Empathy, Participatory Design and People with Dementia

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ABSTRACT

We describe the development, application and evaluation of a design method tailored for working with people with mild to moderate dementia. Our experiences with the approach highlighted areas where designers and participants held radically different views. The tenet of our approach was that to overcome these differences we needed to create an empathic relationship between participants and designers. To achieve this we modified participatory design techniques to foster respectful engagement with participants in the development of a digital aid to facilitate 'safe walking'. The process begins with broad qualitative scoping and design work then moves to developing personally tailored, individual designs to further exploration of the experiential elements of the domain while reducing the need for the participants to engage in abstract thought. Reflection highlights a number of important areas that demand consideration when undertaking research in this area and, more generally, when performing design work with people with dementia.

Author Keywords

Dementia; participatory design; empathy; experience; prompting; cognitive impairment.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

The aging population is one of the defining characteristics of the 21st century [26]. Although widely regarded as a positive trend, with the increase in life expectancy comes with an associated increase in the number of age-related health problems. Amongst the most significant of these is dementia [28]. By 2030 it is estimated that more than 65 million people will have some form of dementia [28]. The mental functions of a person with dementia deteriorate over a period of months or years to the point where they require constant care to perform basic activities of daily living. This is provided by either a professional or informal caregiver. The burden on caregivers' time, effort, and resources can be

enormous [21] and, for many informal caregivers, leads to considerable distress as they witness firsthand the debilitative affects of dementia on their loved one.

Appropriately designed assistive technologies can help people with dementia to maintain their independence for longer and their caregivers to provide more comprehensive care. However, designing appropriately for this group is challenging [11]. Human-computer interaction research places an increasing emphasis on designing for peoples experiences with technology [30], but when designing for people with dementia there is a tendency to focus on the impairments that characterize dementia at the expense of the experiential consequences of design choices. There is a need to also understand the person with dementia's point of view in order to design technologies they will use [24], as Keith and Whitney say *"people are not just the sum of their acquired impairments"* [12].

However, even if a designer accepts the need to be attentive to the experiential consequences of their designs, there is still an enormous gulf between their life-experiences and those of people with dementia. In designing for the experiences of people with dementia, a designer's intuition can drastically mislead them [11] and there is a clear need to bridge this gulf in experiences. Kitwood [13] was concerned with the neglectful culture in dementia healthcare work in the UK, how one could understand the experiences of a person with dementia and ensure they are afforded the respect they deserve. His process of "person centered care" (PCC) focused on respecting the "personhood" and experiences of the person with dementia and understanding that, while their experiences might arise from irrational perceptions of the world around them, for that person those experiences are just as significant as they are for a cognitively unimpaired individual. PCC requires extensive, respectful dialogue with the person being cared for and aims to foster an understanding of their experiences on the part of healthcare professionals.

This paper aims to be a starting point for understanding how empathic relationships can be used to bridge gulfs in experience. While our goal s not to introduce new *methods*, we give details of our approach to framing participatory design to create empathic relationships between participants and designers. We document our experiences of applying this approach to the design of a 'safe walking aid' and present our insights into working with people with dementia in participatory design process.

DEMENTIA, EMAPTHY AND PARTICIPATION

The values espoused by Kitwood are similar to those proposed in *empathic design* [25]. Wright and McCarthy identified three qualities that are central to developing an empathic relationship with participants in design: (i) a quality relationship between the designer and the user that allows the designer to be attuned to their needs; (ii) a sympathetic disposition towards the user; and, (iii) an attention to the affective and emotional quality of their experiences [29]. These need to be realized through a specific design approach. We used participatory methods because: (i) they democratize the design environment [18] mirroring the respect that Kitwood suggests is needed to understand people with dementia's experiences [13] and; (ii) the close contact that they require between the designers and participants, which has that potential to foster the empathy that Wright and McCarthy propose [29].

However, participatory design methodologies originated in workplace contexts as part of the effort to democratize the introduction of new technologies in Sweden in the 1970s. Due to this, many participatory design techniques make inherent assumptions that are not immediately applicable to the daily lives of people with dementia. For example, participatory design techniques assume that there are specific tasks to be understood and designed for, that there are a range of experts that need to be engaged in the design, that the focus is work and productivity, and that the participants are cognitively able. This means that specific techniques within participatory design do not necessarily translate to being used in social contexts, or where issues of experience dominate those of function. However, participatory approaches have been modified, for example, "Empathy probes" [16] are a participatory design approach that promotes a holistic understanding of day-to-day experiences. In addition, there are several examples of participatory techniques being used with older adults [15] and with younger cognitively impaired people [31].

Beyond insights into the experiences of people with dementia, empowering them through engagement in design has the potential to alter the ways in which we think about the role of technology in their lives. Typically, it is the caregiver who is the source of information in the design process [20] and people with dementia are not engaged directly [27]. Consequently, commercially available assistive technologies for people with dementia generally have a *safety focus*. When people with dementia are empowered through being given a voice in design, this has given rise to designs that address social interaction with others [6], facilitate reminiscing about their past or that help the person with dementia maintain their autonomy through support for activities of daily living [9].

The caregiver is not a suitable *substitute* for talking directly to people with dementia. Previous work has shown there was a gap in the requirements generated by caregivers and people with dementia [20] and found that family caregivers do not accurately represent the needs of their loved ones [5]. However, despite caregiver bias, interactions with them were still informative. We need to talk to both people with dementia and their caregivers; but need to engage with caregivers' responses critically if we are to design appropriately for people with dementia.

Empowering people with dementia through design also has practical benefits. When safety-oriented systems are imposed, people do not recognize their utility and tend to be less patient or willing to use them [20]. Even the design of safety oriented technologies can benefit if they can be framed as "enabling" rather than disempowering or dehumanizing. For example, members of the Alzheimer's Society are optimistic about the role that electronic tracking technology can play in the lives of people with dementia because of its potential to let them reclaim the ability to walk safely [1]. However, further work must include people with dementia and caregivers to avoid the tendency to focus on safety oriented technology. In this way, technology can empower the people with dementia rather than simply addressing their impairments.

THE KITE PROJECT'S APPROACH TO DESIGN

The KITE project's design approach engages people with dementia in participatory design. Specifically, the process (Figure 1) aims to foster an empathic relationship between designers and people with dementia by demanding close, respectful contact. The approach focuses on trying to develop a holistic understanding of people with dementia's day-to-day lives and acknowledges that there is likely to be a wide gulf between designers' and people with dementia's life experiences. To address this, the initial stages of the process elicit participants' accounts of experiences relevant to the domain and allow a shared understanding of the domain to develop which can be built upon in later work. In a final, iterative stage the design approach works with individuals to produce personally tailored prototypes that reduce the need for abstract thinking (which can be challenging for people with dementia) and allow an in-depth exploration of individual's thoughts and experiences with the prototypes.

Bridging Divides in Experience

The main tenet of the approach used in the KITE project is creating an empathic relationship between the designers, people with dementia and caregivers. Fostering a sympathetic, empathic disposition on the part of the designers will develop an environment in which people with dementia can speak openly. The attitude of the designer towards the participants is central to creating this relationship. We propose that, for designers to be able to understand the perspective of people with dementia, they need to uncritically accept and engage with the accounts put forward by the participants with dementia. We suggest, as Kitwood did [13], that the factual accuracy of a person's narrative is secondary to what it reveals about their own experiences. Ultimately, the designer comes to the person
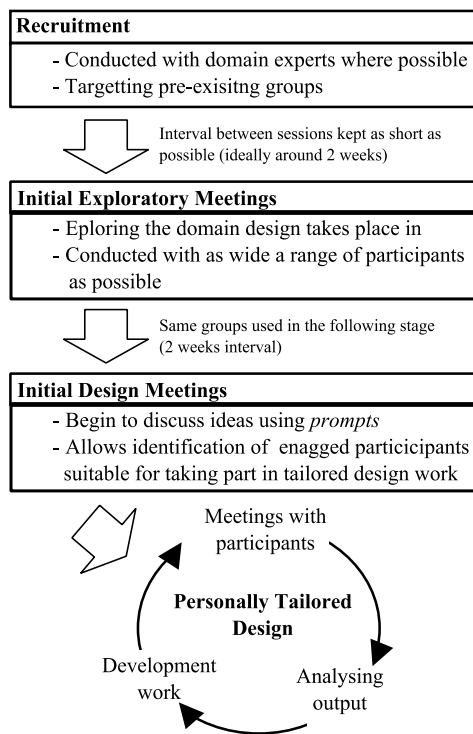
Recruitment
- Conducted with domain experts where possible - Targetting pre-exisitng groups

Interval between sessions kept as short as possible (ideally around 2 weeks)

Initial Exploratory Meetings
- Eploring the domain design takes place in - Conducted with as wide a range of participants as possible

Same groups used in the following stage (2 weeks interval)

Initial Design Meetings
- Begin to discuss ideas using *prompts* - Allows identification of enagged particicipants suitable for taking part in tailored design work

Personally Tailored Design

Meetings with participants

Analysing output

Development work

Figure 1. The KITE approach showing early scoping work and the later, iterative personally tailored design cycles

with dementia in the hope of learning from them. This explicit approach lets participants know that they can state what they feel without the need to justify or defend it.

Achieving this requires designers talking to participants in a way that is clear and free of jargon. The act of sharing experiences and analyzing and developing designs should lead to the development of an understanding of the domain shared between all the design session members. Where possible, the terms that are used by participants need to be used by the designer in facilitating these discussions, (i.e. not the language of the designer). We refer to this as creating a *common frame of reference*.

Addressing Issues Arising from Cognitive Impairment
When they were created, many assumptions were made about the environment in which participatory design techniques would be applied in and the people that would involved. There are several strategies we adopt throughout our process to alleviate issues that arise where these assumptions intersect with cognitive impairment when engaging people with dementia in participatory design. Incorporating *review* into the structure of the meetings focuses attention, ensures that the design team's interpretation of what the participant says is accurate and helps the participants remember the discussion later in the process [23]. This requires the creation of extensive documentation throughout the process. The act of cementing user concerns into this documentation – whether in the form of writing down a note, making a point for a recording device or altering a paper prototype – serves to

focus participants' attention and ensures that concerns are voiced more readily should a participant feel that a point is being made erroneously. If all the participants are consulted at this point, the act also ensures everyone has a chance to voice their opinion and this allows the discussion to move to a new topic by giving a clear indication of the closing of the previous topic.

In our approach, each group will be involved in at least two meetings so as to reduce confusion the meetings will be facilitated by the same person, a *consistent point of contact*. The consistent contact is the closest member of the design team to the participants and will gain the greatest insight into their experiences. The consistent contact can also introduce other members of the design team into meetings with participants, allowing their voice to be heard by, and directly influence the rest of the design team.

Articulating personal narratives can be challenging for people with dementia. The use of *existing groups* can help the individuals articulate themselves. Many people with dementia regularly attend support groups (typically run by voluntary organizations) to help them learn strategies to cope with problems they may face and to provide a venue to talk with other, sympathetic people who understand the challenges they face. Support groups are an ideal place to recruit existing groups as they are a normal venue for the discussion of personal problems for people with dementia. Talking to established support groups leverages existing dynamics within the group (to provide mutual support) and the trusted environment (in which participants feel safe discussing sensitive issues). This approach builds on the underlying focus group concept: that the interplay between the participants can generate new data [7]. This effect can be enhanced by conducting meetings in *familiar environments* in which participants are more likely to feel at ease [8].

Caregivers can also provide support for the person they care for in conversation, when a person with dementia struggles to articulate themselves their caregiver can often help them. However, caregivers may be able to articulate themselves more easily than the person they care for, and therefore it is important that the designer ensures that the caregivers' voices do not dominate discussions. An important role of the consistent contact within the KITE approach is to balance the voice and concerns of the caregiver with the voice of the person with dementia.

At each of the initial stages, one group that exclusively involves caregivers shall be conducted. Talking with caregivers in this way allows the identification of areas of conflict or inconsistencies between their accounts and those put forward in the other groups by people with dementia. These conflicts highlight areas where design work might be focused and helps designers infer which issues that arise in design sessions may be more relevant to caregivers [5,20].

Previous work has highlighted the benefits of working with people with *milder levels of cognitive impairment* as opposed to working with people with severe cognitive impairment [31]. Although conducting a review of the severity of someone's dementia would be impractical, the venues through which people are recruited, and the participants themselves, can provide an indication of the severity of their dementia. As a general rule, support groups for people still living independently are likely to include people less severely impaired than day care centers for people with dementia, which in turn will include people less severely affected than those in dementia care homes.

Identifying *appropriate stakeholders* is a critical part of any participatory design process. The process needs to engage with caregivers as well as people with dementia, engage with people with milder dementia where possible and work with existing groups. These people can be contacted through charitable organizations, support groups, and day care centers. The involvement of professionals with experience of working with people with dementia is particularly helpful at this stage because they can provide insights into stakeholder identification and the avenues for recruiting participants.

Transcript Analysis

Analysis is not the preserve of traditional participatory design practices as participants would usually be more directly involved in the construction of explicit requirements (for themselves and the designers). However, we transcribe all meetings with participants and use a Thematic Analysis [4] of the transcripts to allow designers to engage with the people with dementia and their caregiver's narratives and provide clarity, through reflection on an accurate account of the meetings in the event that a person with dementia cannot clearly articulate their thoughts or experiences due to cognitive impairment.

The analysis begins with identification of interesting or significant sections of the transcript and highlighting, or 'coding', them. Groups of codes with a common underlying theme are identified is a second reading and are grouped into themes. Themes are then grouped into categories which will include all coded sections related to them. Under the hierarchy of concepts and categories, coded work can be re-examined and theories about the domain constructed. The themes and concepts, which the analysis draws out, need to be validated by the participants before they are accepted by re-presenting the themes to them.

Initial Exploratory Meetings

Exploratory meetings develop a broad understanding of living with dementia and establish a common frame of reference for the consistent point of contact and participants. The aim of these sessions is not to imagine new designs so discussion of technology should be limited to accounts of previous encounters with it. As many people with dementia and caregivers as possible should be engaged at this stage. Each meeting will last between forty-five and

ninety minutes and should ideally involve 3-6 people with dementia and their caregivers or 6-8 caregivers [2]. Our experiences showed that in practice numbers cannot be precisely controlled.

The meetings follow a focus group structure, questions are left open in order to stimulate discussion and allow co-questioning to emerge in the process [7]. Co-questioning, when participants ask each other questions rather than the facilitator leading discussion, is particularly valuable at this early stage in the process as it leads to questions that a facilitator who is unfamiliar with the domain might not think to ask. However, meeting facilitators should be prepared to start discussion so research into the design domain should be done to help in the construction of a *topic guide* for the meeting that outlines relevant topics for discussion. The Thematic Analysis of these meetings gives the designers ideas about possible technological interventions. In the next stage of the process the design team will have the chance to feed back their analysis to participants through the *prompts* they select.

Initial Design Work

The aim of the initial design work is to elicit participants' reactions to the designs proposed in response to the Thematic Analysis of the exploratory meetings. Workshops are conducted with the same groups that participated in the exploratory stage. These workshops use the brainstorming technique [23] to generate large amounts of raw ideas. These meetings begin by reviewing the analysis of the previous meetings to focus the attention of participants onto the topics being discussed and to validate it. This also reinforces the common frame of reference for the meetings. The meetings move on to discuss initial design concepts created based on the analysis.

Previous work has noted that many older participants struggle to envision new technologies or discuss intangible issues [15]. To help with this, the consistent point of contact will present a range of physical artifacts to the participants to *prompt* discussion. These devices are chosen to be physical representations of design concepts. The physical devices serve as tangible prompts that remind the participant what is being discussed. A wide range of artifacts should be presented allowing participants to lead the discussion by selecting the ones they want to discuss. Groups with caregivers are presented with the same technologies and asked to envision their own devices. They are also asked about the sorts of devices that their loved ones might carry and their functionality. These sessions are recorded and transcribed and the analysis is used to distil the output of these sessions into problem descriptions and requirements that the design team can respond to.

The most important outcome of these meetings is the identification of participants who are suitable to continue working with. These are participants who are engaged in the process, identify with the problem area and are in some way invested in addressing it. They will be asked to take

part in personally tailored design exercises. In addition, designers should also gain ideas about what sorts of designed interventions are appropriate in this domain.

Personally Tailored Design

The personally tailored design work focuses on developing the relationship between participants and designers through the process of creating individually tailored prototypes. We work with individuals as it is not feasible to create tailored prototypes for all the participants. In addition, the personal nature of the work (addressing the participants own lives and individual problems) can reduce the barrier to envisioning new technology that older adults struggle with [e.g. 15] by reducing the need for them to think in abstract terms. For example, they no longer need to think in generalized terms about the ways that a device might be used or try to imagine what it may look like. The quality of the relationship at this stage should improve designers' understanding of the participant's experiences and the design domain, and allow more critical debate in the meetings to help designers further their understanding. The production of such personal designs might be considered by some to limit the generalizability of the final design; however, others argue that , while the devices produced may not be generalizable [3], the personal approach gives more in-depth insights that can inspire ideas that better generalize to a wider group [10]

This stage follows an iterative approach, with the development cycling every 3-4 weeks with a focus on producing new designs or prototypes to be presented to the participants. This allows them to see that they are having an impact on the process and how their input is being interpreted. These sessions involve prompts in the form of new design objects, storyboards and paper prototypes that help the participants envisioning novel technology. The focus on their own very personal experience of living with dementia contributes significantly to their engagement and, when coupled with the frequent meetings, reduces the chances that topics discussed in one session will be forgotten by the next. The information gathered in these sessions is combined with the information taken from the wider selection of people interviewed in the exploratory stage to produce the design artifacts and, eventually, prototype devices for participants to use. There are a variety of techniques that can concrete user issues in these design sessions and gather more information from the participants. Physical objects are central to these techniques as they play to the strengths of older participants [15].

Storyboards promote discussion around participants' routines, a designer creates storyboards showing how they perceive a typical day in the participants' lives. The participants fill in dialogue and thought bubbles to indicate what they would be thinking about in the various scenes to allow designers to introduce a sense of context to the design of future devices as well as to get at the routines of the participants. *Paper Prototyping* design activities allow the

user to show their ideas on paper. The sessions require a degree of creative engagement (problematic for individuals with cognitive impairment [31]) but allows participants to express themselves through a new modality which may be easier for them to communicate in. These sessions also focus discussion on the problems that the participants have using specific features in relation to their own personal issues. Both approaches allow notes to be tied to visual cues for individuals' reference and places focus on a physical artifact. *Functional prototypes* allow users to evaluate designs by letting them use it in their everyday life. This removes part of the conceptual element of the design process and gives them something very concrete to critique, playing to their strengths in design work [15].

EXPERIENCES WITH THE KITE METHOD

The KITE project design work examined the potential for designing a digital intervention to promote safe walking for people with dementia [22], i.e. walking outdoors unaccompanied by a caregiver with minimal risk of becoming lost or experiences of anxiety. Being able to walk safely has many benefits including reduced reliance upon caregivers, exercise and helping to promote a sense of personhood. However, safe walking activity is threatened by wandering behavior. Wandering behavior is difficult to define but can generally be characterized as occasions when a person with dementia walks somewhere but is not motivated by a specific goal, or is motivated by one that is not rational. A precise definition of wandering is problematic because it has to take into account a wide variety of causes and resultant behaviors [14] ranging from rational movement in the service of non-rational goals, to non-rational movement in pursuit of rational goals.

Stakeholder Identification and Recruitment

We worked with a Social Gerontologist (SG) and General Practitioner (GP) to identify and recruit appropriate stakeholders. They were able to identify suitable venues to perform recruitment and leverage existing contacts with two charitable groups: the Alzheimer's Society (AS), a UK based charity that performs advocacy work for people with dementia and runs support groups. We also worked with The Dementia Care Partnership (DCP), a not-for-profit group that runs day care centers for people with dementia

Workers in these groups were contacted and, because they were familiar with the SG and GP, were happy to engage with us. They discussed the project to get a thorough sense of its aims before offering to approach support groups for people with dementia and caregivers to gauge their interest in the project. The support groups were pre-existing, close-knit, tending to make their decisions as a group, and discussed our proposal in their meetings. At this stage the project was presented as looking at "getting out and about" when someone had dementia with terms felt to be more intimidating, like "wandering" and "participatory design", being avoided because it was felt the might be intimidating. The team was aware that there would be an issue if some

members of the groups wanted to take part and others did not. Given how important these regular support meetings were to the people involved, we felt it was unethical to risk disrupting the groups. Our decision was to only work with groups if all the members agreed to participate. In practice we found that the collective decision making of the groups lead to them reaching their own consensuses on participation.

Initial Exploratory Meetings

The participants from AS1-4 (Table 1) quickly engaged with the idea of "getting out and about" and had many stories about their experiences. Distinct themes emerged around the role of *anxiety and confidence* in getting out and about that related to either the curtailment of walking alone or the need to not allow fears to get in the way, as one female participant said: *"just get on with it"*. This discussion highlighted the *tensions* that emerged between people, one male participant said: *"the family really, they're frightened, you know, but I'm not"*. *M*any caregivers talked about an *incident* that changed their attitudes towards the person they were caring for *"after that, if I went anywhere, he had to stand beside me you know"*.

When discussing strategies for dealing with the threat of becoming lost some participants *used low fidelity solutions: "I always made sure that in his wallet, he had his name and address, as well as our phone number"* A lot of discussions centered on the use of *technology*. Many participants owned mobile phones and at least one male participant had used one when lost *"right, I'm such and such a place, where are you? You stay there and I'll come and find you"*. However, most experiences and opinions of technology were negative: *"once you reach my age, you are faced with something electronic, you would ignore it"*.

There was a lot of concern over the *stigma* that might be associated with carrying devices to help with becoming lost *"if somebody sees you have a card or something, they think well, I'm stupid you know"*. Some people felt the mobiles needed to be *discreet* so they wouldn't make their carriers targets for criminals *"you'd find they'd be getting mugged for it"*. Our understanding of the domain was that the

Group	Caregivers	People with Dementia
AS 1	2 Volunteers	2 People with dementia
AS2	2 Caregivers 1 Volunteer	3 People with dementia
AS 3	3 Caregivers	4 People with dementia
AS 4	6 Caregivers	None
DCP 1	1 Caregiver	5 People with dementia
DCP 2	None	2 People with dementia

Table 1. Group profiles engaged in the process.

participants wanted to walk outdoors but didn't because of a fear of wandering (or getting lost as they usually termed it). They needed a system in place to provide reassurance and improve their confidence.

Initial Design Work

We worked with AS 1, AS 2, DCP 1 and DCP 2 to develop initial design concepts. The AS participants were still living independently but the DCP participants were not and struggled more with the design process. Nevertheless, they still identified with the concept of "getting out and about" and engaged with the ideas from previous sessions and the AS groups were starting to develop a rapport with the consistent point of contact.

The concepts developed in response to the issues raised in the exploratory meetings were presented through a set of *prompts*. An *iPod-nano* was selected to prompt discussion around futuristic aesthetic as we felt participants would feel it was intended for a younger generation. *Digital Jewelry* [19], a custom made piece tailored to an individual¸ was intended to demonstrate to participants that technology did not have to look like a mobile phone or a computer if they did not want it to. The desire for *discreet* devices also seemed to be important to many participants, and both the *iPod* and *digital jewelry* were relatively small. A *Nokia N95 Smartphone* served the purpose of provoking discussion around using Smartphone's as they would allow self-orientation through their GPS and could call a caregiver if help was needed. The *PDA* was intended to spark discussion around touch screen interaction with devices. Demonstrating how a *TomTom* worked was intended to introduce the concept of location aware technologies. Finally, a *Tracking Bracelet* and *Fall Alarm* were intended to promote discussion of tracking and alarm technologies.

Distinct themes emerge in these meetings, the need for devices to be *specific to individuals* was important because individuals' circumstances were so varied. This can be realized through performing personally tailored design. Integration into *routine* was another important aspect of day-to-day life that was identified as determining if a new device would be accepted. This is of note because it is almost a direct articulation of our underlying motivation for carrying out the process: to tap into participants' day-to-day experiences. The participants felt that they used routine to cope with many issues they faced and that new devices would have their benefit weighed up against the cost in terms of disruption to routine. Finally, people identified the main threat to safe walking as *anxiety* about becoming lost and there was *speculation around device function*. These related to three steps taken when lost: self orientation, asking for help and summoning help. There was a distinct lack of discussion around the ethics of tracking with no one taking issue with the concept of tracking people in these sessions. This suggested we needed to develop our relationship with the participants so they would feel more confident working with us in the personally tailored design

stage and be more prepared to criticize the designs we proposed.

Personally Tailored Design

Two members of AS2 were particularly engaged with the ideas being developed: Alice lived on her own, with mild dementia, and John showing signs of early onset dementia and his wife Mary. They were chosen due to the mild nature of their impairments, their very different personal circumstances, and their enthusiasm for the process. John and Alice wanted to maintain their independence; John was a keen runner, and Alice still regularly drove alone to the shops or to visit friends. John had been diagnosed with dementia two years ago but Alice had only been diagnosed recently and both behaved in ways that were consistent with someone with mild dementia. John occasionally displayed some confusion in meetings and both Alice and John struggled to remember past events including discussions from previous meetings. John lived with his wife whilst Alice lived alone, this opened up a field of inquiry that, until this point, had not been drawn out of the work: what the designs could do if no caregiver was available. John did not have any other medical conditions but Alice had arthritis and a problem with her ankle that meant she struggled to manipulate small objects and used a walking stick. Alice and John talked at length about the importance of routine in their lives including its significance when remembering to carry things with them when they went out and remembering to charge mobile phones for later use.

The first personally tailored design meeting presented sketches of designs to participants illustrating a variety of ideas. The second meeting focused on storyboards and eliciting ideas about routine. At this stage, Alice started to express that she would like to be tracked, even if the person informed in the event of a problem could not be established. The debate in the meetings was becoming notably more animated and when the team proposed putting a tracking device on Alice's walking stick (that previous storyboarding revealed as central to routines when leaving the house), she vigorously argued against it. At first Alice could not articulate why, but eventually she revealed it was because she had *"a hatred"* for the stick (*"the blasted thing!"*). Alice had hoped her device could be something she was proud to show off to her friends and placing it on her walking stick, which had the opposite emotional association, was not something she would countenance.

The third meeting focused on trying to paper prototype the interface to the devices and the final meeting presented final prototypes (Figure 2) to the participants. The final prototypes constantly reported their position to a central server that could be interrogated online through a mobile interface. Both devices had a panic button that could be pressed to send a phone call to a pre-determined mobile phone. If the signal was not acknowledged, it could be propagated to other devices. The aesthetic of John's prototype mimicked a runner's arm-band-mp3 holder to

Figure 2. Alice's notebook (left) and John's running band

disguise its tracking functionality. Alice's device was built into a leather bound notebook with her initials embossed on the front. While the size of the device was still an issue for Alice, John liked his device and was happy to carry it on a test run with him after our fourth meeting. He was enthusiastic about the device but still had some small criticism to offer with regards to simple usability issues such as placement of buttons and feedback from the device.

DEMENTIA AND EXPERIENCES WITH TECHNOLOGY

The final designs illustrate key, experiential elements of design in this field. We present our insights in the hopes that others designing aids to promote safe walking, or developing other assistive technologies, might be able to better understand their participants from the outset and so have more meaningful conversations with them.

Safety and design

Both the devices had a GPS tracking system and a GSM unit that could be used to raise an alarm on a caregivers' phone with the carrier's location should they become lost. Despite previous works findings suggesting people with dementia are not concerned about their personal safety [27], this backup needed to be in place before the participants would consider using the devices. The design sessions revealed a desire for a device that went beyond simply tracking its carrier but there was a lack of willingness to engage with less familiar design concepts without this safety net in place. For example, Mary would not consider having a device that gave implicit feedback about John and Alice asked for the device she had to have a tracking unit built into it in the later stages of design process.

The significance of routine in everyday life

The ways that a device interacts with the existing routine of a person with dementia is critical when they are deciding whether or not to use it. The participants used routine as a way to cope with their increasing cognitive impairment, so were sensitive to anything new that interfered with it. They felt integrating into routine, as opposed to being forced to create new ones by new devices, was central to ensuring a device was carried and remembering to charge it. The idea of having a home base for the devices to charge at, some device that looked incongruous without the device plugged into it, arose from aiming to embed our devices into participants routines.

Everyday uses for a device

The participants felt that the designs they created should have some added value beyond just being tracking and locating devices. This stemmed from their desire to not carry a device with them that reminded them they have dementia and that something may go wrong even when performing simple everyday activities. As one participant said, they did not want to have to carry a device that made them *"feel disabled"*.

Concerns about stigma associated with devices

Initially, the participants did not want their devices to identify them as having dementia, they wanted something small enough to hide out of sight or that was disguised as something else, as others have found when working with disabled users [17,24]. However, when the devices were shown to them and were considered aesthetically pleasing this attitude shifted, and the participants became happy to talk about the devices even wanting to show them off to their friends. This sentiment became explicit when Alice was challenged in discussion about having her device built into her walking stick and she resisted the idea, in part because that would mean she would not value it as much.

DISCUSSION

Our experiences showed that working with participants with cognitive impairments poses a variety of challenges for both designers and participants. This discussion highlights three areas we found particularly interesting or challenging in working with our cognitively impaired participants and some of the strategies that we employed to help improve the quality of our relationship with them. We believe that other designers and researchers working with people with dementia (or possibly more generally, with cognitively impaired individuals) might benefit from implementing these strategies.

Working with pre-existing groups was one of the most useful aspects of our work and had an impact in all of the following domains. The environment in these groups lent confidence to the participants and they were able to support each other when articulating their thoughts or in recalling stories they had previously shared in the support group.

Inadvertently Disempowering People with Dementia

Engaging with people with dementia in design is a rarity and our process empowered the participants by giving them a voice in regards to technologies being produced for them. However, the process of analyzing transcripts from the later tailored design sessions with participants with dementia and adding our own layer of interpretation to the needs that they expressed, sometimes had unanticipated adverse effects on this. The analysis could, inadvertently, disempower the participants and undermine our relationship with them if we took action on our analysis too early in the process. For example, when discussing how to feed-back information on the devices location, the designers discounted their desire to get feedback through their TV, instead interpreting it as a desire to have feedback integrated into their day-to-day

lives. The participants had actually carefully considered this issue and further exploration of their idea revealed just how central the TV specifically was to their lives. However, the analysis did reveal interesting aspects of the participant's experiences and underlying themes that tied these together (particularly in the initial exploratory meetings). As such, the process of reflecting on the transcripts is still valuable in the initial stages of the KITE approach.

Taking decisions for participants based on needs that they do not directly articulate (which stemmed from our belief that participants would not be able to articulate themselves) in the personally tailored design work ran counter to our goal of respecting their experiences (and their accounts of these experiences). Our assumption that participants could not directly articulate their needs echoes some of the issues that were highlighted in our review of previous work which spoke to caregivers instead of people with dementia [20] on the assumption that the people with dementia would not be capable of contributing meaningfully to the design process. In the future, we would work harder in these sessions to explicitly construct requirements with the participants.

Empathy's Role Bridging the Gulf in Experience

The time spent with participants fostered a quality relationship between them and the team members present. This changed the nature of the relationship between the consistent point of contact and other members of the design and development team. In addition, because of insights into the participants lives gained from active debates with them, the consistent point of contact found that they became an advocate for the participants at design team meetings that were conducted without them, where their opinions might otherwise have been marginalized. The consistent point of contact and designers who had been introduced to the participants frequently argued for the participants with dementia in these meetings. This created an unusual dynamic in the work with the consistent point of contact becoming more aligned with the group of participants with dementia and less aligned with the rest of the design team during the tailored design process. Furthermore, team members often expressed surprise at the opinions of the people with dementia and re-evaluated their opinions on different aspects of the design as a consequence of members meeting with them. Such meetings were easily facilitated by having the consistent point of contact to make introductions at group meetings.

An example of this was that, although ethical issues around privacy and tracking were frequently discussed in the meetings, participants in the tailored design were unconcerned by the threat to privacy posed by caregivers knowing where they were. This highlighted how the world view of people with dementia differed dramatically from those of the designers and echoes the warnings found in previous work about the gulf in experiences, and the resultant gulf in outlook, between younger and older people [11]. This lack of concern seemed to arise because the

people with dementia could not envisage reasons that their caregiver, typically a partner or adult daughter, should not know where they were. The participants with dementia suggested they would get a sense of comfort either from their spouse knowing their location or, more interestingly, in knowing that their spouse was not worried about them.

Another example of this was the surprising insight in the personally tailored design meetings that John was not afraid for his own safety but wanted something to reassure his wife that he was "okay". An awareness of the problems caregivers encounter is not unknown amongst people with dementia but the desire to lessen that burden is not something we have seen mentioned in other design work. This highlights the emotional burden a person with dementia can experience if they feel, in some ways, they encumber their loved ones.

An issue that arose from the relationship that we had not anticipated was that sometimes participants were unwilling to critique the designs that we placed in front of them. We speculate this is because they were concerned we would be offended if they were too critical. When the consistent point of contact emphasized that the devices were prototypes and downplayed the effort placed into developing them, the participants were much more willing to criticize. A strategy that emerged during this process was establishing a clear separation between the people that they met in design meetings and the rest of the design team through careful use of language. For example, we would ask if "they" (designers) should keep a switch in its location or if "we" (participants and consistent contact) wanted it moved. This strategy emerged naturally and was symptomatic of the shifting alignment of the consistent point of contact.

Mitigating the Impact of Cognitive Impairment

The strategies that we employed to mitigate the impact that our participants' cognitive impairment had on the design process may be more broadly applied to other design projects that engage with people with a variety of cognitive impairments. Giving participants access to physical artifacts to critique, whether prompts as seen in early exploratory work or design artifacts in the tailored design work, helped elicit feedback on designs and design questions. The rapid development of prototypes was crucial, and frequent meetings were also helpful in achieving this. Ensuring that participants felt that their contributions were being acknowledged also maintained their interest in the project. This meant being able to show them, in each meeting, how their contributions have impacted on the design. However, this process could also lead to participants becoming fixated on specific details or characteristics of a prototype that were never intended to be included in final designs and so needs to be carefully managed. Whilst leading into topics which needed discussion was something that was aspired to, there were concerns over certain design decisions being suggested to the participants by the prompts.

When discussing intangible issues of design, such as the safety issues around tracking or alert propagation, participants were much less vocal. The participants struggled to envision theses issues as we did not have physical prompts for them. However, the rare informative discussions around these issues often started based on the tangible prompts. The problem lay in understanding which of the prompts would provoke discussion around more intangible or conceptual aspects of the design and the direction in which the participants would take discussion based on these prompts. The next design process will consider how to better utilize this phenomenon.

The inclusion of family caregivers, who took part in the meeting alongside the person with dementia they cared for helped in discussion as they could articulate problems their loved ones struggled with. However, they were used to speaking for their loved ones and the consistent contact had to be aware of the correspondence between what a caregiver said, and the views expressed (or not expressed) by the person that they cared for. This was done by listening to the caregiver speak on behalf of their loved one then asking the person with dementia the same question the caregiver had just answered, to see if they agreed or had anything to add. Occasionally this revealed new issues, but most of the time the person with dementia simply expressed agreement. In other cases the consistent point of contact aggregated and contrasted the points made by both the caregivers and people with dementia, both within and across meetings. The caregiver meetings acted as a baseline for this process and allowed us to identify more caregiver issues.

CONCLUSION

This paper presents our attempts to design in a participatory manner with frequently marginalized people with dementia and their caregivers. In adopting a participatory approach to design we were able to engage with the participants and develop an empathic relationship that improved both our understanding of the domain we worked in and the issues we encountered. The approach we followed contributes explicit scaffolding for anyone wishing to engage people with dementia in design and the strategies that emerged in meetings may be applied more broadly in work with numerous groups with cognitive impairment.

However, the scope of the work is limited by our decision to work with more cognitively able participants and, to some extent, by the inclusion of caregivers (who introduce their own agenda) into the sessions. In the future, we hope others will develop the use of empathy in understanding different groups in participatory design. Ultimately, if designers and researchers are motivated enough to engage with people with dementia, they will gain unexpected insights and, while our approach holds many lessons for these researchers, it is secondary to their willingness to learn from this group.

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