



DESIGN4 HEALTH

Extract of the
**Proceedings of the 3rd European
Conference on Design4Health**
Sheffield 13-16th July 2015

Editor: Kirsty Christer

ISBN: 978-1-84387-385-3

Sensor e-Textiles: Designing for persons with late stage dementia

Cathy Treadaway¹, Gail Kenning² and Steve Coleman¹

¹Cardiff Metropolitan University, UK

²University of Technology Sydney, AU

Abstract

This paper describes an on-going inclusive, participatory design research project investigating ways of supporting the subjective wellbeing (SWB) of people with late stage dementia through the development of sensory e-textiles. This research addresses the World Health Organisation and G8 call for an international response to the global challenge of the ageing population and, in particular, research into care of people with dementia (WHO, 2012). It presents an international collaboration between researchers at the Centre for Applied Research in Inclusive Arts and Design (CARIAD) Cardiff Metropolitan University and the Faculty of Arts and Social Sciences at University of Technology Sydney. The project is partnered by Gwalia Cyf, one of the leading providers of residential social care for the elderly in Wales, providing access to staff expertise (occupational therapists, home managers and carers) and facilitating the involvement of residents and their families in the research. The research team includes textile designers, computer and materials scientists, software and electrical engineers who have brought their multidisciplinary expertise to the co-design process.

The authors' previous research (Treadaway et al, 2014) has identified the current lack of well-designed products for persons with dementia to enhance subjective wellbeing. In late stage dementia people lose the facility to relate to the external world beyond the body and so garments can be used as an important vehicle to stimulate, distract and soothe individuals (Twigg, 2010; Kontos and Martin, 2013). This paper describes the development of new types of personalised textiles that provide sensory stimulation and encourage 'living in the moment' through the integration of embedded electronics and smart materials. It reports on the design research process, including case study interviews with family members and care professionals, co-design participatory events and evaluation studies. Early findings from the research indicate that textiles that have

been developed to date are having a positive effect on the SWB of persons with dementia and assist with their care.

Keywords: design research, dementia, smart textiles, co-design

The dementia problem

A third of people diagnosed with dementia in the UK live in residential care, however funding and research into dementia care has increasingly focused on enabling people to live in their own environment for as long as possible. Long-term care is often overlooked and perceived as the 'ugly sister' of the care sector.

People with late stage dementia frequently have very little to do; they are often withdrawn, difficult to communicate with and exhibit challenging behaviour (Killick, 2013a). Both anecdotal evidence from carers and care home managers and health care research suggests that physical pain, frustration and boredom can contribute to these difficulties (Chenoweth *et al*, 2009). Boredom and lack of activity contributes to depression that is frequently treated with medication (Zeisel, 2011). This approach is both expensive and can contribute to further withdrawal. There are both social and economic benefits to finding new approaches to care for people with late stage dementia. Designs that encourage fun, joy, laughter and playfulness are urgently needed (Killick, 2013b).

This paper describes design research that aims to develop sensory textiles to stimulate, sooth, distract, engage and occupy people with late stage dementia and bring pleasure back to the final stage of life. The project investigates new ways of personalising designs using embedded technology, to build self-esteem, maintain personhood and promote dignity. This paper focuses on findings from the evaluation of initial prototype designs. The study presented is underpinned by a positive design methodology (Desmet and Pohlmeier, 2013) and practical grounded theory (Craig and Tracey, 2014) using qualitative research approaches (Blessing and Chakrabarti, 2009).

Research Methods

Case Study Interviews

A series of case studies were undertaken to identify the kinds of textiles currently used in the project partner residential care homes. Care professionals including managers, carers and family members, were interviewed about dementia care practice using an informal semi-structured interview process, documented through voice recording and photography. In the final case study family members, the company occupational therapist (OT) and carers were invited to identify specific persons with dementia (PWD) for whom a personalised sensory textile garment or blanket might be beneficial. Three individuals were identified: two male and one female. They were selected based on the level of challenge encountered in their care and the availability of information about their lives.

Personae pro formas were developed from this data and used in group activities in a subsequent design development workshop.

Participatory design research

A 'Dementia Apron Funshop' was held immediately following the case studies. This multi-disciplinary participatory event brought together the research team with textile designers, health professionals, carers, computer scientists, members of the Hack Space community and representatives from social care organisations and charities. The participants worked together in three groups, each with a persona pro forma to scope design ideas.



Figure 1: Hack Funshop event at Cardiff School of Art and Design

Two groups produced textile design prototypes for an apron and the other a blanket. The third group focused on developing functionality using embedded technology integrated into the garment using a series of detachable pockets. This design was able to show proof of concept, but was not sufficiently completed to be trialled with the PWD for whom it was made.

The Hack Funshop produced a wealth of useful data indicating the potential of embedded technologies, the importance of tactility and materiality and highlighted ethical and health and safety issues. Each of the three groups contained an OT who was able to advise on avoiding potential choking and other hazards; hygiene, cross infection concerns and practical care issues such as washing and dressing.

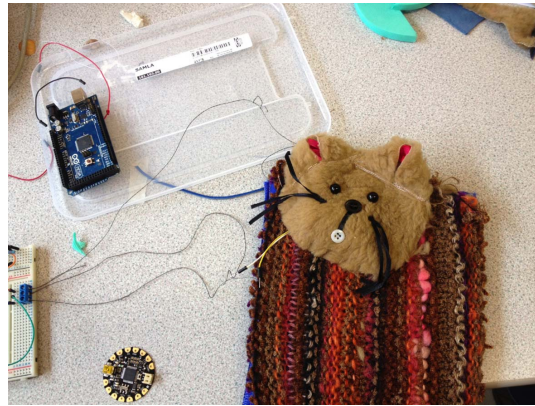


Figure 2. Cat pocket with embedded electronics

Evaluation

Trials and Case Study Interviews

The two completed sensory textiles were trialled with the people for whom they were designed over a two-week period. Photography, video recording and semi-structured interviews were held at the end of the two-week trial period and then again two months later in an informal group event. Two members of the research team met with carers and an OT that knew the PWD and family members well, was familiar with their care patterns, and their cognitive and physical limitations. Both PWD receiving the textiles were in late stage dementia, unable to communicate verbally and had lost bimanual coordination.



Figure 3. Dementia apron made for Participant B

Family members and care staff working directly with the people for whom the sensory textiles had been made, commented positively on their impact. The OT stated that she believed the textiles had been 'a real success.' A family member commented on his father's reaction:

he's been really responsive.... he smiles and there is a sense of enhanced wellbeing... I think it's the objects, they help him connect to the world don't they? And they help... people to connect to him.

Evaluating PWD response is challenging due to lack of verbal communication. However, empathy and resonance with participants is key to both the research and evaluation processes undertaken. Carers and family members were able to provide insights and report on their perceived level of response by the PWD, based on an intimate knowledge of the person. Researchers were able to analyse micro facial expressions and hand movements from direct observation and video recordings of the PWD. The following sections elaborate on the recurrent themes that emerged from the interview data. Findings, while specific to these case studies, build a richer understanding about designing for people with late stage dementia and are therefore potentially transferrable.



Figure 4. Participant A's blanket

Bringing the world to the person

One family member commented that Participant A's blanket was: 'something that brings his world to him.' In particular, the blanket itself became a vehicle for storing useful stuff such as an MP3 player and headphones, family photographs and other small items that could be placed in the pockets. It was noted that the blanket 'becomes something where everything is to hand' and reduced the amount of precious visiting time spent on

looking for items which had been tidied away. The inclusion of technology within the blanket also enables the world to come to the PWD 'in a very practical way'.

Richer conversations and personhood

Both participants are unlikely to initiate interactions with others due to the late stage of their dementia. This can make conversation demanding for carers and difficult even for family members. By providing a personalised textile, containing elements of personal history and individual preferences, new topics of conversation can be stimulated. While there are elements of reminiscence, the material and physical qualities mean that the textile can be experienced in the moment in a tangible way. The textiles become a mediator of conversation, acting on multiple levels and stimulating a shared experience. This act of mutuality can stimulate thoughts and emotions that can be verbalized and shared in a meaningful way with or without relying on memory of past events. A family member commented:

...the music and the photos and the chance to be with Dad and access his life in his lap... means you can have a ... richer conversation. I think on that level... it works.

This opportunity for richer conversation enables a deeper connection for the PWD with other people and the potential for enriching a sense of personhood and maintaining dignity. The OT commented:

Because I know about the apron and I know it was inspired by parts of his life and his personality, I was very gently able to share that with him and he was beaming.

She also noted that the blanket had helped her to communicate about the importance of the PWD's participation in the research and she felt that he had responded positively, saying: 'You know by the smile you get'.

Movement

Both PWD have sedentary lives due to very limited mobility. Participant A's blanket however was being used both by his son and the OT to inspire movement and exercise. His son commented that 'he lights up whenever I do simple movement things'. One of the larger pockets on the blanket contained a series of knotted fabric scarves/flags that had been stitched to the textile. This was being used to inspire a series of stretching exercises involving pulling the fabrics out of the pocket. Although the OT noted that the PWD was unable to initiate this himself, both she and the relative commented on how beneficial playing with the fabrics had been for the PWD:

I sat with him for about half an hour going through the apron and playing with the scarves. And I was really pleased because he was having a difficult afternoon and he just seemed to respond really well to that.

Materiality and tactility

The textile made for Participant B was an apron with ties around the waist. His reaction to was positive from the outset and he explored the textures of the fabrics and threads almost immediately. His wife noted that he was: 'really enjoying having something to fiddle with' and the OT stated enthusiastically:

He's very interested in looking at it and touching it, and most of the time when he's got it on he's at least holding it if not fiddling with it and really enjoying...really enjoying it I think.

Both commented that he was particularly interested in the tactile sensation of the long strands of wool and thread that were stitched onto the apron. He also enjoyed fingering the chunky wooden beads that were threaded on a thong and attached to the blanket.



Figure 5. Participant B touching apron

Participant A's blanket also contained a variety of surfaces intended to stimulate tactile interest. In particular a large leather sheepskin pocket, which was detachable via a Velcro fastening, generated considerable interest. The OT described how she had spent time with Participant A placing his hands inside the sheepskin pocket and feeling the texture and putting it close to his face so that he could smell the fleece. These examples of sensory stimulation were noted as having brought pleasure to the PWD through observable minor changes in facial expressions and sustained interest in the activity.

Relaxation and distraction

One of the most significant stories concerning the beneficial use of the textiles was recounted by the OT concerning the use of the apron with Participant B during meal times. Due to the progression of the disease, this PWD had begun to have difficulties with his swallowing reflex making mealtimes stressful and difficult. The carers decided to use the apron during mealtimes as a distraction and found that it relaxed him and he was able to swallow his food. The OT commented:

I came at teatime yesterday; he had it on then and was playing with it (gestures hands on laps and hand use: rubbing fingers to thumbs). So that was very interesting in terms of relaxing and taking his mind off something else (gestures to throat) so that he naturally swallows. I didn't expect something like that to assist with that. So that was very interesting.

Size, shape and visual characteristics

The interviews also provided an opportunity to evaluate the positive and negative aspects of the shape, size and visual content of the designs. The blanket (1m x 50m) was considered the optimum size and the lightweight woollen fabric, reminiscent of men's suiting fabric, was thought to be an appropriate weight. Participant B's apron was rather deep making it difficult for him to reach the pockets on the lower section of the textile. Ideas were discussed concerning ways in which the textile could be designed to optimize the accessibility of the tactile surfaces for someone with limited movement and no bimanual coordination. Future work will embrace these design challenges. The size of the pockets was also discussed and it was felt that some of the pockets were not large enough to permit the haptic experience of feeling the things that had been stitched inside. Providing adequate peripheral space for hand movement will also be included in subsequent designs since playful sensory experience is one of the major purposes of the textiles.

Technology ideas

Evaluation included discussion concerning the ways in which technology might be incorporated to suggest particular life themes in more appropriate, dynamic and sympathetic ways. The main use of technology in the two textiles evaluated in this section involved the integration of the PWD favourite music via MP3 players. These had been hacked to incorporate a very simple and easy on off control switch, positioned directly underneath a large physical stitched button. Further ideas including integration of LED lights, olfactory dispensers and sound and rhythm microcontrollers were explored and are

being integrated into subsequent work. The OT cautioned against the potential for sensory overstimulation in the development of designs.

Discussion

1. Distributed experts in research and evaluation

A range of experts were involved in the co-production of the sensor e-textiles including carers, family members, health professionals, artists, designers and technologists. The expertise of this group was also used to help evaluate the artefacts that have been created. For example, insights into how the textile was used to overcome difficulties with swallowing at meal times requires knowledge of both dementia care and of the specific individual concerned. Similarly, OT's and carers were able to highlight that Participant A's passive response to the blanket should be regarded as a 'positive' response, in the light of his previous rejection of similar artefacts.

2. Iterative design development

Evaluation of the textiles has been an integral part of an on-going iterative design process. Work began on the development of new design concepts immediately following the evaluation interviews. Three further participatory co-design workshops have been held to develop concepts and extend the sensory functionality of the textiles using microcontrollers and smart materials. Experts in materials science, computer technology and electronics have participated in these workshops and development work continues.

3. Key findings

Three key findings that have emerged from the evaluation of the designs that have been trialled. The textiles have assisted in communication and connection with others; they have provided a means of relaxation and distraction; the physicality of the textiles and the potential to expand their sensory properties through technology, have stimulated and engaged the interest of the people for whom they were made.

Early findings from this research indicate that sensory textiles have contributed positively to the wellbeing of the PWD for whom they were made. Further evaluation and a larger study will be required to establish if these findings can be generalised more widely.

Acknowledgements



Thanks to Gwalia Cyf, Cardiff Metropolitan University REIF and OPAN for supporting this research.

References

- BLESSING, LTM and Chakrabarti A. (2009) *DRM, a Design Research Methodology*: Springer.
- CHENOWETH, L., King M, Jeon Y-H, et al. (2009) Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping and usual care. *Lancet Neural* 8: 317-325.
- CRAIG, R. T. and Tracy, K. (2014) Building Grounded Practical Theory in Applied Communication Research: Introduction to the Special Issue. *Journal of Applied Communication Research* 42 (3). pp. 229–243.
- DESMET, PMA., and Pohlmeier AE. (2013) Positive design: An introduction to design for subjective well-being. *International Journal of Design*, 7: 5-19.
- KILLICK, J. (2013a) *Dementia Positive*, Edinburgh: Luath Press Ltd.
- KILLICK, J. (2013b) *Playfulness and dementia: a practice guide*, London: Jessica Kingsley Publishers.
- KONTOS, P. and Martin W. 2013 Embodiment and dementia: Exploring critical narratives of selfhood, surveillance and dementia care in *Dementia* 12 (3) 288-231
- TREADAWAY, C., Kenning, G. and Coleman S. (2014) Designing for Positive Emotion. In: Salamanca, Desmet, Burbano, et al. (eds) *Colors of Care: 9th International Conference on Design and Emotion* Bogota, Columbia: Design and Emotion Society; Universidad de Los Andes.
- TWIGG, J. (2010). Clothing and dementia: A neglected dimension? *Journal of Aging Studies*, 24(4), 223–230.
- WHO. (2012) *Dementia: A Public Health Priority*. UK: World Health Organisation and Alzheimers Disease International.
- ZEISEL, J. (2011) *I'm Still Here: Creating a better life for a loved one living with Alzheimer's*. Piatkus.