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ReFind: Design, Lived Experience and Ongoingness in Bereavement

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ABSTRACT

We describe the design and use of ReFind, a handheld artefact made for people who are bereaved and are ready to re-explore their relationship to the deceased person. ReFind was made within a project seeking to develop new ways to curate and create digital media to support ongoingness – an active, dynamic component of continuing bonds. We draw on bereavement theory and care championing practices that enable a continued sense of connection between someone bereaved and a person who has died. We present the design development of ReFind and the lived experience of the piece by the first author. We discuss our wider methodology which includes autobiographical design and reflections on if and how the piece supported ongoing connections, the challenges faced, and insights gained.

Author Keywords

Design; continuing bonds; ongoingness; death; grief; bereavement; physical/digital; lived experience; autobiographical; autoethnography; digital images; photographs; relational selves.

CSS Concepts

• **Human-centered computing~Human computer interaction (HCI)**

INTRODUCTION

ReFind (Figure 1) is a handheld, disc-like artefact made from Corian and Brass, housing a circular digital screen. It holds an archive of photographs of someone deceased taken throughout their life – all tagged with semantic metadata describing the content and associated meanings of each photograph. The owner can share new photographs with ReFind relevant to their current life (for instance a selfie or a photograph of something happening in their life now), via a

mobile website, and by rotating the piece in their hands they will see five images selected from the archive of the deceased person, based on their semantic metadata.

Figure 1. ReFind © Jayne Wallace.

We detail the wider context and project from which ReFind originated, the design and making of the artefact, provide an autobiographical lived experience of owning the piece over a number of months and offer new implications for designing for ongoingness that making and owning ReFind helped us to understand. In presenting a research through design case study, an innovative design and an example of autobiographical use, we hope to contribute to the highlighted absence of detailed description of design processes within HCI [6, 8, 9, 28, 40], the emergent practice of autobiographical design in HCI [4, 10, 17, 20, 36] and new ways to consider design and digital technology in relation to continuing bonds, death, bereavement and our relational selves.

CONTEXT

ReFind is a component of an overarching practice-based research project that is seeking to understand if and how new forms of digital media content, curation, creation and consumption can support a continued connection between people and their deceased friends and family members. Our design practice is distinctive in that we are working with people who are already bereaved, who are approaching end

of life, and who are at an early point of living with dementia. In working with people who are approaching end of life or facing the changes that will come through dementia, we are seeking to frame our design research as working with people to put things in place for others for the future. That is, to enable the maintenance of connection after death or when the progress of dementia is profound; and in working with people who are already bereaved we are seeking to design for connection to the person who has already died. In all these cases we are exploring new ways to use digital and physical content – objects, personal media, public media – to enable these ongoing connections.

Existing work on design and mortality in HCI, includes design for looking back and on physical/digital memorials [3, 15, 17, 18, 30, 32, 33, 39, 49, 54]; design perspectives on phases of letting go [38, 45]; time, loss and change in relation to new media [46, 48]; new forms of legacy for the dead [42]; thanatosensitivity [31]; photographs and living on [14]. There is a scarcity of research exploring the value of continuing bonds however, Getty et al [12], Ataguba [2] and Wallace et al [51, 52] being the exceptions.

In contrast to notions of reminiscence, or holding something precious as it was, we take as our starting point the notion of ongoingness in continuing bonds [52]: how ongoing, dynamic, future-focused forms of connection can be fostered, maintained and developed. While static forms of connection such as memorabilia and reminiscence aids can serve as valuable touch points to the past, we are exploring the potential to create forms of connection that are changeable, connected to the present and therefore to the moving dynamics of the ongoing lived experience of the person who is alive. Our approach draws on a rich body of work on continuing bonds in bereavement and grief theory [21, 25, 26, 27, 47].

The dominant grieving practice of Western modernity became one in which the predominant model of grief, and living with bereavement, was a phased disengagement from the dead. Here the living were encouraged to work through stages of detachment from the dead to allow them to find new attachments and continue to live fulfilling lives [5, 29, 43, 57]. Proponents of continuing bonds advocate an alternative approach, one of seeking ways to have a continued connection and relationship with those who were close to them but who have died.

There are social and cultural precedents for such ongoing relationships with the dead within many non-western cultures, including Japanese ancestor rituals [27], Maori practices and the Marae [37] and the Sora of Eastern India [50]. As Howarth asserts, a continued connection to the dead is nothing new, but is something that in the West we lost in the 20th Century "marginalized by the discourses and practices of modernity" [21] p.127.Through their articulation of continuing bonds Klass et al [47] remind us that people are not bounded selves, but instead connect with and are sustained by the selves of others [25, 27, 47]. This is a positioning that echoes strongly with the notion of personhood in the philosophy of dementia care [24, 53] which frames the nexus of people around the person with dementia as 'guardians of their selfhood' acknowledging that even though a person with dementia may not be representing themselves as they once did, they are still that person, and are still an actor in the selfhood of those around them.

Both personhood and continuing bonds point to a design space that acknowledges our non-bounded selves and the value that connections between people bring. Through continuing bonds, we are able to argue that relational instances of supporting the Self do not end when someone dies or has profound dementia.

Continuing bonds can be, and are, enacted through a wide range of means, including conceptual positionings and personal and social acts such as: memorialization [56], ritualization [23], keeping the deceased person's room just as it was [11], keeping belongings of a deceased person [13], having conversations together with other bereaved people that involve 'biographical emplotment' [1], nurturing inner representations of someone deceased [22], and making such inner representations feel tangible through acts such as including the image of someone deceased in new family photos [26].

While continuing bonds can be enacted through practices of looking back and of maintaining something precious as it was, our work envisions dynamic and future-focused forms of continuing bonds and seeks to further develop ongoingness as a theoretical construct and pragmatic resource for design. Previous work has suggested [52] that it is useful to articulate this explicit focus because continuing bonds can be enacted through a wide range of means and practices that span a number of temporal vantage points. Ongoingness as a definition enables us to be more specific about what we are trying to achieve and of the potential role for design and digital technology within this.

We define ongoingness as forms of continuing bonds that are focused on practices dynamically connected to the present by enabling connections to the deceased that respond to the current life experience of the living [52]. Ongoingness practices have characteristics of an *active and dynamic* continuation of a relationship - meaning that it is open to that relationship changing over time. The emphasis is on an evolving, future-focused dialogue as time passes. We use 'dialogue' in the broadest sense here. We are keen to investigate if and how it is possible to go beyond feeling a connection to the deceased to experiencing a form of 'dialogue' with them.

AUTOBIOGRAPHY AS PART OF OUR METHODOLOGY

Across the wider project there has been a mix of approaches to developing ideas and designs. Firstly, we have developed design propositions (storyboards, films, workbooks) that emerged from team discussions inspired partly by our

experiences (either personal or from our lived knowledge of being with people who have dementia, live with bereavement, or who are approaching end of life). These acted as catalysts, stretching us to think about ways in which design and technology could be conceived and nuanced to respond to ongoingness in continuing bonds. Secondly, we have worked closely with individual participants and their family members in order to make bespoke physical/digital pieces for them to live with and own. Thirdly, we have made pieces that have spoken directly to our own experiences of bereavement [51] and of living with family members who have dementia [16].

In reporting on ReFind, we focus on bereavement as one strand of the wider research project. We also focus here on one aspect of our wider project methodology in describing the autobiographical use of ReFind by the first author, which we contextualize now.

We acknowledged very early in to the research programme that the context of enabling ongoingness through technology is both abstract and complex. Consequently, we reasoned that potential participants may struggle to grasp what we were proposing without some tangible exemplars that could demonstrate how ongoingness could play out in practice. From a very pragmatic standpoint, in the first instance, we sought to use our own lives and experiences to create a series of design concepts and artefacts that we could share with others to refine possible directions for what we could make for participants. However, over the course of adopting this approach, we saw the role of making things for ourselves, our families and our experiences as a far more significant methodological decision than just a pragmatic move.

This has enabled nuanced critique of both interaction and technology design and depth to our insights concerning opportunities and limitations regarding if and how it is possible to enable a genuine sense of dynamic connection with someone deceased. Further, making things for our own experience has enabled us to better understand the complex premise of ongoingness in continuing bonds that we are seeking to design for. Moreover, we argue, the development of ReFind benefitted from members of the team not only being both researcher and participant, but also being able to bring their expertise in living with bereavement. It aided the iterative design discussions of the piece, complexities to designing for ongoingness and the potential for technology more broadly (points we develop in the discussion section).

As has been articulated in HCI [7, 35, 36] research accounts employing first-person perspectives are gaining in prominence [4, 10, 19, 20, 34] and there is a move away from skepticism as to the value and rigor of autobiographical research. Driven partly by the development of more research into the acutely "private spheres of life" [7], partly by pragmatic need to test and use research designs in order to better understand them and adjust them to a required outcome, but also partly by the desire to experience them personally driven by authentic need.

Neustaedter et al [35] describe five essential tenets of autobiographical design: *genuine needs* (authentic motivations), *real systems* (a developed and functional system), *fast tinkering* (space for iteration), *record keeping and data collection* (rigorous documentation and honest observations of the design development and lived experience) and *long term usage* (space and time to deeply engage and embed the design into your life). They also detail the kinds of knowledge and limitations to what autobiographical design can yield – namely deep experiential understanding, often leading to reflection on ethical implications of a design, but not generalizable knowledge.

We reflect on our use of autobiographical design, through living with ReFind later in the paper and turn now to describe the design development of the piece.

DESIGN DEVELOPMENT
The initial motivation for ReFind came from questioning how a finite archive of media (finite because someone was deceased) could be repurposed to bring about new meanings, new readings and also new content. Driven by a longstanding inspiration for the work of photographer and artist Moira Ricci [44] our team discussions centered on imagery as media at this time. Ricci's work spoke to us of an act of ongoingness in a very powerful way. One body of work developed between 2004 and 2014 "*Mamma con maestra, 20.12.53 – 10.08.04*" comprises a series of photographs. Here Ricci used digital manipulation to place images of herself as an adult into photographs of her deceased mother from across her lifetime in order to create a particular personal dialogue. The digital manipulation is such that the photographs look believable, as if she were really there, the lighting, aesthetics of clothing worn by Ricci and the quality of her image all match that of each of the photographs. For Ricci this was a way to have a particular conversation with her mother - specifically, about her death. In each photograph she is looking at her mother, her expression serious, and she states that the underlying intention of her presence (within the images) is an attempt to warn her mother of the accident in the future that will cause her death. Through the artwork she was seeking to have a connection or dialogue with her mother about what she was feeling in the present.

As in an earlier piece of work during this project [51] the first author brought personal media to the discussion as source material. To extend the design space that Silverman et al [47] and Ricci opened up to us, the first author shared a series of images of themselves and their mother, who died in 2015. Our discussions centered on the fact that not only were various emotions conveyed across the collection, but there was also a range of associated meanings representing a wider set of emotions than were visible in the photographs themselves. We were inspired by Klass et al highlighting the potential for bereavement to be seen as a continuing process of negotiation and meaning-making and as something fluid that changes as feelings for the deceased periodically lessen

or intensify over time. Along with Ricci's process of using media to have a purposeful dialogue with her mother.

We wanted to see if it was possible to use the finite archive of photographs of the first author's mother in a way that offered a dynamic response to the things that were happening in the first author's current life.

Early ideas focused on a form of conversation between single images of the person alive and a single image of the person deceased. We played with ideas centered on two screens housed within one form, perhaps both facing each other, or pivoting around a central point. In terms of form we talked about clam shells, jewelers' loupes, old sailing and navigation tools and mining lamps.

When exploring interaction ideas, we thought through pulling the screens apart from, or pushing them closer to each other as a way to cause the images to interact; or rolling a form across a surface as a way to move through images. We reasoned, however, that all of these ideas would lead to an object that was complex in both form and interaction, when the context of connecting someone to a deceased relative felt already complex enough. We realized that we needed something simple in form and interaction and sought to make something gentle and calm – with some poetry if possible.

It is significant to mention that although we were clear that the first author was going to use the final design, we were not conceiving something bespoke for them. We wanted to make something that other people could also use and tailor to themselves within the life of the wider project. Our design process took an open, product design route, rather than a bespoke tailored one because of this.

Figure 2. Design Development Components.

Throughout our sketches, circular disc forms dominated, partly because our conversations seemed to settle on making something simple in form, comfortable in the hand – and partly driven by us wanting to see if a smart watch could be repurposed for this idea - circular forms echoing the watch. In tandem we started to make foam models on the lathe of potential forms and to dismantle a smartwatch to see how much of the product design we were able to remove in order to pare the watch back to its essentials (Figure 2). Our design aesthetics were naturally informed by our previous work [51, 55] and we now also see connections to the work of others [41] that we weren't aware of at the time.

From our early ideas of two screens looking at one another our ideas progressed to the potential for an object to have a special kind of reveal of photographs. Similarly, our ideas progressed from a dialogue between just two photographs (one of the person alive and one of the person deceased) to a series of photographs. The final idea that was one image of the bereaved person's current life causing a series of images of the deceased person to appear. Our rationale was that a series of images from the deceased person could convey a range of perceived meanings and emotions and one image from the person alive could give them a focus and didn't feel too arduous an undertaking. When we handled our early foam models we naturally turned and rotated them in our hands, and this led us to the final interaction idea of the piece – an object with one screen which moved from one image to the next as the object was rotated.

Final Design
The final piece, ReFind, (Figures 1, 3 and 4) measures 85mm x 14mm and is made from Corian, Brass, an Android smartwatch, crystal glass and tiny steel screws.

Figure 3. ReFind Artefact © Jayne Wallace.

Corian was chosen for because it can be machined to a high fidelity, which was needed in the internal structure of the piece in order to hold the brass and watch components perfectly and securely, it has a weight or heft to it and finally because it feels pleasant to the touch. It remains cool when you pick it up for quite a while and can be polished to give it a sleek, smooth handle. Brass was used because, again, it could be machined to very specific dimensions, it has a different contrasting feel and look to Corian so we could use it to create a focal point and frame around the screen and because it doesn't rust or degrade with age.

We wanted it to look like a positive object, not something to be wary of and certainly not funeral aesthetically. The scale referenced portable sized things, but the lack of ability to stand the piece up seemed to stop it looking like a picture frame. We enjoyed the fact that it didn't wholly look like a digital object – there are no ports, buttons or explicit controls. We wanted to make something with robust simplicity, with no unnecessary ornamentation, that would feel tactile, comfortable and nice to roll around in the hands.

We felt that the images shown on the screen were the precious element of the piece and sought to make something that had a solid, reliable look and feel to it to hold these images without the aesthetics of this taking away from the images themselves. We made a brass housing that was at the absolute minimum size to mask the watch casing and create
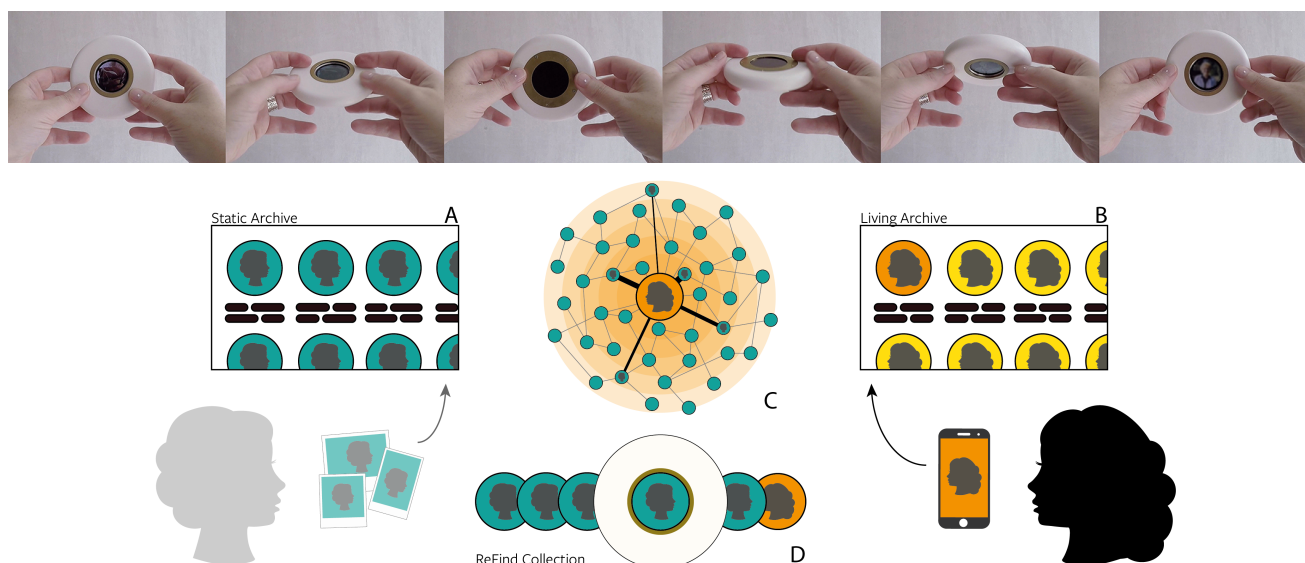
Figure Group 4. ReFind being rotated in use and a visualization of the system. © Jayne Wallace.

a very light framing of the screen and image. The brass form was essentially an architecture to hold the hardware, without compressing it and damaging the deconstructed and exposed watch components and without allowing them to rattle or slide around.

Interaction

By lifting or moving the piece it awakes, showing an ambient screen. This fades to reveal the last image sent by the owner to the piece, depicting something relevant to their life now. From this point, it is possible to explore the collection of five images that have been selected from the deceased person's archive in response. By vertically rotating ReFind (Figure 4) a different photograph from the collection of five will be visible each time the screen is rotated 360º to face the viewer. ReFind can be rotated either away from or towards the viewer which navigates forwards or backwards through the images. An image will remain on display for as long as ReFind is being held. If ReFind is laid down on a stationary surface for an extended period (configured as 2 minutes), the image gradually fades until picked up again.

We wanted to allow repeated engagements with a collection for as long as they were needed. As such, ReFind will hold the latest collection of five images from the deceased person's archive until a new image is uploaded by the owner. When this happens the previous collection of images is replaced by a fresh set of five images.

At present the piece is connected to a digital archive of 63 images of the first author's mother from across her life (Figure 4). Each of these has been tagged with numerous keywords by the first author and they are all held on the ReFind online platform. In order to send a new image to the piece and receive five in response the new image is uploaded to a secure webpage and tagged with keywords that relate to any aspect of the image – which could be people, places,

dates, emotions or other descriptors that feel relevant. Then, by simply picking the ReFind object up the image that has just been uploaded to the webpage is shown on the piece and by rotating the object the five archive photos of the first author's mother selected in response can be seen.

Technical Description

We used a combination of web and wearable technologies in making ReFind comprised of an *Image Archive Service, Image Client* and the *Physical Artifact.*

Our web-based *Image Archive Service* makes use of the OrientDB graph database to store the metadata and express the relationships of the archived images from both the deceased person (static archive) and the bereaved person (living archive). The base metadata types include tags for people, places (symbolic and geolocations), emotions well as miscellaneous keywords. A direct connection can be inferred when two images share a common element – such as an emotion. The strength of a relationship between two images is defined by their shared connections - meaning that images with two shared connections, have a stronger bond than those with only one.

Application logic is written in Nodejs and sits as a layer between the graph database and the API used to communicate with the *Image Client* and *Physical Artifact.* The web-based *Image Client*, can be accessed from any desktop or mobile web browser, through which it is possible to register and login in with a username and password. Once logged in the bereaved person can pair a *Physical Artifact* with the account; or upload new images to their living archive. Uploaded images need to be associated with descriptive metadata (using the aforementioned graph structure). This action triggers a response from the *static archive* to be generated and sends five images to the *Physical Artifact.*

The *Physical Artifact* is made from a deconstructed Fossil Q DW5A smartwatch running Android Wear 2.0 OS. Our ReFind application was developed as a watch face to allow it to launch on boot of the smartwatch device. The design of the *Physical Artifact* includes an additional layer of glass on top of the smartwatch screen, rendering touchscreen interactions impossible. The resolution of the screen was very clear even at such a small scale (resolution of 340x340 pixels and 240 ppi). ReFind uses the built-in Accelerometer and Gyroscope sensors of the smartwatch to measure the orientation of the device and recognize the vertical rotation gestures needed to navigate the image collections. Equally, these sensors are used to detect if the device is no longer being held and puts the device into a low-bit ambient mode, whereby the screen dims and limits the pixel colors to either black or white to preserve battery life. The device will remain in this mode until motion is detected suggesting the device has been picked up and the application presents the latest image collection.

LIVED EXPERIENCE

The first author lived with ReFind for 10 weeks during which time 12 images from their current life were sent to the piece. We now switch to a first-person narrative to describe and reflect on key aspects of the experience through a number of themes.

Expectations, Desires and Documentation

Although I had been part of the design, build and interaction development of ReFind I was intrigued to see how it would actually play out in reality for me. I had an authentic desire to use the piece, for the specific context of connecting, perhaps in new ways, with my mum. Because of this I was aware that I might want to find meaningfulness in what the piece showed me, perhaps even if there was very little, but I was also wary of this and wanted to bring a balanced critique to this work and my experience of it.

As already described, I added keyword tags to 63 images of mum from throughout her life on our secure website. I felt very awkward about having all of these photos of her on there and visible to the team, even though the team were very respectful. The potential of what the piece might give to me was a strong driver however, and I was also acting as a guinea pig in many ways so that we could understand potentials of the piece and more about the context of ongoingness and continuing bonds in action.

I chose to keep a personal diary of each interaction I had with ReFind (Figure 5). Although the images that I sent to the piece were logged, along with their tags, the five images that were shown on ReFind in response were not logged anywhere. My diary was the only place where these collections were documented, which felt right and personal. I followed the same structure for each diary entry of use - drawing the image that I sent to the piece and noting down the five that came back in response. I logged the tags that I had used, the date, technical robustness or problems and

wrote about my experience of seeing each particular collection of five photos – and if/how this changed over time.
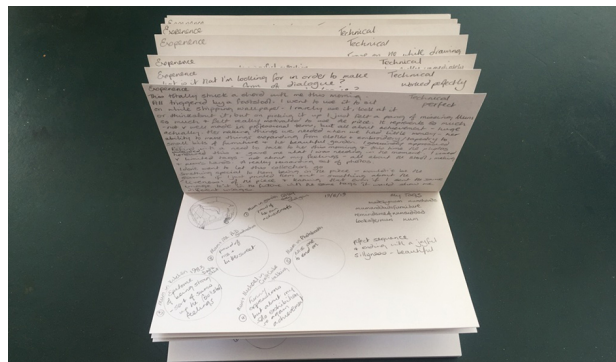

Figure 5. Diary of Use

Different kinds of use and Qualities of Connection

I've looked at ReFind everyday whilst living with it and sent twelve images to it across this time. I had a clear sense of ReFind acting as a kind of bubble of 'mumness' from the very beginning of living with the piece. I suspect this was partly because I had selected 63 images of her that spanned a wide range of emotions, experiences and points in her life (both good and bad) and partly because I had invested thought and effort into tagging them as exhaustively as I could. I didn't want to force my use of the object and didn't send images to it daily, instead doing this only when I felt a genuine personal motivation. On seven occasions I sent photographs to the piece as way of checking in with it. The motivations were somewhat passive and not driven by need or any particular positive or negative dynamic, but more like calling someone to just say 'Hi'. Three times I sent images because I wanted to share significant happy events that were occurring at the time with mum. Twice I sent images to the piece because I felt a genuine need in the moment to connect with mum. Motivated by pangs of missing her and also because in one case something negative had happened and I wanted a sense of what she would have advised me to do. The rotating interaction was something that I found myself doing repeatedly. There was something calming in the interaction and a strong affordance of being able to fiddle with the piece, rotating forwards and back, while I sought to see meanings between the images it was showing me in relation to me current life.

Connecting 'to'

In the case of wanting to share photos of significant events I found it particularly surprising to find myself saying once to my husband "come on, let's take a photo to send to mum". I didn't literally think that the piece was sending a photo to her, but nonetheless it did feel as though ReFind was holding aspects of her and giving me the opportunity to show her things again. There was a willing suspension of disbelief happening, but also a sense that ReFind was representing something of her. I saw it as a genuine repository of a quantity of things (facial expressions, particular contexts, specific narratives, idiosyncrasies, relationships with a range

of people) that were representing or standing for the person that she was, and still felt like to me.

If we think about continuing bonds and ongoingness as a form of connection with the deceased the 'connection' that is being referred to here is not about the photographs that came back to me, but the act of wanting to engage with the piece in the first place and 'send something to her'. There was a genuine sense that the piece was acting as a physical place that I could send things to as an act of sharing something or a way to *speak to* her in some sense. Of course, talking in your head or out loud to someone deceased is a common thing for people who are bereaved to do. It was interesting that I had seen the piece as a facilitator of this so readily.

Communicating 'with'
Speaking *to* is different to speaking *with* and, although this did not happen in most instances, on several occasions, I had a real sense that there was a dialogue occurring when I used ReFind.

Twice this was driven by a clear *visual mirroring* between the image I had sent to the piece and the ones that were returned in response. There was a sense that what had been sent to the piece had been listened to and responded to in kind, through sharing times when mum had experienced something very similar to my life at that moment. The visual mirroring even extended to the positionings of people in the images and I could even see some idiosyncratic traits and similarities between us that I was not aware of previously. This felt like a very human form of communication and had a genuine sense of dialogue around sharing similar experiences. It made me see old photographs in a new light – as closer to my contemporary experience – and see similarities that I hadn't seen before. The sense of being 'in tune' and finding newness in the archive created a sense of dialogue based on reciprocity and similarity.

A different form of dialogue occurred when collections of images *contextualized* my current experiences within mum's, but where mirroring did not feature. Here the piece acted like a window into her experience which gave me an insight into my life now. One collection, for example, showed me photographs of times when she had dealt with specific difficulties, which gave me a sharp sense of what advice she would be giving me in my current context. This form of dialogue was *purposive* in having the dynamic of giving advice or some form of guidance. I had expressed a current difficulty and the archive responses allowed me to tap into how she had overcome difficulties of her own.

In the two instances where I felt a genuine, urgent need to connect with mum one of these interactions led to an extremely meaningful set of photographs. The meaning arose from the *arc of the narrative* that I could clearly build across the five images. There was a clear beginning point where she was struggling with things that were happening at that time, progressing to a time when she had achieved a huge amount,

followed by things that she was proud of, then funny family expressions and close relationships and ending with an example of joyful silliness. The particular sequence created a narrative of things getting better from a low point and ended on a funny, very positive note. Sequences, therefore, at times, facilitated narrative building, often acting to support the meanings of particular individual images and made some collections feel more significant than the sum of their parts.

The images and particularly the sequence of the photographs in this specific collection felt so perfectly in tune with what I wanted and needed to see in that moment that I didn't want to lose it by sending anything else to the piece. After a number of days I decided to video my hands rotating the piece so I could capture the interaction, the sequence and the images that were revealed. I needed to film the piece, rather than printing out the collection of five photographs or just look at them in digital form on a screen. There is a 'liveness' to the images being displayed on ReFind that I was finding significance in.

I'm aware that I most likely felt such strong meaningfulness to collections of photographs, particularly where I had genuine need, partly because I will have wanted them to be meaningful. I think there was something highly serendipitous on these occasions also. Nonetheless, visual mirroring, situated and purposive connections, and certain narrative arcs occurred, and each enabled me to feel an authentic form of dialogue with mum.

Barriers to Connecting
On the majority of occasions, the photographs that I had sent to the piece were not driven by anything more than a desire to connect with mum and share prosaic things about everyday life. Many responses that I received were pleasant, but not particularly significant or causing a sense of being connected in an atypical way i.e. different to looking at photographs in an album. There is something useful to reflect on here however, as just with any relationship with people there are days when nothing spectacular happens and it is enough to just be with someone. If this had been the full extent of my experiences with ReFind then I may have felt differently about this, but as there were times when surprise and genuine forms of dialogue did feel to be happening then the instances that were less intense or significant felt fine.

On a number of occasions, however, there were things that jarred, or broke the sense of ReFind as a meaningful repository holding a representation of mum – and disrupted the feeling of a connection to her.

When do you want to see sad images?
Early in the use of the piece I sent an image to ReFind related to something negative that was happening in my life at the time. The images in response were primarily ones of mum looking anxious and unhappy. Unlike the experience I had with positive visual mirroring, discussed above, seeing unhappy images of her made my current context seem even more miserable. This led us as a team to contemplate when

is it appropriate to see sad images from the archive, to question why have them in the archive at all and to rethink how we were matching images in the piece.

In terms of matching images we had created a system where images were shown that had the most connections and strongest bond to the uploaded image. As a consequence 'sad' images would be matched with other 'sad' ones. However, the occurrence just described made us see the limitations of this. Even at times when images were not tagged with negative emotions or terms this system is likely to only return the most obvious of images – those that feature the same people, in a similar location, and mirror the tagged emotions. Whilst there was value in that we reasoned that it could also be useful to have some images in the collection of five that showed less obvious connections. To achieve this we produced a simple algorithm such that of the five images sent to ReFind, two of them were selected from images that had a 70% or greater match with the image I had sent to it, two had a 60% - 30% match and one had a 20% - 10% match. In this way there could me more potential for images that are obviously linked, through to those that may have a more subtle or abstract relationship to the uploaded image. From experience of living with the piece it is worth noting that there was clear value in having a mix of more and less related images, rather than ones that were all maximally connected. It encouraged serendipity into the exchange of images and we believe there is room for further investigation into this aspect and serendipity as a design resource in ongoingness.

Having 'sad' images in the piece felt important so that the piece could be as complete a representation of mum as was achievable from a relatively small archive of 63 images. It was significant to me that a range of images representing her across her life, in many emotional states and life contexts were in the archive. I did find it difficult when photos were shown of her from times when I knew things were personally hard and I wouldn't want to see a full collection of these kinds of images, but when they were with others with more positive dynamics I was able to view them as part of a bigger narrative and see things in them that were meaningful beyond the obvious negative elements.

Technical Issues and Insights
During the initial few uses there were some technical irregularities in the functioning of ReFind that yielded useful insights into what dynamics disrupted a sense of resonance in engaging with the object.

The first time I used ReFind it seemed to be working perfectly, but each time I returned to it there were a new set of five photos. As new sets kept appearing it interrupted any sense of specific meaning. I was surprised by how significant receiving just one, definitive set of images felt. Receiving multiples could, perhaps for someone else, have felt like an abundance of responses – a series of connections. For me it felt like I was being made aware of the system, the technology and importantly a disingenuous aspect of this and repeated sets of images lost any sense of genuine response.

On the next two occasions of sending images to the piece the quantity of images that ReFind responded with were different - firstly four images and then nine. Receiving four was not a huge disruption, nine, however, felt too loose, unstructured and untailored. Although the design decision that the piece would return five images was initially arbitrary I found it a useful number to be able to build a narrative around and it gave space for one or two of the images to feel less related to the context of what I had sent to the piece without rendering the whole set meaningless.

DISCUSSION

Living with ReFind and reflecting on this experience from within a very personal context was a huge departure from our familiar practice of making work for individual participants within participatory design engagements. It felt a necessary step for us to take, however. Firstly, seeking to support ongoingness in continuing bonds through digital design has little precedent in the work of others. We wanted to gain a deeper level of understanding of the complexities of our goal before working with external participants. Secondly some of the team had authentic, lived experience of the context of bereavement and therefore expertise that they could bring through genuine engagement. Thirdly the first author could see potential personal benefit to experiencing the piece, which in turn would give us a specific form of critique and insight.

Our experiences of autobiographical design echo the tenets that Neustaedter et al [35] describe (*genuine needs* (authentic motivations), *real systems* (a developed and functional system), *fast tinkering* (space for iteration), *record keeping and data collection* (rigorous documentation and honest observations of the design development and lived experience) and *long term usage* (space and time to deeply engage and embed the design into your life). The only caveat being that our usage was for ten weeks, but this was an intense engagement.

What we gained from our own lived experience is not about generalizability of the specifics of the design itself. The approach gave us the ability to critique our design from a new, personally invested vantage point. It also enabled a number of deep insights and understandings of our context, the theory supporting it and authentic experience of the possibilities and challenges to achieving what is a highly complex goal. We offer our personal observations of the work now in the spirit of insights from a particular lived perspective rather than generalizable truths.

Critical Observations on the Design

The characteristics of the design that we think are strong after living with the piece centre on the form and rotational interaction. The piece feels good in the hands; frames the images well; has been robust in use and following early glitches worked consistently as designed. Rotating the form in order to move through a series of images either forwards or backwards brought an intrigue to the use of the piece (for us). There is theatricality with a very small 't' to the piece in

that there is surprise heightened by the reveal of images on each rotation. There is a minimal, but meaningful interaction that seems respectful of the specific bereavement context. Unlike images feeling disposable, which can be a common dynamic to viewing digital images on screens the slow pace of rotating the object to see one image at a time caused us to slow down and pay a different kind of attention to these images. Being able to have a fidgeting, restlessness with the hands seemed to enable a focus in the mind of what the connections between images could mean.

Not all aspects of the piece and interaction were as strong and could be developed further in preparation for if/when ReFind is used by external participants. Firstly there is considerable effort (time and emotional work) needed to initially tag all of the archive images, secondly the stage of tagging new images on the web interface is currently somewhat cumbersome and the structure and support for this could be better supported and thirdly advanced use of the graph database could enable more nuanced understandings of the meanings associated with images and also help establish different weightings or importance to connection types.

An Object for Post Grieving

Living with ReFind, discussing amongst the team iterations in the interaction and system design and using it as a vehicle for complex team conversations around ethics, participation, mortality and grief we were able to see that this was most likely not an object for someone at a fresh stage of bereavement when things are very raw. Instead we envisioned it being used by someone who wanted to reexplore their relationship to someone deceased from a point in their bereavement where it was less viscerally painful and where they could comfortably reflect and seek new continuing bonds.

A Closer Understanding of Theory

Having someone in the team as a researcher/participant enabled us to discuss some of the theoretical concepts driving this work in ways that we would not do with an external participant (because in sensitive and complex contexts this could alienate or seriously detract from what we were trying to achieve/make for them). Team members were able to question and challenge things about the concept of continuing bonds and how technology can support these without fear of saying things or prototyping things insensitively. It gave us a reason and 'way in' to have complex discussions about how we were thinking of the theoretical ideas matching the design exploration.

One of the ways that people enact continuing bonds and find resolution, or the ability to live with grief is to create active inner representations of the deceased for themselves. What we found through our autobiographical experience echoed some of what Silverman et al [47] say about positive grief work (meaning progressive, constructive working through feelings in order to again some personal stability in bereavement). They describe four categories of active inner

representations: the first is as a role model, the second is situation specific guidance, where the primary function of the deceased is to help the living deal with a specific situation, the third centers on values clarification where the bereaved adopt or reject a moral position taken by the deceased and the fourth is remembrance formation without the deceased performing any active function. We experienced all of these through living with ReFind, but situation specific guidance felt a particularly resonant concept in relation to ongoingness. This is because it is less about looking back and more concerned with active, dynamic change in the present.

We were also able to see clearer links between continuing bonds and personhood as theories. As described earlier both personhood and continuing bonds suggest a design space that acknowledges our non-bounded selves. Both acknowledge that the nexus of people around someone support, represent and maintain aspects of who they are in the eyes of others and for the individual themselves. Whilst in personhood those doing the supporting are commonly thought to be the people around an individual with dementia, in continuing bonds the deceased person is framed as providing support for the people who are grieving them. We saw a glimpse through ReFind of digital technology being able to act as both receptacle of things/data/media that represented a range of dynamic elements of who a person was and also the means by which new, dynamic forms of connection to that person could be made.

Articulating Types of Connection

We now have a more developed proposition regarding qualities of connection that could comprise (or at least be part of) the design space around ongoingness as a concept.

Having a place or object which felt like it contained media and data that could stand as a representative for aspects of the dead person seemed extremely important and could enable someone to feel a sense of connecting 'to' (as in reminiscence or memorialization). This is a prerequisite for any search for continuing bonds, but in terms of ongoingness this only takes us part way to any dynamic connection to the present and the future of the living person. Connecting 'with' seemed a stage further towards this goal. We did experience connecting 'with', albeit only several times, and these occurrences helped in articulating three characteristics of the types of connection that may be useful for ongoingness.

The first is *mirroring of positive things*. When images of the deceased visually echoed positive images (i.e. those perceived to be happy, upbeat) of the user the connection was one of reciprocity and as if the piece had paid attention to the image sent to it and was responding with something very similar. This enabled reflection on shared life experiences, shared idiosyncratic traits and new readings of the archive images. Mirroring acted to reinforce the bond between the user and the deceased person and collapse time to show how in tune with one another both people are.

The second quality is *contextualized connection*. This, as mentioned above, echoes ideas in continuing bonds of situation specific guidance. The sense of dialogue that occurred using ReFind here was about a view onto the life of the user's mother that could contextualize how to tackle things that were occurring in their life now. Although there was no literal guidance given in the form of a letter, for example, the user was able to reflect on how their mother had approached a situation and see ways to do this for themselves in the present.

The Third is a connection based on *positive narrative arcs* which is something that occurred across a whole collection of five photographs. Here images acted as more than the sum of their parts and a narrative that had a sense of purpose or positive outcome and that was seen very easily by the user (rather than them having to work hard to craft this) led to a sense of receiving a positive message from the deceased.

These dynamics or qualities that led to a sense of dialogue and connection between the deceased and the bereaved person in the present and looking to the future are not conclusive, of course, and have arisen from our autobiographical experiences. What they give us however is a starting point and a 'way in' to understanding and articulating qualities of connection that could facilitate ongoingness and future roles for design and the digital.

Framing Future Design

Reflecting on ReFind from a wider position we acknowledge that all of our ideas and conceptual thinking relied on metadata. We had adopted a data driven approach to connecting someone bereaved with someone deceased. All of the photographs of the deceased person in our case did not have metadata naturally. For someone deceased who lived a more digital life there would quite likely be a lot of metadata about their media. What we were trying to do was to build this retrospectively and there are limitations and difficulties in hand constructing metadata that made sense.

We were lucky that with a relatively small collection of images and metadata (created not by the deceased person but the bereaved person) that we found several instances that had a strong sense of dialogue in relation to what was happening in the present. Reflecting back on what the underlying computational mechanisms to support ongoingness could be when there is a lack of metadata we see the value of an ontology or knowledge representation of what was meaningful to the deceased person. Equally this work causes us to reflect on other ways beyond metadata to achieve a sense of ongoingness for people.

A goal and motivation for the wider research project is to work with people approaching end of life and help them curate or create digital media that would help others experience ongoingness and continuing bonds after they die. This brings into sharp focus the key thing that was missing in ReFind - the first author's mother. If she had been able to index images with meanings then there would be a more nuanced, richer set of metadata. This would be coupled with the knowledge that she had annotated or indexed them meaning that there would be an intent inherent in all of the data, which brings another level of meaningfulness to it even before being used in a system like ReFind.

There is something that we find very powerful about the idea of ongoingness and continuing bonds through digital design even without the person indexing their media before death. As in conceiving of ways that the digital can be configured and accessed to create a sense of connection in the present between the living and the dead we are effectively involving the deceased person as a dynamic actor in the system. We stress the value of the design space that ongoingness and continuing bonds frames for HCI and Design as it provides nuanced and pragmatic ways for us to see new opportunities for digital design to support people in bereavement and also approaching end of life.

Only by making ReFind, trying to create a computational process to support ongoingness and living with the piece from a genuine point of engagement were we able to really see and feel all of these points of discussion.

CONCLUSION

In this paper we have described the design and autobiographic use of ReFind, an object exploring if and how it is possible to support ongoingness in bereavement through digital design. We have framed ongoingness as a dynamic facet of continuing bonds theory focused on the present and future life of the bereaved and the potentials therein for the deceased to play a positive role. Autobiographical use gave us lived insights, which although not generalizable, offer key 'qualities of connection' that go beyond reminiscence or looking back to suggest ways in which a dialogue or sense of dynamic connection *in the present* to someone deceased could be supported. The case study offers starting points for further research and gives us clues to possible characteristics of digital design and the use of media and metadata to support ongoingness in bereavement. We hope that our case study inspires further work in this area and serves as a useful account of research through design and autobiographical use.

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