Student Engagement in Sensitive Design Contexts: A Case Study in Dementia Care

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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, focused on the design project outcomes. In order to enrich the social context of this work, we explore broadening participation to include student volunteers. To encourage mutually engaging experiences in this design context, careful consideration of how to support both students and people with dementia is needed. In this paper, we present two case-studies of co-design projects between students and people with dementia. Our findings detail the use of design methods to reconfigure the role of the residents in care contexts and the students learning process. We discuss the project learning outcomes as well as practical and ethical considerations to support the use of design methods to support mutual engagement in sensitive contexts.

Author Keywords

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

CSS Concepts

• **Human-centered computing~ Human computer interaction (HCI);** Empirical Studies in HCI

INTRODUCTION

Dementia is a neuro-degenerative condition which results in a progressive decline in cognitive functioning [25]. The experience of dementia can vary greatly, depending on the cause [19] and the stage of dementia the person is experiencing [34]. 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 [37]. Design

processes that support positive relational experiences can provide opportunities for creative expressions of selfhood in dementia care [29, 42, 46]. 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 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 [39], foster empathy [30] and help establish enriching relationships [46] in otherwise clinical settings. The role of this work in ‘reconfiguring the user’ [44] 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 [28]. The turn to experience [31] has resulted in an examination of not only how the users engage with technology and design, but also the consideration 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 university students: ‘Life Story Box’ and ‘History Club’. The contribution of this paper is two-fold: Firstly, we present empirical evidence from an experience-based, co-design project to support mutually beneficial engagement between people with dementia living in care and students. Secondly, we offer insight into how researchers can support students in sensitive design contexts, considering the benefits of introducing design activities as the basis of HCI research in dementia care, and the ethical and practical implications of co-design with students in this context.

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 [38]. Engaging participants in context is a crucial first step in many HCI projects, particularly in accessibility and aging research [12]. While previous work has presented research into the value of inter-generational

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experiences in care homes [10], including quantitative measures of students experiences [9], and the use of traditional forms of person-centered therapies such as reminiscence therapy [11], our work presents qualitative evidence demonstrating the role of design activities in fostering mutually beneficial relationships in dementia care, a context often devoid of socially enriching activities and technologies [15, 16, 48]. This stage of design is under-reported at conferences like CHI but is a key step in the process of community building in sensitive settings and presents both opportunities and challenges for HCI researchers. In this section, we first present recent work in HCI and dementia care, which has focused on design processes as a means of exploring and evolving 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 [20]. 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-centered approach to their research, which has been heavily influenced by Kitwood's work on the importance of honoring the personhood of the individual with dementia, seeing beyond the illness to create socially orientated approaches to care and design [24, 25]. Building on person-centered care in HCI, the work of Wallace et al. [47] reports on designing artefacts to explore the personhood of the individual with dementia, while also examining the empathetic relational dynamic which evolved as the process continued. Lazar et al. [29] also examined the role of co-creative relationships, between art therapists and people with dementia in residential care, to examine 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. [36], who examined the use of 'Swaythe Band' 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 with their care.

Designing for emotion and connection is a route to further understanding the experience of dementia. In their work, Treadaway and Kenning [40] explore the use of exploratory co-design processes to improve well-being for people in the advanced stages of dementia [22, 40, 41]. The inclusion of people with advanced dementia in creative processes, such as working with e-textiles [41], crafts [22] and baking [43] highlights the design process as an opportunity for well-being 'in the moment' and designing for positive emotions [42].

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 [30]. Many projects in HCI have shown an appreciation for empathy as a path to enriching design [45, 50], in which the experience of the participant is fully considered and responded to positively. Due to the nature of dementia, Foley et al. [15] 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 [15]. Recognising the person with dementia as an active contributor to their social world and expanding design participation may be a route to examining and enriching these social processes further.

Expanding Design Participation

Design processes and outcomes which encourage better communication with people with dementia has resulted in an increase in design which is open to enhancement, manipulation and personalization [5, 21, 48]. Branco et al. [5] 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 [5].

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 [17, 18]. Foong et al. [17, 18] 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. [33] examined the role of younger people in dementia care and the potential of technology to support communication. Building on this work, Welsh et al. [48] designed 'Ticket-to-Talk', an app to support intergenerational engagement, by encouraging younger people to set up digital profiles for the person with dementia which held photographs, music and films. This work highlighted the role of younger people in the ecology of care, and the potential to extend the use of technology and design 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 within care which broaden participation for people with dementia and support them to remain socially engaged in their communities.

METHOD

This paper builds on our previous work involving a two-year ethnography in the State-funded residential care unit [14-16]. As part of the project, we recruited eight student volunteers to engage in co-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 two years 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%). This work builds on the first phase of this research, in which 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 [32]. 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 60 hours volunteering over the course of two semesters.

Participants

We worked with 8 students over the course of two years, 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 had previous education in developmental psychology and ageing studies. They were recruited while studying a ‘Psychology in the Community’ module, which involved 70 hours of volunteering and encouraged reflective practice as part of the assessment. Prior to their engagement with the residents, they received training about people with dementia from care staff at Oakfield House. The students worked with residents who had received a diagnosis of dementia (including co-morbid diagnosis) and

who staff felt would enjoy and benefit from more social engagement. We aimed to create an inclusive design space, to avoid further isolation of people with dementia. As such, any resident or family member was welcome. In the table below we present the primary residents we worked with and their diagnosis.

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

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

Ethics

Ethics was sought and approved by the University Ethics Board and the management of the care home. We obtained consent from the students to take part in the project, and guided by the Mental Capacity Act [1], sought proxy consent from staff and family members as required. 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 [3]. In this respect, the role of the lead researcher was key in ensuring the project progressed ethically. We will discuss this in detail in later sections.

Data Collection and Analysis

Fieldnotes were taken throughout the project by the first author, which was the method of data collection agreed by the ethics board. In addition, interviews were conducted with the students at the end of the project in which they reflected on their personal and relational development. Data was analyzed using thematic analysis [8]. In line with Braun and Clarke’s approach [8], analysis involved careful reading and re-reading of the data, line-by-line coding, and the construction of themes and sub-themes. The two case studies were analyzed separately and are presented below. Findings from the interviews (I) and fieldnotes (F) are annotated accordingly.

FINDINGS

In this section, we present the findings of our thematic analysis, which detail the experience of the co-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 personalized artefacts (see figure 1). This approach was informed by the common form of ‘Life Story Work’ which is used in dementia care as a form of reminiscence therapy, but is usually presented in the form of a book [32]. 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 relationships in the care home. As a result of this work, the students and residents formed a close working relationship, which shaped both the students understanding of dementia, and provided space to create mutually enriching experiences. The following themes were constructed to detail this experience; Forming new understandings through relationships; Empathy through design; Navigating roles; and Researchers in practice.

Forming new understanding through relationships

Through the engagement with residents, 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 interview excerpt, one of the students Owen (pseudonym) 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’ understanding of the nuanced experience of dementia 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 rhythm 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, 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 relationships 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 their ability to communicate clearly, as noted by Lucy:

‘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 I just 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...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.’ (F)

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 previous misunderstandings or prejudice against people with dementia. 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 them. 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. (F)

In these examples, comparing the developing relationships to that of a family indicates a growing fondness and mutually positive relationship between the residents and students. Maeve’s 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 holistic 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.

Building 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... 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. (I).

To find common ground with the residents, the students reflected on their everyday lives, and the ways in which the residents 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 resident 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 [15], and their potential to work together to enrich the design process.

The students also expressed strong emotions in relation to 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 researcher 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 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. (F)

This excerpt provides an example of the fresh insight into the lived and felt life of the resident that the students brought to the care environment. 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 student's 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 positioned 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.' (F)

The students' reaction here 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 suggests a passive contribution in the process. The students positioned the resident as an active contributor in their relationship, eradicating 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 undisposed due to feeling unwell or having a visitor. The students discussed this growing attachment with the residents with a concern on what its implications are to the project and themselves, as illustrated in the following excerpt:

Lucy mentioned that she was sad that she couldn't see her (resident 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 her considering this...and she agreed. (F)

Figure 1: Examples of the Life Story Box

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-configure 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. (F)

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, 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 an engaging experience, in which both parties benefited. Here one of the students describes their perception of the project as being mutually beneficial:

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. (I)

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 but Maeve recognised us immediately. 'Oh Hello' she said. The students 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. (F)

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 potential for meaningful communication between her and her son. The addition of the photograph of the students to the wall conveys Maeve's fondness for them, which is also demonstrated in her questions to the students. Her actions here contrast with 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 the other provided an opportunity to refine their interpersonal skills. Reflecting on the opportunity to support more engaged social roles for the residents, we reconfigured the social nature of the second design 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 engaged conversations and highlighted the capabilities of the residents to discuss more serious and varied 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 share their memories and could teach the students about the city. The name ‘History Club’ was chosen to avoid the negative association with ‘Reminiscence Therapy’[49] 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 16 months on a weekly basis with 5 students, with family members, other volunteers and staff often joining. 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 participants and the type of activities that took place in this case study: Sharing Knowledge; Taking Initiative and; Finding Value in Learning.

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 photographs depicted various scenes, people and buildings that shaped the 20th century in Cork City. Some photos resonated with the residents, 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 Rita beside me if she likes him. ‘Yes,’ she nods. She’s been very quiet up to now but she starts to tell us that her husband’s cousins heard the shots that killed him. Kathleen 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. (F)

Drawing on the photograph as a reference, Rita had the opportunity to communicate her knowledge on a very particular topic and becomes the expert in the social group. This created a re-configuration of her role, from passive to active contributor, allowing for a recognition of her experience. 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 change 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. (F)

In this example, Charlie 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.’ (I)

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 cares 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 that? The two men are in the same bedroom. (F)

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.(F)

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 expert 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 main researcher 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 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.’ The other two men are quieter. 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. They congratulate the residents on the Bowls competition that they 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 hold 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.(F)

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 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. I think it’s great and enjoyable and I’m happy to be a part of it.(F)

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. Everything we did was based on what they gave back to us. 'I)

Here the student discusses their motivation for progressing 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 student's 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. At 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. 'I)

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:

'when we first started I was telling my Mam 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.' (I)

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 resident's 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

This work aimed to incorporate co-design methods [6, 13, 22, 41] within the dementia care setting with a view to

examining the role of design at the intersection of care and education. Our findings detail the learning process of the students, which resulted in a more compassionate and nuanced understanding of dementia. We also examined the design space as an outlet in which people with dementia could demonstrate 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 in both the care home and 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 [15, 16]. As is evident in the findings, this can result in mutually beneficial social engagements in which care, intellect and agency are supported and exchanged. Our focus on experience and the gentle introduction of design activities as earlier stages to the design of technology align with the current person-centered movement in HCI & dementia care research [17, 27, 30, 36] as an integral, yet under-examined part of the process and of building trust in communities where there is a dearth of technology. Our previous work [16] details the technology designed as a result of the design process developed throughout this paper. Expanding the design participation in this care context to include students, creates opportunities to expand the means of communication [26] and expressions of personhood [47, 51] which in turn supports the agency and mutual recognition of both groups [14, 15]. Bringing these two groups together in the co-creative design process 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 the ecology of care, in which honoring the personhood of the residents was firmly at the center of their work [47]. This fresh perspective can be highly beneficial particularly for clinical professionals and 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 in 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 ones' role in the process and being open to learning from their participants.

Design Considerations

Co-design methods such as the ones employed in this project demonstrate the use of design and design thinking as an opportunity to foster and support individuals to engage in

creative and active social roles in their communities. Engaging university students in design practices is a common and central part of their training. 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. 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’.

Managing expectations and ensuring wellbeing

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 [35]. 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 [3]. 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 [3]. Design projects such as ours are often given a certain time-scale for completion. Considering the ending of the project from its beginning is a crucial step in ensuring a sensitive approach to the research process. Obtaining consent and honoring this by ensuring that the students feel supported by the main researcher through de-briefing sessions was an important element of research planning. 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 [5]. Translating the findings into useful resources, such as research-led evaluations, which may contribute to the provision of resources for people with dementia can ensure that the institutions are benefitting from engaging in the design process.

Supporting Co-Design with Vulnerable Participants

Co-design projects that encourage an exploration of the lived experience of vulnerable participants are a complex endeavor, both logistically and emotionally. A key consideration is how to initiate and facilitate them. The examination of the role of the students in this design process, highlighted both their innate ability to engage as co-designers, and develop emotionally engaged design processes. 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 encourage students to develop their own ideas about dementia and design. Examining how to navigate this transition is a key step in the design process. The researcher ultimately has a duty of care to all participants, 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 Universities 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 are always open to supporting each other.

Giving Design Away

Design processes and design thinking [23] such as the projects we have described have the potential to be incorporated further into systems of care as alternative activities in which people can engage in creative explorations of their personhood, while engaging in social and emotionally enriching projects. If design processes are to be incorporated into care, designers must work closely with carers and staff to ‘give design away’ [23] and encourage the use of design methods that are feasible and accessible from the carer perspective. The design methods described in this paper are akin to lo-fi prototypes and probes used in the early stages of design as a ‘way in’ to exploring the lived experience of participants. In our project, we found this type of design activity to be most useful and adaptative for care staff who were interested in continuing this type of creative work with residents but didn’t have technical design skills. Many design projects in HCI discuss the need for longevity and legacy of short-term projects [2, 4, 7, 13], and encouraging communities of practice to adopt and adapt design methods can ensure that HCI and design play a more central role in person-centred approaches in social care, nursing and community development. Embedding this transfer of skills into research plans can ensure that design research engages in further dialogue with the disciplines and environments in which we work.

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 between students and people with dementia, 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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