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Barrett, PS, Sharma, M and Zeisel, J

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Optimal spaces for those living with dementia: principles and evidence

Abstract

This paper represents a synthesis of diverse and disparate evidence in the research literature that provide insights into the impacts of aspects of the built environment on the wellbeing of those living with dementia. The individually focused findings are structured into a set of practical design parameters, driven by three overarching needs-driven design principles, namely: manageable cognitive load, clear sequencing, and appropriate level of stimulation. These needs are contextualized within a general model that suggests that action in any one area (such as the built environment) also has to take into account other key dimensions, namely any support from the caring / social environment and any pharmacological treatment. Addressing these elements holistically should maximize the opportunity to improve the quality of life of the individual. This paper, however, explicitly focuses on the built environment.

Key words: dementia, built environment, evidence-based design, social impacts, treatment, literature synthesis, ecopsychosocial, design principles

1 Factors impacting on the living with dementia

1.1 Introduction

According to the World Health Organisation (2018) dementia is "one of the major causes of disability and dependency among older people worldwide". They estimate the scale of the issue is huge and dynamic, with around 50 million people affected now, projected to rise to 82 million in 2030 and 152 million in 2050. They stress that there are "physical, social, and economical impacts, not only on people with dementia, but also on their carers, families and society at large". On this last aspect the societal cost of dementia has been estimated at as much as 1.4% of GDP in high-income countries.

WHO (2018) deliver the bitter fact that: "there is no treatment currently available to cure dementia or to alter its progressive course". But they do stress that there are opportunities to support all involved and improve their quality of life.

At the centre of efforts to address the personal and societal impacts of dementia is the concept of 'living well with dementia' (Rahman, 2014; Banerjee, 2010). This necessarily implies taking the perspective of the person living with dementia. Our proposition is that it is necessary to consider three distinct dimensions within the person's environment, which together contribute to the person's holistic, lived experience. These environmental dimensions are a logical progression from the person in focus, to those around them to the broader material environment, as follows:

- ***The pharmacological/medical environment:*** namely the **drugs** prescribed and the **medical treatments** given to ameliorate the symptoms of the patient's condition;
- ***The social and care/support environment:*** this includes all aspects of support from **people**, ranging from social activities, relatives, friends, the full range of informal and formal care at varying depths of involvement;

- **The material environment:** the **things** in the environment delivered in the form of the characteristics of the inhabited internal and urban built spaces and the potential technological support and opportunities which can be accessed.

A large part of recent and past research efforts in respect of dementia have been focused on the first of these dimensions. The second two dimensions have received less attention, although more recently they have collectively been termed “ecopsychosocial” factors (Zeisel et al., 2016). To fully grasp the optimum way forward for a particular individual the combined holistic impact of *all* of these dimensions, on that specific person living with dementia, in specific environments, needs to be made explicit. This is, of course, how people actually experience daily life – not in the discrete elements of what is around them, but through their combined impact.

1.2 Proposed holistic research landscape

Figure 1 sets out an holistic view of the dementia research landscape taking into account the material, social, and pharmacological context. This essential “hope” model intrinsically accepts that a person with dementia can maintain a reasonable level of quality of life for a significant part of their journey with the condition. The bottom curve represents the general decline in the individual’s quality of life; reflecting observed reality as well as general models of long term life trends in brain functioning (OECD, 2002). The successive curves above this baseline suggest that the individual’s “intrinsic” capacity can be augmented by a combination of: the empowerment provided by the physical / technological environment, the support of the caring / social environment, plus treatment through pharmacological and medical means, where appropriate. Separately and together they can work to deliver a greatly enhanced “effective capacity” for the person to live well with dementia. In sum, “hope” lies in the reality that interventions in these areas can actually make a difference.

Figure 1: Holistic dementia research landscape

Major research questions implied by this model include:

1. How to typify and measure the experienced intensity of the three contextual dimensions?
2. How to typify and measure the capacity/quality of life of those living with dementia?
3. How to identify different broad categories, or “living profiles”, of people living with dementia where the factors impact differently, e.g. age, gender, stage, culture, etc.?
4. How to understand the interactive/synergistic effects between the three contextual dimensions?
5. How to identify key transition points in care and support needs and effective responses at these points?

1.3 Knowledge gaps identified

Initial consideration of these questions using a combination of individual desk research and workshops with co-researchers¹ has established a rough, initial view of the current baseline of knowledge around metrics for the various dimensions of the research landscape. Our findings can be summarised as follows:

- Quality of life measures – this is the most relevant dependent variable in our research landscape. “There is no consensus in the scientific literature on the core domains of QoL” (Pietersma et al, 2014). Specifically for dementia, Bowling (2014) has carried out an extensive review. The front-running measure is QOL-AD (quality of life in Alzheimer’s

¹ This section is based on a series of focused literature reviews about the evidence of the impacts of different aspects on Alzheimer’s: James Chandler and Kate Walter reviewed the literature in relation to QoL; Kate also investigated the literature on the care / support environment; and Chris Pickford focused on the technological environment. The authors of this paper covered the other areas.

disease), but the 15 items used do not have an underpinning logic and Bowling concludes that broader measures created *with* those living with dementia are needed.

- Pharmacological environment – this is encapsulated in the Cochrane reviews that have been carried out in the area of dementia. There have been over a hundred relevant reviews completed and at a rough assessment² about a quarter show some benefit of a given treatment, a quarter show no benefit and the remaining half provide inconsistent or insufficient evidence. It has been suggested in a recent US National Academies publication (Committee on Preventing Dementia and Cognitive Impairment, 2017) that the strength of RCT studies, favoured in the Cochrane reviews, is also a weakness in that “while they are particularly effective for testing single-intervention solutions, the apparent complexity of the pathophysiology underlying cognitive decline and dementia suggests that a multifaceted approach may be most effective” (p11). This resonates with the high level of “inconsistent” results, which are likely to be a consequence of confounding, non-pharmacological factors.
- Care / support environment – here there are quite general statements regarding the stages at which certain types of care may be needed (WHO & Alzheimer’s Disease International, 2012) and an extensive survey of care options based on where they are delivered (Hallberg et al, 2013). With the exception of the specific area of Psychological Therapies (DHSSPS, 2010), there is not an objective measure of the *intensity* of caring support provided by *people*, either trained or not.
- Material environment – comprising the built aspect and technology:
 - Built environment – for this aspect there is quite a lot of isolated evidence for the impacts of specific elements (say light levels) on those living with dementia, but only one “holistic” study by Zeisel et al (2003). This study assessed eight aspects of care

² Provided in a presentation by Sally Spencer, of Lancaster University in the UK, Editor, Cochrane Dementia & Cognitive Improvement Group.

facility design and found statistically significant evidence for the impacts of five of them. In addition there are several general tools for assessing “design quality” and a sub-set focused on design for dementia. Of these the King’s Fund approach is probably the best known (Coulter, Roberts and Dixon, 2003). This tool explicitly mentions the needs of users, but does not accommodate all of the evidence and in places goes beyond it. As in the other areas explored above, there is no objective measure of the *intensity* of the support provided by the built or physical environment.

- Technological environment – The literature and an active marketplace focusing on devices, each mainly targeted at a specific need. There is an emphasis on safety and especially alerts in the case of falls, together with an array of prompts and reminders. New directions are emerging in the area of sensor technologies and monitoring, at its most extreme in the form of “smart homes” (Bennett, Rokas and Chen, 2017). The emphasis is on technical feasibility, with some connection to identified needs, but lacking evidence of impacts. Again there is no objective measure of the *intensity* of the support provided by the technological environment (Parker, Mills and Abbey, 2008).

It can be seen that, quite surprisingly, there are large gaps in the available metrics, especially if the intensity of the various types of support is factored in. Filling these gaps is crucial if an holistic approach of the type set out above is to be operationalized.

This is a large task. Therefore, this paper focuses just on the built environment aspect of the “material” environment. It gathers together the wide-ranging evidence that there is for the impacts of the physical environment on those living with dementia, but crucially it seeks to put this material within as simple a conceptual framework as possible. In doing this actionable design principles surface, so that practical impacts rooted in the detailed evidence can be

stimulated in practice. The scale and urgency of the issues affecting those living with dementia can be seen to demand this emphasis on links to action.

2 Methodology

The methodology adopted is based on secondary sources and driven by the twin features of the current state of knowledge in this area. As set out above, this can be typified, first, as the existence of a lot of isolated pieces of evidence about particular aspects (what Scambler (2001) has termed 'demi-regularities') and, second, a relative gap in relation to the adoption of a person-centric, holistic view. The purpose of this paper is to address this latter gap, whilst building on the evidence that does exist.

This led to a two-pronged approach, first, a bottom-up approach based on the literature, and more particularly, studies that provide clear evidence of impacts of the built environment; second, a top-down approach driven by a strategic consideration of the needs of the person living with dementia. This latter was then used to sharpen the structuring of the emergent issues from the bottom-up effort and to reassess the utility of the conceptual framework being used.

This approach drew on several complementary methodological traditions. In order to collect and synthesize the evidence within the literature in support of gaining a clearer overview, an approach was taken that has features of a grounded theory approach (Glaser and Strauss, 1967; Strauss and Corbin, 1990), especially in its determination to be rooted in reality, as represented by the evidence, and to let categories within the data emerge naturally and iteratively. The progressive articulation of these emergent categories with broad conceptual ideas builds on soft systems' ideas of cycling between "the real world" and theoretical models

(Checkland, 1993). This continues until, in the realist tradition (Sayer, 1992), the coverage and fit between them reinforces the probable “practical adequacy” of the schema developed. This progressive process also reflects more recent grounded theory notions where the approach is not typified as either inductive or deductive, but rather an interactive “truth-tracking” process (Gibson and Hartman, 2014) linking building blocks of theory and practice within broader frameworks of understanding (Barrett and Barrett, 2003).

It is impossible to fully reflect the iterative nature of the process in linear written form, so this paper is written as if the bottom-up literature review was carried out leading to categories of issues that were then drawn into a broader top-down conceptual model. In reality the process was messier than this and accommodations were made in the various possible classifications until a good level of fit was achieved within a framework that was felt to be logical and compelling in itself, as well as strongly connected to the available detailed items of evidence.

Within this broad context, some further details of the methodology employed are given in the respective sections, later in this paper.

3 Bottom up synthesis from the literature

3.1 General approach

Grant and Booth (2009) assess fourteen different approaches to literature reviews and highlight the relative strengths and weaknesses of each. Given the thrust of this study, a “critical review” approach was clearly optimal as it provides the opportunity to “take stock [and] provide a launch pad for a new phase” by drawing material from diverse sources and traditions (p93). A consequence of this necessary flexibility is that critical reviews are not as “systematic” as some approaches, as the study designs encountered are varied and so the

assessment criteria are necessarily more subjective. That said, in this study many potential sources were driven by rhetoric or aesthetic appeal, but these were sifted out and, as far as possible, only the sources based on sound empirical evidence were included. In this way the approach used displays elements of “systematic search and review” (p102). As Hart (1998) points out: “All reviews, irrespective of the topic, are written from a particular perspective or standpoint of the reviewer” (p25). However, to make this process of review more robust, a team of two researchers was formed so affording the opportunity for investigator, and theoretical triangulation (Denzin, 1970) around the emerging themes.

3.2 Initial consideration of scope

The literature was surveyed using search engines that scanned databases of journal papers.

The following three types of data search were conducted:

- Database
- Hand search
- Snow ball i.e. looking at the reference list of the most relevant journal papers

The databases included Science Direct, Academic Search Premier, CINAHL, Google Scholar, MEDLINE via EBSCOhost, Web of Science and Ovid Abstracts. Typical keywords used were: (dementia), (built environment), (sensory enhancement and environments), (wellbeing and building environments), (environments for living well with dementia), (Quality of life for people with dementia and built environments). From this initial sift, one hundred and eighty-five papers published between 1981 and 2016 were carefully reviewed and then only included if they contained empirically derived evidence of the impact of some aspect of the physical design of the built environment on those living with dementia. Working from these papers to other related sources added further evidential papers, resulting in a resource of eighty-six

individual papers, each with evidence of one or more impacts (positive or negative) driven by one or more aspects of the built environment.

These sources are listed in the final column of the table in Appendix 1. Although it is helpful to collect the published sources of evidence together into one place, our objective was to synthesise this material so that, out of the detail of the studies, major dimensions can be identified. Thus, whilst respecting the granularity of the individual studies, we present here two iterations of condensation leading to a simpler categorization reflecting the broad ambient factors that generally impact those living with dementia.

Given the built environment focus of this analysis, the initial categorization taken was a simple, spatial split, namely: internal spaces, external spaces, and the way-finding / circulation spaces between. See Table 1.

Table 1: The emergent built environment issues identified from the literature review.

What emerges strongly from this initial exercise is that there is an entire category of factors concerning “sensory enhancement” that cut across all of the physical spaces. Grouped together at the end of Table 1, these factors appear to relate to the issue of providing the appropriate level of stimulation for occupants.

What also becomes apparent is that, although there are strong attitudes and opinions, and an intuitive sense as to the importance of external spaces, there is actually very little evidence for the impact of external spaces in the context of dementia (Whear et al., 2014). What studies

there are lack meta-analyses and thus the picture remains relatively unclear regarding actual benefits of designed garden spaces for people with dementia. Further there is lack of correlation between incorporated interventions, their evaluation, and outcomes. One of the key issues that past studies have identified and that has implications for outcomes is accessibility of the gardens/ external spaces for residents either alone or accompanied. This area requires more research, but for the purposes of this exercise it was excluded from here on, although, as will be seen, some aspects do appear within the categories taken forward. Now a distinction with external spaces is not needed, and reflecting on the issues under “internal spaces”, they can be better typified under a heading of “scale / familiarity”.

Based on this initial exercise, we focused on the following three categories: scale / familiarity, way finding / circulation spaces, and appropriate levels of stimulation. Reviewing the factors in Table 1, a clear spatial distinction emerges between the issues as they operate in personal spaces compared with shared spaces. This is most clearly seen in the area of “internal spaces” where the issue of “individual space” sits alongside issues of “social environment”, with questions of “privacy and autonomy” at the intersection. It was therefore decided to treat the personal – shared space dichotomy as an overlay to the three categories identified above.

Thus, the analytic framework employed to further organize the findings of the eighty-six individual studies is as shown in Table 2:

Table 2: Analytic framework to structure issues from the literature in Appendix 1

3.3 Detailed examination of the evidence base of impactful studies

The table in Appendix 1 employs this framework to structure the referenced studies. The first two columns distinguish the three categories within the broad classification of personal / internal spaces, followed by a synthesis across the studies of fifty-six identified *factors*. Their evidenced impacts are provided in the fourth and fifth columns. These factors are numbered in the third column and the sources in the literature evidencing the impacts are provided in the sixth column.

The table in the Appendix 1 indicates that there is a reasonable volume of evidence-based studies in each of the cells of the analytical framework given in Table 2. Further, the categories comprehensively capture and structure to some degree the factors at play. However, because the factors draw from a bottom up consideration of a wide range of studies, the logic of how the factors relate to each other within a given area is less clear. In addition fifty-six factors is still too detailed a level of resolution to clearly see the main mechanism at work. To address these issues the next section turns to top down consideration of the driving logic behind why these sorts of factors could have impacts on those living with dementia.

4 Top down driving forces for impacts of built environment

4.1 Rationale for design principles

The aim in this element of the study is to identify a strong person-centric view of the physical environment, given that at that level of analysis it can be anticipated that clearer “emergent properties” (Checkland, 1993) will crystalize, which are practically relevant to those living with dementia. Given that dementia is fundamentally driven by deterioration in the functionality of the brain, it is logical to look to these changes for clues as to the major dimensions and underlying regularities of the issue (Sayer, 1992). These changes can be seen as “generative mechanisms” for the challenges confronted by those living with dementia and through a

creative process of “retroduction” the goal is to suggest a relatively few design principles that respond to these needs (Sayer, 1992).

Zeisel’s (2009) book “I’m Still Here” is taken as the source material for the above exercise. It is based on his earlier empirical work, but also a sustained effort to link the impacts observed to the specifics of the cognitive impairment of those living with dementia. Table 3 draws from this text (pp63-80) and summarises the nature of each aspect of the physical changes in the brain, its cognitive implications, and possibly enabling responses in the built environment that can ameliorate the impact. It also sets out whether these effects arise in early, middle, or late stages. It has to be said that they act cumulatively.

Table 3: Summary table drawing from Zeisel (2009) of: physical damage, impacts on cognition, and possible enabling responses in the design of the environment

The variety and specificity of the physical features is a reminder that particular issues may be in focus at any one time for each person. However, focusing on the cognitive impacts at a general level it is suggested that the underlying issues are driven by a reduced capacity to retrieve and process information, and in particular to sequence information, together with reduced behavioural self-control.

Potential enabling responses can be grouped into the following three “needs”, which in turn are proposed as design principles to be aimed at in order to provide supportive physical environments for those living with dementia:

- Manageable cognitive load

- Clear sequencing
- Appropriate level of stimulation

Just as the individual factors appeared too detailed, the three “needs” above are lacking in practical elaboration. The following discussion synergistically links the two – merging the bottom up evidence of impacts from the literature with the broad logic provided by the needs of those living with dementia.

4.2 Structuring the evidenced factors (from the appendix) within the design principles

The factors given in the table in Appendix 1 were grouped in terms of each of the three top down design principles, both in personal spaces and shared spaces, with the aim of simplifying the built environment factors into a core set of actionable design parameters.

Manageable cognitive load

This principle gives life to consideration of the scale and familiarity of the spaces provided. These should as far as possible “read” clearly and be supportive. For personal spaces this draws on Factors 1-11 and calls for private, adaptable spaces with familiar, personal contents. In shared spaces Factors 25-33 are relevant and stress the importance of a bounded, non-institutional scale to the whole facility and, within that area, legibility with distinctive zones.

Clear sequencing

The principle of clear sequencing links to way-finding, yet works differently in personal space (Factors 12-18) as compared to the way it works in shared spaces (Factors 34-43). In personal spaces, the emphasis is on prompts to support particular activities. In shared spaces clear sequencing is more closely linked to making way-finding intuitive through a clear spatial

connections, destinations, and spatial signs / cues. This is what Norman (1990) terms “naturally mapped” environments.

Appropriate level of stimulation

The principle of appropriate level of stimulation applies across the board. For personal spaces it links to Factors 19-24, stressing the benefits of a comfortable and moderately stimulating sensory environment. This applies to shared spaces as well, but examining Factors 44-56 makes clear that the principle also extends to providing opportunities for the stimulation of social interaction.

Pulling this together into diagrammatic form, Figure 2 summarises the three design principles driving ten, condensed, design parameters. These simplified parameters are explicitly rooted in the fifty-six evidenced factors revealed in the literature.

Figure 2: HEAD-Dementia Model³ linking top down built environment Dementia Design Principles with practical Design Parameters rooted in the literature

This model presents a robust framework of design principles, linked to the needs of those living with dementia, as well as to more detailed design parameters explicitly rooted in the evidence of impacts from the literature. The Dementia HEAD framework shows three “drivers” i.e. manageable cognitive load, clear sequencing, and appropriate level of stimulation for people living with dementia in two types of spaces, namely personal spaces and shared spaces. The articulation in the diagram of the design principles with the parameters emerging from

³ HEAD = Holistic Evidence and Design

the detailed literature-based evidence represents the result of the truth-tracking process described in the methodology section. It highlights that:

- to manage cognitive load, personal spaces must provide the opportunity for privacy / personalisation and be user-adaptable. Personal spaces must be familiar in nature. Shared spaces, to manage cognitive load, need to be bounded and non-institutional in scale. All spaces must be designed to be legible with any zones created having distinctive qualities.
- to provide clear sequencing in personal spaces the environment must provide prompts that support particular activities. Whereas in shared spaces way-finding needs to be intuitive with a clear sequence of spaces, evident destinations, all supported by spatial signs and cues.
- to create the appropriate level of stimulation, both personal and shared spaces must provide a comfortable and moderately stimulating sensory environment. Shared spaces need to offer opportunities for social interaction.

The broad design parameters provided here are actionable in practice in a comprehensive, flexible way, all being strongly substantiated by the more detailed evidence.

5 Conclusions

This paper proposes a broad research landscape to be addressed if a holistic person-centred perspective is to be taken of dementia treatment. We suggest that some combination of support through the material environments, the social environment and pharmacological means must be considered. It is posited that the evidential base is limited in most of these areas regarding impacts on the quality of life of those living with dementia and that the very notion of quality of life in this context is hard to both conceive of and measure. This last point resonates with the findings of recent work in this area, such as Fleming et al (2016).

Against this challenging agenda, this paper focuses on the impacts of the built environment. Here there is much evidence to be found of impacts of the built environment on those living with dementia. Yet each piece of evidence tends to focus on one or another particular issue, with little evidence concerning holistic impacts in physical settings as experienced in normal life.

The main focus of this paper is therefore a synthesis of the evidence about the built environment to create a small actionable set of design principles, supported by more detailed, strongly evidenced, design parameters. This is summarised as the “HEAD-Dementia Model” in Figure 2, offered as a basis for further study and intervention by those supporting those living with dementia.

Our driver for the organisation of the design principles is akin to Marshall’s (1998) “compensate for disability” in its focus on the changes in the brain of the person living with dementia. This in our work then leads to many of her other design considerations, such as allowing for the control of stimuli, but it does not extend as broadly to things such as demonstrating care for staff. We have focused only on the built environment needs of the person with dementia in our detailed consideration, although the broader model given in Figure 1 does clearly identify the social dimension as an related area for study. Fleming and Purandare’s (2010) extensive review of the evidence in the literature using Marshall’s list of eleven desirable design features for residential facilities for people, with dementia provides an interesting benchmark for the review provided in this paper. Not surprisingly many of the factors in the list are similar to those considered in this paper. Typically they are at the level of “design parameters” in our terminology. The evidence is found to vary in strength, for instance, with less agreement around the value of the provision of outside space. The

evidence base continues to build slowly and this paper is part of capturing that progress. What we have added is a reasoned proposition for an additional level of three understandable, actionable design principles.

These principles provide a broad view of the ambient physical design factors that should be conducive to 'living well with dementia' (Rahman, 2014; Banerjee, 2010). Zeisel (2009) lists, among what are generally considered negative symptoms of dementia, the 4A's: apathy, anxiety, agitation and aggression. Figure 3 suggests how the design principles described above may be related to, or effected by, the physical context. Grouping "clear sequencing" and "cognitive load" along the x-axis as Cognitive Demand, with "level of stimulation" along the y-axis, it can be seen that the 4A's are likely outcomes of the extremes of the four broad combinations provided in the diagram.

Figure 3: The link between the 4As and the Design Principles

If 'living well with dementia' relies at least partially on the absence or minimization of the 4As, this view reinforces the evidence that using the design principles elaborated in this paper can help identify ways to positively impact the quality of life of those living with dementia.

It follows that moderate levels of stimulation would contribute to reduced apathy and agitation, whilst a moderate level of cognitive demand should help reduce apathy and anxiety. This latter area deserves further research including the question of the beneficial effects of "environmental press" (Lawton, 1982). Some challenge, as the environmental press model points out, can be beneficial and this reflects the "use it or lose it" mantra that is sometimes heard (eg Zeisel, 2009). To complete the picture, too much on both axes is likely to lead to aggression. The key proposal implicit in this paper is that, judged by the capacities of the

individual, the aim of environmental design must be to identify a mid-point where the individual has interest, but is not over-stretched; is stimulated, but not disturbed. Design parameters available to achieve this subtle balance are set out in Figure2, the “HEAD-Dementia Model.

The authors hope that the general models proposed in this paper lead to further research and design elaborating the models and specifying the needs and design goals of environments that support the quality of life of those living with dementia.

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Appendix 1: Summary of 56 sources in the literature of built environment factors with evidenced impacts

