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Sensory enrichment through textiles for people living with dementia

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Abstract:
The paper discusses the role of textiles in facilitating sensory enriched environments and meaningful activities for people living with dementia. It is based on recent interdisciplinary research, a collaboration between design and healthcare, investigating the provision of multi-sensory experience for people with dementia living in care-homes, particularly the quality and design of Multi-Sensory Environments (MSEs). Results from an ethnographic study conducted in 16 UK care-homes revealed that set-up and design of existing MSEs were often not appropriate and suitable for older people, and facilitation of multi-sensory activities by staff was poor. The absence of textiles and its appropriate use was noticeable, although the multi-sensory qualities intrinsic to textiles offer many benefits. Based on these findings, design criteria improving usability and accessibility for older people with dementia were established and user-centred design recommendations developed, including the use of textiles as an essential aspect.

Keywords: dementia care, well-being, interdisciplinary, sensory

Introduction

This paper discusses the role of textiles in enhancing the quality of life of people living with dementia, particularly in later stages of the disease, and their carers and caregivers. It is based on ongoing interdisciplinary, collaborative research investigating the provision of sensory enriched environments and facilitation of meaningful sensory activities in dementia care. The research evolved from a broader consideration of the role of design in dementia care and how design interventions can contribute to improved care practice. The paper thereby addresses the conference topics of well-being as well as cross- and interdisciplinary collaborations.

Rational and Context

Caring for people living with dementia

Dementia is an umbrella term covering a range of several progressive, neurodegenerative disorders, such as Alzheimer's disease, vascular dementia and dementia with Lewy bodies, detrimentally affecting perception, communication and memory. The process of cognitive decline and loss of brain function impacts a person's ability and capacity to cope with and adjust to their environment, to take part in everyday activities and personal care, to interact with others and to meet their own needs (Cohen-Mansfield et al., 2015). People living with dementia can present psychological, behavioural and emotional symptoms, particularly in the later stages of the disease. Changes in mood and behaviour - such as agitation, depression, anxiety, irritability, apathy, or disinhibition - are often an expression of a person's 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).

There is currently no cure for dementia. Recent treatment and care methods therefore focus on optimising living conditions for people with dementia fostering a sense of wellbeing. Particularly in later stages of the disease, care practice needs to support people living with dementia in maintaining quality of life, dignity and comfort (Strom et al., 2016) by meeting their specific needs and by alleviating behavioural, emotional and psychological changes through non-pharmacological, person-centred approaches (Goris, Ansel, and Schutte, 2016; Bidewell and Chang, 2011).

Today 47 million people live with dementia worldwide and it is expected that this number will have risen to more than 131 million by 2050 (Prince et al., 2016). According to the Alzheimer's Society UK, there are 850,000 people with dementia in the UK, with numbers set to grow to over 1 million by 2025 and 2 million by 2051 (Alzheimer's Society UK). This rapid rise of people affected by dementia as well as a growing ageing population has brought on an urgent need for effective and appropriate interventions in supporting dementia care and care for older people - in particular in respect to one of the most important aspect: the facilitation of meaningful occupation and leisure activities as well as environments appropriate for people living with the condition in residential homes. With 70% of the people in living in care-homes having

dementia, care providers face a huge challenge. Increasingly, it is questioned what the potential impact is of design on the quality of life and wellbeing of people with dementia, as well as their carers and caregivers.

The Multi-Sensory Environment in dementia care: what are the challenges?

People with living dementia are often at risk of sensory deprivation due to their limited abilities and dependency. On the other hand, they might suffer from sensory overstimulation, for example in a care-home environment where common areas can be very noisy with too much going on. Both situations present a significant challenge to wellbeing and health potentially aggravating behavioural symptoms. Facilitating appropriate multi-sensory experiences and environments tailored to the needs of the individual is therefore essential, particularly in late-stage dementia when activities requiring a certain level of cognitive abilities are no longer suitable.

In an attempt to provide a solution, the concept of the Multi-Sensory Environment (MSE) was introduced in dementia care. The MSE – sometimes also referred to as 'Sensory Room' or 'Snoezelen' – is a designated space that aims to provide an enabling, stress-free, positive environment offering sensory enriched experiences and activities - either for stimulation or helping to relax to enhance feelings of comfort and wellbeing and to maximise a person's potential to focus. It addresses the senses of vision, touch, hearing, smell, taste, and movement with limited or no need for higher cognitive processing. First established by Dutch therapists in the 1970's for people with learning disabilities unable to participate in more conventional occupation (Hulsegge and Verheul, 1987), the concept has been successfully applied with a range of users including people with autism, stroke recovery, or small children. Initially featuring equipment and accessories for activities on a multi-sensory level the MSE, however, has recently been criticised for too much emphasis on sight neglecting other senses and the predominance of high-tech equipment (Gaudion, 2011).

Research studies evidenced that the use of MSEs with people with dementia as a resource for meaningful engagement has beneficial effects, such as alleviating behavioural symptoms, e.g. disruptive behaviour and agitation (Maseda et al., 2014) and improving function (Collier et al., 2010). Although little research has been published considering the actual design including functionality and aesthetics of MSEs and its impact on engagement and wellbeing, many MSEs were set up in UK care-homes over the last decade. However, it had been reported that the use of such spaces in practice has been inconsistent and limited (Andrews, 2015; Anderson et al., 2011). It would appear that MSEs were installed with little thought to their design or how they are to be used, and anticipated benefits for residents had not been achieved. Consequently, care-home staff had become discouraged, perceiving the space of little value, resulting in the rooms themselves becoming abandoned (Dalke and Corso, 2011).

The project

Interdisciplinary research into sensory design for dementia - a collaboration between textile design and healthcare

Within this context interdisciplinary research into the use of Multi-Sensory Environments (MSEs) in dementia care evolved, critically investigating the quality and design of such facilities in relation to the specific needs of people with dementia. (Jakob and Collier, 2017).

The investigation emerged from prior research by the authors. Both researchers independently identified essential problems and recognised the need for evidence-based research into the functionality and aesthetics of MSEs for people with dementia, culminating in a unique collaboration between design and occupational therapy. Anke Jakob is a design researcher and practitioner with a background in textile design. Her work is concerned with the design for environments related to therapeutic and sensory experiences, and the application of textiles, light and digital media within such spaces. An occupational therapist by profession, Lesley Collier's research explores sensory processing in people with moderate to severe dementia, in particular the efficacy of multi-sensory stimulation in improving occupational performance as well as mood and behaviour. Further, collaborative partnerships were formed with experts

and professionals from design and health care, including independent provider of health and social care services CARE UK.

The resulting project titled 'The Multi-Sensory Environment (MSE) in dementia care: the role of design' was funded by the Arts & Humanities Research Council UK (AHRC). The overall aim of the research was to establish new knowledge to inform the development of coherent, user-centred design solutions contributing towards improved care services for those living with dementia. In this respect, based on findings from the ethnographic study conducted as part of the research, design recommendation and advice were developed on how to create and design sensory enriched environments that better suit the needs of people living with dementia in care-home settings.

Figure 1. Examples of existing MSEs in care-homes visited during the study. The rooms feature typical MSE equipment such as bubble column, fibre-optic strands, projector with rotating image wheel, glitter/disco ball.
Photos: Anke Jakob

The study: Existing MSEs in UK care-homes

In order to more establish evidence why existing MSEs had not been successful, an ethnographic study was carried out involving 16 care-homes in London and South England. The current use of MSEs, their set up and design were recorded, as well as opinions of 32 staff describing the sensory facilities available and

their experience in using the existing MSE rooms with residents. Ethnographic methods employed included semi-structured interviews; observation of the design and spatial set-up of the facilities; listing sensory equipment and items available under each of the sensory domains; observing sensory sessions from the point of view of the person with dementia; a focus group workshop with activity co-ordinators from several homes.

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 experience and enrichment for their residents (Collier and Jakob, 2016). The findings revealed that, in most cases, set-up and design of these existing MSEs is not appropriate and suitable for older people, and residents struggle to engage with the space appropriately (Jakob and Collier, 2017). The spaces often do not feature an appropriate range of sensory equipment and accessories addressing all senses. Equipment available is predominantly focused on visual and tactile stimulation. Some of the spaces are perceived as too technical and 'cold' in appearance. Some rooms felt overwhelming due to the number of objects and equipment offered at the same time, or were problematic regarding the juvenile aesthetic of some of the imagery and items used. The lack of textiles and its appropriate use was noticeable, although the multi-sensory qualities intrinsic to textiles offer many benefits.

Another important finding was that in the absence of sufficient information and guidance for care practitioners, facilitation of sensory enriched environments and multi-sensory activities by staff was often very poor. Often the care-homes relied on suppliers of multi-sensory equipment and environments to design and set up the room with little or no involvement of care-home staff. This also led to the prevalent assumption that setting up a multi-sensory facility is cost-intensive because of the expensive special equipment involved (i.e. bubble columns, fibre-optic strands, projectors, vinyl-covered furniture – as can be seen in Figure 1).

Designing multi-sensory experiences for people living with dementia

In response to these results of the ethnographic study (see above), the research team went on to investigate and analyse what, in contrast, would represent 'good' design (design that effectively produces the desired benefits). Applying a mixed-method approach, the process of identifying essential design criteria was informed by: conclusions drawn from the study; reviewing recent research and literature; evaluating best-practice examples; the researchers' professional expertise and practical experience.

Examples of best practice

Examples from organizations participating in the study as well as other healthcare and MSE facilities in UK and Finland were evaluated, and successful methods, activities and practices recorded and analysed. Particularly inspiring and insightful were visits to multi-sensory spaces in four homes for older people in Helsinki (Finland) - designed and set up by care home manager and textile artist Sari Hedman (Figure 2). The noticeable difference of these rooms to facilities seen in UK care homes was the extensive use of textiles and fabric. Particularly striking when first entering a room was the employment of plain, neutral-coloured curtains covering the walls and the use of light-weight, soft fabric 'floating' beneath the ceiling. Further, the room featured neutral coloured furnishing and sheepskins, soft blankets and cushions spread across sofas and armchairs. The use of textiles in combination with careful lighting had transformed these rooms into soft, calm spaces, user friendly and appropriate for this age group in terms of both aesthetics and accessibility. The neutral appearance of the fabrics offered flexibility for playing with coloured light and accessories making it possible to adapt the space to the preferences of the user.

Further examples of applying textiles and textile technology approaches are the use of so called 'tactile / sensory cushions'. These cushions designed for people with dementia aim to provide tactile and visual experiences through the application of ribbons, buttons, zips, different textures, embroidery etc. attached to the cushion. They have been found beneficial providing soothing hand occupation as well as stimulation. At the time of the study such items were noted in only 2 of the participating care homes. In recent years, 'tactile / sensory cushions' have been increasingly introduced in care-homes, either through purchase from for example special suppliers of multi-sensory equipment, or by staff making such items themselves for their residents. (Figure 3)

Figure 2. MSEs in care-homes in Helsinki, design and installed by artist and care–home manager Sari Hedman. Noticeable here the extensive use of textiles and plain, neutral-coloured fabrics covering walls, ceiling and furniture. Sheepskins, soft blankets and cushions support the feeling of warmth and softness and provide tactile experience for stimulation or relaxation.
Photos: Anke Jakob

Emerging key criteria

From the research process, it emerged that in order to make a multi-sensory space which maximises the benefits for people with dementia and supports the daily work of their carers and caregivers, following criteria should be considered (Jakob and Collier, 2014):

- comfortable and safe
- meaningful and familiar
- multi-sensory experience
- stimulation and relaxation
- control and interaction
- age-appropriate and usable
- flexible and cost-effective

Creating an environment where the user feels comfortable and safe is vital as this supports the person with dementia to relax reducing stress and anxiety and helping to better focus on activities offered. Similar

important is to offer familiar, personal and meaningful experiences relevant to the individual's life and stage of dementia as this will motivate residents to join in the sensory activities. An MSE should address all the primary senses to maximize the desired effect as well as should offer a range of experiences that can be either stimulating or calming. This will enable the carer to better respond to individual preferences and needs. Within their capacities users should be allowed and encouraged to control and interact with the environment, including modifying the amount and type of stimulating experience received and exploring the space or intervention at their own pace. Encouraging and empowering the user to play a more active role increases confidence and feelings of self-worth (Valenzuela, 2008) and is considered a more effective care method than passive (receptive) interventions (Sanchez et al., 2016). The space should contain equipment and items that are not perceived as juvenile or childish, particularly regarding the aesthetics, to support dignity and respect for the individual living with dementia (Hope and Waterman, 2004). Further, a multi-sensory space in residential homes should be flexible and adaptable providing opportunities for a range of activities and cost-effective in their implementation overcoming economic barriers.

Based on these key criteria, design recommendations for setting up a successful and effective MSE for people with dementia were developed considering aspects including the use of textiles, lighting, accessibility, material, use of technology, climate, and maintenance. These initial guidelines were made accessible through an online hand book titled 'How to make a Sensory Room for people living with dementia' (Jakob and Collier, 2014), available in PDF format on kingston.ac.uk/sensoryroom. This resource offers advice and recommendations on setting up a sensory space tailored towards the needs of people with dementia alongside appropriately designed activities.

Figure 3. Examples of tactile / sensory cushions found in two of the visited care-homes. Embellished with ribbons, zips, buttons etc. they can provide soothing hand occupation, act as a stimulant or/and conversation broker.

Photos: Anke Jakob

The role of textiles in dementia care

In the course of the research project, the important role of textiles to support dementia care became increasingly apparent. As mentioned before, the use of textiles (blankets, cushions, plain curtains, covers, knits, fabrics and accessories) proofs to offer benefits on many levels meeting the design criteria mentioned above.

Neutral, plain, soft fabrics covering walls, ceiling, doors, partitioning larger areas or rooms, or surrounding a room can soften acoustics and light - subsequently creating a warm, intimate and calm atmosphere. The

softness of such transformed spaces support feelings of **safety and comfort** helping to relax. This can be further enhanced by wrapping textiles around the body providing a feeling of protection and security.
Further, the **multi-sensory** aspect of textiles is an intrinsic quality addressing all primary senses. It is not just the colour which can stimulate vision; it is rather the complex, multi-layered visual experience that textiles and non-wovens can offer through a range of optical qualities of the surface, such as shine, texture, reflection, transparency, print. The contrast between opposing qualities (e.g. smooth/textured) and the play of light adds to the experience and playful encounter with textiles. The multifaceted tactile qualities of textiles are another important aspect providing haptic and bodily experiences. Touching velvet and fur for example can create feeling of warm softness; silk pleases the skin and body through its smoothness, lightness and sensual touch. The texture of knitted or woven items can provide reassurance and stimulation. The sense of smell can be stimulated by the material's inherent scent (e.g. sheep skin and wool) but also through fragrances added to the textile (e.g. essential oils such as lavender). Textiles and textile items can create sounds (e.g. rustling satin, clacking beads, cracking foil) stimulating the sense of hearing. They can even provide the experience of taste (chewing as a soothing occupation). Larger upper body exercise and head movement is encouraged when a person observes or reaches out to touch bunting with tactile threads or silk scarfs attached (Treadaway and Kenning, 2016).
The versatility of textiles provides both **relaxation and stimulation.** For example, observing slow movements of fabric floating in the wind can be meditative and calming. Sensory armchair covers with pockets and other accessories for 'fiddling' can provide instant sensory experience and allow residents to calm down and to self-soothe without drawing attention. Encouraging occupation via the hands can also be a stimulating experience increasing emotional wellbeing and useful for starting a dialogue between the person with dementia and others (Treadaway and Kenning, 2016).
Fabric and textile objects, such as sensory cushions, blankets, textile books and clothing made from various textile materials, with zips, ribbons, buttons, pockets and imagery attached, can encourage playful engagement and **interaction**, and **meaningful** occupation providing experiences of pleasure (Treadaway, Fennell, et al. 2016), particularly important for individuals in late stage dementia. Combining low-tech textile technologies such as stitching and knitting with more sophisticated techniques such as digital printing and integrating sound technology allows personalising items to the individual's preferences, including photos and personal objects, favourite songs or smell.
The **flexibility** of the medium 'textile' is an invaluable advantage making **age-appropriate and cost-effective** solutions possible. The use of textiles can make technical items more accessible for the person with dementia and easier to connect with, for example combining LED lights with sheer fabrics to soften the light and add other sensory aspects (Figure 4).

Further work

The research results and outcomes presented in this paper provide an initial understanding of the design features to be considered when setting up multi-sensory facilities to improve and enhance the experiences of the users and to support the daily work of carers. The project also established the significant role and importance of employing textiles in this context. The on-line guide book titled 'How to make a Sensory Room for people living with dementia', developed through this research and the first of its kind, provides advice and information enabling carers and care providers to design conditions that promote the well-being of people living with dementia and their caregivers.
The guide has been very well received amongst the healthcare community; care practitioners have praised the guide as 'very inspiring' and 'useful, clear and readable'. However, in its present form it only serves as a first stepping stone in terms of tackling a more complex problem. Feasibility and the need for additional convincing evidence relating to the benefits of multi-sensory spaces in dementia care requested from stakeholders (e.g. care home managers) have not been addressed in depth yet. Therefore, continued research and proof-of-concept work is required to implement, test, evaluate and, if found necessary, to adjust the design brief. This will involve the participation of the actual users of MSEs, viz. the people with dementia themselves. Their direct involvement had been outside the original research remit. Evaluating

their experience of the new spaces will deliver valuable knowledge for design optimisation and benefit maximisation.

Essentially, further design investigation will utilise co-creation methods and participatory design activities collaborating with end-users (if possible), with carers and healthcare professionals. The co-design process will give carers and care practitioners the opportunity to share their knowledge, concerns and ideas, and provide the opportunity to learn from their expertise. Actively engaging carers and healthcare practitioners in the process will also help to increase impact through direct knowledge exchange informing and educating carers and care practitioners about the importance and relevance of sensory design in dementia care. Involving them as creators/co-creators will also ensuring sustainable impact of design interventions. It is important that people who care for individuals living with dementia are offered training and education on design skills and design making to empower them to adapt a more creative approach in their care practice. Consequently, further research also needs to address how such skills and training can be conveyed to further the understanding of the value of MSEs and sensory activities for older people living with dementia.

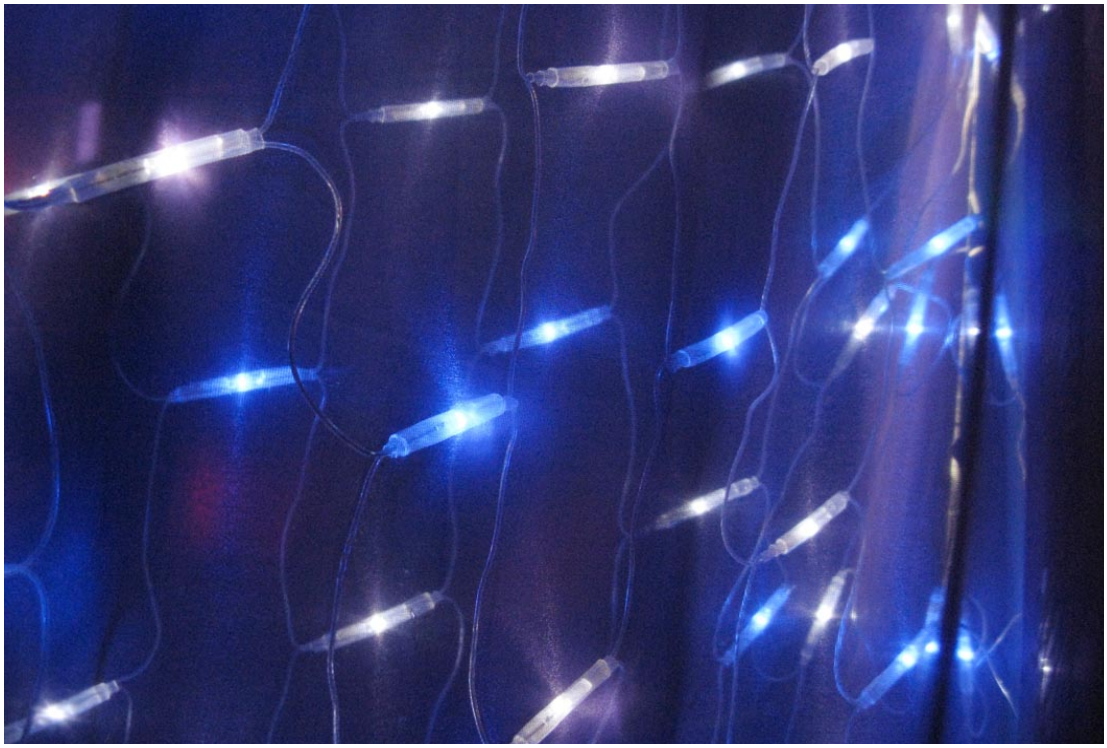

Figure 4. Creating atmospheric, indirect lighting by combining sheer fabric with LED lights. The textile adds a tactile feel as well as diffuses and softens the light.
Photos: Anke Jakob

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