Designing inclusive environments for people living with dementia: how much do we really know?

Simon Chester Evans, Sarah Waller and Jennifer Bray

Abstract

Purpose – *Recent years have seen a growing interest in and awareness of the importance of environmental design to the well-being of people living with dementia, in terms of both policy and practice. This trend has been accompanied by a plethora of advice, guidance and tools that aim to encourage and promote the development of inclusive environments. Not all of these are evidence-based, and even those that claim to be so are limited by a paucity of good quality, comprehensive research studies. This paper aims to consider the current state of knowledge in the field of dementia-friendly design and describes a project that refreshed and updated the suite of Environmental Assessment Tools originally developed by The Kings Fund and now managed by the Association for Dementia Studies.*

Design/methodology/approach – *The mixed methods project reported on in this paper comprised a review of the literature, a survey of people who have used the five design assessment tools and an iterative process of updating the tools to make them as evidence-based and user-friendly as possible.*

Findings – *The suite of five assessment tools was refreshed and updated to reflect the latest evidence and the views of professionals and others who use the tools. The authors conclude that while a focus on dementia-friendly design is to be welcomed, there remains a need for relevant high-quality evidence to inform such work. In particular, there is a lack of research within people's own homes and studies that include the perspectives of people living with dementia.*

Originality/value – *Few assessment tools and guidelines for dementia-friendly environments are truly evidence-based. This paper reports on a project that combined a comprehensive literature review with the views of practitioners to update a widely used suite of tools that aim to make a range of settings more suitable for people living with dementia.*

Keywords *Care homes, Dementia, Design, Hospitals, Extra care housing, Health centres*

Paper type *Research paper*

Simon Chester Evans, Sarah Waller and Jennifer Bray are all based at the Association for Dementia Studies, University of Worcester, Worcester, UK.

Introduction

This paper reports on a project that focused on refreshing and updating the 2014 versions of the widely used (Kings Fund/Association for Dementia Studies) Environmental Assessment Tools in light of the latest evidence. This comprised a review of the recent literature focusing on inclusive design across of a range of settings, a survey of users of the tools and the use of the data generated to inform an update of the tools. We present our analysis of key themes from the literature, followed by the findings of the survey, and then discuss emerging themes in the context of the current state of knowledge and practice for dementia-friendly design.

Background

A growing body of evidence suggests that appropriate design of the environment across a range of settings can promote independence, quality of life and well-being for older people in general, and those living with dementia in particular (Geke *et al.*, 2019;

Powell *et al.*, 2017; Orrell *et al.*, 2013; Marquardt *et al.*, 2014; Parke *et al.*, 2017; Clark *et al.*, 2013). This is reflected in advice and guidance published by government (Department of Health, 2015) and the third sector (Alzheimer's Society, 2017).

Alzheimer's and many other dementias result in significant declines in navigation skills, which can be exacerbated when someone moves to an unfamiliar environment such as a care home or supported housing (O'Malley *et al.*, 2017). In 2009, to support the implementation of the national dementia strategy, the Department of Health commissioned (The Kings Fund) to adapt their [Enhancing the Healing Environment (EHE)] programme to focus on environments of care for people living with dementia. The programme "encouraged and enabled local multi-disciplinary teams to work in partnership with service users to improve the environment where care was delivered" (https://www.kingsfund.org.uk/projects/enhancing-healing-environment). As part of this initiative, a suite of environmental assessment tools was developed to enable a range of settings to become more dementia-friendly.

The first tool focussed on hospital wards and was launched in 2012. Further tools were subsequently developed to cover non-ward hospital areas, health centers, care homes and housing, based on a set of overarching evidence-based design principles across five core domains: meaningful activity, legibility, orientation, wayfinding and familiarity (Waller *et al.*, 2017). The tools aspired to promote a range of positive outcomes for people living with dementia: easier decision-making; reduced agitation and distress; increased independence and social interaction; enhanced safety; and the ability to perform of activities of daily living. The tools are free and over 19,000 have been downloaded, the most popular being those for hospital wards (6,660 downloads) and care homes (5,779). The majority of downloads are from the UK, but other countries include Australia, Belgium, Canada, Ireland, Slovakia, Spain and the USA. In addition, permission has been given for translation of the tools for use in Brazil, Germany and Denmark.

In 2015, the (Enhancing the Healing Environment) programme transferred to (The Association for Dementia Studies at the University of Worcester), where a project to refresh and update the tools was undertaken in 2019/20. This comprised a scoping review of the relevant literature published since the tools were developed and an online survey of professionals who had used the tools. Thirty-seven people representing a range of users of the tools participated in the survey, which explored use of the tools and any environmental changes that were made as a result. The findings were used to inform a redesign and relaunch of all five tools.

The scoping review reported on in this paper explored the evidence published in English in peer-reviewed journals and books since 2014, when a similar review was carried out to inform development of the original tools. A University-based search engine was used covering a range of academic databases, adopting multiple combinations of the following terms: "dementia"; "environment(al)"; "design"; "dementia-friendly"; "cognitive". Websites were also searched, including UK Government and third sector organisations, to find relevant policies and examples from practice. This led to a review based on 45 peer-reviewed publications and three items describing policy or good practice.

In presenting the findings of this review, we start by focusing on two systematic reviews that spanned a range of settings. Following this, we look at single studies across five specific environments: people's own homes, long-term care, hospitals, mental health units and the outdoors.

Design across multiple environments

A systematic review of the literature on designing environments for people with dementia (Bowes and Dawson, 2019) highlighted areas with the strongest evidence base. They suggested that in general a 'homelike' environment (e.g. small scale, familiar objects and

personal space) can promote greater engagement in activities, enhanced social interaction and reduced agitation. Their review also summarised key evidence for dementia-friendly design of specific settings and spaces. For example, bathrooms should be accessible, with familiar fittings and good signage, while hospital patients benefit from having shared and private spaces, sensory stimulation and access to the outdoors. Eating spaces in any setting can provide opportunities for people with dementia to participate in food preparation and serving, using regular crockery, cutlery and glassware. The authors reported little evidence for the effectiveness of assistive technology as part of a supportive environment for people with dementia, and identified many examples of the challenge of implementing technology in real life settings.

Another review published in the same year (Wood-Nartker *et al.*, 2019) focussed on guidelines that aim to reduce the risk of falls in the indoor built environment. The authors assimilated the findings from previous research to provide detailed recommendations across four key categories: Lighting, colour, wayfinding/orientation and fixtures/fittings/furniture. For example, their recommendations for stairwells included handrails that extend 12 inches beyond top and bottom step, defined stair edges and light switches at the top and bottom of stairs.

Design in people's own homes

While living in their own home is the preferred option for most people with dementia, they often face multiple challenges due to deterioration in physical and cognitive abilities. A review of 40 qualitative studies identified a range of strategies that can reduce emotional and physical demands for carers whilst encouraging comfort and independence for the person with dementia (Soilemezi *et al.*, 2017). These include creating wider doorways, adjusting the lighting, de-cluttering, reducing distractions and the use of colour, labelling and handrails.

Evans *et al.* (2019a) found that relatively inexpensive aids, such as key safes, notice boards and touch-activated bedside lights, can contribute towards the maintenance of well-being for people with dementia living in domestic settings.

Design in hospitals

A qualitative study described hospitals as busy, unfamiliar and stressful environments for people living with dementia, leading to an experience that can be distressing and disorientating (Xidous *et al.*, 2019). Another study argued that well-being-focused design in acute dementia wards is particularly beneficial for people in the less advanced stages of dementia (Catt and Giridharan, 2018). The authors suggested that building design standards are too generic and should offer greater consideration of patient group specifics and non-clinical spaces.

Design in mental health units

One publication explored the specific challenges of design for mental health units, which are characterised by complex combinations of mental and physical health issues, including depression, visual impairment and hearing impairment and behaviours that challenge (Marshall, 2014). The author suggested a range of key design features to support clients, including layout to promote maximum visibility, opportunities for safe walking, floors with one consistent non-reflective tone and pictures and photographs of local interest. It was also suggested that being able to see nature from a window speeds healing, while doors to outside areas should be visible, unlocked and easy to use.

Design in long-term care

A review of the evidence for the impact of physical environment interventions on residents with dementia in long-term care settings identified the importance of a supportive dining setting (Chaudhury *et al.*, 2013). It was suggested that this can foster functional ability, orientation, safety and security, sensory stimulation and social interaction. A systematic review identified four types of mealtime intervention: music, changes to food service, dining environment alteration and group conversation (Whear *et al.*, 2014). The authors concluded that mealtime interventions can improve behavioural symptoms in people with dementia living in residential care, including agitation and aggression, although weak study designs limited the generalisability of their findings.

A mixed methods study of eight Hong Kong care homes identified four environmental factors that positively predicted the physical health, psychological health and social relationships of residents: lighting, temperature, lifts and water supply (Leung *et al.*, 2019). The authors offered a range of practical recommendations, including access to a sky garden on each floor, signage with iconic information at strategic locations and colour-contrasting decor. Another study identified several practical interventions to provide a supportive mealtime environment included noise reduction and enhancement, the use of appropriate music and a more homelike environment to provide cues to eating and drinking (Martin, 2019).

A systematic review focusing on spatial and environmental design in long-term care identified three key characteristics that affect positive social interaction: the physical environment and setting; accessibility, legibility and layout; and the social environment and network (Ferdous, 2019). Recommendations based on the review to promote positive social interaction included units supporting no more than ten residents, gardens that provide continuous wandering paths, scented but nontoxic plants, raised beds and use of colour, texture, landmark and signage to facilitate wayfinding. The author also highlighted a paucity of good quality research addressing key design features in relation to the health and well-being of service users.

A substantial body of literature suggests that small-scale "homely" long-term care environments provide positive outcomes for residents, including better psychosocial care, more social involvement, and fewer behavioural symptoms (Fishman *et al.*, 2016). "Homeliness" is central to the "Green House Model" that has become popular in the USA and elsewhere, which features a small-scale, non-institutional, domestic approach to care and support.

Design of outdoor spaces

Evans *et al.* (2019b) reported on a research study exploring the opportunities, benefits, barriers and enablers to interaction with nature for people living with dementia in residential care and extra care housing schemes in the UK. Many positive benefits were reported including (for residents) improved mood, higher levels of social interaction, increased motivation and (for staff) greater job satisfaction and reduced sickness. The design and layout of indoor and outdoor spaces appeared to play a key role, along with staff who feel enabled to promote connections with nature.

A narrative review of the literature (Motealleh *et al.*, 2019) highlighted the positive effects of outdoor natural landscapes on agitation, apathy and engagement of people living with dementia, but raised concerns about the methodological quality of many studies and little inclusion of the voice of people living with dementia. Another review confirmed the positive health implications of "therapeutic" gardens for people living with dementia, partly because of the opportunities they offer for a range of activities including sitting indoors and looking out, sitting outdoors and hands on gardening (Uwajeh *et al.*, 2019). The authors concluded that there is a need to explore the specific aspects of these environments in greater depth.

Other design studies

A review of the literature in relation to residential environments for people living with dementia and sight loss found that there was little high-quality research (Bowes *et al.*, 2016), making it difficult to draw any firm conclusions. Consistent findings were highlighted, including the importance of strong contrast rather than specific colours to promote wayfinding and orientation, and the need for adequate lighting levels and natural light, particularly in kitchens and bathing areas. Some studies included in the review suggested that automatic lighting can cause distress. Advice on exits and entrances is varied, with some papers suggesting disguised exits to discourage exit attempts, and others advocating strong contrasting colours to facilitate the use of entrances and exits. One paper drew attention to the importance of thermal conditions in extra care housing, characterising residents as vulnerable to cold, at risk from fuel poverty and liable to be burned by hot surfaces (Lewis, 2015).

Survey methods and findings

To ensure a consistent approach, the online survey was based on questions used for a previous review of the EHE tools in 2012. The survey combined multiple choice questions, a rating scale and open questions. The online survey was promoted via social media, a link embedded in the web page where people download the tools and an invitation to relevant organisations such as the Housing and Dementia Research Consortium and the National Dementia Action Alliance for circulation to their networks. The survey remained open for four weeks, with reminders being circulated after two weeks. Descriptive statistics were used to analyse the quantitative data and a thematic approach was taken for the qualitative feedback.

Thirty-five people completed the survey: 15 (43%) nurses or other health professionals, nine (26%) managers, five (14%) researchers, three (8%) architects or designers, one housing scheme manager, one lecturer and one CQC inspector. Ten (34%) worked for an acute trust, five (17%) for a care home, three (10%) worked in specialist or supported housing, three (10%) for a mental health trust and one (3%) for a community hospital. People completing the survey were asked which of the five tools they had used, with multiple options possible for those who had used more than one. Of the 56 tools used in total, 15 (42%) were for care homes, 12 (33%) hospitals, 11 (31%) hospital wards, eight (22%) housing and four (11%) health centers. Six (17%) respondents indicated that they had not used any of the tools and they therefore answered no further questions.

The tools were designed to be completed jointly by staff from different disciplines together with people living with dementia, to encourage discussion and aid understanding. In total, 17 respondents (77%) to the survey had used the tool with another person, either a clinical professional, a family carer, an estate's professional or someone living with dementia.

When asked if the design and format of the tool was appealing and easy to use, 21 (95%) people answered "Yes" and one (5%) answered "No". A range of reasons for using the tool were reported including: 13 (59%) to improve the care environment; 12 (55%) to gather evidence for investment; 11 (50%) to create a baseline across a number of sites; ten (45%) to demonstrate the impact of changes to the environment; seven (32%) due to concerns about the care environment; and five (23%) as part of local quality assurance processes.

All respondents said that the results generated by the tools were "helpful" or "very helpful". Examples of how the results were used included: to influence others concerning the need for change, to prioritise areas for improvement; to secure finance for improvements; to educate staff on how to make appropriate environmental changes at little or no cost; and to help change attitudes.

Seventeen respondents (81%) felt that using the tools had led to environmental improvements. Examples given included developing an interior design strategy, improved signage, informing refurbishments, enhanced training on dementia environments, changes to artwork and better wayfinding. Respondents felt that the tools were user-friendly, evidence based and well designed. Respondents gave the tools an average rating of 8.3 on a ten-point scale and 13 (59%) had used the tool more than once to assess environmental changes that had been made. All respondents said that they would value electronic versions of the tools. Additional comments were positive, with one responding saying "It is a great tool and has helped me to educate and bring changes for the better for people living in care homes. Thank you!".

Refreshing the tools

The findings from the literature and survey were used to inform a detailed review of all five tools. Changes included revised questions and wording to better align with current guidelines and best practice, for example clock size and improved provision for family carers. Overall, more attention has been given to the sensory challenges that can affect people living with dementia including acoustic management, ambient temperature control and the avoidance of odours. The importance of a dining environment that can encourage socialisation has also been highlighted, along with the need for toilet fixtures and fittings to be familiar and easily accessible. The challenges posed by automatic sensor lighting have been emphasised and the overarching design principles have been refreshed to accommodate these changes.

Discussion and conclusion

The project described in this paper has confirmed the original evidence base for the EHE Environmental Assessment tools, while also providing the opportunity to make some important changes. The large and continuing number of downloads of this suite of tools suggests that they are highly valued across the UK and further afield. The responses to our survey show that they are used by a broad range of professionals in multiple settings, with hospital wards and care homes being the most popular. Experiences of using the tools were positive and reasons for using them focused on improving the care environment and monitoring the impact of any subsequent changes. Use of the tools appears to be having considerable impact by informing spending decisions, supporting implementation of environmental improvements, increasing staff awareness of the importance of the environment and promoting wayfinding.

There is overall a paucity of peer-reviewed literature on environmental design for people with dementia published in recent years. The systematic review by Bowes and Dawson (2019) concluded that while the evidence base is growing, most research studies are small scale and of limited quality. Their review, while providing a comprehensive and valuable summary of existing evidence, includes only two publications since 2014. Several design features of dementia-friendly design have become very popular in recent years but without a solid evidence base, such as murals and immersive reality. Does this reflect a widespread view that we already know what works and does not work in terms of inclusive design? This would be surprising, given the generally low quality of the research carried out previously, and emphasises the need for rigorous, large-scale, experimental studies with the potential to provide detailed evidence for the impact of multiple elements of dementia-friendly environments. There is a particular lack of research about household models of care, the use of assistive technology and studies that include the perspectives of people living with dementia (Geke *et al.*, 2019).

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About the authors

Simon Chester Evans PhD is a Principal Research Fellow with the Association for Dementia Studies, University of Worcester. His research interests include dementia, ageing, housing, health and social care, care homes and communities. Simon Chester Evans is the corresponding author and can be contacted at: simon.evans@worc.ac.uk

Sarah Waller CBE is an Associate Specialist with the Association for Dementia Studies, University of Worcester. She was formally the Programme Director of the Enhancing the Healing Environment Programme, The King's Fund and has a particular interest in dementia-friendly design.

Jennifer Bray is a Research Assistant with the Association for Dementia Studies, University of Worcester. Her research interests include intergenerational aspects of dementia awareness, dementia in different care settings and the use of technology with people living with dementia.