
Designing for Dementia: Iterative Grief and Transitional Objects

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Introduction

Material objects are an important part of the grieving process and act as memorials to loss. Objects owned by, or shared with, a loved one can help individuals as they transition through bereavement to a stage where they can come to terms with their loss and the permanent absence of the person they loved.¹ Material objects can play a similar role for people living with dementia and their family members and carers (also known as caregivers and caretakers) as they transition through the degenerative disease toward the inevitable end of life. Dementia is terminal. Individuals with dementia might experience grief and loss at the initial diagnosis, only to find these feelings compounded as they become aware of their own declining abilities. Similarly, family members and carers might experience anticipatory grief at the diagnosis and then find that grief and loss build on each other iteratively as the person they know and love is changed by the condition and when the person they knew is seemingly no longer present.²

This paper reports on design research to make sensory textiles for people with advanced dementia – a time often marked by feelings of sadness and loss. The project aimed to provide sensory stimulation to support “in the moment” pleasure and positive well-being through interaction and engagement with material objects. The study found that the objects promoted engagement and interaction between the person with dementia and the object, as well as between the person with dementia and his or her family members and carers; they became a point of focus during a time of transition and transformation; and when death occurred, they acted as a memorial to the latter stages of life of the person with dementia. This paper discusses transformational and transitional objects and reports on the methodology and findings of the study. It argues that transitional objects, which offer comfort and security in the transition into independence (and so are often associated with children), can also provide support to individuals in the transition into greater dependence (as occurs with aging and dementia) and can offer an ongoing sense of connection for family members and carers at the end of life.

Background

Ongoing iterative forms of grief and loss, such as those that follow a diagnosis of dementia, are likely to become more prevalent. As people live longer, the occurrences of age-related conditions like dementia will be higher, and dementia inevitably will become more apparent in many areas of everyday life.³ For example, by 2050 the number of people in Australia over the age of 80 will increase to almost four times that of 2001.⁴ In 2015 an estimated 46.8 million people worldwide were living with dementia, and the number is expected to reach 131.5 million by 2050.⁵ Dementia is a syndrome comprising a range of neurodegenerative diseases, such as Alzheimer’s disease and vascular dementia, which are the most common. Dementia manifests in a

variety of conditions that includes significant memory loss; limitations in communication abilities; changed perception; and reduced physical and cognitive functioning. However, consciousness is not affected, and individuals with dementia are able to experience pleasure and retain emotional memory.⁶

Dementia affects not only the person living with the condition, as they transition into greater dependency, but also family members and carers. They all might experience grief and multiple losses. In the early stages of dementia, individuals often have a clear awareness of the symptoms of their decline and experience ongoing grief as they recognize a loss of knowledge, memories, and abilities.⁷ People living with dementia might experience a “pseudo-death”—that is, “as you mourn the loss of not being able to do or remember one thing, you find that you lose another function or capacity.”⁸ However, despite loss of cognition, people with dementia retain the ability to experience emotion.⁹

The grief of family members and carers is complex and ongoing because they experience no finality to their loss.¹⁰ They might grieve the loss of the person they knew, feel that they are “losing them,” and perceive them as “fading away.”¹¹ They also might experience anticipatory grief; mourn, pre-death, the loss of the person with dementia; or be troubled by feelings of freedom when death occurs.¹² Family members and carers might mourn a symbolic loss for their future self, as they no longer can define themselves in any other way than carer. They might have feelings of guilt about institutionalizing their loved one.¹³ Their grief might be “latent”—that is, concealed, hidden, or lying dormant—and because of the stigma associated with dementia, carers and family members often experience disenfranchised grief.¹⁴ They are not able to mourn openly for the perceived or actual death of their loved one and have few social mechanisms to support them and the complexities of the situation.¹⁵ They have difficulty focusing on the potential for pleasurable experiences that remains—even for a brief period—and catalysts are needed to refocus attention.

For the person living with dementia, the aging process, the disease, and the feelings of loss, separation, and insecurity might cause individuals to form attachments to people, or objects. Winnicott’s theory of transitional objects suggests that children form attachments with objects that offer security and comfort as they transition through individuation.¹⁶ Inverse parallels have been drawn between the development of people in later stages of dementia and early childhood development. This move is intended not to infantilize or to ignore their wealth of life experiences, but to provide a framework to comprehend the normal attachment to objects and the relevance of transitional objects throughout the lifespan.¹⁷ For people with advanced dementia, attachment to objects might become more intense in times of insecurity, and transitional objects can act as an anchor as they transition into greater dependency.¹⁸

“Precursor objects” comfort and soothe children and are selected for their tactile qualities to provide an emotional response.¹⁹ These objects often take the form of textiles; toys; blankets; or items of clothing.²⁰ Tactile objects also can be used in this way to engage people with dementia and to promote well-being and positive emotions.²¹ These objects often are provided by family members to encourage tactile engagement, to fulfill the need for attachment and security, and to provide activity and status.²² They can connect the past and the present, particularly when they include personalized memorabilia, such as photographs, personal shared possessions, or music. The use of transformational objects is an aesthetic experience enabling

individuals to connect to their past, present, and future self through an emotional engagement with art forms, such as music, art, or poetry.²³

Material objects are important in the grieving process, and research increasingly shows how transitional, precursor, and transformational objects support adults through grief and loss.²⁴ Personal or shared objects are embedded with the construction of identity; they become symbolic of the person being grieved for and mediate and signify absence.²⁵ These objects come to stand as memorial, as “human corporeal existence is both compensated for and replaced by representation and objects.”²⁶ Viewing objects and activities through this lens has implications both for the care of people with dementia and for how we design for people in later stages of the condition.²⁷

The Study

The design research study took place over a period of a year. During this period a range of personalized objects and blankets were made for residents at Gwalia Mynydd Mawr residential care facility in Llanelli, Wales. This paper reports on two objects.

Designing Objects for “in the Moment Experience”

Caring for and visiting a person in the later stages of dementia often pose challenges, even for the most loving family members, because of the difficulties with verbal communication, withdrawal resulting from depression, and sedation as a side effect of medication. The design research presented in this paper focused on developing sensory textile artifacts (garments and blankets) to support the well-being of people living with advanced dementia in residential care. These textiles are designed to comfort, amuse, stimulate, and distract a person living with dementia by encouraging “in the moment” experiences and physical interaction. Each one is highly personalized, tactile, and colorful and includes embedded technology to extend the sensory experience. They provide the person living with dementia with something to do and help broker positive interactions that are also “in the moment” with professional carers, family members, and visitors.

Designs are developed specifically to tap into emotional memory, rather than episodic or semantic memory, which is significantly impaired through the progression of the disease.²⁸ This access to emotional memory is achieved through the integration of elements reflecting the life history and personal preferences of the person for whom the textile is designed. Consequently, family members, partners, and close friends who know the person living with dementia well are vital to the design research process. In addition, professional carers and health professionals, who understand the everyday needs of the person in residential care, are able to contribute invaluable insights. These narrative accounts have contributed rich qualitative data to the research process.

Dementia care advocates and organizations frequently use the analogy of a journey to discuss how each individual with dementia follows his or her own path through the disease, highlighting how progression is neither uniform nor consistent. The challenge of developing designs therefore means ensuring that the design has the capacity to adapt and change with the needs of the person as they change. The following sections present two examples drawn from 13 design case studies undertaken as part of the Sensor e-Textiles research project, funded by OPAN (Older

People and Ageing Research and Development Network) and Cardiff Metropolitan University.²⁹

The Objects

The design research took place over the course of a two-year period between 2014 and 2016. This study builds on earlier research that identified the important synergy between playfulness and well-being and highlighted the need for playful objects that could be used to promote playful experiences for older people.³⁰ The Sensor e-Textiles research project explored the use of embedded technology to extend the sensory properties and to allow items to become more highly personalized, in line with the person-centered care ethos of the project partner company and government guidelines for care.³¹

Methodology

The project used interpretative qualitative methodologies including interview, observation, and case studies from Gwalia care facilities.³² Semi-structured interviews were conducted with key care staff, the care facility manager, and occupational therapists. Interview questions were framed to identify the level of need for sensory textiles and the interest and expectations of the care facility staff in the research, as well as to identify suitable participants for the study. Participants were selected in consultation with the care facility staff. Family members and professional carers provided personalized specifications for the design of bespoke objects. The specifications included the person's individual preferences and interests, and were written up as "persona cards" and used in subsequent participatory design workshops to stimulate and direct ideas. Two participants are discussed in this paper.

Seven participatory events were held over a period of a year. The materials used in the creative participatory workshops included a variety of different weights, colors, and types of fabrics; haberdashery, including buttons, lace, zips, and beads; and assorted yarn and threads. Sewing machines were provided, and textile design specialists contributed their expertise to guide construction and ensure elements were securely stitched. Occupational therapists contributed useful advice concerning, for example, infection control requirements choking hazards. Technologists provided expertise in electronics and software development. Simple microcontrollers, including Arduino™ and Touchboard™ technologies, were used to add functionality through embedded electronics.

Participatory "funshops" (a term first coined by Killick) enabled carers, managers, health professionals, charity representatives and volunteers, and artists and designers to be involved in the design process, and "tech workshops" (i.e., technical workshop approaches, as used by the Maker Movement) enabled experts in materials, electronics, and computer science to be involved.³³ Working in small groups, with a persona card to guide concept development, participants developed ideas for the sensory textiles in an iterative process of ideation, design development using materials, integration of technology, evaluation, and refinement. Workshop data were collected in the form of interviews with participants, design worksheets, and photographic and video documentation, and in the course of the development of a series of textile artifacts.

Sample

Participants were selected following initial case study interviews with health and care professionals from the partner organization, Gwalia Cyf. Selection was based on the following criteria:

- The perceived level of individual need and therefore the likely enhanced observable effect from the intervention;
- Interest and approval from family members;
- The perceived disposition of the person living with dementia to be involved in the study, based on the family's knowledge of that person during their lifetime and following the diagnosis of dementia; and
- Family willingness to give assent for the relative with dementia to be involved in the research.

Evaluation

The “funshop” and “tech workshop” analysis was informed by a review of relevant literature, and used an inductive approach as common themes were identified and explored through an iterative process.³⁴ Using an interpretive approach, researchers were able to work closely with family members and staff who had an intimate knowledge of the participants—and therefore were experts in the field—in the analysis of participant responses.³⁵ This process recognized the importance of drawing on the experiences of a range of experts in the given field and of comparing findings with established practices and theories.³⁶

Figure 1

John's Blanket

A blanket was made for a resident who had a keen interest in technology all his life; his family felt this interest made him a suitable participant for the research. The blanket was made from a woven grey woolen suit fabric and contained tactile elements, including a sheepskin-lined leather pocket, evocative of a working apron worn during John's earlier life. His love of music was incorporated into the design by embedding an MP3 player containing his personalized music playlist of favorite tunes. This device was integrated into the blanket and a clothes button was used to operate the on/off power switch. A larger pocket at the side enabled his headphones to be kept within easy reach at all times. John's son confirmed that his father appeared to really enjoy the music and observed that it calmed him when he became agitated and helped him to relax.

Following the first evaluation session in the care facility, one month after the textile was handed over, amendments were made to improve the design. Changes included making the electronics more robust and adding a digitally printed fabric family photograph album (Figure 1) with photographs selected by John. Although he had limited ability to communicate verbally, John was able to indicate with facial expressions (interpreted by his son), which photographs he wanted to have included in the book. When the album was printed and buttoned on to the blanket, John spoke for the first time in many weeks, identifying himself in the photographs and affirming verbally that he liked the album. This communication surprised his son and carers, indicating a level of interest and stimulation that had not been evident for some time.

John's son found that the blanket became the basis for interesting activities that he could do with his father during visiting times. A string of colorful silk fabric

bunting was attached inside one pocket that he and the occupational therapist were able to use in simple arm exercises. The blanket also helped to stimulate interaction between John and his son and initiated conversations with carers and other residents. The personalized motifs conveyed themes that were important to John and that had been part of the life he could no longer remember; the object helped to retain his sense of identity and personhood.

When John died, his son reported that he was able to find comfort in the blanket when grieving. In an email sent shortly after his father's death, he wrote:

He passed peacefully while I sat beside him holding his hand.

I just want to say thank you for including Dad in your studies and offering us both such a rich experience. I have and will treasure the blanket we developed and feel very connected to him through it.

Bill's Blanket

Bill was a resident with late-stage dementia who was bed-bound and had limited vision. The sensory textile developed for him was based on the theme of Aberglasney Gardens near Swansea, which is a place that he and his wife enjoyed visiting together (Figure 2). Members of the design team were given photographs of the gardens, and using the persona sheet, they developed a concept that integrated Bill's personal color preferences and his love of trees, birds, and walking in the natural environment. Because Bill was bed-bound, a lap blanket was considered more appropriate than a garment. The fabric selected, chenille, was a heavyweight one but soft to the touch, and the blanket was edged with rich green cotton velvet, used to evoke the hedges in the formal gardens at Aberglasney. The visual motifs used in the concept included wild birds and ducks, and trees and their fruits—nuts and acorns, for example. The textile contained five tree motifs connected to electronic touch sensors. When very lightly touched, they played five different woodland sounds to evoke the feeling of walking in the gardens, including running water, wind in the trees, ducks quacking, wood pigeons cooing, and wild birds singing. The blanket also incorporated things of tactile interest, such as beads, zippers, tassels; a stitched fabric book containing digitally printed photographs of wild birds; and stitched beaded tactile pages, reminiscent of braille.

Bill learned how to use the blanket and made the sounds himself within 20 minutes of receiving it. His wife expressed her amazement:

He pulled it up a bit onto his lap, and he tried to find where it was—you could see him try to find them [the buttons]. He found them and touched them!

Amazing!

In subsequent evaluation visits, his wife described how using the blanket made visiting times easier. It enabled them to have visits that were more intimate, where she could reflect on memories of their happy times walking together and simultaneously have special time together “in the moment” at Bill's bedside, seeing the pleasure he derived from exploring the sensory blanket with her. She explained that she would take the blanket home with her after visiting and was unwilling to leave it at the care facility for others to use with him. It was a special object for her and her husband to connect with each other—for maintaining intimate special moments, hand on hand, as they retraced walking together at Aberglasney on the textile. After his death, Bill's

wife kept the blanket to remind her of the times she had shared during the later stages of his life.

In designing the electronic component, ease of use for someone with only limited manual dexterity and vision was important to consider, as were basic necessities, such as washing the blanket and recharging batteries. The microcontroller (Touchboard™) was placed inside a removable leather pouch attached to the textile with metal press-studs. This approach had a dual function as the press-studs also completed the electronic circuit to operate the device by connecting to strands of conductive thread through the fabric, ending in the on/off switch behind clothing buttons. Appropriate sounds were selected from a free on-line file source and uploaded onto the Touchboard™. The battery pack was contained in a separate leather pouch to ensure insulation from the microcontroller, and the entire pouch fastened together with strong Velcro, to ensure both safety and ease of access for recharging the device. A ball speaker was used to provide sound. Although the electronics worked well and were easy to recharge, refinement to make the electronics and speaker more discrete would further enhance the design.

Discussion

The two blanket objects were designed to help support people living with dementia as they approached the end of life and their families. In the later stages of the disease, a person living with dementia might no longer experience the acute sense of grief and loss he or she had experienced earlier but might be in need of basic comfort and soothing. The materials chosen in the construction of the sensory textile object fulfilled this need by offering fabrics, such as chenille, that are warm and pleasant to touch. These choices have parallels with the types of pre-cursor and transitional objects selected by and for children.³⁷ Furthermore, the blanket format meant that the objects were brought into close proximity to the body and so provided a further sense of comfort, based on Gibson's discussion of how objects sooth.³⁸

For families and carers, grief, loss, decline, and withdrawal all too often mark the later stage of the disease. However, people with dementia retain capacity to experience pleasure, and carers and families often welcome opportunities to focus on this during their visit, and to have a reprieve from the ongoing sense of loss, grief, or guilt they feel. Bill's sensory textile showed how a "connection" with another can be maintained through focus on an object and how it is possible to maintain personhood and to sustain relationships. For Bill and his wife, the blanket became transformational as it rekindled and reinvigorated intimacy in their relationship. The use of the blanket redirected focus away from Bill's condition by stimulating emotional memories through virtual experiences of walking in a garden and listening to the sounds of nature. For Bill and his wife, it was an "in the moment" aesthetic experience on which they could build and, for Bill's wife, a reminder of aesthetic experiences they had shared.³⁹

The personalization of the sensory textiles affected how the objects were received in a number of ways. For the family members, the objects assisted their visits by creating opportunities for "in the moment" pleasure, connection, and conversation. The personalization encouraged the participants in the study to focus fully on their intimate and personal time together. This focus on the present was further reinforced by the design process, which reiterated the shared experience through the making of something together—as suggested by the email from John's son following his father's

death. Personalized elements for the person living with dementia were used to stimulate emotional memory and encourage a connection or attachment to the object. For John, both the music and the photographs of him as a child made an impact.

Focusing on personalization supported the retention of a person's identity, even when they could no longer remember or communicate their past. The inclusion of personal photographs, music, and references to favorite places provided continuity (for John's son and Bill's wife) between the person with whom they now engaged and their private memories of the person they had known as they shared experiences through life. The sensory textile object made reference to past experiences and became catalysts for new memories and shared intimate experiences.

The person-to-person and person-to-object experiences had a heightened poignancy as dependency increased. For John's son and Bill's wife, the objects became a point of focus as they transitioned toward the end of the life of their loved ones. A transformation took place after death, and the objects, embedded with personal memories, became memorials.⁴⁰ John's son communicated that the blanket continues to offer him a sense of connection to his father and has become a highly personalized memorial keepsake—a process recognized by Gibson in her discussion of memoria.⁴¹ John's son retains memories of his father in his active earlier lifetime but also embraces his later years when he was living with dementia—the part of a person's life that might not normally be acknowledged. Similarly, Bill's wife retains the blanket she used with Bill to reconstruct the walks they took earlier in their lives. It too has become a memorial to Bill that allows her to acknowledge all stages of his life.

Both participants developed an attachment to the objects, in that they recognized the blankets each time they were introduced, engaged with them, and did not reject them at any time—a likely response for people with advanced dementia. In both cases, attachment grew stronger as their physical condition deteriorated, and the objects themselves became increasingly important as channels of connection and non-verbal communication between family members and the person living with dementia diminished.⁴²

The design of the objects enabled a focus on “in the moment” pleasure. Visual, tactile, and auditory interest was specifically designed to elicit emotional memory, providing moments of intimacy and connection with others. The objects were designed to be adaptable as the person with dementia transitioned into greater dependency and were used increasingly to soothe and calm in times of agitation. Neither participant living with dementia in this study was able to directly articulate his own experiences. However, researcher observation and interviews with family members and care staff verified that pleasurable emotions were experienced, expressed, and shared.

Conclusion

The study began with the intention of creating sensory objects to promote positive well-being for people with dementia and their immediate family members or carers. However, once shared, such objects can take on “a life of their own.” They can represent different things for different people, promote differing types of connections, and fulfill a variety of needs. Existing research shows the importance of objects for people living with dementia. However, this study shows how sensory objects can enable people in the latter stages of life to connect socially, engage meaningfully with

objects, and experience pleasure. As people living with dementia approach the end of life, attention is often focused on their clinical and medical rather than emotional needs. This study shows the importance of maintaining a sense of personhood throughout the life term and how attachments can be created with personalized sensory objects to support this aim. The study is part of a greater body of research being undertaken to understand the relationships between objects and people with dementia, their family members, and carers. The study cannot make claims that these sensory objects are transitional and transformational objects in the strictest terms given by Winnicott. However, in taking a highly customized approach and designing bespoke objects, the sensory textiles prompted emotional memories and facilitated moments of connection that provided comfort in a time of transition and transformation for both the person with dementia and his family member. For both John's son and Bill's wife, the sensory textile objects became memorials enabling them to acknowledge a significant part of their loved one's lives: the time when they were living in the later stages of dementia. This important period of time is all too often ignored in the post-death remembering of individuals.

This study has illuminated that objects can be designed specifically to support people living with advanced dementia and their loved ones to transition through the difficult later stages of the disease

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- ¹³ Doka, "Grief, Multiple Loss and Dementia." 17-18.
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²⁵ Gibson, *Objects of the Dead*.

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²⁹ Further descriptions and photographs of the work developed during this research project can be found on the website, www.laughproject.info, and in Treadaway, "Sensor e-Textiles: Person Centred Co-design for People with Later Stage Dementia." This work is being continued in the LAUGH international research project funded by the Arts and Humanities Research Council (AHRC), UK, which focuses on developing playful objects for people with late-stage dementia.

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