in activity with resident creating time & space
        - Joins the team
        - Different social relationship in the quiz;
  - Asked her feedback on what worked well and what didn't
    - Noted that music was really engaging — Positive feedback
    - Everyone was singing along
      - Normally not shy to sing a song; Normal behaviour
      - Natural part of social life in the care home
    - Moment of connectivity

opportunity for staff & residents to engage as equals

(Co-construction of Knowledge. takes knowledge of interests - but enables PwD to take the lead

7



- C was joining along with the singing too
- No embarrassment for singing along too
- People were swaying their chair if they couldn't move
- And clapped at the end for people
  - Songs were chosen from previous knowledge of which ones people enjoyed.
- Asked C on her thoughts about the camera in the lid
  - Explained its use and field of view
  - Seemed indifferent to it
    - Made a point about no internet so C was aware everything was local.
  - Cameras and sensors were common place throughout the home
- Conversation about skins for printer-pals
  - We explained you can make them from A3 paper
  - People could decorate the paper
    - C gave ideas on theming printer-pals around each season
    - Do a lot of seasonal artwork
      - Part of reality orientation

When

- Stated late afternoon - 15:30 PM
  - After Mass
    - Normally takes a while to get everyone together for an activity
    - People who don't need assistance are often waiting on their own for everyone else to join them
    - Normally annoyed before the activity begins
      - Normally go for a passive activity after mass
      - Gave them a boost of energy
        - Music and laughter a key component
        - No one was under pressure
        - It was novel
- Finished 16:45
  - Longer than the average activity
  - No one complained about the length of the activity
  - No one complained about the activity
  - People felt surprised when they realised how much time had elapsed.
  - Had to finish for dinner
  - Everyone was engaged throughout.

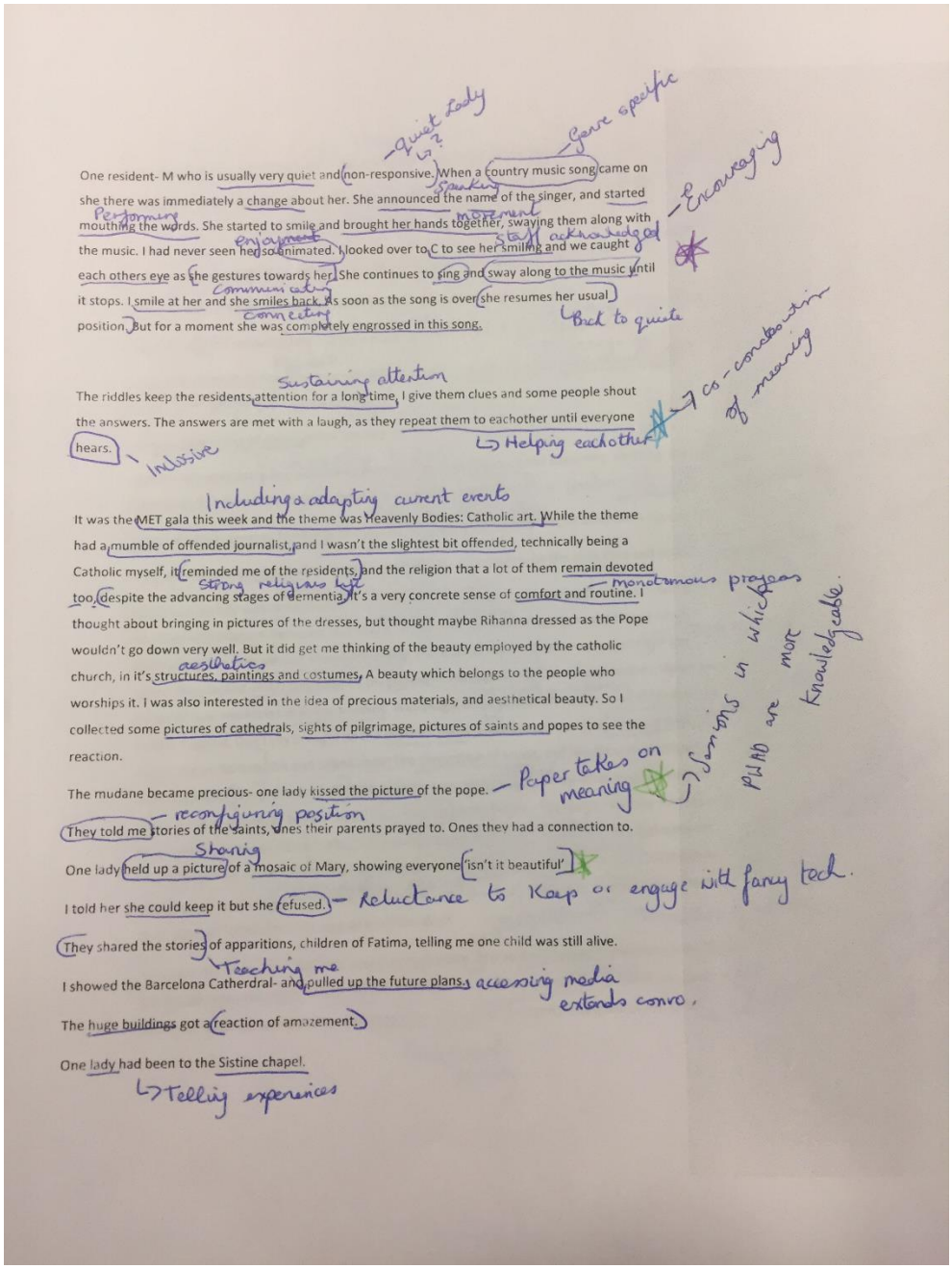
The sound is too quiet, residents complain they can't hear.

P, with visual impairment answered lots of the audio based questions

Quiz consisted of riddles (maybe too difficult) famous voices, songs and movie clips.

The group chatted in between questions, didn't need much prompt.

Music encouraged residents to sing along.



One resident- M who is usually very quiet and non-responsive. When a country music song came on she there was immediately a change about her. She announced the name of the singer, and started mouthing the words. She started to smile and brought her hands together, swaying them along with the music. I had never seen her so animated. I looked over to C to see her smiling and we caught each others eye as she gestures towards her. She continues to sing and sway along to the music until it stops. I smile at her and she smiles back. As soon as the song is over she resumes her usual position. But for a moment she was completely engrossed in this song.

The riddles keep the residents attention for a long time, I give them clues and some people shout the answers. The answers are met with a laugh, as they repeat them to eachother until everyone hears.

It was the MET gala this week and the theme was Heavenly Bodies: Catholic art. While the theme had a mumble of offended journalist, and I wasn't the slightest bit offended, technically being a Catholic myself, it reminded me of the residents, and the religion that a lot of them remain devoted too, despite the advancing stages of dementia. It's a very concrete sense of comfort and routine. I thought about bringing in pictures of the dresses, but thought maybe Rihanna dressed as the Pope wouldn't go down very well. But it did get me thinking of the beauty employed by the catholic church, in it's structures, paintings and costumes. A beauty which belongs to the people who worships it. I was also interested in the idea of precious materials, and aesthetical beauty. So I collected some pictures of cathedrals, sights of pilgrimage, pictures of saints and popes to see the reaction.

The mudane became precious- one lady kissed the picture of the pope.

They told me stories of the saints, ones their parents prayed to. Ones they had a connection to.

One lady held up a picture of a mosaic of Mary, showing everyone 'isn't it beautiful'

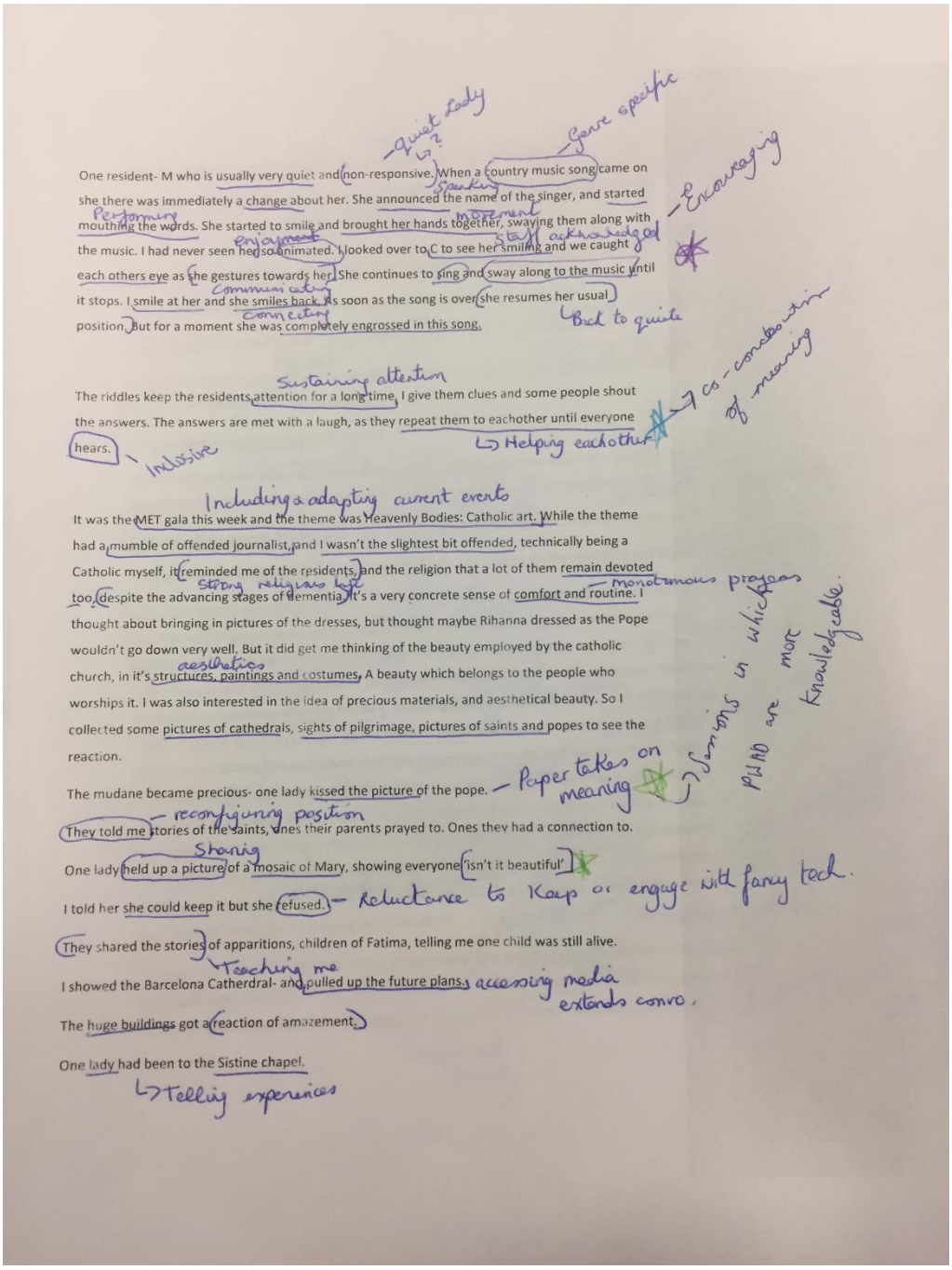
I told her she could keep it but she refused.

They shared the stories of apparitions, children of Fatima, telling me one child was still alive.

I showed the Barcelona Catherdral- and pulled up the future plans.

The huge buildings got a reaction of amazement.

One lady had been to the Sistine chapel.



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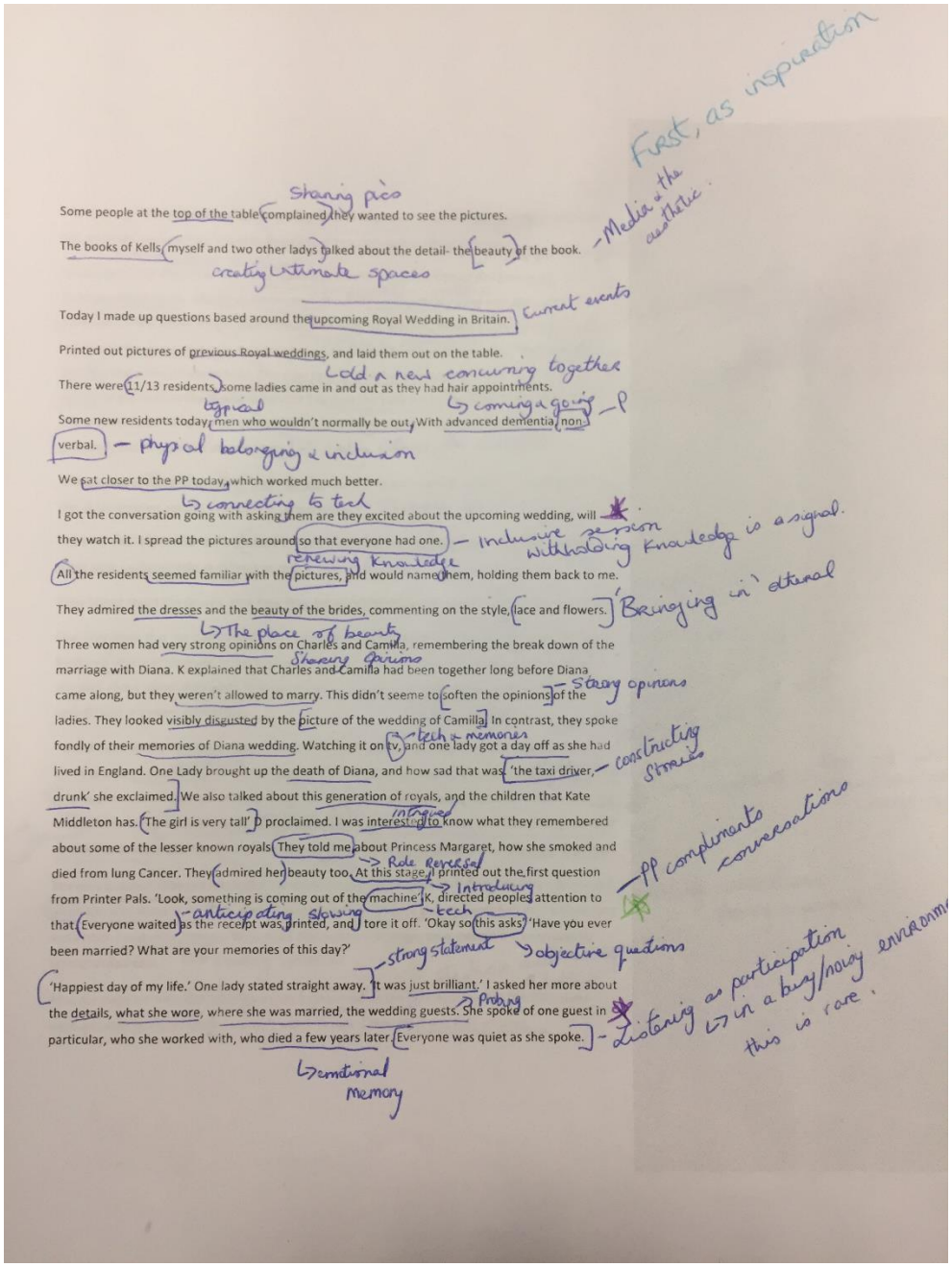
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Some people at the top of the table complained they wanted to see the pictures.

The books of Kells, myself and two other ladys talked about the detail- the beauty of the book.

Today I made up questions based around the upcoming Royal Wedding in Britain.

Printed out pictures of previous Royal weddings, and laid them out on the table.

There were 11/13 residents, some ladies came in and out as they had hair appointments.

Some new residents today, men who wouldn't normally be out, With advanced dementia, non-verbal.

We sat closer to the PP today, which worked much better.

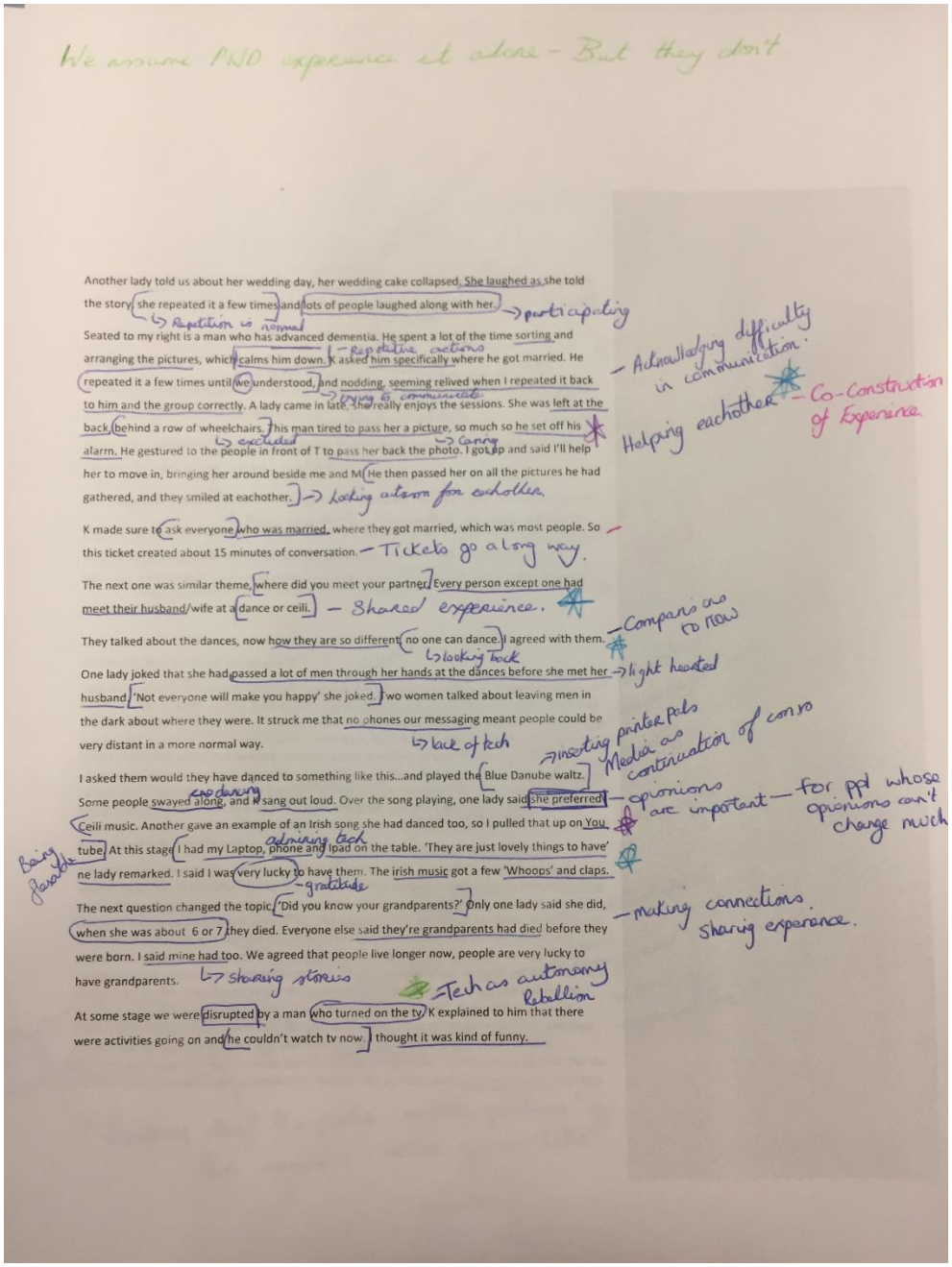
I got the conversation going with asking them are they excited about the upcoming wedding, will they watch it. I spread the pictures around so that everyone had one.

All the residents seemed familiar with the pictures, and would name them, holding them back to me.

They admired the dresses and the beauty of the brides, commenting on the style, lace and flowers.

Three women had very strong opinions on Charles and Camilla, remembering the break down of the marriage with Diana. K explained that Charles and Camilla had been together long before Diana came along, but they weren't allowed to marry. This didn't seeme to soften the opinions of the ladies. They looked visibly disgusted by the picture of the wedding of Camilla. In contrast, they spoke fondly of their memories of Diana wedding. Watching it on tv, and one lady got a day off as she had lived in England. One Lady brought up the death of Diana, and how sad that was 'the taxi driver, drunk' she exclaimed. We also talked about this generation of royals, and the children that Kate Middleton has. 'The girl is very tall' D proclaimed. I was interested to know what they remembered about some of the lesser known royals. They told me about Princess Margaret, how she smoked and died from lung Cancer. They admired her beauty too. At this stage, I printed out the first question from Printer Pals. 'Look, something is coming out of the machine' K, directed peoples attention to that. Everyone waited as the receipt was printed, and I tore it off. 'Okay so this asks' 'Have you ever been married? What are your memories of this day?'

'Happiest day of my life.' One lady stated straight away. 'It was just brilliant.' I asked her more about the details, what she wore, where she was married, the wedding guests. She spoke of one guest in particular, who she worked with, who died a few years later. Everyone was quiet as she spoke.



We assume PWD experience it alone - But they don't

Another lady told us about her wedding day, her wedding cake collapsed. She laughed as she told the story, she repeated it a few times and lots of people laughed along with her. → participating
↳ Repetition is normal

Seated to my right is a man who has advanced dementia. He spent a lot of the time sorting and arranging the pictures, which calms him down. K asked him specifically where he got married. He repeated it a few times until we understood, and nodding, seeming relived when I repeated it back to him and the group correctly. A lady came in late, she really enjoys the sessions. She was left at the back, behind a row of wheelchairs. This man tired to pass her a picture, so much so he set off his alarm. He gestured to the people in front of T to pass her back the photo. I got up and said I'll help her to move in, bringing her around beside me and M. He then passed her on all the pictures he had gathered, and they smiled at eachother. → Looking at each for eachother.

↳ Repetitive actions
↳ trying to communicate
↳ excluded
↳ Caring

– Acknowledging difficulty in communication.
Helping eachother – Co-Construction of Experience.

K made sure to ask everyone who was married, where they got married, which was most people. So this ticket created about 15 minutes of conversation. – Tickets go a long way.

The next one was similar theme, where did you meet your partner. Every person except one had meet their husband/wife at a dance or ceili. – Shared experience.

They talked about the dances, now how they are so different, no one can dance. I agreed with them.
↳ looking back

– Comparisons are to now

One lady joked that she had passed a lot of men through her hands at the dances before she met her husband. 'Not everyone will make you happy' she joked. → light hearted

Two women talked about leaving men in the dark about where they were. It struck me that no phones our messaging meant people could be very distant in a more normal way.
↳ lack of tech

→ inserting printer pals
Media as continuation of convo

I asked them would they have danced to something like this...and played the Blue Danube waltz. Some people swayed along, and it sang out loud. Over the song playing, one lady said she preferred Ceili music. Another gave an example of an Irish song she had danced too, so I pulled that up on You tube. At this stage I had my Laptop, phone and Ipad on the table. 'They are just lovely things to have' one lady remarked. I said I was very lucky to have them. The irish music got a few 'Whoops' and claps.

↳ swaying along
↳ admiring tech
↳ gratitude

– opinions are important – for ppl whose opinions can't change much

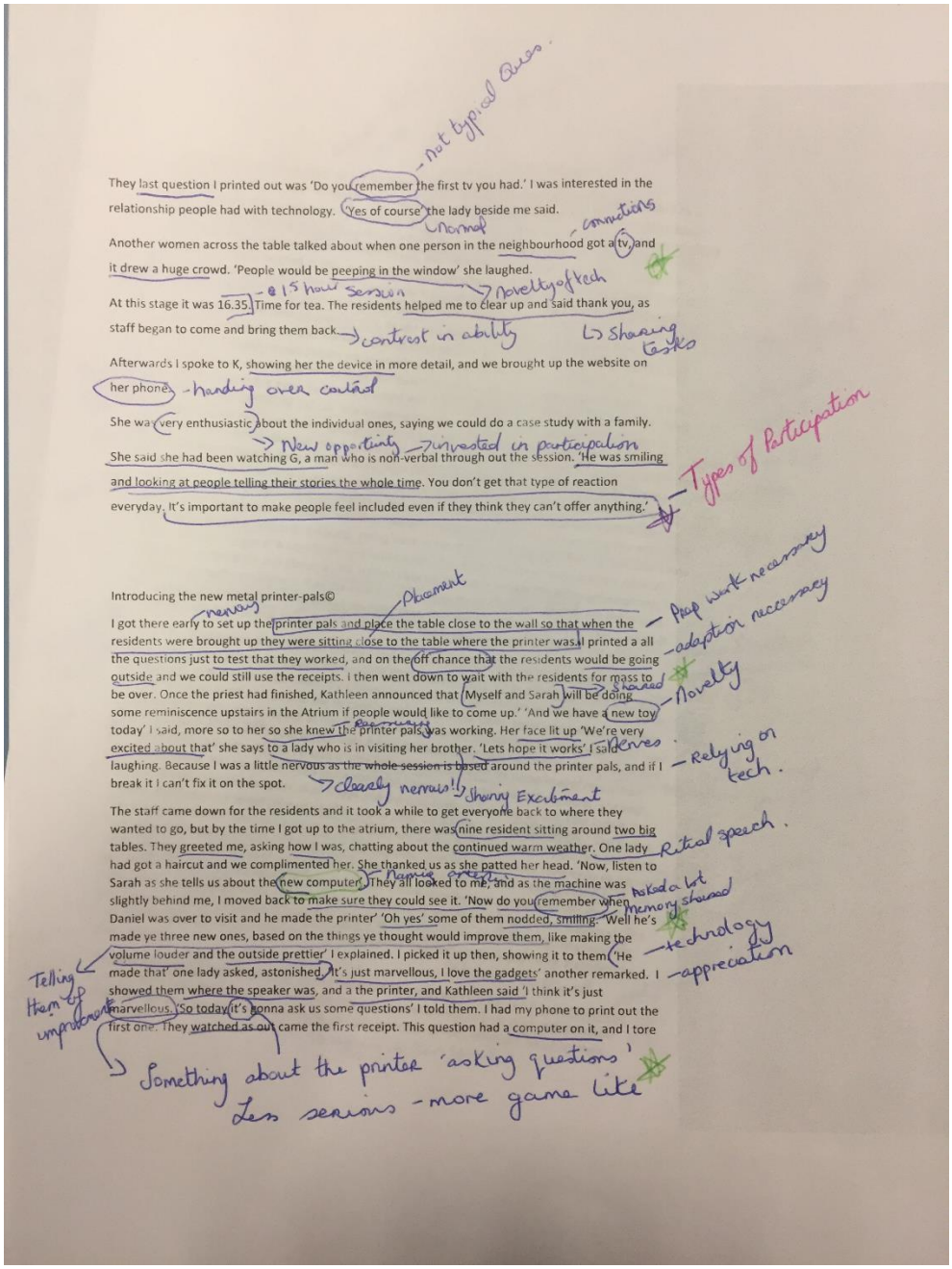
being flexible

The next question changed the topic 'Did you know your grandparents?' Only one lady said she did, when she was about 6 or 7 they died. Everyone else said they're grandparents had died before they were born. I said mine had too. We agreed that people live longer now, people are very lucky to have grandparents.
↳ sharing stories

– making connections. Sharing experience.

– Tech as autonomy Rebellion

At some stage we were disrupted by a man who turned on the tv. K explained to him that there were activities going on and he couldn't watch tv now. I thought it was kind of funny.



They last question I printed out was 'Do you remember the first tv you had.' I was interested in the relationship people had with technology. 'Yes of course' the lady beside me said.

Another women across the table talked about when one person in the neighbourhood got a tv, and it drew a huge crowd. 'People would be peeping in the window' she laughed.

At this stage it was 16.35. Time for tea. The residents helped me to clear up and said thank you, as staff began to come and bring them back.

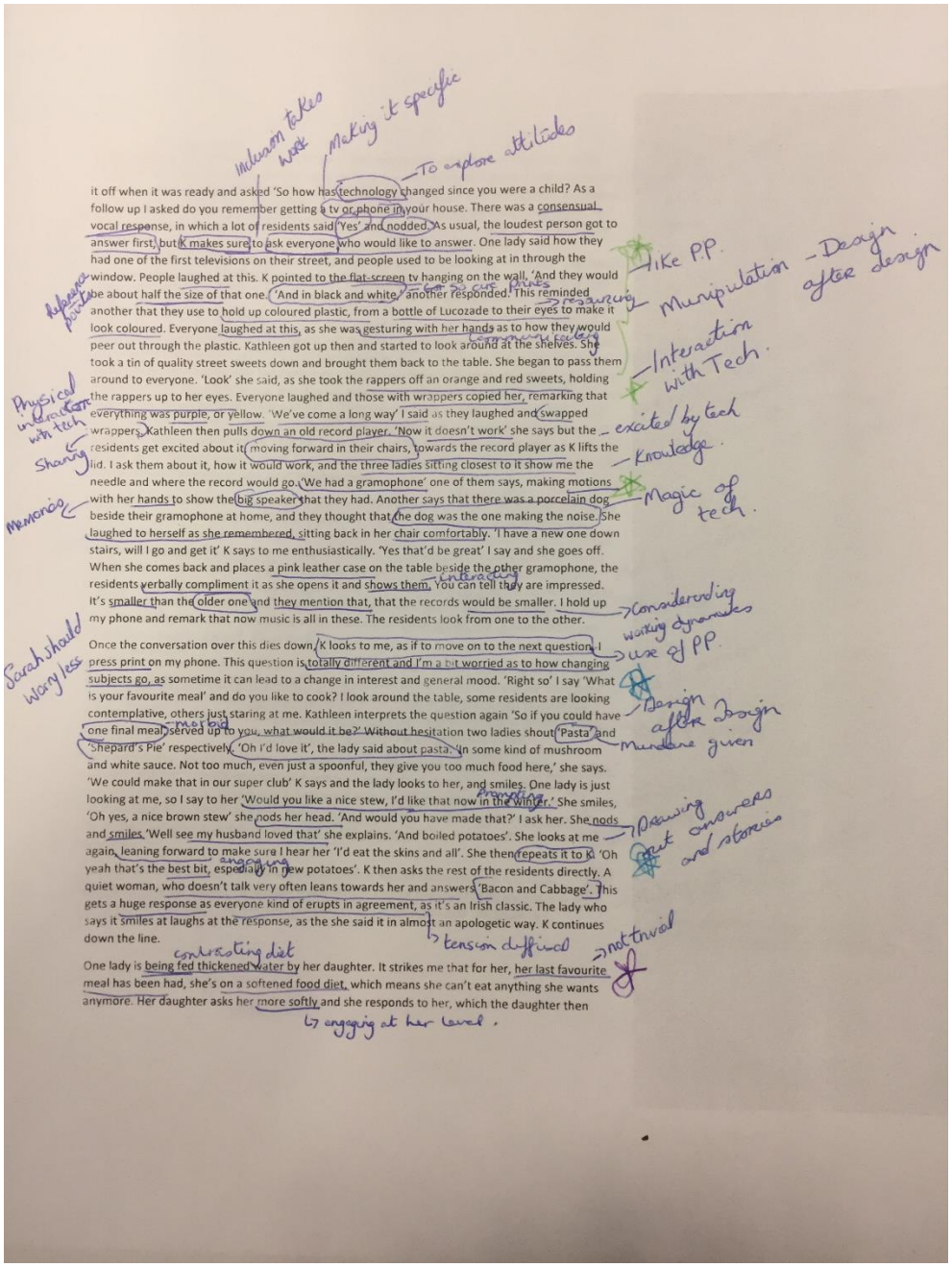
Afterwards I spoke to K, showing her the device in more detail, and we brought up the website on her phone.

She was very enthusiastic about the individual ones, saying we could do a case study with a family. She said she had been watching G, a man who is non-verbal through out the session. 'He was smiling and looking at people telling their stories the whole time. You don't get that type of reaction everyday. It's important to make people feel included even if they think they can't offer anything.'

Introducing the new metal printer-pals©

I got there early to set up the printer pals and place the table close to the wall so that when the residents were brought up they were sitting close to the table where the printer was. I printed a all the questions just to test that they worked, and on the off chance that the residents would be going outside and we could still use the receipts. I then went down to wait with the residents for mass to be over. Once the priest had finished, Kathleen announced that Myself and Sarah will be doing some reminiscence upstairs in the Atrium if people would like to come up.' 'And we have a new toy today' I said, more so to her so she knew the printer pals was working. Her face lit up 'We're very excited about that' she says to a lady who is in visiting her brother. 'Lets hope it works' I said laughing. Because I was a little nervous as the whole session is based around the printer pals, and if I break it I can't fix it on the spot.

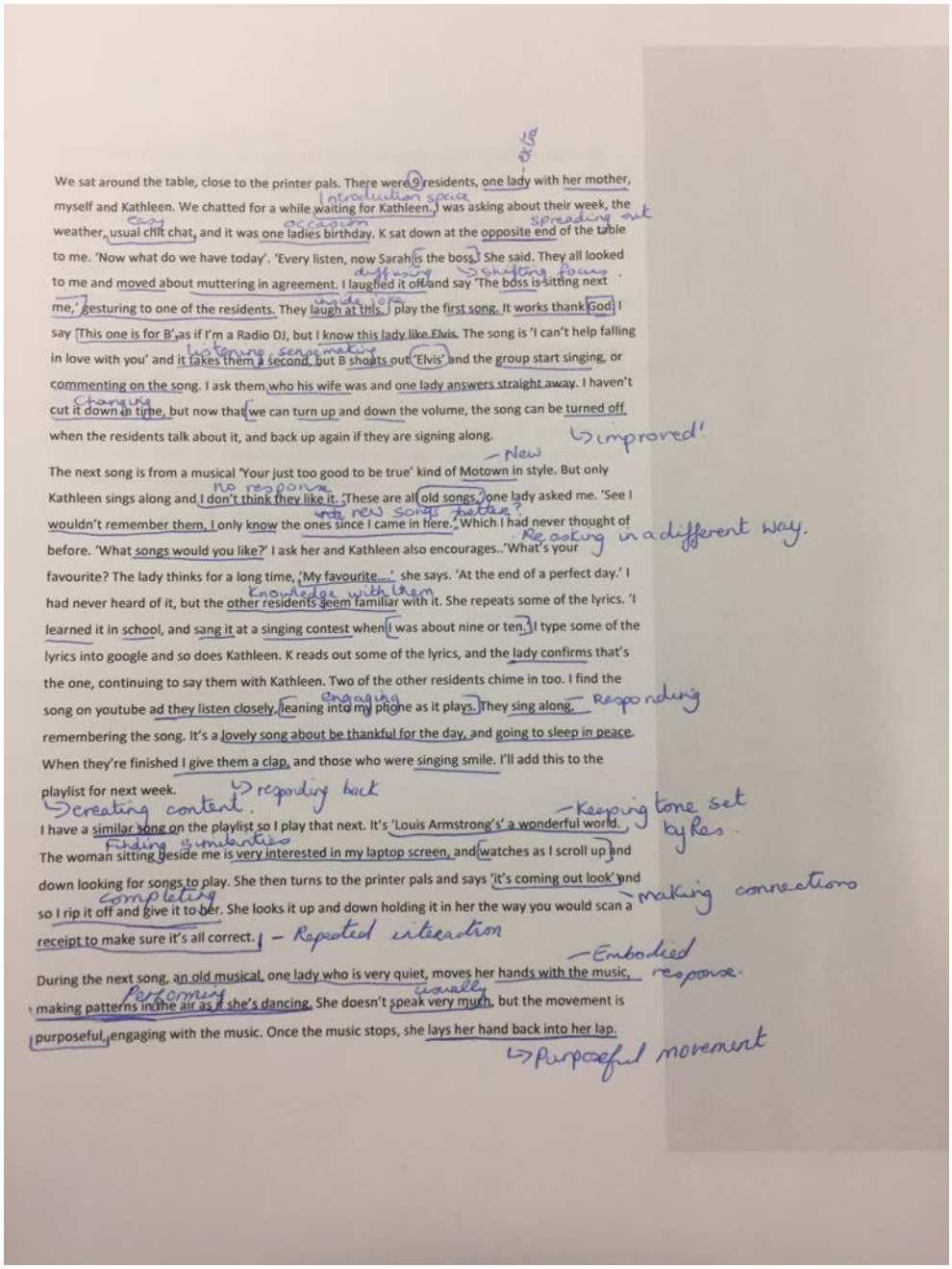
The staff came down for the residents and it took a while to get everyone back to where they wanted to go, but by the time I got up to the atrium, there was nine resident sitting around two big tables. They greeted me, asking how I was, chatting about the continued warm weather. One lady had got a haircut and we complimented her. She thanked us as she patted her head. 'Now, listen to Sarah as she tells us about the new computer.' They all looked to me, and as the machine was slightly behind me, I moved back to make sure they could see it. 'Now do you remember when Daniel was over to visit and he made the printer' 'Oh yes' some of them nodded, smiling. 'Well he's made ye three new ones, based on the things ye thought would improve them, like making the volume louder and the outside prettier' I explained. I picked it up then, showing it to them. 'He made that' one lady asked, astonished. 'It's just marvellous, I love the gadgets' another remarked. I showed them where the speaker was, and a the printer, and Kathleen said 'I think it's just marvellous. So today it's gonna ask us some questions' I told them. I had my phone to print out the first one. They watched as out came the first receipt. This question had a computer on it, and I tore



it off when it was ready and asked 'So how has technology changed since you were a child? As a follow up I asked do you remember getting a tv or phone in your house. There was a consensual vocal response, in which a lot of residents said 'Yes' and nodded. As usual, the loudest person got to answer first, but K makes sure to ask everyone who would like to answer. One lady said how they had one of the first televisions on their street, and people used to be looking at in through the window. People laughed at this. K pointed to the flat-screen tv hanging on the wall, 'And they would be about half the size of that one.' 'And in black and white,' another responded. This reminded another that they use to hold up coloured plastic, from a bottle of Lucozade to their eyes to make it look coloured. Everyone laughed at this, as she was gesturing with her hands as to how they would peer out through the plastic. Kathleen got up then and started to look around at the shelves. She took a tin of quality street sweets down and brought them back to the table. She began to pass them around to everyone. 'Look' she said, as she took the rappers off an orange and red sweets, holding the rappers up to her eyes. Everyone laughed and those with wrappers copied her, remarking that everything was purple, or yellow. 'We've come a long way' I said as they laughed and swapped wrappers. Kathleen then pulls down an old record player. 'Now it doesn't work' she says but the residents get excited about it, moving forward in their chairs, towards the record player as K lifts the lid. I ask them about it, how it would work, and the three ladies sitting closest to it show me the needle and where the record would go. 'We had a gramophone' one of them says, making motions with her hands to show the big speaker that they had. Another says that there was a porcelain dog beside their gramophone at home, and they thought that the dog was the one making the noise. She laughed to herself as she remembered, sitting back in her chair comfortably. 'I have a new one down stairs, will I go and get it' K says to me enthusiastically. 'Yes that'd be great' I say and she goes off. When she comes back and places a pink leather case on the table beside the other gramophone, the residents verbally compliment it as she opens it and shows them. You can tell they are impressed. It's smaller than the older one and they mention that, that the records would be smaller. I hold up my phone and remark that now music is all in these. The residents look from one to the other.

Once the conversation over this dies down, K looks to me, as if to move on to the next question. I press print on my phone. This question is totally different and I'm a bit worried as to how changing subjects go, as sometime it can lead to a change in interest and general mood. 'Right so' I say 'What is your favourite meal' and do you like to cook? I look around the table, some residents are looking contemplative, others just staring at me. Kathleen interprets the question again 'So if you could have one final meal served up to you, what would it be?' Without hesitation two ladies shout 'Pasta' and 'Shepard's Pie' respectively. 'Oh I'd love it', the lady said about pasta. 'In some kind of mushroom and white sauce. Not too much, even just a spoonful, they give you too much food here,' she says. 'We could make that in our super club' K says and the lady looks to her, and smiles. One lady is just looking at me, so I say to her 'Would you like a nice stew, I'd like that now in the winter.' She smiles, 'Oh yes, a nice brown stew' she nods her head. 'And would you have made that?' I ask her. She nods and smiles 'Well see my husband loved that' she explains. 'And boiled potatoes'. She looks at me again, leaning forward to make sure I hear her 'I'd eat the skins and all'. She then repeats it to K 'Oh yeah that's the best bit, especially in new potatoes'. K then asks the rest of the residents directly. A quiet woman, who doesn't talk very often leans towards her and answers 'Bacon and Cabbage'. This gets a huge response as everyone kind of erupts in agreement, as it's an Irish classic. The lady who says it smiles at laughs at the response, as the she said it in almost an apologetic way. K continues down the line.

One lady is being fed thickened water by her daughter. It strikes me that for her, her last favourite meal has been had, she's on a softened food diet, which means she can't eat anything she wants anymore. Her daughter asks her more softly and she responds to her, which the daughter then

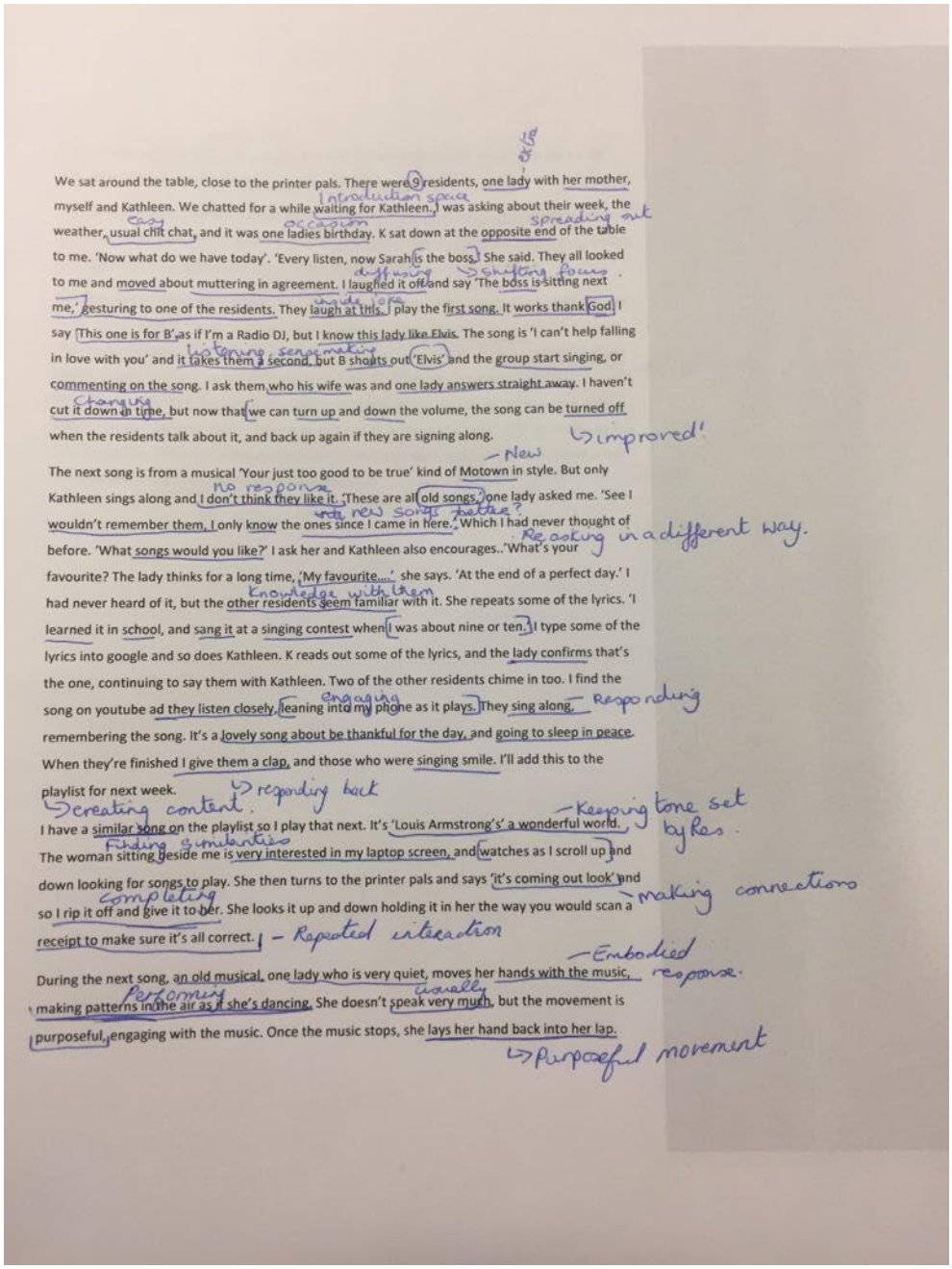


We sat around the table, close to the printer pals. There were 9 residents, one lady with her mother, myself and Kathleen. We chatted for a while waiting for Kathleen. I was asking about their week, the weather, usual chit chat, and it was one ladies birthday. K sat down at the opposite end of the table to me. 'Now what do we have today'. 'Every listen, now Sarah is the boss.' She said. They all looked to me and moved about muttering in agreement. I laughed it off and say 'The boss is sitting next me,' gesturing to one of the residents. They laugh at this. I play the first song. It works thank God. I say 'This one is for B', as if I'm a Radio DJ, but I know this lady like Elvis. The song is 'I can't help falling in love with you' and it takes them a second, but B shouts out 'Elvis' and the group start singing, or commenting on the song. I ask them who his wife was and one lady answers straight away. I haven't cut it down in time, but now that we can turn up and down the volume, the song can be turned off when the residents talk about it, and back up again if they are signing along.

The next song is from a musical 'Your just too good to be true' kind of Motown in style. But only Kathleen sings along and I don't think they like it. 'These are all old songs,' one lady asked me. 'See I wouldn't remember them, I only know the ones since I came in here.' Which I had never thought of before. 'What songs would you like?' I ask her and Kathleen also encourages..'What's your favourite? The lady thinks for a long time, 'My favourite....' she says. 'At the end of a perfect day.' I had never heard of it, but the other residents seem familiar with it. She repeats some of the lyrics. 'I learned it in school, and sang it at a singing contest when I was about nine or ten.' I type some of the lyrics into google and so does Kathleen. K reads out some of the lyrics, and the lady confirms that's the one, continuing to say them with Kathleen. Two of the other residents chime in too. I find the song on youtube ad they listen closely, leaning into my phone as it plays. They sing along, remembering the song. It's a lovely song about be thankful for the day, and going to sleep in peace. When they're finished I give them a clap, and those who were singing smile. I'll add this to the playlist for next week.

I have a similar song on the playlist so I play that next. It's 'Louis Armstrong's' a wonderful world. The woman sitting beside me is very interested in my laptop screen, and watches as I scroll up and down looking for songs to play. She then turns to the printer pals and says 'it's coming out look' and so I rip it off and give it to her. She looks it up and down holding it in her the way you would scan a receipt to make sure it's all correct.

During the next song, an old musical, one lady who is very quiet, moves her hands with the music, making patterns in the air as if she's dancing. She doesn't speak very much, but the movement is purposeful, engaging with the music. Once the music stops, she lays her hand back into her lap.

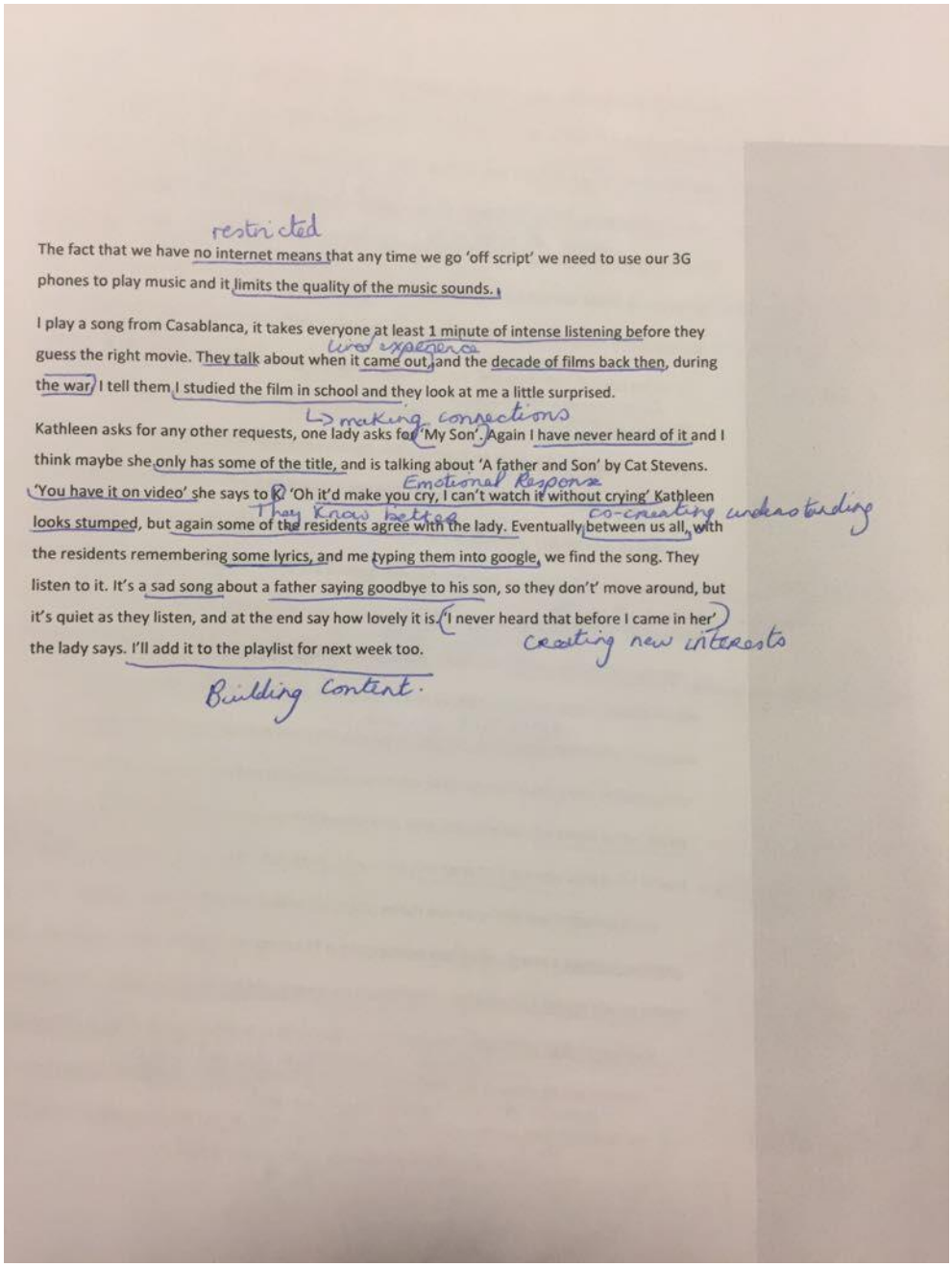


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restricted

The fact that we have no internet means that any time we go 'off script' we need to use our 3G phones to play music and it limits the quality of the music sounds.

I play a song from Casablanca, it takes everyone at least 1 minute of intense listening before they guess the right movie. They talk about when it came out, and the decade of films back then, during the war. I tell them I studied the film in school and they look at me a little surprised.

shared experience

↳ making connections

Kathleen asks for any other requests, one lady asks for 'My Son'. Again I have never heard of it and I think maybe she only has some of the title, and is talking about 'A father and Son' by Cat Stevens. 'You have it on video' she says to me. 'Oh it'd make you cry, I can't watch it without crying' Kathleen looks stumped, but again some of the residents agree with the lady. Eventually between us all, with the residents remembering some lyrics, and me typing them into google, we find the song. They listen to it. It's a sad song about a father saying goodbye to his son, so they don't' move around, but it's quiet as they listen, and at the end say how lovely it is. 'I never heard that before I came in her' the lady says. I'll add it to the playlist for next week too.

Emotional Response

They Know better

Co-creating understanding

creating new interests

Building Content.