

DESIGNING FOR WELLBEING IN LATE STAGE DEMENTIA

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Abstract

This paper presents research that is developing new ways of supporting the wellbeing of people with late stage dementia through the development of playful objects. The LAUGH project is an international AHRC funded design research project that is using qualitative and participatory approaches to inform innovative concepts for new playful artefacts to stimulate fun, joy and in the moment pleasure for people living with dementia. The research is partnered by Gwalia Cyf and supported by Age Cymru and Alzheimer's Society, including people living with dementia from their Service User Review Panels (SURP). Data presented is informed by three pre-design development workshops in which a multidisciplinary group of experts in the fields of dementia care and design have contributed their professional experience. This paper specifically focuses on data from the third of these workshops exploring procedural memory in relation to hand-use and craft making. This paper contends that hand-use, gesture and haptic sensibilities can provide access to procedural and emotional memories, which are retained even into the late stages of the disease. Craft and making activities learned in earlier life, provide rhythmic patterns of hand activity that can enhance wellbeing by supporting in the moment sensory experience, competency and reaffirmation of personhood. Playful activities provide a person with dementia freedom to explore, learn and have positive experiences even when cognitive function and memory recall is severely impaired. Future planned workshops will see the iterative development of prototype designs and their evaluation in 'live labs' with people living with late stage dementia.

Keywords: dementia, wellbeing, design, procedural memory, hand-use

Introduction

Dementia is one of the major health challenges of the 21st century (WHO, 2012). The numbers of those diagnosed with the disease is estimated to be 46 million globally and this is projected to rise to 131.5 million by 2050 (Prince et al., 2015). This will impact individuals, families and society as a whole due to the large numbers of carers that will be required and corresponding economic demands on health care and social services (UK Department of Health, 2013). Many people with the advanced stages of the disease require care in specialist dementia units in residential care or nursing homes. Once they are relocated from their personal home environment they lose motivation and necessity to engage in many of the activities that have punctuated their daily experience throughout their lives. The essentials of daily living are provided for them and the effort needed to engage with life diminishes (Brooker, 2008). People living with dementia often become passive recipients of care and this impacts their wellbeing and sense of identity.

Dementia is a syndrome that encompasses a range of neurodegenerative diseases that detrimentally affect perception, communication and memory (Hughes, 2014; Alzheimer's Research UK, 2016). Episodic and semantic memory is significantly compromised, however, emotional and procedural memories are often retained into the later stages of the disease (Hughes, 2014; Zeisel, 2011). Previous research has identified that promoting *in the moment* experience that engages the senses, particularly tactile stimulation and haptic touch via the hands, is very beneficial to wellbeing (Treadaway & Kenning, 2016; Treadaway, Prytherch & Kenning et al. 2016)

Positive emotion has significant health benefits and has been found to correlate with a reduction in requirement for prescribed medication and hospital admission (Huppert, Baylis, & Keverne, 2005). The LAUGH research project (www.laughproject.info) aims to understand better how people with dementia experience positive emotions and to create designs specifically to stimulate and support subjective wellbeing. It is partnered by leading charities in the field and informed by an expert group of advisors working in health and social care with relevant dementia experience. People living with dementia, their relatives and carers are also participants in the research via project partner Gwalia Cyf and SE Wales Alzheimer's Society SURP members.

A literature review and a series of case studies with carers, health professionals, family members and people living with early stage dementia was undertaken to help identify key issues to inform design development. In addition three expert group participatory workshops have been held in the first year of the study to explore the following themes:

- Hand-use and playfulness
- Positive emotion and memory
- Procedural memory and craft

Workshop 1 and 2 are reported on in: Treadaway, Prytherch & Kenning et al. (2016) and Treadaway, Kenning, Prytherch et al. (2016). This paper specifically presents information and findings from the third LAUGH workshop that focussed on hand use and procedural memory in relation to advanced dementia. A synthesis of findings from all three workshops is contributing to the development of design specifications for playful objects to be used in the next phase of the project.

Effort driven rewards and hand use

The theme of procedural memory and craft was identified as being a significant topic to be explored in this research following the review of the literature and case study interviews with those working in the field.

Recent research has identified the therapeutic benefits of hand use on emotional wellbeing (Lambert, 2008). Lambert identifies a particular brain circuit, which she calls the '*effort-driven reward circuit*', as crucial in maintaining emotional resilience and avoiding depression. She contends that 'engaging the effort driven rewards circuit appears to be the equivalent of taking a preventative dose of the most powerful anti depressants' (Lambert, 2008 pp90). Her theory identifies and implicates a neural network comprising three particular regions of the brain - the accumbens-striatal-cortical regions, which are intimately connected and located in close proximity. The accumbens is identified as 'a critical interface between our emotions and actions' and is positioned between the area of the brain that controls movement (striatum) and

the prefrontal cortex that controls thought processes, problem solving decision-making and planning. The hands dominate the activity of the motor cortex and 'moving them activates larger areas of the brain's complex cortex than moving much larger parts of our bodies' (Lambert, 2008 pp33). Activating the effort-driven rewards circuit results in the secretion of neurochemicals such as dopamine and serotonin, which contribute to the stimulation of positive emotions. This theory is supported by the everyday experience of emotional satisfaction and wellbeing that most people gain from activities requiring physical effort, hand movement and coordination - with a degree of cognitive challenge. This pleasure is often derived from activities such as crafts and hobbies (e.g. knitting, woodwork, drawing) and even simple day-to-day chores such as folding and ironing clothes or cooking. Most people living with advanced dementia are passive recipients of care and have little opportunity to engage in the routine activities likely to stimulate the effort-driven reward brain circuitry. Activities involving craft and making with people living with dementia in residential care and day centres are often heavily directed and hands that have experienced a lifetime of skilled work or domestic chores often rest in the lap with nothing purposeful to do. Nevertheless, despite impairment of memory by the disease, some people living with dementia continue to be able to access a range of procedural skills such as playing the piano, knitting, bread making etc. although they may not be able to follow instructions, patterns, sequences or recipes.

The third LAUGH workshop sought to understand how people living with advanced dementia engage in activities involving hand-use, to inform the design development phase of the project.

Methodology

LAUGH research engages experts in creative workshops to collect qualitative insights, practical knowledge and narratives concerning their work or experience of being with people with advanced dementia. The study has been informed by a series of one to one case study interviews and three practical participatory workshops. Data has been captured using audio-visual technology, still photography and materials created during the workshops, including participant completed question cards and flipchart diagrams created in small groups. The intention was to gain in-depth personal knowledge and creative ideas. Empathy, role play and self-reflection on participating in practical creative activities are techniques that have been used extensively to encourage participants to sharpen their focus on the key themes in each workshop and help to analyse their experiences of working with people with dementia.

A compassionate design methodology is being used to underpin the research as a whole (Treadaway 2016). This modification of Positive Design (Desmet & Pohlmeier, 2013) accommodates the complex requirements of designing for people with dementia. Compassionate design puts love at the heart of the design process and prioritises three constituent elements: sensory experience (to keep in the moment and not rely on past or future), personalisation (to retain a sense of self and maintain dignity) and positivity resonance (designing for moments of high quality connection with others).

Data derived from the workshops is being interrogated using both deductive and inductive analysis techniques. Recurrent themes, also identified in the literature review and case study interviews, are being highlighted as significant. Those that arise frequently in the data as well as intense responses, irrespective of frequency, are being noted.

Study: LAUGH workshop 3

Those attending the participatory workshop (n=25) included occupational therapists based in hospital dementia units and residential care, art therapists, representatives from the charity sector, carers, designers and researchers. The event took place over three hours and was divided into four stages: two practical activity sessions each followed by a group discussion session. The aim was to enable participants to sharpen insights into their observations of activities with people living with late stage dementia involving hand-use and procedural memory in the discussion sessions. For further information about the workshop structure and content see: www.laughproject.info

Analysis and findings

Six key themes were identified from the data that will inform the design phase of the project:

Nurturing

One of the fundamental aspects of being human is the desire to nurture others. This is manifest in self grooming, cuddling, cradling and caring for others, animals, plants and things. The desire to nurture is instinctive, low level and subconscious and frequently involves touch and hand-use. Participants at the workshop identified activities that involved people living with dementia in nurturing activities they had observed that were beneficial to their wellbeing. Their examples included: stroking pets, visitors bringing animals, children and babies into care homes, dolls and soft toys. Textile and animal fur was highlighted as being comforting and one occupational therapist noted that '*fur is always appealing*'. Textile blankets, towels and clothing can be nurturing and comforting – wrapping and enfolding the body. Participants also included caring for plants and described activities involving simple hand-based gardening tasks such as potting plants, that they had observed bringing pleasure to people living with dementia.

Security

Aspects of security and objects that represent home, personal identity or *keeping things safe* were noted as being vitally important. These included items such as handbags, wallets, purses, pens, key rings and money. Pockets were considered particularly important for men and handbags for women. The idea of being able to grasp, hold, finger or fiddle with the item provides a sense of security and therefore comfort.

Movement

Although movement maybe increasingly restricted through the progression of the disease, the desire to move, particularly to music and rhythm, is fundamental and intuitive. Dance and larger body movements are encouraged in residential care using simple activities and props such as balls, balloons and Wii. Drumming and rhythmic responses in group situations can involve people living with dementia in both hand and foot movement. One participant described music as '*a lubricant to move*'. Many of those in the more advanced stages of the disease however are chair or bed bound with limited ability to move, often requiring greater assistance or motivation to participate in activities. Occupational therapists working in a hospital environment noted that on admission to hospital people often exhibit 'pyjama paralysis' and become increasingly sedentary and immobile.

Purposeful

A dominant theme that emerged from the data was the importance of purposefulness and meaningful activities. One of the participants commented on the ways in which people who

are capable of domestic activities find themselves without a sense of purpose and without opportunity to contribute to their care:

'People moving into care homes suddenly have everything taken away from them (purposeful activities), even if they're able. You then see a sudden decline.'

Activities that replicate baking and cooking become more like entertainment rather than integral components of daily life and lack the rewards of social appreciation and sense of achievement. Purposeful tasks, such as folding napkins and clothing, dusting, laying the table and washing up, are examples of activities that some people living with dementia are able to do with assistance. There was a consensus that craft activities were seen as being imposed on residents in care, often directed by external facilitators and viewed as entertainment. Hobbies and craft activities that were intrinsically motivated by people with dementia were considered more beneficial and examples given by participants included knitting and collage.

A need was highlighted for gender-neutral activities and participants noted there are more activities available for women than men. There was some discussion around observations by participants that men like to take things apart whereas women enjoy repetitive tasks.

Attention

Participants commented on the need for activities to help with every day tasks that people living with dementia find stressful, such as washing and dressing, and to *'turn around some of that anxiety and turn it into something fun'*. As the disease progresses and mobility decreases *'there is a need for distractions – something to focus on'*. Suggestions included: *'something at the window'* and mobile kinetic devices. Twiddle muffs and textiles that are personalised can be used to refocus attention and soothe, but it was noted that people with advanced dementia often needed help or encouragement to use them.

Re-play

The final theme brings together a number of sub themes including music and rhythm, reminiscence and playfulness. Rummage boxes and memorabilia are frequently used in dementia care to stimulate interest. In the later stages of the disease these may arouse emotional memories and fingering and touching objects can evoke new thoughts and feelings. Music in particular was noted as being important as a prompt for procedural memory, such as the use of musical jingles (e.g. Fairy liquid washing-up commercial song) to help in hand washing.

Discussion

Music was identified throughout the workshop as being vitally important in the care of people with dementia and can be linked with each of the above themes. It can be used to soothe, calm and relax, initiate waking or sleeping, be individual or social, participatory, performative or passive and can stimulate emotion. When combined with hand activities it can assist movement, speed up or slow down action and provide a regular rhythm. Many participants commented on the fact that people with dementia continue to be able to learn new things e.g. learning to sing new songs. With practice, it is also possible for them to learn new repetitive handcraft activities using procedural memory. The value of 'achievement' when learning something new was highlighted, as was the observation that the more challenging a hand task, the more engaging and rewarding the experience became. A balance between the difficulty of the task and level of

competency required was noted, as was frustration at no longer being able to do something as a result of the progression of the disease or for other health reasons, such as arthritis in the fingers.

Future work

Findings indicate that people living with dementia are capable (and would like opportunity) to engage in hand-based tasks that are meaningful and draw upon a lifetime of acquired hand skills. Six themes have been identified: nurturing, security, movement, purposeful, attention and re-play and these will be used to inform the design specification for new playful objects designed specifically to engage hands and fingers to stimulate the effort driven rewards circuit in the brain. These will aim to support wellbeing of people with advanced dementia by providing amusement, sensory pleasure and satisfaction. Future workshops will involve an iterative design development process that will scope, propose, ideate, prototype, test and refine concepts for hand-held playful objects. These will be evaluated by people living with dementia and their carers during the prototype stage of the design process in a series of live labs.

Acknowledgments

This research is supported by an AHRC Standard Grant Ref: AH/M005607/1; we would like to acknowledge our project partner Gwalia Cyf and are grateful for the support and participation of Alzheimer's Society, Dementia Positive and Age Cymru in this research.

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