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Title	Printer Pals: experience-centered design to support agency for people with dementia
Authors	Foley, Sarah;Welsh, Daniel;Pantidi, Nadia;Morrissey, Kellie;Nappey, Tom;McCarthy, John
Publication date	2019-05
Original Citation	Foley, S., Welsh, D., Pantidi, N., Morrissey, K., Nappey, T. and McCarthy, J. (2019) 'Printer Pals: experience-centered design to support agency for people with dementia', CHI 2019: Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems, Glasgow, Scotland, 4-9 May, Paper 404 (13pp). doi: 10.1145/3290605.3300634
Type of publication	Conference item
Link to publisher's version	https://chi2019.acm.org/ - 10.1145/3290605.3300634
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Download date	2024-04-25 03:30:58
Item downloaded from	https://hdl.handle.net/10468/8250

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Printer Pals: Experience-Centered Design to Support Agency for People with Dementia

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

Daniel Welsh
Open Lab
Newcastle University
Newcastle Upon Tyne, UK
d.welsh@ncl.ac.uk

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

Kellie Morrissey
Open Lab
Newcastle University
Newcastle Upon Tyne, UK
kellie.morrissey@ncl.ac.uk

Tom Nappey
Open Lab
Newcastle University
Newcastle Upon Tyne, UK
tom.nappeyl@ncl.ac.uk

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

ABSTRACT

Whereas there have been significant improvements in the quality of care provided for people with dementia, limited attention to the importance of people with dementia making positive social contributions within care home contexts can restrict their sense of agency. In this paper we describe the design and deployment of 'Printer Pals' a receipt-based print media device, which encourages social contribution and agency within a care home environment. The design followed a two-year ethnography, from which the need for highlighting participation and supporting agency for residents within the care home became clear. The residents use of Printer Pals mediated participation in a number of different ways, such as engaging with the technology itself, offering shared experiences and participating in co-constructive and meaningful ways, each of which is discussed. We conclude with a series of design consideration to support agentic and caring interactions through inclusive design practices.

CCS CONCEPTS

• Human-centered computing ~User studies

KEYWORDS

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

ACM Reference format:
Sarah Foley, Daniel Welsh, Nadia Pantidi, Kellie Morrissey, Tom Nappey & John McCarthy. 2019. Printer Pals: Experience-Centered Design to Support Agency for People with Dementia. In *2019 CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2019), May 4–9, 2019, Glasgow Scotland, UK.* ACM, New York, NY, USA. **XX** pages.

1 INTRODUCTION

In order to appropriately respond to the needs of the increasingly ageing population, dementia has received growing attention within HCI [16, 21] examining the ways technology and design can respond to the various needs of people with dementia and their care environments. HCI has only recently begun to explore the potential of design to enrich the lived experience of people with dementia, their carers and the wider care ecology through designing for experience and social connection [3, 11, 15, 23, 34, 35]. However, people with dementia, particularly those in the later stages of the illness, are often presented as disinterested [32] or unable to engage with design processes and technological outcomes [28].

Within the care home environment, opportunities for people with dementia to express their agency and make social contributions are often restricted, as they are positioned as 'passive' patients in need of care [20]. This can result in people with dementia experiencing significant social 'loss of self', and the social contribution

of the person with dementia being conceptualized within a narrative of loss and compensation [1, 28]. A lack of opportunity to take an active role in the care environment can further this experience of loss of self. Designing to support the person with dementia to express their sense of agency and ability to participate within design practices has the potential to address this issue.

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

The paper provides a detailed account of how people with dementia engaged with Printer Pals and what their engagement demonstrates about the potential of technology to support social identity in people with dementia. Specific findings include their easy engagement with the materiality of technology, a surprise in light of the general assumption that older people tend not to be interested in technology, as well as their willingness to engage in playful, challenging and topical questioning using Printer Pals. The contribution of this research is two-fold. Firstly, we extend McCarthy and Wright's experience-centered design [18] approach by highlighting the experiences of people with advanced dementia, a particularly challenging setting for HCI research. Secondly, we present a series of design considerations when working with and for people with dementia, including the broader implications of our findings for inclusive design practices and outcomes.

2 BACKGROUND AND RELATED WORK

Whereas design responses to dementia have in the past largely focused on cognitive assistance, safety monitoring, and assessment [25], in recent years HCI has explored dementia as a social, cultural and interpersonal experience, reflecting the social constructs of dementia and the potential to enrich this experience through design practices and outcomes. In this section we discuss previous work in HCI that has informed the current project, taking an experience-based approach [18, 23] to understanding and responding to the social consequences of dementia, and the place of HCI in creating socially enriching experiences within the care environment.

2.1 Dementia and HCI

Dementia is a multi-faceted, complex illness which is predominately associated with changes and decline in cognitive functions such as memory, executive functioning, communication, planning and decision-making [19]. In addition to the cognitive aspects of dementia, considering the experience of dementia within social and cultural constructs- e.g. how a diagnosis can result in negative social consequences-is also very important [2]. The close association between cognitive ability and selfhood within Western culture has resulted in the construction of dementia as an experience of 'deficit' and 'passivity' [2, 6, 24, 29] as people with dementia report a loss of selfhood due to lack of opportunities to engage in their social world [5, 27].

In response to this, a socio-psychological approach to dementia care has been developed, which aims to understand and support the 'personhood' of people with dementia, and acknowledges their need for engagement, respect and agency [12]. This person-centered approach to care has been adopted within experience-based methods of designing with and for people with dementia in HCI, resulting in an exploration of the ways in which people with dementia experience their social worlds, and how supportive technologies can enrich interactions [17, 34]. The Experience-Centered Design (ECD) approach, as established by McCarthy and Wright [18, 36, 37], examines the iterative, dialogical construction of experience and the place of design in enriching this experience, and has contributed to the growing inclusion of people with dementia in research [23]. The work of Wallace et al. [34] was foundational in applying the concept of personhood and dementia in ECD. Wallace's engagement with a couple, Gillian and John explored the potential of design, in this case digital jewellery, to reflect the lived experience of Gillian, and the aspects of their lives that they wanted others to remember and engage with [34].

The potential of technology to extend, maintain and celebrate personhood has been explored in several

recent projects. Lazar et al. [15], highlight the opportunity to support agency using technology, through the design of a photo sharing tool, in which the person with dementia can creatively express themselves through art therapy and communicate their creations through sharing it with their family and friends [15]. Hodge et al. [11], have explored the use of Virtual Reality to recreate meaningful places for people with dementia. Through creating immersive opportunities in which the person with dementia can engage in new experiences, Hodge et al., also contest the idea that people with dementia are opposed to engaging with technologies, framing experiences with technology as shared social engagements:

'Our workshops have indicated that…short, playful VR experiences can be shared even in an ad-hoc basis with friends and family, and people can discuss what they are experiencing even while they are experiencing it' [11].

Similarly, the experience of the person with dementia is central to the design and use of 'Ticket to Talk', an application developed by Welsh et al. [35], which encourages intergenerational engagement, based around a series of probes and the curation of media specifically tailored for the person with dementia. Within these design approaches, there is a space for what Branco et al. [3], describe as 'Open Design' and 'Design after Design' in which the technologies are used to hold, display and engage the experiences of people with dementia, and in doing so, provide an opportunity for others to engage more meaningfully with the person with dementia. Whereas these design interventions focus on supporting and maintaining relationships with close family and friends, many people with dementia experience the transition into residential care, which creates a different set of challenges in the maintenance of personhood and social belonging.

2.2 The Care Home and Social Agency

As people with dementia transition into care, many of their previous roles within their families and wider communities come to an end. This can often result in them being seen as 'patients' who depend on staff to attend to their physical care [13, 30]. Within a care home setting, it may be taken for granted that the physical proximity in which staff and residents work results in a natural development of friendships and close relationships. However, much of the conversation and daily activity of the care home is focused on physical care, such as bathing, eating and assisting residents in their wheelchairs [30]. The nature of the environment, shared spaces and staff demands can mean there is little time and few resources to support people with dementia to engage more actively to maintain and develop their social identity. HCI has explored the potential of designing for this space to encourage more social connection and engagement within the care environment.

Wallace et al. [33] were commissioned to design and install 'Tales of I', an interactive display consisting of a traditional dresser which held decorative globes representing different topics for reminiscence and when placed on top of a retro-fit television, would play a short film to encourage discussion between residents and staff or family members. The use of images and media within shared spaces was also central to 'Photostroller', an interactive photo-display tool which was placed in a care home to encourage conversation and playful, ludic experiences inspired by the media [9]. This work highlighted the use of media as an anchor for connecting and engaging with each other. In designing for connecting and belonging, Morrissey et al. [23], explored the embodied nature of connecting and communicating, in which people with dementia express their ability and need to engage in social activities through music and dance. In supporting people with dementia to move and connect through the design of 'Swaytheband', an interactive baton that changes colour as it is moved to the beat of music, Morrissey highlighted the nuanced ways in which people with dementia engage and participate in their social environment, as well as the legitimacy of embodied selfhood as a means of maintaining social identities [22, 23].

The design and implementation of Printer Pals is the final outcome of a larger project which examined the experience of people with dementia living in residential care and the potential of design processes to enrich this experience. The first phase of the project involved an ethnography in a state-funded residential care unit, in which the first author engaged with people in the advanced stages of dementia with a view to understanding the nature of mutual engagement, supporting agency and introducing appropriate technologies into the care environment [Foley et al., CHI2019]. The findings of this ethnography suggested that people with dementia often express care, and a willingness to interact with those around them through

subtle embodied actions and expressions. One of the key aims of the project is to encourage social participation with people with more advanced dementia, to ensure that they can engage meaningfully in the social aspects of the care home. In order to examine those subtle engagements more closely, we engaged student volunteers to participate in activities in which the residents and students were mutually supported by each other to learn from and teach each other. As described in the next section, the work with the student volunteers was the basis of the design of Printer Pals.

3 METHOD

3.1 Setting

To support people with dementia to take on a more active role in the care home, we engaged with student volunteers to set up a 'History Club' in which the residents would share their stories and memories from growing up, supported by historical photographs which were provided by the research team. We chose to name the sessions 'History Club' to encourage intergenerational engagement and facilitate social and political discussion. This positioned the person with dementia's role in the group as an expert rather than observer, who discussed the political and historical events which shaped society. These discussions often took on a competitive and playful nature, as we guessed famous cultural and political figures in the photographs. The nature of these engagements led us to reflect how to ensure access to media for people with dementia which was more personal and open to interpretation. Introducing media and personalised content was somewhat restricted, as the care home was not supplied with Wi-Fi. Therefore, media had to be printed in other locations and shared with residents, slowing down the ways in which we could respond to their interests and opinion. We used touch screens (e.g. tablets) in the History Club but found residents were reluctant to engage with them as the interface would often change when the resident wished to point out something on the screen. As such we found paper copies were more appropriate. The initial design of Printer Pals aimed to further support and enrich these activities.

3.2 Ethics

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

3.1 Study Design and Analytic Approach

Data collection for the design and implementation of Printer Pals took place over the course of eight months, from January to August 2018. We carried out iterative sessions and evaluations, once a week over this period, to introduce our early ideations, prototype and refined models for interaction and critique with the residents and staff. Each session was typically attended by approximately 10-14 residents, 2-3 volunteers and 2 staff members. As stated previously, field notes were taken during session and expanded upon after the workshops [7]. The research team examined both the nature of residents' participation, as well as the pragmatic considerations of designing and introducing media and technology to the environment.

In our setting, like in most care homes, residents living together have varied diagnoses and abilities. The aim of the project was to encourage people with advanced dementia (who may be non-verbal, have severe memory loss and different ways of communicating) to mix socially with others in earlier stages and exert their social agency during the Printer Pals sessions. The residents who took part in the sessions had various diagnosis (see below) which resulted in different types of participation. The symptoms of dementia can vary depending of the type of dementia [NHS.uk] that the individual has and the stage they are experiencing [Alzheimer's.org]. For example, someone in the early stages of dementia can often live independently, experiencing some memory issues or confusion. In contrast advanced dementia is associated with severe memory loss, agitation and a dependency on non-verbal communication [Mitchell, 2009]. We viewed all these

types of participation as valid, paying particular attention to the participation of people with advanced dementia, which is often not fully captured in research.

Table 1. Diagnosis of residents and nature of participation.

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

We adopted a thematic analysis [4] approach to data analysis of the field notes, which involved initial coding, interpretation of the content, and generation of themes and sub-themes based on this analysis, informing both the second iteration of the design, and the analysis of the nature of participation and curation of media to reflect the engagement of the residents. We conducted a bottom-up, latent analysis in which we were interested in examining the experience of engaging with Printer Pals and the types of interactions which occurred amongst the residents. We took a constructionist approach to the analysis, in which meaning was socially constructed by the participants through their engagement with each other and their environment [4]. This approach served to further emphasise the ability of the residents to construct meaning and experience, which has been traditionally questioned within research and dementia [29].

4 DESIGN

The aim of Printer Pals is to ease facilitation of interactive group activities, while simultaneously challenging perceptions of the abilities and agency of people with dementia. In its first iteration, Printer Pals was a media-centered print-based quiz in the form of a Raspberry Pi, receipt printer, and speaker enclosed in a laser cut cardboard cylinder (see figure 1). Group sessions with Printer Pals took the form of a quiz, following a familiar format taken from the previous history club that researchers conducted in the care home. We chose the names of the activities with staff, volunteers and residents to encourage fun social engagement. By positioning the person with dementia as an 'expert' we aimed to highlight what participants offered in this social context. Printer Pals was kept in the public space in the care home and was brought to host quizzes and storytelling for the residents. In these sessions, Printer Pals would print tasks for the group to complete. Before sessions, volunteers would use a web interface to create and upload tasks to Printer Pals, such as songs with instructions to guess the artist, images of famous faces, riddles, and jokes. Tasks could also be a question asking the residents to share their opinions or preferences. Volunteers would then print these in the group session using the web interface, choosing which task to print next in a way that naturally followed the group discussion around the tasks.

Figure 1: An example of a printed receipt (left) and the original cardboard encased prototype (right).

Printer Pals was iteratively developed over two deployments through an experience-centered design approach [18]. This process was heavily influenced from our understanding of the residents from our previous ethnography, which was implemented into the design. For example, the printer forces a slow interaction as the group waits for a task to print, affording everyone the chance to participate. It was also important that the activity should leave something behind, so that those who have played will have a physical cue to remind them of the recent activity. We chose a familiar medium of receipts to deliver tasks, as almost everyone has experience with receipts and they encourage people to take and keep them. The design also accounted for

limitations presented by the care home setting, such as a lack of internet access. Observations from the previous ethnography influenced our decision for the initial prototype to have both a robust and inexpensive aesthetic and haptic qualities. We hoped this design choice would encourage physical interaction with the artefact.

4.1 Deployment

4.1.1 1st Deployment

The first iteration of Printer Pals had a rough cardboard housing, with a largely exposed receipt printer. It had a solid body, with a camera embedded into the lid of the device. This camera would be used to scan QR codes printed onto tasks, forcing the device to reprint a task should a resident wish to keep it for themselves. This camera was removed before the first deployment in consideration of the staff's reactions to a camera being introduced in a group activity. As such the internal components were left exposed. Printer Pals was used in the initial deployment as a "Quiz-Master", which would ask questions of the groups, instead of a volunteer asking questions themselves. Residents would gather around Printer Pals, as researchers printed tasks for the group to complete. Many of these tasks were themed on historical facts of the local area, following on from a previous history club reminiscence activity that residents were already familiar with. Tasks also extended to more general pop culture, such as guessing famous faces, along with more challenging jokes and riddles. Residents responded well to Printer Pals, particularly enjoying the famous faces, riddles, and jokes. We observed some of the residents keeping the receipts to show family members when they next visited. Residents noticed the exposed components of Printer Pals and reacted excitedly, asking questions about what they were and expressing their desire to have a computer, having never had one when they were younger.

4.1.2 2nd Deployment

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

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

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

Figure 2: The final three Printer Pals.

5 FINDINGS

The following themes describe both moments of interaction with Printer Pals, as well as the conversations and activities that came because of the media content of the tool. To explore the ways in which interaction with Printer Pals supported and encouraged agentic

interaction, we present the following themes; At Home with Technology, Co-Constructing Knowledge and Experience; and Levels of Participation. Within these themes we examine the nature of participation and how people with dementia contribute to their social environment, often taking the lead and building on each other's experiences to create new shared experiences.

5.1 At Home with Technology

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

5.1.1 Appropriating Content

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

I asked them would they have danced to something like this…and played the Blue Danube waltz. Some people swayed along. Over the song playing, one lady said she preferred Irish music. Another gave an example of an Irish song she had danced to, so I pulled that up on YouTube. At this stage I had my Laptop, phone and iPad on the table. 'They are just lovely things to have' one lady remarked. I said I was very lucky to have them. The Irish music got a few 'Whoops' and claps as the residents moved to the music.

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

5.1.2 Ownership and Enjoyment

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

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

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

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

The description of the technical aspects of Printer Pals as objects that are 'cute' or 'doty' (an Irish term for cute or disarming) highlights the residents' excitement and willingness to engage with the mechanics of the device. We were eager to show the residents what Printer Pals

consisted of, to create a sense of understanding and inclusion in the process, while also challenging the assumptions that older people, and people with dementia are unable or disinterested in engaging with technology.

5.1.3 Bringing People Together with Technology

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

'So how has technology changed since you were a child? As a follow up I asked, 'do you remember getting a television or phone in your house?' There was a consensual vocal response, in which a lot of residents said 'Yes' and nodded…One lady said how they had one of the first televisions on their street, and people used to be looking at in through the window. People laughed at this. K pointed to the flat-screen TV hanging on the wall. 'And they would be about half the size of that one.' 'And in black and white,' another responded. Then another lady offered that they use to hold up coloured plastic, from a bottle of 'Lucozade' to their eyes to make it look coloured. Everyone laughed at this, as she was gesturing with her hands as to how they would peer out through the plastic. K got up then and started to look around at the shelves. She took a tin of sweets down and brought them back to the table. She began to pass them around to everyone. 'Look' she said, as she took the rappers off an orange and red sweets, holding the rappers up to her eyes. Everyone laughed and those with wrappers copied her, remarking that everything was purple, or yellow and swapping wrappers around.

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

The woman sitting beside me is very interested in my laptop screen, and watches as I scroll up and down looking for songs to play. She then turns to the printer pals and says 'it's coming out look' and so I rip it off and give it to her. She looks it up and down holding it in her the way you would scan a receipt to make sure it's all correct.

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

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

5.2 Co-Creating Knowledge and Experience

The introduction of Printer Pals, and the nature of interactions facilitated around it, provided an opportunity for the residents to contribute their own experiences and opinions to the group. However, it was the ways in which understanding, and knowledge was co-created within the sessions that highlighted the agentic contribution of each individual, resulting in a process of sense-making together. In the following theme, we examine the nature of collaboration and co-creation amongst the residents as a means of examining the function the Printer Pals sessions, highlighting the various social contributions of the residents.

5.2.1 Sharing Experiences

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

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

In the telling and sharing of these important milestones of their lives, the residents offer both an insight into their lived experiences before coming into the care home, but also connect and compare these experiences as a way of sharing common interests and memories. In listening to the stories of others, the residents create space for sharing and connecting with the story of others, while also reflecting on memories of their own. Weaving together their own stories into a new, shared experience creates opportunities for more meaningful engagement.

5.2.2 Taking the Lead

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

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

In taking the original question produced by Printer Pals, and re-interpreting it to take the lead in a conversation, the resident demonstrated their ability to shape and contribute to the nature of the conversation. In this instance, the simple question evolved into something much more specific, which created a more detailed memory to be shared by another resident who would normally remain silent. Through the evolving nature of the conversation, the residents created their own meaning from the topic.

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

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

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

5.2.3 Challenging Ability and Perceptions

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

created an opportunity to take the lead in challenging others:

I read it out to them. 'I travel around the world but stay in one corner, what am I?' I repeated it on request, and the residents began to shout out answers. We all complimented them on their guesses, and gave them some hints; that is was small, and cheap and there would be more around at Christmas. One lady got close with a post-card so we told her so was the closest. Eventually one person a lady got it right and shouted out 'Stamp.' We all gave her a cheer. She said she thought that was very clever. I give her the receipts and tell her to quiz the staff on the war. 'Sure I have two from before' she says referring to earlier sessions. From then, anytime a new person comes in she asks them the question. One man rolls in in his wheelchair and she tells him she has a question. 'He'll get it he's a genius' the women beside me says. 'It's simple' the woman with the receipt tells him. Kathleen says 'You're only saying that because you know it now' and everyone laughs. The man gets in very fast. 'A stamp' he says. Everyone gives him a cheer. He smiles at everyone. *A few minutes later the manager of the care home comes up to talk to Kate. Before she goes, the lady tells her to come here, she has a question. 'See will you get this now, he got it in two seconds.' 'I'm very proud of myself there now.' He says and he looks it. The manager takes a few guesses and eventually she gets it too. They give her a cheer as well.*

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

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

5.3 Levels of Participation

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

5.3.1 Communicating Care Through Object Interactions

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

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

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

5.3.2 Subtle Participation

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

attention of a resident, and prompted her from quiet to more active participation:

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

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

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

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

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

6 DISCUSSION

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

6.1 Challenging Negative Perceptions of Technology for People with Dementia

Within HCI, there has been a narrative surrounding the use of technology with older individuals and within care homes as problematic and unsuitable [32]. While there needs to be critical consideration in the use and propose of technology in care homes, the perception that older people and people with dementia are unfamiliar with, or

averse to technology can prevent them from engaging and enjoying socially enriching technologies. As demonstrated in our findings, the residents have lived with technology for most of their lives. They have an interest and willingness to engage in the physicality and mechanics of the Printer Pals, as well as enjoying the content together, as was common with more traditional entertainment technologies such as television. While the technology itself was aesthetically novel, the receipts and media were familiar. Through their involvement in design processes and evaluation, people with dementia challenged the perception that they cannot enjoy technology and showcased that they can create more suitable high-quality technologies to become part of the care home environment and care practices [31, 32]. Involving people with dementia in the design of technologies can help ensure they have a more meaningful role in older peoples lives, while also conveying a more positive perception of ageing [Ref].

6.2 Reconsidering Agentic Behaviors and Social Contribution.

The nature of everyday life in a care home can be restrictive in terms of practicing one's agency and making what is traditionally considered positive social contributions. The ways in which people with dementia, especially advanced dementia, are considered passive [5, 20], or unable to make positive social contributions may be due to a narrow sense of what activities, such as paid work, are considered contributions in Western society [8]. In examining the subtle ways in which the residents expressed care for each other, such as offering stories and sharing social experiences, design processes and outcomes can further examine what is deemed as a worthy contribution, and in doing so support the agentic abilities of the person with advanced dementia. By considering agency in terms of caring, emotional responses to those around them, we can shift the debate away from whether people with dementia have agency, and towards best understanding how to support them in expressing their agency with experienced-based technology. The work of our volunteers in this setting was vital to supporting the content creation and scaffolding the sessions, but it also ensured more opportunities for social contribution from the residents. By incorporating a critical approach to understanding agency as a socially realized ability, we can design technologies which support the playful, caring and emotional elements of agency for people with dementia.

6.3 Inclusivity and Accessibility

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

Finding the balance between aesthetics and functionality was a concern from the beginning of the project, as many residents were reluctant to engage directly with certain types of technology used by the research team, specifically those with touch screen technology. Through introducing Printer Pals first in cardboard, and then encased in robust materials in the final evaluation, the residents felt more comfortable engaging with the technology itself, and the printed receipts. The iterative nature of the design process ensured that the residents were included and consulted within each stage of the project, creating space for people with dementia to have a direct input into the technology that was built. Supporting appropriate inclusion for people in the later stages of dementia within design processes can result not only in more enriching technologies, but also furthers our understanding of how to best support and include people with advanced dementia in participatory design and research work, building of the previous work [17] in HCI which calls for participatory approaches to design and dementia.

The nature of some of the activities, riddles, and quizzes challenge the perceived capabilities of people with dementia [27]. While we are sensitive to the nature of questioning, to position people with dementia as 'beyond' being challenged in this way can be equally insensitive. Presenting these challenges and quizzes to a group ensured that no one was directly challenged, but also gave the residents the opportunity to be part of a team. The fact that the questions were presented by Printer Pals, rather than the researcher or staff directly, changed the nature of questioning, as the questions were delivered by a third-party object, which was sometimes challenging, but always playful in the nature. We were particularly eager to ensure that people with advanced dementia were included in the social activity, and considered their participation, whether it was listening,

smiling, singing or dancing valued participation and feedback. Through inclusive design practices, we can challenge the perceptions of people with dementia as incapable of engaging with playful and fun activities, opening the space for design in dementia which encourages fun, social connection and competition. Designing for competition, playfulness and emotion can create a broader outlook on the nature of life with dementia, extending the possible aspects of the lived experience to capture within experienced-centered design [17].

6.4 The Use of Technology to Encourage Social Connection

While it is important to consider the unique experience of dementia in how we design, what we learn *from* people with dementia can be translated into more universal design practices. Designing for dementia requires a careful consideration of social environments and dynamics, and how to support opportunities for social agency. Printer Pals was used in this context as a way of bringing a group of strangers together, to create a sense of understanding and belonging in an environment in which few choose to live. Many people find themselves in similar social contexts, such as hospitals, temporary accommodations, work places [14, 26] etc. in which social connections need support to be established and maintained. As is the case of designing for dementia, a focus on technological solutions for the more obvious challenges facing the individual can overlook the social and cultural consequences for those living in socially restrictive environments. In this context, Printer Pals was an opportunity to listen to each other, laugh together and build a form of cohesion as a group. In designing technology to bring people together and co-construct meaning, we can examine what this means for individuals within their social environment, broadening the scope of designing for social belonging.

7 CONCLUSION

In this paper, we presented the findings from the design, implementation and evaluation of Printer Pals, as a means of exploring and supporting the agentic social contributions of people with dementia in the care home environment. Through our findings, it is evident that people with dementia play an active and engaged role within the care home and can be further supported in their agentic abilities through the inclusion in design processes and outcomes which provide opportunities for further participation.

ACKNOWLEDGEMENTS

We would like to thank the residents, staff and volunteers from 'Oakfield House' for sharing their time and experience. This project has been funded by the Irish Research Council (GOIPG/2016/1470) and the EPSRC Centre for Doctoral Training in Digital Civics and Newcastle University (EP/L016176/1),

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