Structured Abstract

Sensor e-Textiles: person centered co-design for people with late stage dementia

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<th>Purpose of the paper</th>
<th>This paper presents design research investigating the development of sensory textiles with embedded electronics to support the wellbeing of people with late stage dementia in residential care.</th>
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<td>Design/methodology/approach</td>
<td>The research presented is qualitative and uses a mixed method approach informed by grounded practical theory and positive design methodologies. It uses an inclusive and participatory co-design process involving people with dementia and their families with an interdisciplinary team of experts.</td>
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<td>Findings</td>
<td>Both the co-design process and the artefacts developed have been beneficial in supporting wellbeing. The textile artefacts have been found to soothe, distract and comfort people with dementia. They have also been shown to facilitate in the moment conversational bridges between family members and carers with people with dementia.</td>
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<td>Practical implications (if applicable)</td>
<td>The paper proposes ways in which simple hand crafted textiles can be used beneficially to support wellbeing and provides examples of how technology can be used to personalise and extend the sensory properties of the artefacts created.</td>
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<td>The paper describes new ways of extending sensory properties of textiles through the integration of technology.</td>
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1.0 Introduction
The level of need for residential long-term care will rise significantly over the next thirty years due to the projected increase in the number of older people and in particular the rise in numbers of people with dementia. According statistics from the Global Observatory for Ageing and Dementia Care over 46 million people live with dementia worldwide and this number is estimated to increase to 131.5 million by 2050 (Prince et al., 2015).

By 2040, nearly one in four people in the UK (24.2%) will be aged 65 or over and the percentage of the total population who are over 60 is predicted to rise from 24.2% to over 29% in 2035 (Age UK, 2015). In 2030 there will be over 2 million adults in the UK over the age of 65 without adult children to look after them and places in nursing homes and residential care will need to increase by around 150% over the next 50 years (Innovate UK, 2015). 80% of residents in long-term care have been diagnosed as having a form of dementia (Alzheimer’s 2015). Many of these people are chair or bed-bound, and have high support needs. New approaches, strategies and designs for caring for older people — particularly for persons with dementia in residential care — are desperately needed (Innovate UK, 2015).

Understanding the actual requirements of people with dementia in residential care is a challenge for design professionals who often have limited knowledge and experience of the disease, care needs and the environment in which they live. Therefore, a ‘top-down’ design model where the designer proposes solutions to a pre-developed brief is often not the most appropriate way to meet the complex needs of service users. An inclusive and participatory approach is proposed in this paper, in which persons with dementia, carers and care and health professionals are brought together to share their expertise. This ‘distributed expertise’ approach provides potential to leverage creative solutions that are more appropriate for the end users (Krippendorff, 2006). The inclusion of both carers and people with dementia enables personal experiences, their stories and responses to shape the design solution. This paper describes an inclusive co-design approach to designing sensory textiles for people with late stage dementia.

2.0 Textiles and Personhood
Previous research has revealed the importance of textiles and clothing in establishing and maintaining a sense of personhood (Ward et al., 2008; Ward and Campbell, 2013; Kontos and Martin, 2013). When people enter residential care they are often parted from personal possessions ‘disrupting connections to memories, biography and identity’ (Twigg and Buse, 2013, pp. 330). This loss of identity is compounded by linguistic cognitive dysfunction and social withdrawal that are symptoms of dementia (Zeisel, 2011). Clothing and material possessions are able to reconnect the sense of self of people with dementia with carers and family members, for whom they help to ‘maintain continuity with the embodied biography of the person they love and knew’ (Ward et al., 2008 cited in Twigg and Buse, 2013 pp.330). The sensory tactile material qualities of textiles are also beneficial for people with dementia at a pre-reflexive level (i.e. non cognitive) and provide interest, comfort and emotional connection to memory where recall of events, names of objects or people
may no longer be available (Brooker and Duce, 2000). Textiles on the body are also useful for maintaining a connection with the world when a person’s perception of physical space beyond the self begins to diminish. The textile is able to bring the physical world to the person with dementia providing connection with others and continuity of personhood (Van Steenwinkel et al., 2014).

Many people with dementia live a sedentary life in residential care and reports from carers and health care professionals suggests that physical pain, frustration and boredom can contribute to withdrawal and so-called challenging behaviours often associated with dementia (Chenoweth et al., 2009). Boredom and lack of activity contributes to depression, which often leads to the use of medication that contributes to further deeper withdrawal and loss of interest in life (Zeisel, 2011). Killick, (2013) contends that there is a great need for activities for persons with dementia that are playful, fun and help to encourage laughter and ‘in the moment’ living. Previous research has shown that engaging in ‘ludic’ or ‘playful playing’ can contribute to wellbeing throughout life, even into old age (Rogerson et al., 2013). By encouraging positive emotion and enhancing wellbeing, there is potential for a reduction in the need for medication.

The research described in this paper explores the development of textiles that are designed specifically to stimulate the senses, which are fun to fiddle with and also communicate a sense personhood. Sensory textile artefacts are already used in residential dementia care however, their use is limited. This research aims to develop new types of sensory e-textiles using electronics and new technologies, in order to extend sensory properties and embed personalisation into the textiles.

3.0 Methodology
This research is underpinned by grounded practical theory approaches (Craig and Tracy, 2014) using a mix of creative practice based and qualitative ethnographic methodologies. Case study interviews with carers and health practitioners were undertaken to gain an understanding of individuals and the environment in which they live. In addition, practical participatory making sessions were conducted. These sessions were documented using video and still photography for further analysis. As an alternative to the problem-solution approach to design this study was informed by a Positive Design framework (Desmet and Pohlmeier, 2013) with the intention of designing to promote positive emotion through ‘pleasure, personal significance and virtue’. The project partner, Gwalia, is one of the major providers of social care for persons with dementia in Wales and gave researchers access to people with dementia and their families, care professionals and managers. Participants in workshop events comprised members of the research development group established during a previous funded project (Treadaway et al., 2014). This group included occupational and art therapists, psychologists, designers, carers, family members, older people and representatives of key stakeholder groups and charities including Alzheimer’s Society, Age Cymru and Dementia Positive charities.

Collection of the qualitative data involved unstructured interviews, which provided a series of narratives to inform the design process. These included background and environmental information about the people with dementia and their lives, families and preferences. Visits to residential care homes and interviews with staff and family members at the beginning of the project provided insights into the assessment of cognitive ability and approaches to care giving by care professionals in each home. From this data a group of persons with dementia were selected as case studies for the design process in the participatory workshops. The selection criteria for participants was based on the level of challenge presented by the individual for
carers, the willingness of family members to engage with the research and the willingness of the management and care staff to contribute their expertise.

Three people with dementia were selected in the first phase of the research: two males and one female; all with late stage dementia, little ability to communicate verbally and with limited hand use and mobility. In the second phase of the project a ‘Funshop’ social event was held in the care home with the family and friends association. Seven more persons with dementia were selected at this stage. The selection criteria for this group of residents included diagnosis of late stage dementia, attendance at the social event and enthusiasm of their family members to be involved in the research. The narratives collected from the unstructured interviews were developed into Personas (individual preferences and interests) and were used in the ‘Funshop’ and subsequent participatory workshops that informed the development of personalised designs for sensory textiles.

Evaluation involved both deductive and inductive analysis of the data. The data was analysed for references and examples of known themes arising from the literature review and from the narratives provided by family members, care staff and health professionals. These include references to specific individuals, for example, behavior, background, or ability, and general themes such as positive emotion, wellbeing, pleasure, play, and fun. In addition, both themes that arose frequently were noted, and themes that provoked intense responses, regardless of frequency. Observations made during researchers visits and analysis of videos of people with dementia with the finished textiles, provided insights of the level of engagement, interaction, and emotional response of the people for whom they were made.

4.0 The project
The project was planned in two phases. The first of these was informed by case study research undertaken at three Gwalia residential homes with specialist dementia units in South Wales. The participants included the company occupational therapist, care home managers, carers and family members of people with dementia. The case study interviews contextualized the research and provided three initial personas of selected residents to be used in the first participatory event.

4.1 Phase 1 - Dementia Apron Hack1 ‘Funshop’
The first Hack ‘Funshop’ event comprised 30 members of the Dementia Apron Research Development Group (RDG)2. In addition to the RDG were several members of the Cardiff Hack Space who contributed their expertise in electronics and computing.

The workshop involved a two-stage design process:
1. Concept design: participants worked in three groups, each guided by a written persona brief sheet describing a specific person for whom they were designing. Ideas were discussed by the group and sketched out on paper.
2. Design development: participants selected appropriate materials and developed stitched and constructed prototype designs – some of which included embedded electronics.

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1 Hacking refers to the act of modifying or customizing computer code/electronics and everyday products to improve their functionality, to repurpose them or simply as a creative activity.
2 The first Hack ‘Funshop’ event was held in June 2014 at Cardiff Metropolitan University and comprised 30 members of the Dementia Apron Research Development Group, funded by OPAN (Older People and Ageing research Development Network)
Following the workshop some of the textiles required further refinement and finishing so that they were safe to evaluate with the person for whom they were designed.

Participants in the ‘Funshop’ were allocated to groups to ensure that each group reflected the diverse skill sets and experiences available. For example, each group included an occupational therapist, a carer, a technologist and a textile designer. Each member of the group was able to contribute based on their expertise; for example occupational therapists were particularly influential in advising on health and safety constraints in design specifications (Fig 1.).

The Hack ‘Funshop’ took place in a textile studio with access to sewing machines and textile equipment and tools. A wide variety of materials: fabric, leather, plastic, wool, lace, haberdashery etc. in a variety of colours, weights and textures was provided. The art school studio was perceived as creative location, particularly by those not familiar with this type of environment, and together with the sensory stimulation provided by the variety of materials at hand inspired creativity amongst participants. Many of them were reluctant to leave at the end of the day and commented on their sense of enjoyment and fun at participating in the event.

4.2 Phase 1 Evaluation
Two garments and a textile blanket were developed as a result of this initial workshop. Once each item had been completed and was deemed safe for use with a person with late stage dementia, they were taken for evaluation with the people for whom they were designed (Fig. 2). Sadly one of these people died before she received her garment.
The research team made two visits to the care home, with a two-week interval, during this time family members, carers and occupational therapists observed the interaction of the people with dementia with the textile artefacts. Researchers visits were video documented and observations made of any indication of expression of interest or emotional response. Those people who received the personalised textiles showed visible interest in the tactile qualities of the textiles and pleasure at the interaction they stimulated with the research team, family members and carers; smiles, touching with the hands and exploratory hand movements were observed. The occupational therapist, care professionals and family members were video interviewed during the return visit two weeks later. Their observations and reflections on the use of the textiles were collected to inform the evaluation and validate the earlier observations made by the research team. Their interviews were audio recorded, transcribed and analysed using a thematic approach. The findings informed phase two of the project and are included in the overall research findings.

4.3 Phase Two – Sensor e-Textiles 'Tech' Workshops
The second phase of the project investigated the potential of the latest advances in materials science and technology and explored how they might be integrated into sensory textiles for use with people with dementia. The earlier research had identified the difficulties associated with integrating electronics into sensory textiles for use with people with late stage dementia and found that they would need to be sufficiently robust to withstand day-to-day use, laundering and handling by non-technical experts in a care home environment.

One of the first textiles tested was a blanket with embedded MP3 player with a personalised favorite music playlist, taking in to account the preferences of the person for whom it was made. The electronic device was placed in a small pouch and attached to the blanket using Velcro ®. A slightly larger pocket was placed on the blanket containing a set of headphones. The device was hacked to enable it to be operated by the person with dementia with a large tactile on/off button. Although the device worked when tested in the lab it was not sufficiently robust for use in the care home environment (Fig. 3).
electronics might be integrated in sensory textiles. New conductive coatings and approaches to energy storage were discussed, explored and tested during four one-day events spread over four months.

4.4 Phase 2 Sensor e-Textiles Hack ‘Funshop’s

Three further Hack ‘Funshop’ events took place in parallel with the ‘Tech’ Workshops over a period of four months. The first of these was held in one of the participating Gwalia care homes in conjunction with the Friends and Family Association (Fig. 4). People with dementia and their family members, staff and managers were invited to the event in order to enlist more participants and collect personal histories and preferences for subsequent participatory design events. As a result seven more people with dementia and their families chose to attend the event and provide persona information to be used in subsequent design-focused ‘Funshop’s.

![Fig. 4 Funshop event held at Gwalia residential care home](image)

The second participatory ‘Funshop’ focused on care professionals, technologists and designers: occupational therapists, care home managers, carers, dementia charity representatives, two music therapists, an assistive technology expert, and designers. The design ‘Funshop’ involved concept generation for textile garments (based on the persona information). Participants worked in four groups to generate storyboards containing ideas, colours, fabric swatches and imagery. The workshop was video documented and the storyboards created by each group evidenced the concepts generated (Fig. 5). Design members of the research team developed the participatory design storyboards and documented concepts from the design ‘Funshop’ into a series of base textile garments and blankets; building on the shapes, colours and concepts provided.

![Fig. 5 Design storyboard](image)
A two-day participatory combined ‘Tech’ Workshop and Hack ‘Funshop’ event was held to develop and prototype the personalised textile concepts from the previous ‘Funshop’. The aim was to complete seven personalised textiles with working electronics during the two-day event. However, this time frame was over ambitious and not all of the work was finished. The textile artefacts that were not completed needed careful stitching, checking for safety, and further refinement of the electronics before they could be evaluated in the care home with the people for whom they were made. This final stage of refinement and evaluation is currently in progress. A total of nine personalised sensory textile garments and blankets have been designed and produced, each with integrated electronic functionality to add personalisation.

5.0 Findings
The following section identifies a number of findings from the research related to the co-design methodology and evaluation of the sensory textiles. The project is ongoing and further evaluation of the textiles made during the second phase is currently on going.

5.1 Co-design and participation
The Hack ‘Funshops’ and ‘Tech’ Workshops provided a pool of experts to inform design research. The multidisciplinary team brought specific subject knowledge to each event providing clarity about design specification, highlighting potential dangers and stimulating creative discussion. Occupational therapists, care home managers and carers were quick to identify potential problems and dangers with designs and helped to ensure that the concepts were appropriate for people with dementia. The designers and textile specialists were able to stimulate creative possibilities and inspire, encourage and teach textile skills to less confident participants. People with dementia were involved in one ‘Funshop’ held in their care home and were encouraged to participate by handling the materials and threads. The stimulating impact and creative energy of this ‘Funshop’ was palpable, as demonstrated by a 93-year-old lady who began recounting memories of her earlier life, to the surprise of her son who said she had not spoken for months prior to the event.

The role of the technologists and materials scientists was crucial to the success of the project. In the initial Hack ‘Funshop’ they worked in the same physical space as other participants, but due to the level of concentration required to programme the electronics, they preferred to work separately. Therefore, ‘Tech’ Workshops were set up in Phase 2 of the project to enable the electronics to be developed independently, on different days. When it was necessary to combine the ‘Funshops’ and ‘Tech’ Workshops in the same event, technologists worked in a different physical location – a room along the corridor. However, they had access to other participants as needed, to gain information and to establish specifications for the electronic components.

The multidisciplinary community created a substantial amount of work in a relatively short amount of time through the co-design ‘make together’ process. Having a range of expertise on hand in one physical location reduced time spent revising inappropriate designs and importantly provided a stimulating, creative and productive environment. Participants with design training shared their textile skills and carers and health care professionals were able to exchange their knowledge of working with people with dementia. The opportunity to experience working in this way provided participants with confidence to have a go themselves and to inspire others to create sensory textiles for people with dementia in their places of work.
5.2 Evaluation of textile artefacts produced
The sensory textiles created during the project were found to be beneficial not only to
people with dementia, but also family members and carers. The themes that emerged from the analysis of the evaluation data include the following: maintaining
care personhood, physical experience, bringing the world to the person and relationships and communication. Each of these were noted by the occupational therapist and family members as contributing to an enhanced sense of wellbeing for the people with dementia.

5.2.1 Maintaining personhood
The design approach underpinning the research has kept the individual person at the heart of the work through the integration of life stories, personal preferences and awareness of physical and cognitive limitations. This is consistent with Kitwood’s work on Person Centred Care (Kitwood, 1997), John Zeisel’s guidance on design for dementia (Zeisel, 2013) and Killick’s advocacy for supporting wellbeing through playfulness (Killick 2013). Findings from the evaluation indicate ways in which the textiles were able to capture and present a ‘fabric of life’ in which occupations, family pets, holidays, favorite music, colours and smells were reflected in the created artefact. Despite the fact that associated memories might no longer be accessible to the people with dementia, the textile maintains opportunities to communicate the sense of personhood to others. For example, it provides cues about the person for shift working carers, who might not have the opportunity to get to know the details of a person’s life and interests, or health professionals who visit large numbers of people in their working day. One of the first garments was created for a person with dementia who had worked as a fisherman and contained references to his profession in the form of textile nets, fabric fish motifs and rope-like tactile threads (Fig 6).

5.2.2 Physical experience
In addition to communicating life history, the designs also incorporated favorite music, smells and colours that were selected with the intention of connecting with the emotional memory of the person. According to (LeDoux, 1998) emotional memories can be accessed independently of memories of life events, providing feelings of remembered pleasure. The cat pocket (Fig. 7) provides an example of a textile pocket for a garment to stimulate the emotional memory of stroking a cat. The embedded electronics enable the cat to purr through a small vibrating motor, which is activated via a sensor when a hand is placed on the cat’s head.
Smell was incorporated into a garment made for a person who had worked during her life as a waitress. Her apron incorporated a sachet containing a vanilla scent along with a textile victoria sandwich cake, stitched knife and fork and serviette intended for folding, rolling and fiddling with.

Music was incorporated into the textiles using programmable microcontrollers with MP3 players. Favorite music was selected by family members, uploaded onto the embedded device via a computer and played through headphones. One family member noted that his father’s music accessed via ‘his little player and the headphones really brings him an immense amount of pleasure’.

Colour and light were also noted as being significant in the design of engaging experiences. Colour preferences were noted and integrated wherever possible in the designs. One of the persons with dementia was particularly fascinated by reflective surfaces, sparkle and light and so stitched light emitting diodes (LED) have been integrated into some of the textiles. In one particular garment, made for a woman who was a regular church attendee, the design incorporates a stitched church motif with a stained glass window made from translucent fabric lit by LED light.

Both the occupational therapist and family members commented on the ways in which the textiles had been used to stimulate movement: hand use and larger upper body exercise. The tactile threads and surfaces had been observed to stimulate hand movement: fiddling, touching, stroking and feeling around inside pockets. The pocket surfaces inside and out were designed to be stimulating to the senses. For example, one blanket contained a sheepskin leather pocket with fur inside and many of the garments contained pockets within pockets with stitched bags of shells, buttons or beads secured safely to the textile so that they were interesting to fiddle with but could not be put in the mouth. The occupational therapist described the successful interaction of one of the people with his personalised textile: 
_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 it I think._

Larger movements were stimulated through the use of stitched textile bunting made of silk scarves attached to the pocket on one of the blankets. The occupational therapist and family member had discovered that by using the bunting the person with dementia could be encouraged to lift and move his arms to pull it from the pocket. The occupational therapist commented on the activity as a form of simple...
exercise, which involved ‘pulling the scarves up and reaching up with them… [we were] moving our arms with the colourful scarves.’

5.2.3 Bringing the world to the person
One of the most significant findings from the evaluation was the ways in which the personalised textiles assisted in bringing the world to the person with dementia. Research by (Van Steenwinkel et al., 2014) illuminates the ways in which persons with dementia find that their personhood is entwined with their environment and as the condition progresses the connection with the environment slips away and their sense of identity diminishes. By organizing environments around a person so that belongings are ‘ready to hand’ it is possible to create little worlds that maintain personhood and make life easier to manage (ibid). In the evaluation of the sensory textiles, a family member commented on how his father’s blanket enabled the world to come to him:

‘and I think that's what is nice about the blanket and some sense of interactive technology within it, it actually means that the world can come to him and be with him in a very practical way.’

Having the MP3 player, headphones and family photographs, which were printed as a textile book and attached to the blanket, meant that key possessions could be available in one place and the blanket ‘becomes something where everything is to hand’.

5.2.4 Relationships and communication
The importance of social connectivity and communication to individual subjective wellbeing cannot be over estimated (Wildevuur et al., 2013). Carers and family members often have difficulty in communicating and connecting with person with dementia who have diminishing capacity for verbal communication. The sensory textiles were found to mediate the interaction providing a bridge or interaction play-space for ‘in the moment’ sharing. The tactile and physical qualities of the textiles can be responded to as sensory experiences that can be shared and yet can also present metaphors representing previous lived experience to which family members or carers might respond, even if the person can no longer remember events. In this way the textile helps reconnect others with their life story, thereby maintaining their sense of personhood. Visiting a person with dementia in care can be difficult for family members and the textiles provide a focus for conversation and gentle activity, enhancing in the moment relationships and creating a ‘shared world’. One of the family members commented that his father’s sensory textile provided a ‘chance to be with Dad and access his life in his lap, and it means you can have a richer conversation.’

5.2.5 Wellbeing: relaxation and pleasure
One of the surprising findings from the evaluation data emerged from an interview with the occupational therapist who described how carers had used one of the garments to relax and soothe a person who had lost his swallowing reflex and was having difficulty eating. The textile was provided as a sensory distraction and was found to relax him sufficiently so that he was able to regain his pleasure in eating:

“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 this to assist with that.’

Carers, occupational therapist and family members identified moments of pleasure experienced by the person with dementia when interacting with the textiles. They evidenced their observations of the person’s emotional response in facial expressions with comments such as ‘his face was beaming’; in tactile activity: ‘he’s really enjoying having something to fiddle with, really really enjoying that’, and
occasionally in the recovery of speech. When asked if they were enjoying the textile, one person with very limited speech replied clearly and unexpectedly with the affirmative - ‘Yes’.

6.0 Conclusions and future work
The design research presented in this paper has taken a Positive Design approach in which ‘explicit attention is paid to the effects of design on the subjective wellbeing and communities’ (Desmet and Pohlmeyer, 2013 p.6). Pleasure, personal significance and virtue are cited as being essential ingredients in designing for wellbeing. This approach fits well with Person Centred Care (Kitwood 1997) in which the needs of the individual are considered paramount, identity is retained and emotions are validated. In designing for people with late stage dementia in residential care, understanding what is meant by pleasure and what remains personally significant when each person’s journey through the condition is different, is immensely challenging. The co-design methodology adopted in this research has enabled a multi disciplinary team of experts, including people with dementia and their families, to contribute to the development of design concepts for sensory textiles: garments and blankets. Although the evaluation process is still in progress, the textiles that have already been trialed have made a positive contribution to the wellbeing of the people for whom they were designed. In addition, they have been useful as ‘conversation brokers’ to stimulate dialogue and provide shared in-the-moment sensory experience for carers and family members with people with dementia.

The research described has used qualitative approaches, purposive sampling of participants and makes no claims for statistical validity or generalizations. It does, however, present research findings that have transferability and can contribute practical knowledge to the important field of design research for people with dementia.

Implications for practice
1. Co-design is a valuable method of addressing the complex needs of people with dementia to develop appropriate designs to support their wellbeing.  
2. Pleasure, fun and playfulness are important ways of keeping people with dementia in the moment and enhancing positive emotion.    
3. Sensory textiles can provide important conversational bridges between people with dementia, family members and carers, particularly when visiting is challenging.    
4. Personalised sensory textiles can assist in maintaining the sense of self and perceived dignity of a person with dementia.    
5. Textiles (on the body) can be used to enable the world to come to the person with dementia when their perception of the world beyond the self is diminished and they are no longer able to actively engage with it.

Acknowledgements

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