

IMPROVING THE EMOTIONAL WELL-BEING OF PEOPLE LIVING WITH DEMENTIA

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ABSTRACT

The research project presented in this short paper/poster evolved from broader consideration in respect to the rising number of people affected by dementia, the rapid growth of an ageing population, and the over-prescribed use of antipsychotic medication in dementia treatment. Alternative treatment methods and cost-effective interventions optimising dementia care are urgently needed. Against this background the research examines strategies of providing specific sensory experiences for people living with dementia – focusing on Multi Sensory Environments (MSEs), their design, and their current and future demanding role within homes caring for residents living with this condition. The aesthetic and functional qualities of MSE facilities (such as material/colour/imagery applied, spatial set up, usability, accessibility) currently provided in care homes for people with dementia, and their success and failure, are examined and evaluated. MSEs are now widely used in dementia care as both a resource for meaningful leisure activity and a therapeutic intervention. But evidence suggests that they often fail to succeed because of inadequate design and arrangements not addressing the needs of people with dementia or older people in general. The project investigates to what extent the above criticisms can be substantiated via a study involving 15 care homes in Greater London that have some type of MSE facility. The study aims to establish whether improved overall design of the MSE could add value to the experience maximising the benefit for the users and their carers, subsequently informing the development of design ideas and recommendations for a MSE template tailored towards people with dementia and their physical and emotional needs.

Keywords: dementia, multi sensory experience and environment, inclusive design, evidenced-based design, health care environment

CONTEXT

Over 750,000 people in the UK are living with dementia - a figure expected to double in the next 30 years. Dementia is a terminal illness with no cure available currently, but people may live with it for 7-12 years. People with dementia experience various psychological and behavioural symptoms, depending on the type of dementia they are diagnosed with. Apart from memory loss and cognitive impairment, they might become depressed, agitated, confused, irritated and/or aggressive.

As our population grows older and percentage of individuals affected rises, the need for cost efficient interventions optimising treatment and care options for people living with dementia are urgently required. The guidance document *Living well with dementia - a National Dementia Strategy*, published by the government in February 2009, emphasises the importance of providing “good-quality care for all with dementia from diagnosis to the end of life”. In November 2009, the subsequent publication of a follow-up report made reference to the over-prescription of antipsychotic medication in treating the symptoms of dementia. Out of 180,000 people receiving this form of drug therapy two-thirds of the prescriptions the report deemed unnecessary. The Alzheimer’s Society argues that “in many cases the behavioural and psychological symptoms can be prevented and managed without resorting to antipsychotic drugs”. (source: dh.gov.uk, alzheimers.org.uk, viewed 12 May 2012)

One of the alternative treatment options to drug therapy and a potentially valid intervention in providing good quality care for all with dementia is the use and application of Multi Sensory Environments (MSEs), sometimes also referred to as Snoezelen or Sensory Rooms. Utilising sensory equipment MSE facilities offer stimulation to the senses of vision, touch, hearing and smell, and sometimes also taste. The concept originated in 1966, when American psychologists Cleland and Clark set up several sensory rooms they referred to collectively as a 'sensory cafeteria'. Following on from this early approach the first Snoezelen (the term derived from the Dutch verbs 'snuffelen' – to explore - and 'soezelen' – to relax) was subsequently developed by Dutch therapists Jan Hulsegge and Ad Verheul in the 1970s.

The MSE concept has since been applied worldwide offering a range of activities for diverse populations. Claiming to be a failure-free, non-directive, enabling environment, it is particularly effective for individuals with a low level of intellectual skills and high sensory perception. "Most of us are able to order and structure the stimuli that reach us, however chaotic all these together may seem. But the question remains open as to how far someone who ... has lesser intellectual powers is capable of processing and arranging the same dataflow.... Starting from this question the concept of what we call 'snoezelen' today has in fact emerged." (Hulsegge, Verheul, 1987). MSEs aim to enhance feelings of comfort and wellbeing supporting positive emotions, relieve stress and pain, maximise a person's potential to focus, support communication and memory performance. These effects are facilitated by a specially dedicated and designed space, or by mobile equipment to be set up in various locations, including the user's home.

In dementia care, the observed benefits of MSE include improved function and alleviated psychological and behavioural symptoms e.g. challenging behaviour and depression, increased appropriate communication, and improved staff morale (Baillon et al 2002). Occupational therapists advocate the beneficial use of MSEs, backed up by recent scientific research supporting their effectiveness as a strategy

for enhancing functional performance in individuals with dementia (Collier et al 2010).

As a consequence MSEs are now widely specified in dementia care and used as both a resource for meaningful leisure activity and a therapeutic intervention. But evidence suggests that they often fail to succeed because of inadequate/poor design and haphazard arrangements (Dalke et al 2010). Conversely, to date no design informed investigation has addressed the provision of sensory experiences for people with dementia and their carers and there is a lack of research into the future design of MSEs for this user group. Due to inadequate data there is no specific design model for MSEs which addresses the needs of people with dementia or older people in general that might benefit from the MSE experience. Consequently, in the case of care home operators there is a tendency to rely on supplier led convenience design solutions which are not necessarily informed by systematic user-centred design research.

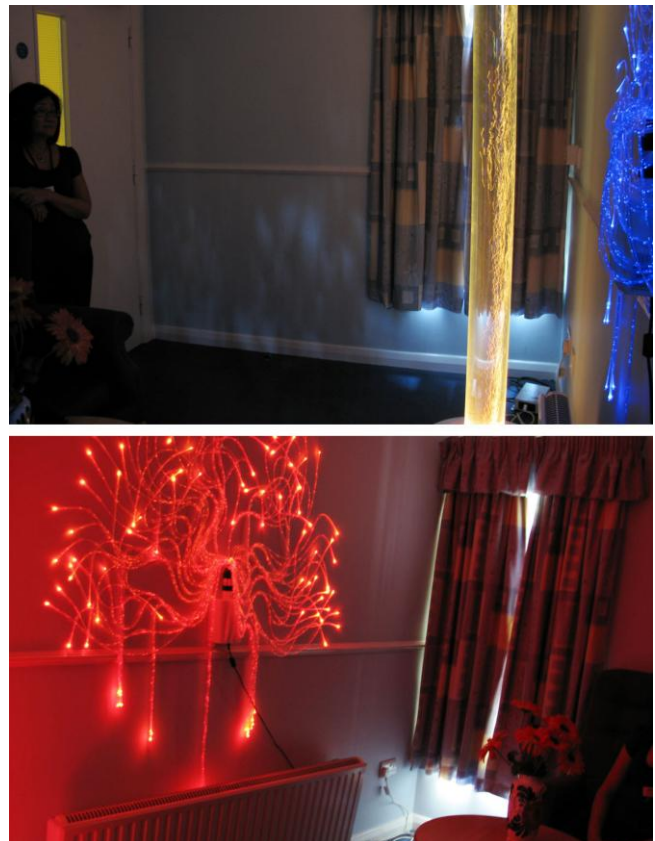


Figure 1. The images shows an example of a poorly set up MSE in a care home in London with randomly placed and wrongly applied MSE equipment ('Bubble tube', 'Light shower' from fibre optics fixed to the wall), insufficient sensory stimulation (offers no tactile experience), and inadequate furnishing (uncomfortable chairs, curtains leaking light from outside, table with artificial flowers).



Figure 2. MSE facilities and equipment by ROMPA, one of the largest suppliers of MSE, currently promoted on their websites. Image sources: rompa.com/multi-sensory-environments-rooms (viewed 12 May 2012)

PROJECT

Against this background the project presented in this short paper/poster sets out to examine a range of strategies of providing specific sensory experiences for people living with dementia. It focuses on exploring the potential of MSEs, their design, and their current and future demanding role within homes caring for residents living with this condition. The aesthetic and functional qualities of MSE facilities (such as material/colour/imagery applied, spatial set up, usability, accessibility) currently provided in care homes for people with dementia, and their success and failure, are examined and evaluated.

The project investigates to what extent the above criticisms can be substantiated via a study involving 15 care homes in Greater London that have some type of MSE facility. The study comprises interviews with and observation of staff and examining the facilities in order to evaluate service and usage. The central aims of this study are to establish whether the design of current facilities and the aesthetic experience on offer is adequate for those living with dementia and their carers, and whether improved overall design of the MSE could add value to the experience maximising the benefit for the users and their carers.

The outcomes and findings of the study will inform the development of design ideas and recommendations for a MSE template tailored towards people with dementia and their physical and emotional needs. Thereby it considers the capacity for improving the

design of multi-sensory facilities in care homes by re-engaging with the original concept of the MSE as a holistic and integrated design. Designing an improved MSE experience is not about changing the equipment and replacing items. It means considering and designing the space as a whole to achieve aesthetically inspiring, stimulating environments which are flexible in order to adapt to specific individual needs of users. Embracing an inclusive design approach, such spaces should generate a sense of wellbeing not only for people with dementia but also for staff and relatives who accompany service users there sharing their experience. The project probes the value of aesthetics in relation to issues such as emotions, dignity, stigmatisation and respect.



Figure 3. Examples of more successful MSE applications for older people living with dementia disseminated via the internet. Left image: The multi sensory room at the Mount centre of Leeds Partnership NHS Foundation Trust. (source: communitycare.co.uk/blogs/mental-health/2010/02/multisensory-snoezelen-room-fo.html, viewed 12 May 2012) Right image: A resident of the Brian Center Health & Rehabilitation, Brevard, North Carolina, USA, enjoys a multi sensory experience in the Snoezelen room. (source: tlmagazine.com/article/2005-optima-award-entry-adventure-snoezelen-therapy, viewed 12 May 2012. Photo by Julie Cooley)

The presented project emerged from previous research in two different areas. Prior research of the author investigated the development of 'new materiality' defined through the experimental use of light and colour, projected imagery, textiles and space. The new project extends this previous research into the field of special sensory needs of people with dementia and other cognitive impairments. These people are often excluded from many activities and could find inspiration and stimulation from new kinds of sensory input tailored towards their individual requirements.

Further, the project builds on research undertaken by the Design + Environments Research Group with its successful track record for investigating the needs of people with dementia (*Living with dementia: Can design make a difference?* Dalke H., Corso A., 2010) This research community, located within Design Research at Kingston University London, is concerned with designing for the environmental needs of different population groups, including the aged and disabled. Through the strong links to the Faculty of Health & Social Care Sciences at Kingston and St George's University the project receives valuable input from the medical field, not only in terms of knowledge and expertise, but also in respect of robust research methods.



Figure 4. A 'tactile cushion' especially designed for people with dementia providing tactile and visual experiences, distributed by PSS, a charity that provides care, health, and community services in UK.

Rooted within Design for Environments and Design for Health & Wellbeing, the research presented is interdisciplinary in nature drawing on disciplines such as textile/surface design, sensory design, inclusive design, digital media technology and the application of light and colour. Thereby it goes beyond design research reaching into the relevant fields of health and social care science and occupational therapy focusing on dementia care. Consequently, the project brings together academics and professionals from both areas by inviting relevant specialists into the project's Advisory Group of Experts as well as by engaging an occupational therapist specialised in dementia care and sensory stimulation as Co-investigator in the project.

PROJECTED OUTCOME

The project is in its very early stages. Projected outcomes include the development of design ideas and recommendations for inclusive, cost-effective solutions for a MSE used by people with dementia. These recommendations and ideas will be written up in a Design sourcebook, which will be of help to occupational therapists, activity co-ordinators, managers and designers of care homes when making improvements to existing MSE facilities or setting up new ones. The Design sourcebook as well as all other research findings and results will be published on-line via the Kingston University's website and displayed at a public exhibition at the end of the project.

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