

DESIGN FOR DEMENTIA CARE: MAKING A DIFFERENCE

ENGAGEMENTS

ANKE JAKOB

KINGSTON UNIVERSITY LONDON, UK

A.JAKOB@KINGSTON.AC.UK

HELEN MANCHESTER

UNIVERSITY OF BRISTOL, UK

HELEN.MANCHESTER@BRISTOL.AC.UK

RELATIONS

CATHY TREADAWAY

CARDIFF METROPOLITAN UNIVERSITY, UK

CTREADAWAY@CARDIFFMET.AC.UK

ABSTRACT

The paper discusses the growing role of design in dementia care and its power to enhance the wellbeing of people living with dementia, their carers and caregivers. It refers to three examples of recent design research focusing on creating environments, objects and technologies to support appropriate person-centred stimulation and activities in dementia care.

The projects use interdisciplinary co-design approaches and ethnographic methods to establish new knowledge and develop user-centred design solutions to improve care. The authors debate that engaging end-users in the design process not only empowers the designer; the collaborative approach enables in particular the carer / caregiver to reflect on their important task and to mobilise their creativity.

INTRODUCTION

The paper discusses the power of design contributing to improved care for people living with dementia enhancing their wellbeing as well as their carers and caregivers. Three examples of recent research and their outcomes are presented focusing on some of the most

important aspects in dementia care: the provision and facilitation of appropriate person-centred stimulation and activities. Key to all three of these projects is a collaborative, inclusive co-design approach and practice to empower designers, carers and caregivers to empower people living with dementia. The paper explains how this engagement has impacted the design outcomes as well as attitudes and approaches in care practice subsequently improving the lives of those affected by dementia.

CONTEXT

According to the World Alzheimer Report 2016, there are 47 million people living with dementia worldwide today, and it is expected that this number will rise to more than 131 million by 2050 (Prince et al. 2016). Dementia - an umbrella term describing several disorders, such as Alzheimer's disease, vascular dementia and dementia with Lewy bodies - is a process of cognitive decline that impacts a person's ability to take part in everyday activities such as personal care and leisure, to cope with and adjust to their environment, to interact with others and to meet their own needs (Cohen-Mansfield et al. 2015). People living with dementia may present psychological and behavioural symptoms such as apathy, challenging behaviour, depression. Such behaviour and symptoms are often an expression of confusion or frustration resulting from limited abilities to communicate and interact, loneliness, need for meaningful activity, too much or too little stimulation, and discomfort (Cohen-Mansfield et al. 2015).

The rapid rise of people affected by dementia as mentioned above has brought an urgent need for effective interventions in supporting dementia care. As there is currently no cure for dementia, recent treatment

and care methods focus on optimising living conditions for people with dementia fostering a sense of wellbeing. Care practice needs to support the person living with the condition in maintaining quality of life by alleviating behavioural, emotional and psychological changes without resorting to antipsychotic medication (Strom et al. 2016).

Increasingly, design research and practice has been responding to this need as illustrated by the following three examples. Environments, technologies and artefacts are being developed that aim to support individuals living with dementia to re-connect with people and places, maintain their dignity, and re-gain a sense of belonging, purpose and accomplishment.

CO-DESIGNING MULTI-SENSORY SPACES

People with dementia are often at risk of sensory deprivation as they are limited in their ability to access meaningful and suitable activities. On the other hand, they might be exposed to sensory overstimulation, for example in a care-home environment where common living areas might be very noisy and busy. Both situations present a significant challenge to wellbeing and health potentially aggravating behavioural symptoms. Facilitating appropriate multi-sensory experiences tailored to the needs of the individual (either stimulating or relaxing) is therefore important, particularly for people in late stage dementia.

In an attempt to provide a solution, the concept of the Multi-Sensory Environment – also referred to as Sensory Room – was introduced in dementia care as a resource for meaningful engagement reducing agitation and improving functional performance (Maseda et al. 2014, Collier et al. 2010). However, it had been reported that the use of such spaces in practice has been inconsistent and limited (Anderson et al. 2011). The anticipated benefits for residents were not achieved and staff had become discouraged perceiving the space of little value (Dalke and Corso 2011).

Within this context, the interdisciplinary research project ‘The Multi-Sensory Environment (MSE) in dementia care: the role of design’ investigated the quality and use of MSEs currently provided in care-homes in the UK (Jakob and Collier 2017). A study utilising ethnographic methods such as observation, semi-structured interviews and a participatory workshop with care-home staff was conducted to examine existing facilities and their use in 16 participating care-homes in London and South England. The results from this critical survey confirmed that most MSEs in care-home settings do not reach their full potential in providing appropriate multi-sensory enrichment for their residents (Collier and Jakob 2017). This was mainly due to their aesthetically and functionally inappropriate design and set-up, the limited range of sensory accessories and

equipment available, and a lack of attention to how these spaces are meant to be used. The study’s findings also revealed an absence of sufficient information and guidance for care practitioners on how to provide sensory enriched environments and multi-sensory activities for residents with dementia resulting in often very poor facilitation by staff.

In direct response to these results, the research team identified a number of essential design criteria to be considered when creating sensory spaces to maximise the benefit for the users and to support the daily work of carers and caregivers. These are: comfortable and safe; meaningful and familiar; multi-sensory experience; stimulation and relaxation; control and interaction; age-appropriate and usable; flexible and cost-effective (Jakob and Collier 2017). Based on this design brief, initial design guidelines for setting up a successful and effective MSE for people living with dementia were developed considering aspects such as lighting, accessibility, material, use of technology, climate and maintenance (see Figure 1).



Figure 1: Examples of sensory enriched environments appropriate for people living with dementia (Photos © A. Jakob)

As a first step towards closing the identified knowledge gap amongst healthcare practitioners, these guidelines were made available as an online hand book titled ‘How to make a Sensory Room for people living with dementia’ (kingston.ac.uk/sensoryroom) - offering advice and ideas on designing multi-sensory spaces and activities that meet the specific needs of the users.

Considering the economic challenges faced in dementia care today, this ‘DIY’ design guide aims to be an enabling tool for care practitioners and informal carers supporting them in providing the right environment for the people they care for, without necessarily the need for cost-intensive input from design experts and consultants. In this way, the guide book invites and encourages design participation; co-design is the plausible consequence and desirable outcome.

CO-DESIGNING TECHNOLOGIES FOR ENGAGEMENT WITH NATURE

Recent research has shown that contact with nature and natural elements can reduce anxiety, lower blood pressure, and lessen pain in care settings (Ulrich 1999). Yet in the UK people living in care-homes are three times less likely than the general population to go outdoors for more than five hours a week (Handler 2014). Many homes find it challenging to take residents outside, as they worry about the safety of those they are caring for. Issues related to their condition may also make it difficult for those living with dementia to spend time outside.

The ‘Tangible Memories’ research project (tangible-memories.com) brings together an interdisciplinary team including digital artists and makers, learning researchers, computer scientists, historians, older people, charitable organisation and their carers and families. The project, and its various spin offs, has been working to co-design a set of new digital tools to enhance democratic community building through story sharing and multi-sensory experiences.



Figure 2: ‘Tangible Memories’ Sound Chair, design by Heidi Hinder and Peter Bennett (Photo © J. Rowley)

In the initial forays into the care settings it was observed how different materials, texts, technologies and human relations align and are contested in forming practices of care. Hidden aspects of care here came to the fore. For instance, it was noticed how care staff and residents practiced touching and enjoyed sensory pleasures together such as nail painting, and how non-human actors can be a key part of caring relations - such as Charlie, the blackbird, one resident talked about and who sings outside her window. Working from these more embodied practices of care design probes were then introduced that encouraged carers and residents to explore these practices further.

Noticing a disconnect from nature and the outside and observing the sensuous engagement with fabrics and music for many of those living with dementia, the researchers worked alongside care staff and residents to co-design a sound chair (see Figure 2) specifically for those who found it difficult to go outside. The chair plays therapeutic sounds from nature, music and poetry, through speakers in the chair’s headrests, activated by the rocking motion. As the residents gently rock and listen to the dawn chorus, or to crickets singing on a summer’s evening, their journeys of the imagination can rekindle memories, or in the moment stories, that help to assist story sharing through multi-sensory engagement.

The development and testing of the chair was conducted in close collaboration with one care-home. Working alongside the care manager the idea was carefully discussed from the initial stages of the design process. From an original reaction of ‘no, this is too risky for us’ the project moved to negotiating a date, and a location for a trial with residents and carers.

Residents’ reactions to the prototype chair were varied and left lasting impressions. One resident, a former pilot, first explored the surface of the chair through touch, commenting that it reminded her of the cockpit of an aeroplane. Then, listening carefully to the different sounds she cooed back to an owl in reply. As she heard the rhythmic sound of someone walking on snow, she lifted her legs up and down in time, keeping pace with them, and telling a vivid story about what was happening in her imagination: ‘The farmer is on his way.’ Another resident, who usually doesn’t speak or sing, sat in the chair and sang ‘Rock a Bye baby’ from beginning to end, causing an emotional response from the care staff present (Bennet, Hinder and Cater 2016).

The co-design process here involved ‘tinkering with care practices’ (Winance 2010). Co-design is viewed as a ‘collective interweaving of people, objects and processes’ (Björgvinsson, Ehn and Hillgren 2012). Designs do not sit on their own but rather connect with wider systems of care. It is through noticing promising practices of care and working alongside carers to build ‘experimental collectives’ that these processes can raise questions and build new alliances able to design new practices of care.

CO-DESIGNING PLAYFUL OBJECTS AND TEXTILES

People in the advanced stages of dementia are often bored and have little to do (Chenoweth et al. 2009) which can lead to an increase in distress or result in a person becoming very withdrawn, making day-to-day care difficult. One of the key design challenges in this context therefore is that of designing safe, purposeful activity that gives pleasure.

Recent research undertaken by members of CARIAD (cariadresearchgroup.cariadinteractive.com) has evidenced ways in which people with advanced dementia living in residential care can benefit from experiencing sensory playful artefacts that can interest, comfort and soothe those who are often chair or bed bound with severe verbal communication impairment. Over the last five years, knowledge and expertise of designing for dementia has been developed via a series of related projects creating bespoke playful objects, textiles, garments and blankets for people living with advanced dementia: Making a difference, Dementia Aprons (see Figure 3), Hand i Pockets, Sensor e-Textiles (Treadaway et al. 2014, 2016) and LAUGH (laughproject.info) (Treadaway and Kenning 2016).



Figure 3: Sensory textile ‘dementia aprons’ (Photo © C. Treadaway)

Dementia is a complex syndrome, which presents and progresses uniquely; each person’s experience of dementia is different and there is no ‘one size fits all’ when it comes to developing design solutions. This design complexity requires expert knowledge that can only be acquired from those who have intimate experience of caring for people living with advanced dementia. Adopting a co-design approach each of these projects therefore has been participatory and involved people living with dementia and their carers.

One of the challenges in the co-design process has been the development of a common language around dementia care. This includes the nuanced meanings and interpretations of words that can cause offence to families and those living with the disease. For example, use of the words ‘patient’, ‘sufferer’, the need to ‘distract’ someone and ‘toys’, which is considered infantilising. Nevertheless, a person living in hospital may be a *patient* on a hospital ward and may enjoy nursing a *teddy bear* in order to be *distracted* from a procedure that causes them distress. These linguistic issues require sensitivity and understanding when undertaking participatory group work with multidisciplinary teams. Design jargon is equally challenging when explaining concepts to those outside the discipline. The rich semantic dialectic and the thinking it provokes have helped to inform the design process. It has contributed to a deeper understanding by the research team of the need for empathy and

compassion in the design process and has led to the development of Compassionate Design as an approach to inform design for advanced dementia (compassionatedesign.org).

Interdisciplinary workshop events have been integral to the CARIAD design for dementia research. They have brought together a range of participants in a co-design process that has both informed the project and increased the potential impact of the research. This ‘expert group’ comprising health professionals, scientists and carers has helped to shape the design requirements, contributed novel ideas and provided critique at various stages in the design process.

The development of playful objects and textiles with carers, care-home managers and health professionals has led to greater enthusiasm for playfulness in day to day care activities and a commitment to continue to use the designed objects in the future, once the project is concluded. The workshops have also given the carers a voice; empowered them to contribute to designing to make a real difference to the lives of those they care for.

EPILOGUE

By engaging carers and health professionals in the co-design process it is possible to learn from their expertise concerning the disease, as well as influence a more creative approach to care that supports the wellbeing of the person living with dementia. The co-design process gives carers and care practitioners the opportunity to share their knowledge, concerns and ideas, and build their confidence.

Consequently, the participatory approaches bring benefits to all involved. Designers gain from expert knowledge of dementia impacting on the design solutions developed. Carers and caregivers are able to understand the value of their caring role re-framing the significance of their daily tasks in the light of the insights shared through working with other workshop participants. Being involved in the design process encourages them to adapt a designing attitude supporting care practices.

REFERENCES

- Anderson, K., Bird, M., MacPherson, S., McDonough, V. and Davis, T. (2011) ‘Findings from a Pilot Investigation of the Effectiveness of a Snoezelen Room in Residential Care: Should We Be Engaging with Our Residents More?’, *Geriatric Nursing*, vol. 32, no. 3, pp. 166-177.
- Bennett, P., Hinder, H. and Cater, K. (2016) ‘Rekindling Imagination in Dementia Care with the Resonant Interface Rocking Chair’, in *CHI EA '16 Proceedings of the 2016 CHI Conference: Extended Abstracts on Human Factors in*

Computing Systems, New York: Association for Computing Machinery (ACM).

- Björgvinsson, E., Ehn, P. and Hillgren, P-A. (2012) 'Agonistic participatory design: working with marginalised social movements', *CoDesign*, Vol. 8, Nos. 2-3, pp. 127-144.
- Chenoweth, L., King, M., Jeon, Y. et al. (2009) 'Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping and usual care', *Lancet Neural*, vol. 8, pp. 317-325.
- Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M., Thein, K. and Regier, N. (2015) 'Which unmet needs contribute to behavior problems in persons with advanced dementia', *Psychiatry Research*, vol. 228, no. 1, pp. 59-64.
- Collier, L. and Jakob, A. (2016) 'The Multisensory Environment (MSE) in Dementia Care: Examining its Role and Quality from a User Perspective', *Health Environments Research & Design Journal*, doi:10.1177/1937586716683508.
- Collier, L., McPherson, K., Ellis-Hill, C., Staal, J. and Bucks, R. (2010) 'Multisensory Stimulation to Improve Functional Performance in Moderate to Severe Dementia - Interim Results', *American Journal of Alzheimer's Disease and Other Dementias*, vol. 25, no. 8, pp. 698-703.
- Dalke, H. and Corso, A. (2011) *Living with dementia: Can design make a difference?*, London: Kingston University.
- Handler, S. (2014) *A Research and Evaluation framework for Age-friendly cities*, Manchester: UK Urban Ageing Consortium.
- Jakob, A. and Collier, L. (2017) 'Sensory enrichment for people living with dementia: increasing the benefits of Multisensory Environments in dementia care through design', *Design for Health*, vol. 1, no. 1, pp. 115-133.
- Maseda, A., Sanchez, A., Pilar Marante, M., Gonzalez-Abraldes, I., Bujan, A. and Millan-Calenti, J. (2014) 'Effects of Multisensory Stimulation on a Sample of Institutionalized Elderly People With Dementia Diagnosis: A Controlled Longitudinal Trial', *American Journal of Alzheimer's Disease and other Dementias*, vol. 29, no. 5, pp. 463-473.
- Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M. and Karagiannidou, M. (2016) *World Alzheimer Report 2016: Improving healthcare for people living with dementia - Coverage, Quality and Costs now and in the future*, London: Alzheimer's Disease International (ADI).
- Strøm, B., Ytrehus, S. and Grov, E. (2016) 'Sensory stimulation for persons with dementia: a review of the literature', *Journal of Clinical Nursing*, vol. 25, no. 13-14, pp. 1805-1834.
- Treadaway, C., Kenning, G. and Coleman, S. (2014) 'Designing for Positive Emotion: ludic artefacts to support wellbeing for people with dementia', in Salamanca, J., Desmet, P., Burbano, A. et al. (ed.) *Colors of Care: 9th International Conference on Design and Emotion Bogota*, Columbia: The Design & Emotion Society.
- Treadaway, C. and Kenning, G. (2016) 'Sensor e-textiles: person centered co-design for people with late stage dementia', *Working with Older People*, vol. 20, no. 2, pp. 76-85.
- Treadaway, C., Kenning, G., Prytherch, D. and Fennell, J. (2016) 'LAUGH: Designing to enhance positive emotion for people living with dementia', in Desmet, P., Fokkinga, S., Ludden, G., Cila, N. and Van Zuthem, H. (ed.) *Celebration & Contemplation: Proceedings of the Tenth International Conference on Design and Emotion*, Amsterdam: The Design & Emotion Society.
- Ulrich, R. (1999) 'Effects of Gardens on Health Outcomes: Theory and Research', in Cooper Marcus, C. and Barnes, M. (ed.) *Healing Gardens' Therapeutic Benefits and Design Recommendations*, New York: Wiley.
- Winance, M. (2010) 'Care and disability: practices of experimenting, tinkering with, and arranging people and technical aids', in Mol, A., Moser, I. and Pols, J. (ed.) *Care in practice: on tinkering in clinics, homes and farms*, Bielefeld: Transaction Publishers.