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Authors	Foley, Sarah;Pantidi, Nadia;McCarthy, John
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Care and Design: An Ethnography of Mutual Recognition in the Context of Advanced Dementia

Sarah Foley
School of Applied Psychology
University College Cork
Ireland
sarah.foley@ucc.ie

Nadia Pantidi
School of Applied Psychology
University College Cork
Ireland
konstantia.pantidi@ucc.ie

John McCarthy
School of Applied Psychology
University College Cork
Ireland
john.mccarthy@ucc.ie

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 studies**

KEYWORDS

Dementia; Ethnography; Recognition Theory; Experience-Centered Design

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1 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-centered care model. Such work has stressed the importance of social connection [33], creative expressions of personhood [41], and maintaining meaningful relationships [11] 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 [2, 24, 32, 41].

However, there is still a dearth of HCI research for people with advanced dementia [15, 38]. The experience of advanced dementia is associated with increased agitation, severe memory loss and physical frailty [31] 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 [21, 26]. 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) [27] for people with dementia [11, 34, 41], 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 [19]. 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-centered 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 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.

2 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.

2.1 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 [16, 23, 25, 34, 36, 42]. An appreciation for experience, as established by McCarthy and Wright [28, 43], 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 emphasizes. For example, Morrissey's ethnographic work [32] 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. [34], 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 and highlighted the role of design in encouraging meaning-making and embodied connections in dementia care. Similarly, the ethnographic work of Lazar et al. [23], 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.

Ethnography in this space has also considered the relational aspects between people with dementia and their carers [8, 38] 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. [11] 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. [11] 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 [37]. 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. [41], 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 [41]. The work between Wallace and the couple established a sense of trust between them, resulting in more rich and 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 ingrate 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.

2.2 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 [31]. 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 [7]. The personal experience of living with advanced dementia has been traditionally excluded from research in HCI and in general [38], 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.

2.3 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-centered 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 [9, 20]. 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 [29] 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 [1, 17]. 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 [14], and the various barriers to receiving recognition. These barriers may manifest as discrimination against aspects of one's identity, such as gender or race [9], or through lack of access to education, health care and employment. Failure

to be recognized 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 [40].

As we discussed earlier, the person-centered approach to care (as introduced by Kitwood) 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 (Kontos, 2006), identity maintenance (Sabat, 2002) and the need for acknowledging the individual with dementia within relational dynamics (Nolan et al., 2002). 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 -recognition- and a relational social and civic justification to do so.

3 METHOD

This paper reports on the first phase of a long-term design ethnography, which took place in Oakfield House, a State-funded residential unit providing care for people with dementia and end of life care. 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 [8]. 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 [6, 13]. 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.

3.1 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-centered approach to care [22].



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

3.2 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 [8]. 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 [3]. Drawing on previous ethnographic work which has applied theory as a means of further analysing and understanding the experience of dementia [30, 39], we applied the theory of recognition [9, 17, 40] to the data by adopting a theory driven, thematic analysis[3].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.

4 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.

4.1 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.

4.1.1 Embodied Recognition

The central concept of recognition is the need to give and receive basic recognition and care from those around us [18]. 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 [29]. 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 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 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 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 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.

4.1.2 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 [40]. 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 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. 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 (Honneth). 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.

4.2 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 (Honneth). 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.

4.2.1 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 [5] 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 (Fraser).

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.

4.2.2 Acknowledging Misrecognition

Due to the nature of the illness, the person with advanced dementia can have fragmented or intermitted 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 (Fraser). 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.

4.3 Recognition Through Agency

Key facets of recognition such as respect and esteem [12] results from a person's role or contribution to the social world, for example by means of their job or civic duty [10]. For people living with advanced dementia, their right to work or contribute through civic engagement is often the first significant role that they lose [35] and this lack of opportunity to contribute continues as the illness progresses, and the need for physical care increases. However, our 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.

4.3.1 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 K, who is clearly trying her best on her own to do the work of at least three people.

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.

4.3.2 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 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. 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.' 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' [10] and considering the ways in which people with dementia contribute to their social worlds, building on this within our approaches to interactions and design of interactions in HCI.

5 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, talk about people long since gone as efforts to communicate and make meaningful contact with the other can be considered opportunities for recognition [4]. 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 looks out for and pays 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.

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

realizing 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 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 request 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 present 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 recognize your creativity and you can recognize mine. In 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 [32], the need to support relationships [11], and the potential of design to support agency [24]. 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.

5.1 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.

5.1.1 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 [36]. 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 [40]. 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 which in turn 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 (Taylor), to engage in collaborative action (Treadaway), and the co-creation of experience (Life Story Work, Kontos). 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 (Honneth).

5.1.2 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, can be seen as 'ways in' to establishing mutual understanding and 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 [17]. In terms of design, using tools or probes, a common design practice (Treadaway), to encourage and anchor the conversation in advanced dementia creates opportunities for mutual recognition to occur. As shown in our analysis, embodied communication (Kontos) 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.

5.1.3 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 [10]. 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 restricted (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, poor 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.

5.1.4 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 within dementia within their new lived experience. Design interventions can support this by widening the ecology of care such as, 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 dementia [40], 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 (Honneth) which is based on their common life experiences. Setting up inclusive design processes helps counteract the idea of grouping people with dementia together as the 'other', 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 [17]. 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.

6 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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