
Beyond reminiscing: Looking back to look forward in dementia

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Abstract

Improved treatment and early diagnosis of dementia facilitates people to be their own vocal advocates in life in general and in research on dementia [4]. Our position is that by involving someone with dementia deeply within a design process they can articulate their sense of self in relation to their biography, their relationships with other people, and also to the profound context of living with dementia. Through an empathic and creative engagement between researchers/designers and participants a co-creative practice can open the space for someone living with dementia to revive memories and aspects of self and to turn reminiscence into something very future focused. By drawing on the notion of *personhood* [5], where self is viewed as something relational rather than individualistic, we developed a design inquiry with Gillian who is living with early stage dementia and involve her friends and family (predominantly her husband John) in the design and making of a series of digital jewelry pieces to support her memories, sense of self and relationships with others. By Gillian and John's own hands reminiscence became a seamless transition into legacy and a new design space has been opened up to us by their relational approach to experience and personhood.

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ACM Classification Keywords

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

General Terms

Design

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A cornerstone of our research is Harris and Keady's [4] affirmation that new treatment and early detection of dementia enable people living with dementia to be their own vocal advocate. This potential for participation has resonated strongly with us and has underpinned a design-led inquiry that centers on a deep engagement between designers (us) and participants (Gillian and John, a married couple, who are experiencing extreme changes in their lives now Gillian has early-stage dementia) in a process of co-design and co-learning. Through our project, we have explored the concept of self in dementia in relation to the design and making of a series of digital jewelry artifacts for Gillian and John. Central to this process has been reminiscence to support self, to nurture relationships and to provide a way of looking back to create something unique for the future.

In HCI much attention has been paid to the potential value of digital technologies in support of reminiscence [8]. 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 this can reframe the present as something less than what it might have been.

We have aimed 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 an imagined future. We have sought to understand how these different orientations to self are amenable to new digital interventions.

In contrast to traditional views of dementia as a condition leading to an erosion of self [2,1] we situate this work as part of a movement that re-conceptualizes the self in dementia as something profoundly relational, centering on the concept of *personhood* [5] whereby someone's self and identity as a person is nurtured and sustained by the nexus of people around them. This re-conceptualization of self in dementia echoes the emergence of dialogical perspectives on self in experience-centered design [6,10], which we use to develop new perspectives on the design space of digital technology to support reminiscence in dementia care.

In emphasizing personhood, the dialogical aspect of self, in dementia, we see the potential of reminiscing to support a more relational appreciation of self and the kind of sense we make of our experience through reflection, storytelling, and dialogue to mediate who we are for ourselves and for others.

Our design focus throughout the project has been on digital jewelry objects. We have previously contended that jewelry objects have a particular intimacy [9,7], distinct from many other kinds of digital or other object, both in terms of their physical connection with the body, and their human-relational contexts. As a symbol of self, of identity and of inter-personal relationships, jewelry often becomes a conduit to

transport us to other times, places and people and also a container for our feelings about that associated 'other'. As such jewelry and digital jewelry is interestingly positioned to have a valuable role for someone with dementia; namely to hold, carry and display personal meanings relating to memories, biographical experiences and relationships with other people.

The design-led inquiry

My (Jayne) way of opening up a dialogue around personal meanings with participants is through the use of probe methods [3]. I carefully design probes that pose questions, supportive of inner identity and what is meaningful to someone. Vitally the probe process enables parties to develop a relationship of trust. This mode of inquiry can be gentle, multi-angled and reciprocal. It becomes a dialogical encounter in which designers and participants give to each other and meet in the middle. My set of ten probes within this project related strongly to elements of remembering, focusing on things that held strong feelings for Gillian and her family, whilst opening up a dialogue to learn about Gillian's personality.



Close up of 'Preserves' probe, comprising a small (7cm high) glass jar, label and package label providing instructions.



Close up of 'Self Tree' probe showing more detail of the space available on the reverse of the oval disks (a concertina of paper) on which to write a response.

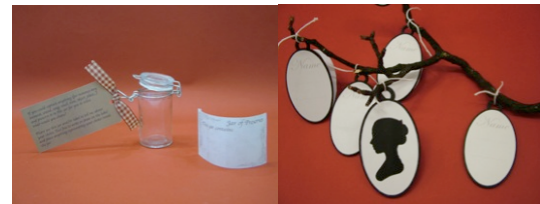


Figure 1. Examples of probe set. From left to right 'Preserves', and 'Self Tree'.

For example, 'Preserves' (figure 1) was a set of small preserves jars asking Gillian to imagine: "*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?*" Gillian could place something within the jar to represent her choice or she and John could write on the jar's label. Another probe, 'Self Tree' (figure 1), comprised a series of oval locket-like forms hung from a small branch. One object had a silhouetted image of a woman (representing Gillian) on the front and instructions on the back: "*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.

Gillian and John's responses

Although Gillian's dementia was at a mild stage and she was involved in reminiscence games and active remembering both at home and at the local Alzheimer's Society group, it was clear that the *level* to which she had been able to remember was surprising to her husband (John) as the following sections illustrate. This clearly pleased both Gillian and John and from a very early stage in their response process they began to regard the probes as both worthwhile and personally meaningful.

John: I mean that was probably the most significant one [Self Tree]... I was astonished how quickly you came up with ehm, But those were...stepping stones, really, to a huge volume of items that Gillian came up

with... Absolutely astounding (...)Y'you know she remembered that her Mum and Dad used to say 'If you want to make something of yourself in life, you have to work hard at it' (...) and some of the things that other people came back with, like Julian, 'Mum, thank you always for believing in me' (...) You know, I mean these are jewels! (...) So. That was definitely, for Gillian and I, the thing that opened up a huuge amount of looking back"

To feel such a 'fit' with a particular probe seemed to secure the significance of the whole probe activity for Gillian and John. In discussing the action of remembering and how the probes facilitated this, Gillian was moved to describe what it felt like to feel memories coming back to her:

Gillian: It it's, it was all the memories that kept coming back (...) Things that I..I'd totally forgotten about for years (...) and then all of a sudden, it was just it was like ehm, ehm, a lot 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' (...) Amazing. (...) it's when you started it, it it's just like, you just open a little bit to start with... Can I can I c c can I can I, and then you go a bit further and you think 'Wellll, yes I'm going to have a try at that!'. And this is what it's been like, and it's, and then, it's it's where when suddenly, I've totally forgotten about something and it's, it's come back! Y, and it's wonderful it re..[laughs] "

Gillian's rich description of the dynamics and physicality of what remembering felt like to her gives us an intricate insight into her act of remembering. Her descriptions enabled us to imagine how it feels to try to remember in very bodily and emotional ways. She

helped us to empathize with this initial trepidation and sense of doubtfulness in one's own ability to do it, followed by finding a way that leads us further into the activity of remembering, until memories come back in a rush to us that feels as if something very physical and all encompassing has occurred. This probe-centered dialogue with Gillian enabled us all to empathize and share such experiences.

The collaborative nature of the inquiry was also evident in a particular initiative taken by John. From very early in the project John began making a book about the process for himself and Gillian to keep. He took photographs of their completed probes and furnished his record of the process with additional images and personal insights. He started to see the value in the project as more than the outcome of pieces of digital jewelry for Gillian and the family to interact with. He saw the process as something that captured aspects of Gillian, himself and the family, and as something to pass on in the future:

John: Oh yes, yeah! (...) I think this is a rather odd thing to say..but...when Gillian's not here anymore, when she's died, passed on, gone to oblivion or whatever you believe in, then, what we have here really is an aMAZing thing to pass on to our children..and...you know that's without any jewelry box or anything [laughs] like that. Just this folder..[Gillian: Mm]..just going through it again you know, it's very much about Gillian and it'll be treasured I'm sure.(...)

Design responses

I (Jayne) designed jewelry pieces for Gillian and John inspired by our developing relationship and specifically in response to their engagement with the probes.

'Locket' (Figure 2) is a piece to hold many of Gillian's



Close up of 'Locket' (Figure 2) digital jewelry piece made from silver, velvet, digital screen, memory card, rechargeable battery, electronic components. Once opened an image is displayed. The piece can be customized to show one image or a succession of images on repeated opening of the locket.

memories. It is a silver locket housing a small digital screen. Each time the locket is opened a different image from her life is displayed.



Figure 2. 'Locket' (in silver) with digital display.

The form was consciously made to be recognizable as a locket in the hope that even after a long period of time Gillian might still recognize its form and function and be drawn to open it. I hoped it would accompany Gillian through her future experiences, bringing the signifiers (photos) of meaningful people, places, and events along too. I hoped that she would be comforted by knowing that all of these photographs were with her all the time and that in addition the locket would be a reason for her and family members to keep taking new photographs.

During our conversations it was mentioned many times that Gillian had always been an excellent listener. The abundance of anecdotes that Gillian and John shared with me during my visits felt like aspects to life that Gillian might appreciate being able to hear from time to time. During one of our conversations John was moved to hunt out a bag of dress fabric remnants from the attic. Gillian's eyes widened and lit up immediately as she recognized the fabrics as pieces from her old dresses. We spent an afternoon listening to Gillian's recollections of the holidays where she had worn the dresses, the music they reminded her of and the stories that were connected to each fabric. I could see from John's reactions that it was clearly extraordinary for

Gillian to be remembering these things. It was also obvious that the dress fabrics held intense meaning and were acting as triggers to past experiences for the couple. I was inspired to make a piece that would enable Gillian to wear her dresses again in a new form. 'Dress Brooch' (Figure 3) can hold taught pieces of Gillian's fabrics, which she can interchange as she wishes. A jewelry box (Figure 3) to house all of the jewelry pieces became a site where Gillian and her family could record sound to the dress pieces. Each piece of dress fabric has a small RFID ampoule connected to it. The jewelry box houses the technology to record sound and play it back.



Figure 3. 'Dress Brooch' and 'Jewelry Box' which can record and play sound.

The inquiry as a whole

Relationships are deeply implicated in self and the scope for design of digital technologies to help us reminisce, construct self, reflect on self and nurture our relationships has a deeper relevance than often credited in HCI. The orientation of self toward relationship and change in this project has a strange effect on the temporal aspects of inquiry and design related to reminiscence. What starts as inward and backward-looking can easily become outward and forward-looking. 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



Close up of 'Dress' brooch (Figure 3) made from wood veneers, silver, Gillian's dress fabrics and RFID ampoules.



Close up of 'Jewelry Box' (Figure 3) made from walnut, velvet, brass, leather, RFID reader, computer, microphone, speakers, and electronic components. By placing one of the pieces of dress fabrics onto the velvet interior lid of the box and pushing the button sound can be recorded. On lifting the dress fabric away the recording will stop. On re-placing the dress material on the velvet lid interior the recorded sound associated to that piece of dress fabric will be played.

self as a legacy for those around them. For Gillian and John, what started as a process of reminiscence through the probe objects, by their own hands also became an act of anticipating the future. It is in this important sense that what happened goes beyond reminiscing.

Remembering and imagining are central activities in making sense in dementia. Both in terms of retaining some of what has been but also in the power and value of imagined futures. Reminiscing as a way of looking back in order to look forward introduces the notions of legacy, heritage and creating something to leave behind for others. The probes and final digital jewelry pieces celebrate Gillian, her quirks, her memories and her connections to other people. Gillian and John have been able to use reminiscence activities as a vehicle to articulate 'self as I want to be celebrated' and 'self as I want to be remembered'. All of these aspects to reminiscing help a person to locate themselves and those of whom they feel part.

The co-creative nature of the engagement was embedded in the project from the outset. To involve someone with dementia in a design process is a rare thing, but we feel necessary if the starting assumption is that she is truly her own vocal advocate. In the relationship that developed between us (Jayne, and Gillian and John) feelings, memories, hopes and imaginations were reinvigorated. Working together, we have been able to build layers onto each of Gillian's reminiscences that are now anchored in tangible things that have clear connections to both Gillian's and John's futures. And for us a new design space has been unpacked through dialogues of personhood and fresh understandings of what reminiscence can become.

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