

Exploring Media Capture of Meaningful Experiences to Support Families Living with Dementia

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ABSTRACT

Although designing interactive media experiences for people with dementia has become a growing interest in HCI, a strong focus on family members has rarely been recognised as worthy of design intervention. This paper presents a research through design (RTD) approach working closely with families living with dementia in order to create personalised media experiences. Three families took part in day trips, which they co-planned, with data collection during these days providing insights into their shared social experiences. Workshops were also held in order to personalise the experience of the media created during these days out. Our qualitative analysis outlines themes focusing on individuality, relationships, and accepting changed realities. Furthermore, we outline directions for future research focusing on designing for contested realities, the personhood of carers, and the ageing body and immersion.

CCS CONCEPTS

• **Human-centered computing** → **HCI design and evaluation methods; Empirical studies in HCI.**

KEYWORDS

Dementia, family, care, experience-centered design, virtual reality, media, personalisation, research through design

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1 INTRODUCTION

A growing body of work in HCI focuses on how to best conduct design research in sensitive settings with participants who might be considered “vulnerable” [55]. One of these populations frequently designed “for and with” are people with dementia [10]. Historically, dementia is often represented as a ‘loss of self’ or as a ‘non-person’ [58]; these perceptions, if accepted and acted upon by others, can create a decline in meaningful social interactions [15, 57]. Beyond this, the social roles a person may play can also change after a diagnosis of dementia [4, 33]. People living with dementia can find themselves feeling stigmatised within new roles or of ‘patient’, ‘demented’, and ‘in need of care’ [55]. This can create social exclusion by depriving the person with dementia of their personhood and changing their quality of life [23, 28]. The progression of dementia means that the individual’s role within the family structure can change, as they become the care-receiver, and therefore, the impact of dementia can be troubling for both parties [58]. In particular, social activity can decrease, which entails several “knock-on” effects, such as a decline in emotional well-being, and increased social isolation and depression [17, 37, 61]. With all of these complexities to deal with and bearing in mind the individuality of each person with dementia, endeavouring to design to enrich the lives of those living with dementia may benefit from taking a personalised approach.

Researchers such as Beard, McKeown, and Killick and Craig [9, 26, 45] have considered a number of activities to enhance social interaction including reminiscence, life story work and use of the arts, each of which carries with its own promising evidence base. While these activities can be beneficial as an aid to reminisce and provide opportunities of engagement, for generic media technology it often requires technical expertise for setup or use which can create difficulties for independent use or for caregivers [36, 59], and can sometimes suffer from an infantilised or impersonal nature

[36, 47]. Recent work in HCI has seen how careful design of digital interactions in dementia might instead be supported in order to emphasise the importance of change in communication, rather than the loss of ability to communicate [48, 67].

In this study, three families living with dementia engaged in a piece of research through design (RTD) work to explore the opportunities and challenges of designing enriched personalised multimedia experiences with people with dementia and their families. Each family engaged in a family trip (or a “day out”) in order to capture meaningful moments through photography, 360-degree videos (intended to be deployed through Virtual Reality (VR), and audio. With our RTD aim being to design personalised media captured throughout the day out, we subsequently held a series of design workshops, whereby families worked with the researchers and media designers to curate personalised media experiences from their meaningful moments. Our analysis focuses on the family-designer discussion during the curation process, as a means to draw a contextual understanding of what each family member would like to express and/or experience from captured moments of days out.

While prior works have explored the creation of personalised media experiences [48, 66, 67], their focus has primarily been on reminiscence. Although seeking to place the person with dementia at the centre of the design, they utilized methods that limited the active participation of the person with dementia in these design processes. Our work focuses on personalising media experiences by gaining an understanding of the individual and their ecology of care and placing the individuals’ choices at the forefront of engagement - both the individual with dementia and those supporting them. Through its rich, embedded RTD (research through design) methodology, this paper offers two novel contributions: a) a new model of practice for creating personalised media experiences for marginalised participants, or those with special needs, and b) a series of design findings to direct work in this ever-growing area of HCI, including directions focusing on conflicting realities as dementia progresses, extended ecologies of personhood, and the ageing body in immersive media.

2 RELATED WORK

The following section summarises existing research focusing on people with dementia, and places emphasis on family roles and carers. Beyond this, we also review extant work in immersive and personalised media for people with dementia and their families.

Continuing to Experience the World with Dementia

Traditional accounts of dementia often emphasise its biomedical origins [38]. However, the condition also has significant

social ramifications, and as dementia inevitably progresses, the experience of the world around the person with the condition can worsen [23]. Because of their condition, many people with dementia experience a lack of meaningful interactions, relationships and activities [26, 28, 31]. However, to a certain degree, this is a self-fulfilling prophecy – as we live in a society that places great value on cognitive ability, many believe that people with dementia are poor at social contact, which then prohibits many from interacting with people with dementia at all, in turn [27, 44].

However, in recent HCI research, there has been a push towards care and maintenance of quality of life as opposed to tackling cognitive deficits and other behavioural symptoms [51]. For instance, Morrissey et al. discuss how creative activities, structured through digital means, can help to foster a heightening of subjective well-being, maintaining skills, and providing social engagement [35, 52]. Given the overwhelming focus on cognitive deficits in dementia in design research to date [34], tasks which leverage creativity and expression can be valuable in allowing creative communication. Coupled with this move towards experience-centered, creative technologies, and at a wider scale, HCI research continues to move away from simply designing for people [10], to recognising that those in the community are equal partners in design and research. Work by Wallace uses a tailored design approach to focus on the participant’s own, unique lived experiences of personhood that is separate from the way in which dementia impacts their lives [65]. Wallace stresses the value of understanding personhood in more nuanced ways to design for more meaningful experiences. Similarly, through intersections of technology, reminiscence and Life Story Work (LSW), technology can support the collection of media such as photos, texts, or other memorable artefacts, from the person with dementia’s past [46, 47]. The media can then be used as a method for conversation, reminiscence, and interaction between the person with dementia and family caregivers and care staff.

Although reminiscence often involves pleasant memories that promote enjoyment, reminiscence can cause distress when a person with dementia fails to recognise themselves or others in the media provided [3, 22, 69]. While prior HCI works have developed ‘successful’ reminiscence tools [36, 67], these tend to draw on a stability in long-term memory. We must question whether approaches that rely on the person’s ability to recognise or articulate past events is an appropriate activity to enhance emotional connection. In a similar vein, we might also ask how we could provide opportunities for people to interact with evocative immersive experiences with differing emotional valence. It could be that are not necessarily ‘pleasant’ memories, but are not distressing, and are valid and important experiences with which it may be valuable to interact.

Sharing and Caring with Loved Ones

Family and carers play an influential role in the lives of the person with dementia [68]. Ryan et al [58] explored a sense of a loss of roles for the person with dementia within the family as the condition progresses. As roles rapidly change, responsibilities shift onto other family members, which often results in unwelcome changes in the person with dementia's daily routine. This decrease in control means that tasks — such as paying bills, driving, cleaning the house — are no longer placed onto the individual with dementia. Ryan et al. used writing as a way to reclaim some sense of social identity, structure, and clarity on distinct thoughts and feelings [25]. Furthermore, writing projects a sense of self to loved ones, helping family members see past a relative's dementia and drawing attention to the creative potential of the person with dementia.

In a similar vein, some HCI research has expanded to explored the impact of new technologies on the familial roles can be affected by the advent of new technologies. Vetere et al. [63] indicate ways in which system design for family communication must be flexible, allowing for the expression of different roles in communication which explored playfulness between grandparents and grandchildren over distance. At first, the technology probe mediated intergenerational play through shared displays for synchronous interaction between the children and their grandparents. However, although the technology mediated shared experiences between distances, at times it also caused disruption within the family routines: for instance, children purposely used the tool to avoid less 'fun' tasks such as chores.

Digital technology has begun to offer intimate, emotive communication for family lives, and this has been evidenced in several HCI studies. Chatting's work [14] focuses on designing for family rituals: for instance, by using scent placed into a picture frame of a loved one, connection through ritualistic communication brings forth implicit, personal, and expressive communication as opposed to explicit, goal-oriented, and informative communication. In similar technologically-mediated work, Leong [39] describes the way technology has influenced and changed music as a form of sharing. Leong described Facebook as a 'virtual lounge room' that mediates music sharing through an online audience who can comment, discuss, (dis)like, creating opportunities for sharing experiences and using music to communicate through non-verbal ways. The study indicates how good design can allow people to pursue everyday opportunities pertaining to communication, sharing, bonding, and celebrating their lives with others [39].

As both memory and communicative abilities change in dementia, so too can social opportunities, which can cause

strain on relationships between family members [41]. In order to ameliorate this difficult situation, Maiden et al [42] facilitated a set of co-design activities to facilitate the connection between the carer and person with dementia and resulted in a set of improvements for the aspect of care that revolves around communication, collaboration and interaction. By designing mobile applications to be used by the carers, researchers in this study [42] explored ways carers could log and reflect on their interactions with people with dementia to prompt future improvements in methods for delivering person-centred care. This highlights that personalisation of technology in care homes is important to help support residents with or without dementia, and to enrich their individual care strategies.

Immersive Media Experiences in Dementia

Much digital media research in dementia has focused on stimulating interactions between the person with dementia and the carer, more specifically, to stimulate conversation. As previously mentioned, much of this work has focused on reminiscence through sharing common media from either past eras or family history. Centering an activity around the stability of long-term memory can lead to distress and raised expectations for the person living with dementia who may be unable to meaningfully connect with the activity. Other work that aims to provide a failure-free environment has been exemplified by systems such as CIRCA [2]. The CIRCA technology consisted of a touch screen that displayed music, video, photos and text to support general reminiscence rather than targeting specific life experiences or relationships. The interface was designed such that the individual or care giver could easily progress the media if it was not providing adequate stimulus. Later studies of the system found that users found the touch screen interface encouraging for users with dementia, who were able to use the system with little prompting [36].

As the physical design of our systems moves away from excluding those with different needs, our media experiences similarly need to be accepting of differences. For instance, for such technologies and technologically-mediated experiences to become more than mere tools or functions, they should become part of bodily experience [29, 30, 49]. In writing on embodiment and the use of tools, Merleau-Ponty argues that the cane for the blind person moves away from being an object to becoming an extension of the body's senses [49]. If technology allows someone to perceive an experience, the technology can, in itself, become embodied. Research such as CIRCA places a strong focus on the necessities of recognition and visual stimulation; however, other HCI and dementia research has embraced the person with dementia's continuing bodily abilities. For instance, work by Wallace, as mentioned above, looks at interactive jewellery that is

based on the values and interests of a woman with dementia and her husband [64], and which entails a deeply physical, material and sensitive component.

VR has similarly seen few co-design initiatives in diverse sensitive settings. However, recent research has begun to explore the way the benefits of the immersive quality of this technology, which can be meditative and calming for people living with dementia [24, 43, 48, 52]. While therapeutic use offers great promises, more recent studies has followed using immersive reality technology as an expressive and creative medium that is entirely separate from cognitive assessment and therapy. Previous work in VR for people with dementia has explored how to provide comfortable and enriching experiences [24]. This research highlights several opportunities for HCI work to ensure the “perceiver” as the focal point that drives the experience, and to project their selves through embodied selfhood. Finally, research such as this calls for design that is not burdened by the past or focused on perceived cognitive deficits, but where the person with dementia is enabled to drive the experience in all its richness.

This study progresses from a rich and growing body of work in HCI which has indicated a clear need for sensitivity in design for people with dementia, along with a shifting focus from cognition to embodiment in new technologies. With this in mind, the following section describes our research approach in more detail.

3 METHODOLOGY

Motivated by the aforementioned literature, we set out to explore the role of rich personalised media experiences as a support to families living with dementia. Recognising the ever-changing nature of the familial roles in this context, it was vital that the personalised media experiences could adapt to the needs and desires of the family. Moreover, it was important that these experiences were meaningful to the family – not just the person with dementia. While prior works have leveraged passive algorithmic techniques to curate personalised experiences of memories, we wanted to facilitate active participation of the families to capture authentic, meaningful moments - which has been shown to great effect in work such as Wallace’s, Maiden’s, and Alm’s [2].

Our work was carried out as a piece of (RTD) research through design. RTD is a way of doing research which is the practice of design used to address wicked problems [56], which entail a sense of complexity, and which have no current solution. RTD seeks to address the problem within its current situation and is generally acknowledged to involve end users within the design process in order to result in the addressing of, and reflecting on, problems within the associated design space. The output of RTD is the creation of artefacts, digitally-mediated experiences, and systems,

which are applied to new problems to create new knowledge [5, 19, 70]. The knowledge produced can only be elicited by the creation of these artefacts, which offer a novel and embodied method of knowledge production.

In order to explore the opportunities and challenges of designing enriched personalised multimedia experiences with people with dementia and their families, we codesigned a set of days out with all three families to create enjoyable or memorable moments, which we then sought to capture and document with rich multimedia. We captured these moments using photography and audio recordings, as well more contemporary technologies such as 360-degree video cameras. In order to ensure the captured moments was engaging, we held individual workshops after the days out. With RTD having a focus on addressing problems within specific situations, our study emphasised ecological validity, by placing our research into the settings and situations they would naturally occur: days out in environments which were emotionally meaningful to our participants.

Participants

Table 1: Participant Information

Day Out One				
Surname	Name	Relationship	Age	SoD
Anderson	<i>Lauren</i>	<i>Wife</i>	70	Moderate -
	Michael	Husband	80	Advanced
Beckett	<i>Sarah</i>	<i>Wife</i>	76	Early -
	John	Husband	70	Moderate
Second Day Out				
Clark	<i>Philip</i>	<i>Husband / Father</i>	85	
	Kate	Wife / Mother	85	Advanced
	Jen	Daughter	59	
	Chloe	Daughter	55	

We recruited three families: two married couples, both with the wife living with dementia, and where the husbands had formed a close relationship through attending a support group. We also recruited a family of four where the father was living with dementia. These participants were recruited through a local registered charity (Silverline Memories). One of the services the charity prides itself by, is supporting its members (and their families) with meaningful outings and day trips. Participant recruitment was supported by Sandra, the head of a local dementia café. Sandra also runs many of the activities, as well as organising celebrations for members birthdays and other special occasions. Participant details including stage of dementia (SoD) are listed in Table 1, with all participants who had a diagnosis of dementia italicised.

Participants have been anonymised, organised into their families and structured in order of the day out they took part in.

Family members met with the researchers to organise and plan their outing. As travelling can cause discomfort to many, we hired the driver (Dave) from Silverline Memories who not only gave comfort to the families as he was a familiar face, he acted as a tour guide, which the families appreciated, and found his presence to be enjoyable.

Ethics

Ethical approval was granted by Newcastle University. From the first conversations with the families, we ensured that each participant had a clear idea of what would be expected from them as they were told about the study and were provided information sheets. With the research focusing on enriching the experience of the person with dementia, carers in the family had no problem deciding to participate, as they felt enthusiastic about the research [45]. To verify that all participants were capable of providing informed consent and participating in the research, we carried out capacity assessments, as detailed in the Mental Capacity Act 2005 [54]. These assessments were carried out before the days out, by a member of the research team, who is a trained psychologist with seven years’ experience of working with people with dementia. To further reassure the families, we re-introduced the purpose of the project throughout the day out and in subsequent workshops.

Data Collection

Data was collected in several different stages, detailed below.

Initial Conversations

To begin conversations about participating in the project, we met the families during one of the weekly events at Silverline Memories. We used this as an opportunity to get to know the families, explain the purpose of research, and to ascertain whether they wanted to take part. Family member were then invited to consider the type of locations that held significance and value to them or were simply a desirable destination for a future family outing.

Throughout the day, Sandra introduced the lead researcher to three individual families that had expressed interest in using multimedia experiences to capture moments from a day chosen by the families. Each conversation lasted 15-20 minutes and resulted in a set of field notes. Our conversations with the family involved explanation of the research and what the family would be expected to do as part of the research.



Figure 1: The Anderson Family

Days Out

The days out took place at two different locations located in the North East. Our first day out included the Anderson and Beckett family. As the two families had formed a close friendship over the last year from going to the same dementia friendly community events, they felt it would be comfortable to be part of the same day out together. The two families decided on a **National Trust Site** as this is a place Michael and Lauren had become fond of over the past decade.

Our second day out was with the *Clark* family. From initial conversations, a day at the coast appealed most to them as they grew up by the coast. Through numerous emails, we tailored their day out with Jen (their daughter) by narrowing down the ideal coastal attraction for the family. We concluded on a large village on the coast, with the place holding a lot of family value to them.

Table 2: Data Collection on Days Out

	Audio (Minutes)	Photographs	VR Videos (minutes)
First Day Out	343	311	25
Second Day Out	278	236	16
Total	621	447	41

Each day out was directed by the family to capture their desired moments which was captured with audio recordings, photography and 360-degree videos. Our data collection captured insights into each family’s history, the families’ care for the person with dementia, and meaningful interactions between the family members. (see Table 2).

Workshops

Having captured content on the days out, we then ran individual workshops with each family as a way to consolidate the personalisation and storing of the created moments from their days out. In this workshop, we shared pictures and VR videos in each workshop to give participants a perspective of the day out, and to see the digital moments they had co-created (see figure 2). The first workshop activity was for participants to create and share a salient memory from their past. Our participants were prompted to think of the context, the sensory stimulation, others involved in that memory, and then finally to share the memory with the group. Discussion then focused on how memories such as these could be translated into technological media in order to be able to relive or experience that memory in tandem with others. To structure this discussion of unfamiliar technological interactions, participants used an adapted version of Tiles IoT toolkit [50].



Figure 2: Workshop Activities

Our days out for each family followed a very similar pattern. On arrival of the desired location, families took charge of activities and route to take on foot while we (researchers) accompanied the families. Activities included lunch, walking by the pier, engaging with the history of the place through museums and tourist guides, and conversations of getting to know one another and sharing our own stories within the group. As a family, they decided on the places and moments they wanted to capture through the 360-degree cameras and photographs. Throughout the day, our conversations followed a loosely-structured interview technique where we had a set of questions to address in our conversations, which we sought to address comfortably and naturally as possible through the six-hour long day out between the family and accompanying researchers. We combined the toolkit with cards and activities we created ourselves based on the interactions with the families prior to this, in order to generate

ideas and conceptualise technology interventions based on their past.

Data Treatment and Analysis

With an extensive amount of data in a variety of different formats, we carefully removed insignificant data such as repeated photos and unrelated conversations, and edited the videos to remove recordings of any disruptions to the camera in Premiere Pro. Our data continued to be edited through colour grading, and through the creation of interactive features which participants wanted. One such feature was the “tour guide” requested by Michael. Creating this tour guide interaction meant the stitching together of multiple of the 360-degree videos from the day out and fitting them accordingly with the recorded audio from the tour guide, Kevin. After exporting the file, to make it work on YouTube for viewing, we used a Google tool called “Spatial Media metadata Injector” [21] which adds metadata for VR play.

Our analytic approach followed Thematic Analysis (TA) guidelines in line with the instructions set out by Braun and Clarke, and analysed using NVivo [11]. TA is a method for identifying patterns across datasets that can be very useful when exploring under-researched areas [12]. Our study used an inductive approach to TA where codes were identified from participant’s discussions, rather than being imposed as part of a top-down theoretical structure. The data analysis was conducted by first author, who led the workshops and days out. We reviewed each data item individually, highlighting any items of interest. Our coding and analysis followed a four-step process. Our first step generated codes as labels that captured what we found salient in the data as pertaining to our research question, such as ‘showing humour’, ‘experiencing distance’, and ‘maintaining friendship’. We completed this step with a list of codes, linked to the data relevant to each code collated. Our second round saw us organising the codes into potential themes that had been generated throughout our analysis. In the third step, we started to identify the ‘nature’ of the potential themes and consider if our themes were meaningful in terms of the research question set out at the beginning of the study. Finally, our fourth stage saw us define and name our themes in a way which gave an overall structure to our analytic account.

4 FINDINGS

Our findings centre around three main themes, which have been identified through a semantic approach to analysing the data corpus. Our themes are the following: a) accepting a different reality, b) nurturing caring relationships, and c) honouring the individuals’ choice. Taken together, these themes advance the importance of personalising media experiences for people with dementia and their families in a way which can fully account for the complexities of familial

relationships, and which can also make room for changing experiences and cognitive abilities.

Accepting a Different Reality

At Silverline Memories, the dementia support group follows the philosophy of “[if] the present is all that person has, [then] that is their reality”. As all three of our families were weekly-attending members, they understood the importance of emotional response in the moment as a way of connecting with their loved one that didn’t rely on an intact memory. Although the families show and enact great love and care for their family members with dementia, it can also be difficult for them to accept and engage in their reality as this reality changes in ways which conflict with their own. In our workshops, Michael reflected on Lauren always having had “two constants in her life... her mother, and her dogs”. After this, Michael then described his own sense of conflict when Lauren asks often:

“... is my mother coming around today? You go through time and time again, as gently as you can that mother died 20 odd years ago and that she was cremated, and her ashes were buried with your dad’s, etc.”

Michael’s reminding Lauren that her mother has passed away causes a brand-new grief experience for both her and Michael. The question therefore must be raised whether such a reality should be returned to, rather letting Lauren live in her new reality instead. A similar instance of family members accepting a changed reality was evident in the ways Kate and her family continue to promote and validate Philip’s feelings and ensure to connect with his reality even as his communicative abilities have changed. Philip’s interactions through the day out were originally not very energetic or verbally engaged, but as we got to the end of the day, Philip’s playfulness with his family changed markedly. The lead author’s field notes here indicate that:

“we all sat in the hired bus going to the next and final location, Philip turned to Kate and told her ‘I love you’. Continuing on from his change of showing compassion, he started to play and tickle his two daughters’ necks and ended up prodding me in the side with laughter.”

While Philip’s experience and interaction strongly relies on the family that surrounds him, it demonstrates the importance of designing for supported family moments. The two daughters expressed that they wanted to be able to continue recording and sharing moments with the family as time went on and as their lives progressed. Jen mentioned that she would like to capture other family members, including the ‘little ones’ because “they’re going to change, more than us,

you know, quite dramatically over time, so I think [recording more moments] would be a lovely thing to do”. With the family expressing a wish to capture further meaningful moments, we suggested that we design tutorial guides, assisting the creation of 360-degree videos for their family gatherings. Upon capturing the moments, the family can place their videos on YouTube and create QR codes (see figure 1), which individuals can scan on their phone camera and allow them to share their 360-degree video moments. While time spent with the family can increase Philip’s meaningful interactions with the family, having a family archive of moments could also help to explore ways in which Philip can interact and experience familiar positive memories through hearing and seeing his much-loved family interact with one another [1, 22].

Lauren’s reality is very different to Philip’s. When talking to Michael about how Lauren would react to pictures and VR videos from the day out, he said:

“I don’t think virtual reality will be something that ... I’m going to try with her ... I don’t think that she will have much of a memory about [the day out] at all. I was telling Sandra in a taxi coming over here that last week I took her on a memory day. I took her out for the day because we used to live in a little village in the North called Saxondale. But Lauren didn’t remember anything of it. She couldn’t recognise anything at all, which is very sad.”

Although Michael expressed disappointment with Lauren’s lack of recognition, people with dementia can continue to experience a range of emotions which can express their inner emotions and wishes [6, 7]. To overcome this, our set of media experiences for the family focus less on revisiting past experiences, instead fostering emotional connections through a range of multi-sensory aspects such as VR, and the strategic inclusion of tactile, scented artefacts, such as pinecones taken from the forest on days out, to accompany the media. While the families directed the researchers to take the videos and photographs throughout the day, the videos and numerous photos are structured in a way that most can be enjoyed by anyone, even those who do not know about past events in the family’s histories. Even though family members can be seen in the videos, by capturing 360-degrees, we sought to allow the individual to become the focal point, driving the experience, and giving the perceiver freedom to decide on what they’d like to focus on. For example, one of our films has Michael and Lauren walking through the National Trust gardens, but, in the way the film has been captured, the viewer is given freedom to focus on the ducks in the Chinese pond, or the family (see figure 3).



Figure 3: Different ways to experience the captured moments. A-Chinese Pond and ducks, B-the families together

Honouring the Individual's Choice

Sometimes, a need to protect a “vulnerable” partner saw spouses acting in an arguably overprotective way towards the person with dementia. The below extract, although perhaps minor, shows the importance of honouring the individuals’ choice. The situation came about while we were sat down with the participants for a brief lunch on our first day out. While one of the researchers sat down with Lauren, she asked for milk in her coffee, and with the researcher about to pour milk, the following occurred:

Michael: “She doesn’t have milk...no. She doesn’t have milk. Do you want milk in your coffee? You don’t normally have milk, darling.”

Lauren: “Sometimes I do and sometimes I don’t.”

Michael: “Yes, well, put some milk in then. Go on. Put some milk.”

Lauren: “Sorry. No, I like coffee, but I do appreciate the milk in it.”

Although it was only a decision about milk in her coffee, it highlights the importance of the relationship between the individual and the carer in which the person with dementia should remain as an active partner in their own care [60] and make their own choices as much as is possible.

As we got to know each family in the days out and workshops, the idea of expressing choices in design processes was expressed several times. Bartlett [6] writes that a sense of citizenship in dementia embraces the concept of choice and extends from person-centered care and relational care. By including the individual’s relations with others in the broader social-political landscape, it addresses influences regarding

individual experiences and opportunities to grow and participate in life to the fullest extent possible [6, 30]. As previously mentioned, it is important to allow the person with dementia to express, and exist within, their own perception of reality. In the absence of Michael, Lauren could sometimes seem to the research team to lack a sense of individuality. As they followed the larger group, she said to the co-author:

Lauren: “You take note because I forget which way I come from, where I’m going to.”

Researcher: “Don’t worry. No problem. If we get lost, we’ll get lost together. That’s fine. It’s so beautiful. You’ve been here quite a few times. Is that right?”

Lauren: “Yes. Yes.”

Our media experiences for Lauren are heavily influenced by attempts to honour her choice as an individual, however abstractly it may be phrased. Throughout our analysis, Lauren’s expressions ranged from moments of anxiety like the above, to confident chat about hobbies and interests, from wildlife to the carefully modelled miniature figurines she admired in the national trust site for a lengthy amount of time. To honour Lauren’s choices and preferences, her media experiences focus on the miniature houses and figurines that the family looked at together. Through our day out and workshop conversations, the importance of Lauren’s and Sarah’s relationship became evident to us. Michael recalled their family holiday with the Beckett family, and Michael mentioned that Lauren and Sarah “walked up the seafront hand in hand all the time chatting away. What they talk about, one never knows.” In designing for this new but clearly meaningful relationship, we sought to create a set of videos and photos that are focused on their relationship solely – with audio extracts of their conversations placed over videos we captured throughout the day, including intimate moments between the two showing friendship and respect for one another, acknowledging the other’s dementia and increased need for care.

Nurture Caring Relationships

From early on, the participating families were aware that our intentions were to design media experiences not only for the person with dementia, but for family members too. Through this approach, support in and through relationships for the carer, outside of the care-giver, care-receiver pair, was as important for us as design researchers as the relationships for the person with dementia. For instance, while Sarah and John were interested in, and excited for, sharing experiences with the different forms of media, the couple focused more on the day out itself when talking to the first

author one-on-one. While both felt *‘lucky — [that they’ve] got a social life, which is fantastic for [them]’*, their attention was directed towards their busy social life rather than necessarily needing new ways to approach a shared experience when their experiences were already fun and rich. As John reflected on his and Sarah’s social life, it was evident the media experiences would instead be something they would show others to engage them in situated remembering:

“we’re lucky in that we’re still managing to get a holiday, we’ve still got a social life which is fantastic for us, because we go out on a Saturday night, put the world to rights as you normally do and have good bit of laugh ... then being in Michael and Lauren’s company, just great people, just nice people”

Although John and Sarah still have a good quality of life, the moments they captured may also be useful as Sarah’s condition progresses. John is aware of Sarah’s cognitive decline; saying *“we’re lucky”*, he told the lead researcher that he finds the diagnosis to be *“life-changing”* but finds that *“going to [dementia coffee mornings] is a massive help, because of the social side of things.”* The design of our media aimed to enrich shared experiences; while previous VR work [24] looked at issues of sharing experiences, our media package includes a feature which allows the user to place the 360-degree videos on a separate tablet or a device to access YouTube, allowing the watching of the same experience together, and in turn allowing relationships to be maintained through shared experiences for all those involved.



Figure 4: Sarah enjoying a 1970’s inspired item of clothing

For Michael and Lauren, this situation is becoming dramatically different [53]. As Michael sees his wife within a social context, where she is more socially active and depends less on him, he feels like he is missing out. A common problem caused by close, intimate relationships is the overprotection

and *“doing too much”* for the person with dementia. This can lead to potentially depriving them as being agents who are able to initiate actions on their own self and can contribute to excess disability. As previously mentioned, Michael wanted to share experiences that would place Lauren in experiences that required to articulate past events as their history held significant importance to him. For this reason, our VR experiences tailored for them combines 360-degree videos from their day out with a voice-over to explore the estate and history through the day out. With the videos allowing Michael to express his experiences through recognition, If Lauren chooses to do so, she can join the experience through the exploration of the history of the estate.

From the conversations and notes made in our workshops, Lauren’s engagement in social settings changed markedly depending on if Michael was around. Through our conversations, Michael reflected on her social engagement at dementia coffee mornings, which she attends alone:

“I’m told that she participates, and I’m told that she is much better when I am not there than she is when I’m there ... Very often she has got her hand on Kym’s walker (a friend), walking her down as though she is looking after her and helping her.”

To allow for coherent continuation of Lauren’s sense of self, our design for the media moments focused on ways to support and maintain a sense of self through creating activities that Lauren could use with others outside of her relationship with Michael. As Lauren has a close relationship with Sarah and others from the dementia friendly communities of which she is a part, it is a necessity for the media experiences to encourage shared, meaningful interactions. While this may seem like we are ignoring Michael’s needs, we are instead respecting the whole spectrum of relationships that individuals have within the ecology of care is important. As the media is designed for shared experiences, this leaves it open as an experience that both partners can interact with solely, as a couple, or together with other loved ones to enrich their lives and provide comfortable, evocative experiences.

Our analysis has indicated that the rich ways in which the families captured moments can be combined with careful digital media in meaningful ways and can allow them to express themselves whether that was on their own or with others. This analytic account also forwards a significant role for the personalisation of media for the individual to have an opportunity to experience evocative, comfortable media journeys in nuanced and meaningful ways.

5 DISCUSSION

Our thematic analysis of data from our days out and workshops pointed towards three themes which have been identified through a semantic approach: 1) accepting a different reality, 2) honouring the individual's choice 3) nurture authentic, caring relationships. Our themes indicate areas where media technology can be designed for and be improved. Below, we reflect on our own findings by positioning our work with previous design research and discuss future directions for immersive media experiences.

In our days out, the “directing” and creating of media moments was remarkably engaging for the families, added to the experience of the day, and to some degree, served as conversational prompts. Welsh et al. [67] discusses, in their design of Ticket To Talk, a app to provide conversational guidance in dementia, that carefully designed technology can provide important conduits for social chat in dementia when social partners are unsure what to talk about. By personalising our media experiences to each individual, each family had the choice of using the media as a conversational starter by either using the media to reminisce [1, 22], or by focusing on ‘being in the moment’. While the family cannot experience the person with dementia's reality, through exploring their directed and curated media, the family can begin to understand and reflect on that person's experiences in a way which may allow them to communicate between their experiences.

Our study design aimed to ensure that participation was as meaningful as possible for the families by having them make an impactful choice as to when, what and how the study design was ran. Our attempt to place particular value into making the participants' time worthwhile had an unexpected turn in the gratitude expressed by all three families concerning the opportunities they had to spend a day out with one another, telling stories of the past. Through our design approach, it created a strong bond between the researcher and the families, and helped us reflect on how dementia affected the family in both positive and negative ways. Our closeness to the families then helped to structure important qualities in how we designed technology for each individual.

We intended our media to honour the individual's choice which, overall, aimed to respect the person with dementia's agency, and allow expressions of selfhood which they may have lost as their diagnosis progressed [8, 58]. For Lauren and Michael, Lauren's daily routine was often set in a very rigid way by Michael, which left Lauren with few opportunities to confidently express herself outside their relationship. In a conversation about the activities they partake in at the dementia friendly communities, Michael reflected on how Lauren “participates [when Michael isn't around], and is much better when [Michael] is not there than she is when [he's] there

”. By creating media experiences for Lauren to share with her Sarah, her friends or even on her own, we set out to help her re-claim, even in a small way, roles and relationships, or aid in the gaining of new ones [58]. It is also possible to imagine how the sharing of the media moments could be further improved by adding other opportunities for multiple people to explore together. For example, one person could experience the moments through a VR headset, while another uses a connected tablet that would allow them to engage with the narrative or change what the VR user could see.

Finally, it's worthwhile to reflect on the challenges and opportunities for how we involve people with dementia in research. In prior work, dementia and design research has focused on cognitive deficits, which positions the cognitive impairment at the forefront of the research rather than the personhood of the person with dementia [23, 40]. Recent HCI research has since moved to a recognition that those in the community are equal partners in design and research. As this shift occurs, researchers have begun to reconsider existing approaches of how we engage and interact with participants. Previous work has seen design research in care homes, or in-depth studies in family homes, which have been carried out with great designedly empathy and care to place the person with dementia at the centre of the design research [18, 35, 52, 65, 67]. However, we argue that there is a new space to occupy that focuses on shaping the research study around the individual participants who are involved — one which does not place studies in a lab, or co-create on the participants' behalf, but instead facilitates active participation of the participants.

Future directions in designing immersive media for sensitive settings

Our final section lays out three future directions for design work to design for people with dementia and others who face similar challenges in the context of personalised interactive media experiences.

Designing for contested realities

It is clear from the above work that participants with dementia can slip in and out of realities which can then be contested by those around them, who struggle with these conflicting accounts of reality. Our analysis describes how Michael struggles sometimes to orient Lauren to reality, creating new experiences of grief when she is told, time and again, that her mother is dead. This echoes work by Morrissey et al [52], who describe a care resident who seems to “enter” musical media that she is presented with:

As the song finished, she would applaud loudly and wave to the smiling singer on-screen, blowing kisses . . . , she began to tell me that she and the singer were friends. ‘He came to

visit me last summer,' she said. 'His wife is a lovely woman.' The delusions and hallucinations which come with dementia are often listed as a negative characteristic of the disease; here, however, they acted as a way for Maggie to both make sense of her experience retroactively, as well as a conduit into media that clearly gave her a sense of pleasure.

Orienting the person with dementia towards the “right” reality has very little effect; if the dementia is sufficiently progressed, the person will simply forget this reorientation again. It is also considered to be poor practice [16]. It is imperative to remember that a sense of self can come from more just our ability to recall and recount memories. Working with people with dementia in a sensitive way should push us to reflect on the structural challenges of understanding the reality of the person living with dementia and designing for this often ‘dreamlike’ state, depending on the stage of dementia [13]. With this in mind, **we should consider what it means to design media experiences for realities which may eclipse each other briefly rather than conflict with each other entirely.** In a similar vein, although our work has indicated how activities taking place outside can be captured via media, we must stress that this is no substitute for going outside, or for care homes to replace (for instance) gardening or nature walks with virtual realities of the same. Actually engaging in such activities has multiple psychological and physiological benefits [20] – we should instead begin to think about how both activities can overlap and eclipse each other: for instance, participants could collect rocks from beach walks – these are easily fitted with RFID tags which, when touched or otherwise triggered, lead to a change or simple interaction in the immersive environment.

Every person has personhood

We designed our media not only for and with people with dementia but including their family members as well. This is in contrast to other studies in HCI and dementia, which tend to focus on the person with dementia as the recipient of the designed object or technology. When carers are designed for/with, the technologies are typically more focused on duties of care. In spending time with the carers as much as we did the people with dementia, and with our focus on memorable and pleasurable activities, our media often included snippets from them which related to their own interests or lives apart from the person they cared for. In one meeting, Michael is swept away in retelling a drinking and hunting tale from his past which focuses on his own inchoate experiences, not those experienced solely with Lauren:

We ended up in a little village called Farnworth. And in Farnworth there's a stream that runs through it. There is a road bridge, and underneath the road bridge, there is a deep

place where you can get your horse in and you can wash all its legs off and get all of the mud off the bottom of it. Then ... [a lady] went right under, which of course was hilarious to some of us who were still slightly uninhibited. But I can see the whole thing in my mind. It was just a fun day. It's all down to 150% whiskey spirit.

In preserving this vividly-recalled memory through including it in the audio package received by the family, we sought to value the ecology of care around the person with dementia as well as the person themselves. In dementia, our close and familial relationships can be constitutive of our selves [64]. With many carers reporting high levels of burnout and burden [62], and, as we have seen in the above work, **targeting carers as research participants worthy of digital interventions focusing on personhood (as much as we target those with dementia) means treating them with respect, and as whole persons, rather than defining them by their roles.**

The ageing body and immersion

As mentioned in our findings section, several of our participants reported feeling a lack of confidence when getting out and about, due to the progression of their dementia. As we age, our body typically degrades as well, and people with dementia are often “reduced” to the bodily as their communicative abilities change and they move into care. Kontos describes much of the life of nursing homes in terms of their embodied potential – for instance, choosing to dress in certain ways, participating in the sleep-wake cycle of nursing homes, the attempts of care workers to transform (via various methods) residents into ‘docile, dementing bodies’ [29, 30]. However, through embodied actions, residents can retain and communicate a strong sense of selfhood:

The Health Care Aide tried to give Molly another spoonful of cereal, but Molly pushed her hand away as she established eye contact with each of the others at the table to acknowledge their presence. Then reaching her wavering hand to the back of her neck, she struggled to pull something from underneath her bib. Extending her arm appeared to cause her pain and discomfort and yet she persisted. Molly eventually revealed a string of pearls she was wearing that had been covered by her bib. She allowed the pearls to pass through her long slender perfectly manicured fingers placing them ever so delicately atop her bib. With this simple gesture, Molly emerged from her world of decrepitude, incontinence, dementia and helplessness as a woman of grace and style [32].

Kontos positions the body as a site for knowing the world – which can be fruitful when we consider designing media experiences for people living with dementia. As evidenced

above, Morrissey describes how a care resident in her study moved bodily to music; additional work by the same authors describe the rich power of touch in dementia when mediated by sensitive, experience-centred design interventions [52]. In seeking to design media for people with dementia, **we should therefore consider how we represent those ageing bodies.** Do we preserve physical ailments and disabilities that often accompany dementia when, for instance, we design immersive or virtual realities for them? Progressing in this area will mean careful co-design intervention that pays attention to the bodily as a means to communicate just as well as the verbal.

6 CONCLUSION

This paper provides a detailed account of careful, situated design of personalised interactive media for people with dementia. We worked with three families who attended a local care charity to co-design personalised days out, where we captured moments of the family's experiences by recording photo, audio and 360-degree videos. Our analysis of data collected during these days out produced three themes: accepting a changed reality, nurturing caring relationships, and honouring the individual's choice. We proceed from this analytic account to offer recommendations concerning contested realities, the personhood of carers, and representations of the ageing body in immersive media. By adopting an RTD approach, our study considers how the sensitive capture and curation of digital media can help to keep experience alive for participants with dementia who might seek to experience such media "in the moment", in shared social contexts.

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