A Design-led Inquiry into Personhood in Dementia

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ABSTRACT

Writers and practitioners in dementia care have invoked personhood to offer potential for preserving the agency of people living with dementia. In this context we use personhood to explore how relationships bring agentive potential to experience-centered design through a co-creative, design-led inquiry with Gillian, a woman living with dementia, and John her husband. We designed bespoke probes to empathically engage the couple in the design of both jewellery and digital jewellery to support Gillian’s personhood. Our design activity addressed the relationships involved in the context of Gillian’s family life and the progression of her illness and how they could be mediated technologically. Reminiscence became, through Gillian and John’s own hands, acts of sense making and legacy. The process of design became the way of conducting the inquiry and the designed artifacts became ways of posing questions to make sense of our experiences together.

Author Keywords
Personhood; Self; Experience-centered design; Dementia; Empathy; Reminiscence; Reflection; Memory; Probes.

ACM Classification Keywords
H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Improved treatment and early diagnosis facilitates people with dementia to be their own vocal advocates in life in general and in research on dementia [8]. In this paper we leverage this potential for participation in a design-led inquiry that centers on a deep engagement between a design researcher and participants in a process of co-design and co-learning. Gillian, a woman living with dementia, and her husband John participated in this design-led inquiry and our documentation and evaluation of this process yields a number of insights on experience-centered design for personhood and the self in HCI. In particular, through this process of co-design, the research team developed a richer understanding of the experience of personhood in dementia and the potential of digital jewellery to enrich that experience, and Gillian and John created something that would help them through the life changes involved in living with dementia and also provide a legacy of their life together.

To ground our account of digital technologies of self [1], we first describe a movement in jewellery design toward explorations of the embodied self, and we consider the potential of digital jewellery to extend those explorations. We then situate the inquiry within the conceptualization of the self in dementia as something profoundly relational stemming from philosophy of dementia care, a positioning that insists on the revision of conventional understandings of loss of self in dementia and that, as a consequence, also requires a revision of models of practical care and patient agency. We then describe the design project, discussing the development of empathic Design Probes to explore challenging aspects of life with the participants and the creation of interventions in the form of digital jewellery that sought to support Gillian’s sense of who she is and her relationships with other people. The process led Gillian and John to reflect on the experience of living with dementia and on the experience of a life lived together. By reflection on both the whole design processes we identify the characteristics of anchoring, capturing, supporting sense of self and connecting to relationships with others as guides within design for personhood and we discuss how we were able to engage deeply with someone with dementia to bring them into the center of the design process. Finally, we discuss the insights gained in relation to the challenge of understanding and designing for personhood in dementia (in particular), but also the wider implications for experience-centered design-led inquiry.

THE SELF, DIGITAL JEWELLERY AND DEMENTIA

In HCI, self has tended to be theorised either as a quality of individuals or as a social construction that mediates social life [9, 10, 19, 25]. However, with the turn to the experiential in HCI, a more relational appreciation of self is apparent [18, 32]. These ‘dialogical’ accounts reflect recent developments in theories of self in the psychological, health and social sciences, which emphasise self as constructed through reflection, storytelling and dialogue which
mediates who we are for ourselves and for others. Such accounts have provided concepts that help not only health researchers understand dementia as a social process but also HCI researchers understand personal technologies, as sustaining self-other relations.

Dementia, personhood and the self

Traditional accounts present the view that “individuals with dementia experience a steady erosion of selfhood to the point at which no person remains” [15, p. 553]. At the extreme, dementia has been described as causing the death of self [3] and as a deteriorating state of unbecoming a person [4]. These accounts describe self as something that is possessed by an individual and lost by them. Even Kitwood, the principal advocate of person-centered care, has suggested that the patient’s self becomes shattered as dementia progresses [14].

In a move that echoes the emergence of dialogical perspectives on self in HCI, writers and practitioners concerned with the experience of dementia and the practical care of dementia have invoked relational accounts of self to offer greater potential for preserving the agency of people living with dementia. For example, Kitwood & Bredin argue that “personhood is not, at first, a property of the individual; rather, it is provided or guaranteed by the presence of others” [14]. Such views have been the basis for recent attempts to engender changes in patient care, but more recently have also influenced interaction designers both in their engagement of people with dementia and their carers in design processes [17, 27] and in their design of digital technologies that remediate person-centered care practices [30].

Sabat and Harre [24] maintain that it is not cognitive function that constitutes a self of personal identity and suggest that care for people living with dementia could be improved by focusing on the nexus of relationships in which their personhood is nurtured. Interestingly, the invocation of a dialogical self in dementia care and dementia studies has become associated with an emphasis on personhood over self. In this context, the use of ‘self’ is generally seen as emphasizing the individualistic approach and the use of ‘personhood’ is seen as invoking the relational approach and we see pragmatic value for design in maintaining this distinction. In emphasizing personhood, the dialogical aspect of self, in dementia, the immediate social circle of the person with dementia become guardians and potentially active participants in the maintenance of their sense of self. Of course, the guardian’s sense of self is also transformed in their relationship with the person with dementia – it is not a one-way process.

Personhood can therefore be seen as something internally changing and externally nurtured through relational and social contexts, continually constructed by the peculiarities of experience and relationships. From this perspective, experience of dementia is an evolving dynamic that embraces the whole person and covers ethical, social-psychological and neurological significance. Kontos & Naglie [16] suggests that personhood can reside in the pre-cognitive existential expressiveness of the body. She gives the example of a woman with severe dementia who would “pull out a string of pearls from underneath her bib so that they can be seen by the other residents seated at her table” [16, p. 552]. Kontos discusses how through this act others could understand much about this woman such as: that her habitual engagement with the pearls suggested they were often worn by her, that she had pride in her appearance and that the pearls indicated her sense of personal taste. Kontos acknowledged that jewellery could function as pre-cognitive expression of self for others. Relatedly, we invoke jewellery’s potential as signifier of aspects of the self to design digital jewellery to open up spaces for someone with dementia to explore and express their sense of self and their relationships with others.

The self and digital jewellery

It has been argued that jewellery objects have a particular intimacy, distinct from many other kinds of object, both in terms of their physical connection with the body, and their human-relational contexts [20, 29]. Thus, as a symbol of self, identity and inter-personal relationships, jewellery has the potential to act as a conduit to transport us to other times, places and people and also a container for our feelings about that associated ‘other’ [23, 28, 33].

In recent years a number of contemporary jewellers have explored the potential of adding a digital layer, in part as a critical reflection and analysis of what both jewellery and wearable computers are [6, 11, 12], and also as a means of adding additional depth to the meaning of jewellery [31]. In this way digital jewellery offers new scope for interaction design that allows us to explore emotional aspects of our lives and our sense of self in new ways. As a category of object that is at the same time familiar (form) and unfamiliar (behavior) it allows us to circumvent some very basic views we have of digital technologies and create meaningful interactions for individuals and between individuals.

DIGITAL JEWELLERY & DEMENTIA: A DESIGN INQUIRY

By combining the notion of jewellery and digital technologies we can extend contemporary jewellery practice, explore alternatives to the conventional application of technology in people’s lives and offer rich sites for reflection and communication on self. Such artifacts have significant potential within dementia, as objects that hold meaning, act as sites for reflection and comfort, communicate meaning to others and potentially act as a bridge between the inner self and the outer world. The concept of personhood in dementia is clearly powerful as a means to continuously see someone with dementia as a person, in every sense of what that means, but how does this theoretical orientation play out in the lived experience
of someone who has dementia? In the following account we describe our explorations of just this through a design-led inquiry with Gillian, who had mild dementia when we first met her, and John her husband and full time carer. Living in the North of the UK, Gillian and John had been married for 43 years and were in their early 60s. Gillian had been a mother and housewife until she became a bereavement counselor in her 50s and John was a retired school headmaster. They were recruited to the project through the Alzheimer’s Society UK.

Exploring personhood through empathic design probes

In our research with Gillian and John we sought to make pieces of digital jewellery that reflected aspects of meaningful experiences that they shared with us. This was approached through a co-creative process with Gillian and John that foregrounded their personal biographies as they told them. As a way to open up a dialogue around personal meanings we used probe methods [7, 26], now widely used in human-computer interaction [2]. Our Design Probes sought to empathically pose questions in inventive, creative ways to give participants varied means to scaffold reflection and dialogue around personhood, and in particular social and relational aspects of their sense of self.

We used a heterogeneous set of probes to invite a range of different kinds of responses, and this has a number of benefits. Firstly they enable the inquiry to take multiple perspectives at the same time and furnish participants with the space to think in unobvious ways. Secondly they allow participants to gravitate towards the questions and modes of response that feel comfortable to them. Finally, whilst some probes may require considerable reflection, others may involve far more immediate response or action, and act as icebreakers or spurs. This heterogeneity opens up the responses to the participant’s own creativity in the safety of a specific context supported by probes as already half completed objects. Vitally an empathic probe process, through investment by both designer and participant, enables parties to develop a relationship of trust. The inquiry becomes a dialogical encounter in which designers and participants give to each other, rather than designers trying to extract information from participants. This meeting in the middle paves the way for a co-creative endeavor among equals who are respectful of each other.

The probes and the probes approach

The process of designing the probes for Gillian and John was grounded not only in current thinking in the philosophy of dementia care [13; 15; 24], but also in the design researcher’s interactions with clients of an Alzheimer’s day care centre and visits to the Alzheimer’s Deep Thinkers sessions, a support and discussion group for people who live with dementia to share experiences. The probes were designed to be attentive to aspects of personhood in terms of Gillian’s sense of self, self worth and projecting self into the future, as well as key experiences and relationships with other people. The set of ten probes (Figure 1) relate in part to elements of remembering and reflecting, focusing on things that hold strong feelings for Gillian and her family, whilst also opening up a dialogue to learn about Gillian’s personhood:

1. **Camera**: Gillian was asked to use the disposable camera to take photographs in response to a series of prompts: favorite things (a view, an object, a place, clothes, jewellery), reminders of things (family, wedding day, her children, her husband) aspects of Gillian’s personality (a skill, a quirk of her nature, her strength, something she was proud of, something funny, her idea of happiness, something unique to her) and ‘anything else’.

2. **Personal Treasure**: a tin with soft clay inside. Gillian and John were asked to make indentations in the clay of objects that are meaningful to them.

3-4. **1st Prize Rosette** and **2nd Prize Rosette** asked Gillian to share something she would like to be acknowledged for: something already achieved, or a current goal. A concertina of paper on the reverse of each rosette provided a space for the response to be written.

5. **Preserves** comprised three small jars with the question: If you could capture anything (for instance any moment,
sound, song, smell, view, object, place...) and preserve it in this jar for you to relive what would you choose? The label could be used to describe the choice (through writing or drawing on it) and/or something could be placed inside the jar to represent their choice.

6. Self-Seeding was a seed packet and plant labels asking: If you could turn your qualities, personality traits or idiosyncrasies into seeds that could be planted and grown, what would these be? This required Gillian to talk about her chosen qualities, what the seeds would bloom into and where she would plant them.

7. Dress Pattern addressed key outfits (clothing) from Gillian’s life. The outer casing depicted a montage of different styles of female clothing from different eras. Inside the packet were sheets of dress pattern paper with general dress making motifs on them.

8. Home was a small wooden house (16×12×10cm) with a note asking: tell me what home means to you personally (for instance home-like feelings, places, aesthetics, words and objects). Gillian and John were asked to use the object however they saw fit (e.g. to draw or stick anything onto or into it).

9. Pearls of Wisdom consisted of a large, oversized string of pearls (painted matt white to provide a surface to write onto) with this accompanying text Please use these pearls to share with me some of your wisdom (for instance your sayings, thoughts or advice relating to anything at all).

10. Self Tree was a series of oval locket-like forms hung from a small branch. One form had the silhouetted image of a woman (representing Gillian) on the front and instructions on the back reading: Please use these objects to tell me about some of the people who make you who you are (family, friends, even people who you’ve never met, but who have had a real influence on you). Gillian and John could write their responses on the other seven oval objects which each had paper on the front and a fold out concertina of paper on the reverse.

Our inquiry was first and foremost about Gillian’s experience of living with dementia (though the question was never explicitly posed to her in that way) and how we might make a practical contribution to understanding and enriching her experience through design. Notably, enquiring into Gillian’s experience entailed engaging with John’s experience too as their lives and their experiences of dementia were so tightly intertwined.

Responses to the Design Probes
As expected, some probes were a better fit for Gillian and John than others and they were equally honest and frank about aspects that hadn’t worked for them (in particular, the Personal Treasure and 2ndPrize probes) as those that had. They completed all of the probes however, and reported considerable resonance with many. Their responses resulted in a series of intricate perspectives on their lives and personalities. In the following sections we present key categories that the responses related to. Notably, many of the moments of surprise were particularly revealing of Gillian and John’s experiences. Gillian’s dementia was at a mild stage and she was involved in memory games and active remembering both at home and at the Alzheimer’s Society, yet it was clear that the level to which she had been able to remember, and the probes’ role in facilitating this, was surprising to both Gillian and John.

Caring for people
Many of Gillian’s responses illustrated that she is someone who has always cared for people. Gillian’s response to the Self Seeding probe was to enable and offer comfort to people, extending her propensity for empathy and nurturing to others. Her response to the 1st Prive probe was caring for the people I love. And the Home probe (Figure 3) showed how Gillian was always the enabler, looking after their children and supporting John in his career. Through Self Tree (Figure 2) a number of people close to Gillian thanked her for her unconditional love, her friendship and her support. This probe in particular became both a way in to the whole response process and a stepping-stone to remembering.

The home as sanctuary
Home was described as a sanctuary and center of experience for Gillian and John. They had always been very welcoming hosts, echoing how their own parents had been so hospitable to people as they had grown up. Gillian reflected that she had always been a person to open her home to people “the more the merrier”, but now home was more of a cocoon for them and a comforting, familiar place.

In response to the Camera probe they showed images of home through the years. Through the Home probe (Figure 3) they described home as a happy sanctuary using such descriptors as: protective, belonging, laughter, welcoming, caring, warm and safe and they described home as a...
consistently non-judgmental environment fostered by Gillian: no pretence, problems shared. As a housewife who waited until her children had left home before embarking on her career, home had been the center of Gillian’s world for most of her adult life.

Notably Home probe was used to represent a shift in their roles pre and post Gillian’s diagnosis. They presented home life for themselves and for their children in terms of ‘then’ and ‘now’, creating a clear delineation defined by dementia. John was now the ‘carer’ in very explicit terms, he referred to himself by this title many times during our conversations and through written responses to the Home and Self Tree probes. There was a strong sense that whilst this task was difficult at times John saw it as a sort of balancing, where he was now able to reciprocate and give the care to Gillian that she had always given to him. Gillian’s role had changed from facilitator and guardian of John and their children to now being cared for.

**Humor and positivity**
Throughout the responses, and conversations Gillian and John’s humor and positive way of looking at life shone through. Gillian’s warm character was a force within this project as was apparent in her response to the Self Seeding probe where she chose to turn her qualities into: “Hugging seeds: as a comfort to anyone sad, or in trouble and where people who care about each other meet”; “Smiling seeds: to be near people who are not very happy for whatever reason” and “Enabling seeds: to flourish wherever someone needs help to achieve something.”

The probes acted as conversational instruments within our process of working together and we would spend time focusing on one probe or another, talking through their thoughts or related stories that came to mind. Gillian’s abundant sense of humor led to fits of laughter relating to family anecdotes and even aspects of memory loss. Each of Gillian’s Pearls of Wisdom were positive and optimistic, proffering advice and peppered with humor: “Never go to bed on a quarrel”; “Seize the day”; “Have empathy with other people and don’t judge”; “It’s hard for someone to be mad with you when you smile at them” and “You can’t give away too many hugs”. Another encapsulation of Gillian’s sense of fun and enjoyment of life came through when she told us about her love of watching clouds. This was something she had loved since being a child and had used as a game to quieten her children when they were very young with them finding shapes in the clouds. Equally it is something she loved to do now from her lounge window.

**Design Responses**
The primary response themes dominated our thinking in the development of our design responses, in particular the rich context of home and what felt familiar over time, Gillian’s personality and sense of fun, and her caring nature. In contrast to a focus on reminiscence, the pieces were not intended to simply focus on the past (and risk creating a maudlin atmosphere around memory loss) but to make reference to joyful and meaningful aspects of Gillian and John’s lives enabling them to capture experience as events occurred. We sought to create jewellery that was as much about current and future experience as it was about the past, and pieces that could be nurtured by Gillian and the nexus of people close to her. Designs were developed through a cycle of iterations with Gillian and John.

**Locket**
Locket (Figure 4) is a piece to hold many of Gillian’s memories and to accompany her through her experiences.

![Figure 4. Locket that can hold and display many photographs](Image 334x509 to 541x587)

Each time the silver locket is opened a different digital image of hers is displayed on a small screen. The software and hardware is such that new photographs can easily be added (using a USB connection). The element of surprise created by not knowing which photograph would appear next was intended to intrigue Gillian and inspire her to continue opening it. The recognizable form of a locket was used in the hope that even after a long period of time Gillian might still recognize it to be a locket and open it. We hoped that it would serve as a reason for John and the couple’s friends and family to keep taking photographs with and for Gillian (thereby capturing future events).

The value that the couple had put on their photographs was part of our inspiration for this piece. John had always made humorous photomontages for family members to celebrate key events and it was clear in their probe responses and our conversations that photographs were a source of great pleasure and sanctuary for the couple. We wanted to offer new ways for photographs to continue to have these meanings and to support Gillian’s family and friends to continue demonstrating their care for her in the taking of new photographs to place in the locket. We hoped that the locket would live with Gillian through her future experiences; accompanying her through what the coming years have to bring and bringing the signifiers (photos) of meaningful people, humorous events, home, places, and events along too.

**Dress Brooch and Jewellery Box**
Gillian’s role as a good listener was an element of many probe responses and associated conversations and this partly underpinned the idea to develop pieces of jewellery that could record sound for Gillian to listen to whenever she wanted (recordings that both she and other people could create). Such an object could be something that family could use both to reminisce and to capture conversations or
life just as it happened. During one of the conversations around the couple’s aesthetic tastes John was moved to hunt out a bag full of remnants of dress fabrics from the attic. When throwing the dresses out years ago he couldn’t bring himself to get rid of them entirely and had cut sections from each to keep. When pulling pieces of fabric from the bag Gillian freely reminisced about the holidays for which she had worn the dresses, the music they reminded her of and the other stories that were connected to each fabric. Her level of recall deeply surprised and delighted John and signified how potent the fabrics were. Indeed, many of the dresses had been made by Gillian, she knew them intimately and they clearly held intensely strong connections to particular experiences for her.

Gillian often lamented that she would never wear dresses like those again and this served as further inspiration for a design, to allow Gillian to do just that, albeit in a new related form. We designed Dress Brooch (Figure 5) to essentially act like an embroidery hoop to hold taught remnant pieces of fabric from Gillian’s old dress.

Many of Gillian’s dresses were of a similar shape: a three-quarter sleeve ‘A-line’ mini dress. By making the shape of the brooch echo this outline the brooch appears to be one of her beloved dresses. Gillian could interchange fabrics in the brooch to wear different dresses as she wished.

By making Jewellery Box to house all of the jewellery pieces (Figure 6) we were able to use the box as a site where Gillian and her family could record sound associated with each of the dress pieces. Evoking the age-old context of the jewellery box as a site where stories are told whilst jewellery objects, often originating from different generations of a family, are handled and explored [5, 22].

Each piece of dress fabric had a small RFID ampoule connected to it and the box housed the technology (RFID reader, microphone, speakers, and computer) to record sound and play it back. In considering this aspect of the pieces we sought to make it as simple as possible for Gillian, John and others to use as well as safeguarding the recordings so that they cannot be lost (see accompanying video figure for description). The aim of Dress Brooch was not only to give Gillian ways to wear her dresses again, but to enable her, family and friends to capture sound to each piece as they felt relevant. Jewellery Box echoes the couple’s aesthetic tastes from their home and that they wanted it to live in their main family room. Both pieces are highly social in that they continue to be co-created over time as both new materials and audio recordings are added. While there is a clear connection to the past, the pieces largely seek to support the now and hopefully the future.

Cloud Watcher
The Cloud Watcher necklace (Figure 7) was inspired by Gillian’s sense of humor and fun, her wonder at beautiful things, and her description of herself as a cloud watcher (described earlier) and is a (non-digital) piece of jewellery intended to be both beautiful and fun. The rubber cloud-shaped spyglass pendant wobbles when held aloft and through which everything looks like a cloud. Attending to fun and silliness acted as a counterbalance to the more serious considerations addressed by Locket, Dress Brooch and Jewellery Box.

Reflections on Designing for Personhood
In this section we move to consider dynamics of the design inquiry as a whole. We have described the probe designs and final jewellery objects, here we pull back to consider dynamics of how they worked in the inquiry and to identify particular characteristics shared by both probes and final designs that enabled them to serve as the means by which personhood could be considered, supported and explored not only by Gillian and John, but also by us.

Reflections on the roles of the Design Probes
The probes were intended to create space for Gillian to reflect on things that were meaningful to her and in part on her experience of dementia. For many reasons including Gillian and John’s very close relationship, John caring for Gillian, and their embracing of the project as a way for them to make sense of their experience, the probes became a resource through which to purposefully and directly reflect on and talk about aspects of living with dementia in ways that they had not done previously. The level to which the probes had facilitated accessing memories had surprised and thrilled Gillian and John and they had found significant
value in the probes, early in the process, which fuelled their investment in the project as a whole.

The co-creative nature of the engagement was implicit from the outset. To involve someone with dementia in a design process is still a rare occurrence, but necessary if the starting assumption is that she is her own vocal advocate. As such, our emphasis was on how to use our design practice in gentle and sensitive ways to enable Gillian’s involvement. The success and value of the probes in this endeavor can best be seen in Gillian’s response to them: “it's just like, you just open a little bit to start with (gestures prizing a door open with fingertips)... and then you go a bit further and you think Well, yes I'm going to have a try at that!...and then, it's it’s where when suddenly, I've totally forgotten about something and it's, it's come back!” (...) Things that I, I'd totally forgotten about for years (...) and then all of a sudden, it was just it was like ehm, alot of water all just co, co coming down all at once, you know saying It's alright you can say this, you can do this’ [John and design researcher laugh followed by Gillian] Gillian: Amazing.

The probes mediated the development of a close relationship between design researcher and participants and their empathic use acted to help deepen and sustain this relationship, as well as turning the focus towards design and co-creativity. By reflecting, post design, on our probes and jewellery pieces we are able to see particular sensibilities that proved central to designing for personhood in our inquiry and may be useful for other researchers. We broadly categorize these capabilities as: Anchoring & Capturing, Supporting Sense of Self, and Connecting to Relationships.

Anchoring & Capturing
Probes such as the Dress Pattern were designed to explore potential anchor points for Gillian; things that she remembered vividly and that resonated so strongly for her, that if woven into designs, these resonances could potentially endure over time. Similarly, the Home probe sought to use the home as an anchoring environment that would speak of comfort, happiness and belonging. Note that the probes also played an important function in anchoring Gillian’s responses for herself, acting as aide memoire to aspects of her life. Anchoring also became resonant in the final Dress Brooch design that was not only cast as a familiar jewellery object but contained important elements, especially fabrics, which served as anchors for cherished memories and future sharing.

Capturing is a process inherent in ‘taking a photograph’ (Camera probe) and ‘pushing objects into clay’ (Personal Treasure probe). But for less tangible meanings probes such as Preserves and Self Seeding were used to target imagined meanings and experiences; be it imagining what you would love to relive if you could, or imagining what some of your qualities could blossom into if planted like seeds. The physical activity in Preserves and Self Seeding was writing, but the mental and emotional activity is much more about attending to personal appreciation, holding onto a moment, projection into the future and re-living precious moments. Capturing also became a starting point for Gillian and John in their appropriation of the completed designs. By using the Jewellery Box to capture songs that Gillian associates with each dress fabric they were able to use music to anchor the jewellery objects in a particular time of their lives. The various songs circumscribe much of the rich texture of Gillian and John’s shared past experiences and act as a starting point for further recollections.

Supporting sense of self
The Self Seeding and 1st Prize probes scaffolded the process of working with Gillian to understand what she was proud about (of herself). Creating space for dialogue around personal pride, sense of achievement, talents, abilities and goals in life can be a particularly challenging topic in the context of dementia and here the metaphorical character of the probes was critical. Self Seeding invoked notions of growing and blooming as well as small seeds having the potential to extend themselves. Gillian described how her nurturing nature if planted like seeds could blossom into a tree where people could find solace and meet other people for comfort. These probes also gave John a way to express himself in relation to Gillian and showed us elements of his personhood as well as their joint identities as husband and wife. Again, the forms that the probes took gave us gentle ways to explore these complexities and gave Gillian and John comprehensible structures and subtle contexts within which to present themselves.

Gillian’s sense of self was central to the jewellery designs. If Gillian were to wear the objects in severe dementia, the potential for them as carriers of meaning and bridges from the person that Gillian is to the outer world are significant. In this respect the design intent that a person with dementia wear these declarations of self on his or her body is on our part both deliberate and distinctive. Objects that give someone with dementia the ability to convey aspects of themselves over time, even in severe dementia, offer ways ‘in’ to the person.

Connecting to relationships
The Self Tree probe asked Gillian to place herself at the centre of a collection of rich relationships over her lifetime that show aspects of who she is, how she is valued by other people and how this network of individuals is connected through her. The organic nature of Self Tree sidesteps notions of hierarchy and priority in relationships and once completed Gillian could see herself nurtured and supported within this web. Indeed, Gillian and John described this probe to be deeply rewarding and wrote about each relationship in intense and poignant terms. Friends and family were called upon to give a quote about his/her feelings towards Gillian and where a description related to someone no longer alive a quote from something they had
once said was used. The probe embraced the nexus of people around Gillian regardless of time. In contrast, the Home probe allowed Gillian and John to articulate and reflect upon the social dynamic of home-life both before and after Gillian’s diagnosis. They used the object to weave a tapestry of family sayings from when their children were young, feelings of home such as a cocoon and nest, but also to mark how Gillian and John’s roles had reversed.

The intention of the jewellery designs themselves was that they would be used in an increasingly social manner; becoming objects that would contribute to support the social network around Gillian and thus to nurture her personhood. There is no prescribed ‘use’ for Dress Brooch and Jewellery Box; together they can be used to record and replay sounds, but this function is open to appropriation. One dress fabric may be accompanied only by music and another by jokes or conversations had one Christmas over the family dining table. Similarly, while the locket provides a place to hold photographs for Gillian, it has the potential to be embraced by friends and family as an opportunity for them to keep taking photographs for and with Gillian.

DISCUSSION
Our design-led inquiry is intended as a contribution to the understanding of personhood, particularly in dementia, and how self as a social and relational concept can be a productive resource in HCI design, as well as an exemplar of an approach where design (for personhood) is an inquiry that is experience-centered and design led.

Personhood and relationships in HCI
Understanding personhood is critical to any interaction design that mediates self for participants and the people who are important to them. An important distinction to emphasize is that we did not design for dementia we designed for personhood. To date design research in HCI foregrounding personhood and the self is extremely rare. As relationships are deeply implicated in self, the scope for design of digital technologies to help us construct self, reflect on self and nurture our relationships has a deeper relevance than often credited in HCI. Viewing self as co-constructed and potentially protected by others shows us that in dementia it is not only the self of the person with dementia that is dramatically shifting, but that of the partner/chief-carer also. This came through strongly in our design inquiry. This orientation of self toward relationship and change has a strange effect on the temporal aspects of inquiry and design. What starts as inward and backward looking easily becomes outward and forward-looking. For Gillian and John what started as a process of reflection through the probes actually became something much more future orientated by their own hands. The pieces became about something that could hold manifest quirks of their natures and aspects of their personalities for their families to enjoy as time moves on; a multi-layered representation of self as a legacy for those around them.

In HCI much attention has been paid to the potential value of digital technologies in support of reminiscence [21]. In reminiscence people re-live and re-tell previous experiences, remember old associates, revisit only half-remembered places and rediscover and celebrate a previous sense of self. But looking back can also be associated with a sense of what has been lost and cannot be recovered and can reframe the now as something less than what it might have been. We intended to open up a broader canvas of human experience and self, to focus not only on remembering the past but also on (celebrating) the present and imagined futures, in order to understand how these different orientations offer new potential for digital interventions. In the relationship that developed between Gillian, John and the design researcher, feelings, memories, hopes and imaginations came to life. Gillian’s sense of who she is has also been supported through the co-creation of connections between her past, present, and future experiences. Working on this together, we were able to build layers onto each of these aspects of her personhood that are now anchored in tangible things that have clear connections to both Gillian’s and John’s futures.

We (not only the project team, but also Gillian and John) would not have been able to make sense of this richly textured experience of living with dementia without all of the components of the process, the probes, the jewellery, the theory, the conversations and the making together. The process is a particularly dialogical approach to design-led inquiry that we have exemplified in this paper. The project is more than the jewellery or even the process, it is primarily about the relationships as will become clear in our reflections below.

Design-led and experience centered inquiry
Our process of design-led inquiry differs from a more traditional user-centered inquiry in that the early stages of research are not dominated by either a strong theoretical analysis of the situation from which design principles or values are operationalized, nor from a deep ethnographical or ethnomethodological analysis of the situations from which user needs or other forms of design implication are drawn out. These more traditional approaches can reinforce distinctions between understanding the use context and the design problem, and forging a design solution (understanding work and designing artifacts) that is not always helpful. Likewise these traditional inquiry methods tend to reinforce clear distinctions between the inquiry process and the inquiry outcomes. The process of user inquiry leads to outcomes such as a detailed ethnographic account of the problem situation (for example), while the process of design (not often construed as inquiry in its own terms) responds to that understanding with a new product, which is made sense of and evaluated in terms of the ethnographic account.

In our design-led inquiry, we did spend time trying to make sense of the inquiry situation (digital jewellery, personhood
and dementia), through the lens of theory (for example, both theories of personhood and dementia) and through a traditional form of participant observation (for example, attending local day care centers for people with dementia). But these forms of sense making did not dominate the design process. Instead, we used the process of designing and making (firstly, in the case of the probes, secondly in the case of the digital jewellery), not to present solutions emerging from our analysis, but to help us structure our inquiry into personhood, to frame the questions to which we sought answers in ways which were valuable, meaningful and interpretable both by us and by Gillian and John.

Our process is not only design-led however, it is also experience-centered. That is to say, it is not just an inquiry into jewellery, personhood and dementia in general as a reified concept in which participants serve as informants as people living with dementia, but rather, the inquiry is about Gillian’s and John’s own (potentially unique) lived experiences of personhood from their current situation as people experiencing life with dementia. The process of design, and making, runs throughout the whole process. It is the way of conducting the inquiry (just like an ethnographic interview is another way of conducting an inquiry), and in this design-led approach, the designed artifacts are ways of posing questions through which we can make sense of our experiences together.

Thus, we did not presume that Gillian and John would come to the process with already formed understandings of personhood or dementia as a reified concept (although of course they might have). But neither did we presume they would come to the situation with pre-given understandings of theory regarding Gillian’s struggles with memory loss. Rather the important thing for us was that through the process, each of us would find new insights. We sought neither to construe Gillian and John, nor ourselves, as sources of knowledge, information or wisdom, which somehow the inquiry would reveal. Rather the inquiry itself is a structured process, which allows participants to co-construct an experience for each other, which is oriented to allowing these new ways of understanding to emerge.

Within this experience are multiple moments of significance which participants stand in different relations to and make sense of in different ways, but which nevertheless become shared moments of great achievement. As an example of central significance in this regard, we would point to Gillian’s description of her experience of remembering (see p. 7), and the support the probes gave to this, which significantly shaped the direction of designs. For Gillian and John, the experience was not only a source of great pride in achievement, but also something they had not expected would come from the process, leading them to understand the potential of the process differently.

There is an important distinction at play in this form of experience-centered project, focusing as it does on the lived experience of individuals through the process of design. In focusing on individuals, on getting close-up to and intimate with each other, and in designing and making in response to these relationships, the aim is not only to produce something of meaning and value to them, but to others more generally. And clearly the set of probes were designed in a general sense to scaffold reflection and dialogue around social and relational aspects of personhood and could be used for this context again and as a starting point for further probe development by others. But importantly it is not simply to generalize indiscriminately or by unspoken implication (e.g. an unwritten argument that goes along the lines of ‘what we have done here in this singular situation would self-evidently work across of range of settings for a range of different people who also suffer from early stage dementia’). Rather, the aim is that some things that emerge out of the experience live beyond it in various forms and media and in some cases as contributions to knowledge in a general sense. Here we would point to Gillian and John’s new-found understandings, the legacy they have created for their significant others, the deeper understandings of the complex relationships between personhood, dementia and digital jewellery, the digital jewellery artifacts themselves, the process we have developed, the idea that certain forms of making can be powerful ways to understanding, the idea that looking forward may be as important as looking back in dementia therapy and so on. Our methodological contribution relates to the quality of the engagement achieved, in challenging circumstances centered on the development of empathic Design Probes. The main contribution however is empirical, arising from what Gillian and John described about their experience of dementia, both in their actual responses to probes and discussions around them. What we learned from this fed into the sensibilities arising in the design process (creating new anchor points for personhood by supporting relationships and sense of self). We now understand not only much more about personhood in dementia, but also how we can get into that world.

We stress the value of understanding personhood in more nuanced ways in HCI if we are to design more meaningful digital artifacts for people with dementia. Whilst current technologies in this area serve to support assistive contexts they pay little attention to the experience of dementia and focus on a very limited, functional framing. We hope that the outcomes from the inquiry offer resources for inspiration, challenge, hope and design for a range of interested parties. In this form of experience-centered project, there are multiple outcomes, multiple values, multiple ways of making sense of and finding value in this process.

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