

Defining the desirable characteristics of physical environments for the delivery of support and care to people in the final stages of dementia

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1. Background

This report discusses findings from three focus groups with people with dementia, family carers and practitioners carried out in Eastern Australia in August 2011 to inform our understanding of the characteristics of environments that support good practice and promote optimum experience for people with dementia who are nearing the end of their lives.

The importance of ensuring that the design of buildings, specifically residential facilities, meets the needs of people with dementia and makes sense to them has been championed by Marshall (1998). Marshall's (1998) summary of the key principles of design and dementia from existing literature continues to be used as the quality standard of good design. She asserted that design should:

- Compensate for disability
- Maximise independence
- Enhance self-esteem and confidence
- Demonstrate care for staff
- Be orientating and understandable
- Reinforce personal identity
- Welcome relatives and the local community
- Allow for stimuli

(Marshall, 1998)

A review of the literature on the design of physical environments for people with dementia found substantial empirical support for these principles (Fleming and Purandare, 2010).

Fleming used a set of principles that are consistent with Marshall's in his early work on the design of facilities for confused and disturbed elderly people: CADE units (Fleming and Bowles, 1987; Fleming et al., 1989). These were used as the basis for the development of the Environmental Audit Tool (Fleming et al. 2003; Fleming, 2011). These principles state that environments that are used to provide care 'aimed at maintaining the abilities of people with dementia should':

- Be safe and secure
- Be small
- Be simple and provide good 'visual access'
- Reduce unwanted stimulation
- Highlight helpful stimuli
- Provide for planned wandering
- Be familiar
- Provide a variety of spaces with opportunities for both privacy and community
- Provide links to the community
- Be domestic and homelike

(Fleming et al., 2003: v-vii)

Fleming et al. (2003) assert that working with such principles allows staff and management to gain an understanding of any problems that are caused by the environment in which people with dementia live, allowing for the implementation of short-term and long-term plans for improvement of their environment. Both Marshall's and Fleming's sets of principles describe the components of a 'dementia friendly' environment; described by Davis et al. (2009) as:

'a cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way'.

(Davis et al., 2009: 187)

However, any definition of a dementia friendly environment should consider both the importance for the person with dementia of his/her experiences within the environment and also the social, physical and organisational environments which impact on these experiences. Lyman (1999:15) states that 'care providers and care recipients inhabit the unique world of dementia care. If designers and programme planners can understand this world from the perspective of persons living with dementia, an "enabling" environment can minimise disability and provide opportunities to live a meaningful life, despite losses and challenges associated with dementing illnesses.'

This definition highlights a shift in emphasis from care environments designed to keep people safe and meet their physical needs to care environments that are designed to maximise existing skills and retain independence. Chalfont and Rodiek (2005) argue that we need to move away from designing for the purposes of control, surveillance or to diminish behavioural difficulties to considering how environments can encourage curiosity and engagement in everyday activities. This is as important for the outside as inside environments (Chalfont, 2008).

It is clear, however, that the focus of dementia friendly environments is on maintaining independence and well-being and is therefore aimed at those who are relatively fit and mobile. With an increasing, and increasingly frail, population of people with dementia receiving care in formal care settings, these design principles might not accurately reflect their needs and wishes; this might particularly be the case for people with dementia approaching the end of their lives.

End of life care for people with dementia

There are growing calls for end of life care to be provided, not just to those with cancer (NHS, 2000; Scottish Executive, 2001) but for people with coronary heart disease, older people (Department of Health, 2001) and, indeed all people approaching the end of life regardless of age, diagnosis, gender, ethnicity, sexual orientation, religious belief, disability or socio-economic status (Department of Health, 2008). In the UK, the Department of Health (2008) also proposes that high quality care at end of life should be available wherever the person may be – at home, in a care home, a hospice, hospital or elsewhere.

The National Institute for Clinical Excellence (NICE, 2004), in reference to palliative care for people with cancer, suggests that supportive care is the responsibility of all health and social care professionals. Supportive care is an umbrella term for the support and care given by all staff (professionals, care workers, GPs) and staff specially trained in providing palliative care and encompasses promoting and supporting self-help groups, offering appropriate and timely information, offering psychological support, ensuring effective symptom control, offering spiritual and social support, offering complementary therapies and ensuring excellent palliative, end of life and bereavement care (NICE, 2004). Although specifically aimed at cancer care, it is clear that a supportive care approach can be applicable for people with dementia and their carers also. The crucial point about supportive care is that it is not a response to a particular stage in the illness, but a recognition that people and their families will need different forms of support from the onset of their illness, through deterioration and up to and beyond their death.

A palliative approach should, therefore, be an integral part of all clinical practice, when needed, whatever the illness or stage (Albinsson, 2002). The case for making palliative care available for people with dementia has been made on the grounds of equity, need and on the basis that adopting a palliative approach would improve the quality of care available to people with dementia; throughout their journey (Small et al., 2007). In the United Kingdom, the philosophy of palliative care emphasizes care and communication rather than intervention and treatment (ten Have, 2004); it attempts to redirect the emphasis on technology-driven medicine. In Australia, guidance on palliative and end of life care emphasizes a person-centered (Kitwood, 1997) approach which meets physical, psycho-social and spiritual needs and addresses aspects of the environment such as ensuring bedrooms are of sufficient size to accommodate visitors and equipment and that sensory support is offered

(DoHA, 2010).

The National End of Life Care Intelligence Network (2010) report that the largest percentages of deaths of people with dementia occur in hospital (36%), followed by nursing homes (30%) and old people's homes (26%). Relatively small percentages die in their own homes, in hospices, or elsewhere. In a study looking at place of death of people with dementia in five European countries (Belgium, the Netherlands, England, Wales and Scotland), Houttekier et al. (2010) found a similar pattern, apart from the Netherlands where the majority (92.3%) of people with dementia die in nursing homes with 3.8% dying at home and 2.8% dying in hospital. The Netherlands has developed nursing home provision to include long-term end of life care, with 24 hour nursing care and staffed by specialist nursing home physicians. They are therefore well equipped to offer specialist care to people in nursing homes until they die. Australian Institute of Health and Welfare (AIHW) statistics demonstrate that in 2006-2007 72.7 % of people admitted to care homes were 80+ years of age, an increase from 64.1 % in 1998-1999 (AIHW, 2009). The association between advanced age and dementia indicates a rapidly increasing prevalence of people with dementia resident in the care home sector. In 2008 it was estimated that there were 227,350 people with dementia in care facilities across Australia and the demand for these places is estimated to grow at 4%pa between now and 2029 (Access Economics, 2009).

The increasing numbers of people entering care homes in a frailer state and policy drivers to provide high quality palliative and end of life care to people with dementia prompt the following questions:

- What is the evidence base for designing for people with dementia who are nearing the end of their lives?
- What are the needs and wishes (in terms of the design of care settings) of people with dementia who are nearing the end of their lives?
- What are the needs and wishes (in terms of the design of care settings) of family members of people with dementia who are nearing the end of their lives?
- What are the needs and wishes (in terms of the design of care settings) of practitioners caring for people with dementia who are nearing the end of their lives?
- What (if anything) needs to be changed in existing design principles to meet all their needs?

Aims of the project

- To gain a better understanding of the needs of people with dementia in the final stages of their lives and the physical resources required by the staff caring for them.

- To identify a set of principles that will inform the design of physical environments that accommodate the needs of people with dementia in the final stages of their lives.

2. Methods

Two methods were used to inform the definition of desirable characteristics of physical environments for the delivery of support and care to people with dementia nearing the end of their lives. These were 1. an initial review of relevant literature and 2. exploration of key informants' views using a topic guide developed using key themes from the literature.

Ethical approval for the study was obtained from the University of Wollongong/South Eastern Sydney and Illawarra Area Health Service Human Research Ethics Committee (Australia) and the School of Applied Social Science Ethics Committee, University of Stirling (Scotland). Ethical processes to ensure informed consent, anonymity, confidentiality and prevention of harm were followed.

Literature review

Data bases searched for English language literature dating from 1980-2012 were CINHAL, Psychinfo, Health Source, Web of knowledge, Cochrane, Bandolier, CSA Illumina (including Medline, Sociological Abstracts and Social Services Abstracts). Google was also searched for grey or policy literature. The term 'dementia or Alzheimer's disease' was accompanied in different combinations by 'design', 'palliative care', 'spiritual', 'hospice', 'hospice care', 'end of life', 'physical environment' and 'nursing homes' to identify literature that was relevant to the topic area: namely empirical literature on elements of design of a care setting appropriate to meeting the needs of people with dementia who are nearing the end of life or dying, and to facilitate good practice. A hand search of any literature derived from the searches or identified subsequent to searches was carried out.

In total, 164 articles were selected for review, of which 40 were not specifically design related but covered areas such as spirituality or practices at end of life that warranted further scrutiny. The abstracts of all articles were examined (FK) for their relevance to the topic and those without reference to design were discarded. 17 empirical articles or systematic reviews were identified as being potentially useful and these were independently evaluated by FK and RF using the Australian National Health and Medical Research Council (NHMRC, 2009) framework to grade the level of evidence of empirical studies. The NHMRC Evidence Statement Form sets out the basis for rating five key components of the 'body of evidence' being evaluated. These components are:

- The evidence base, in terms of the number of studies, level of evidence and quality of studies (risk of bias).

- The consistency of the study results.
 - The potential clinical impact of the proposed recommendation.
 - The generalisability of the body of evidence to the target population for the guideline.
 - The applicability of the body of evidence to the Australian healthcare context.
- (NHMRC, 2009)

Focus groups

Three focus groups (FG) were carried out by FK and RF in three cities along the East coast of Australia. Focus groups comprised recently bereaved family carers of people with dementia (FG1), people with dementia and family carers of people with dementia (FG2) and practitioners caring for people with dementia nearing or at the end of their lives (FG3).

Participants with dementia and family carers were recruited via Alzheimer's Australia Consumer Dementia Research Network. Members of the Dementia Research Network are people in the early stages of dementia who volunteer to provide comments on research applications and to offer suggestions for areas of research.

Practitioners were recruited by invitation via NSW/ACT Dementia Training Study Centre mailing list.

All focus groups started with the researchers serving tea and coffee and offering participants food such as fruit and cakes. In this way an informal atmosphere was created in which participants who knew each other could catch up and those who didn't could be introduced to each other. Formal introductions were made, information sheets reviewed (Appendix 2) and consent forms signed (Appendix 3). Topic guides developed using key themes arising from the literature review were used to structure the focus groups (Appendices 4 and 5). The focus groups were lively, with participants expressing opinions and experiences quite freely and, particularly in focus group 2, listening respectfully to each person's contributions. Each focus group lasted approximately one and a half hours and were audio-recorded with participants' consent. Fieldnotes and notes of debriefing sessions following the focus groups were made to record developments in thinking and researchers' impressions.

3. Analysis and findings

Literature review

With a focus on the first component of the NHMRC Evidence Statement Form, which examines the evidence base, in terms of the number of studies, levels of evidence and quality of studies (risk of bias), the consensus from FK and RF was that none of

the literature met the highest grade (a systematic review of randomised controlled trials), 8 were not rateable as they were more descriptive or opinion pieces than empirical studies with the remaining 9 falling between III-2 (comparative studies) and IV (case or cohort studies). Although under the NHMRC framework, these offered the lowest evidence base, methodological and ethical constraints (frail population, access, sensitivity of topic) necessitate that smaller, qualitative studies are best suited to addressing this topic. Therefore any key design-related themes or findings were identified from these papers and used to develop the topic guide for focus groups. See Appendix 1 for details of papers reviewed.

Key points arising from the 17 papers reviewed, and other emerging literature, will be discussed under the following themes: environmental factors, practices at end of life and spiritual care. These reflect key areas addressed in the literature.

Environmental factors

Much of the literature on design for people with dementia, as identified in Calkins's (2009) updated review, focuses on the needs of people with dementia who are relatively mobile. In a rare study, however, Godwin and Water (2009) interviewed 12 people with dementia on their wishes or discussion they had engaged in with others (family members or professionals) on end of life care. Their views on what constituted a helpful environment for them included maintaining contact with family, a quiet, tranquil space, privacy, access to the outdoors, comfort (soft toys, nice smells), minimal physical intervention and consideration of religious needs. This study illustrates the ability of people with advanced dementia to know and express their views on end of life care. Lindstrom et al. (2011) also provide useful tips on caregiving in advanced dementia, including paying attention to ensuring a calm environment. Their work, however, is not empirically based.

Despite the relatively large body of work on identifying optimum design principles for people with dementia (Day et al., 2000, Fleming and Purandare, 2010), with a focus on maintaining independence and balancing sensory stimulation according to needs, there is little literature and even less research into design that focuses on the needs of those with advanced dementia (Martin et al., 2011), or those with dementia who are nearing the end of life or dying. Martin et al. (2011) advocate extending the definition of the physical environment beyond that of the immediate setting (furniture, windows etc) to thinking about the mood, atmosphere and feel of the setting for those who live there. Their concept of 'milieu' captures the therapeutic essence of a space, one that does not require cognition to influence well-being and ensure comfort.

Practices at end of life

Despite policy goals to improve palliative and end of life care for people with dementia, the concept of palliative care seems to be poorly understood amongst professionals (Powers and Watson, 2008). Sampson et al. (2006) note that people

with dementia admitted to acute hospital care received different end of life care to those without dementia, including less invasive procedures, possibly in recognition of their poor prognosis, however, they were significantly less likely to be referred to specialist palliative care teams prior to death. This seems to reflect a lack of awareness by staff of the appropriateness of palliative care for people with dementia, as identified by Powers and Watson (2008). Sloane et al. (2008) interviewed long-term care staff who had cared for people with dementia and people without dementia who had died in the US, and they also interviewed the family members of some of those who had died. They concluded that dying people with dementia experienced more physical restraints and sedative medications than those without dementia who were dying. Mitchell et al. (2004) also identified higher levels of physical restraint of people dying from dementia as opposed to those dying from cancer, but also increased rates of tube feeding. Allen et al. (2005) had similar findings from their study: identifying that residents in nursing homes who died during a 6-month period displayed more verbal agitation, less time in verbal interaction and spent almost twice as much time restrained in bed than those who did not die during the 6-month period. Reid (2008), exploring the effect of quality of care on resident mortality during 12 months following admission to long-term facilities throughout the Canadian province of British Columbia, identified that physical restraint was associated with higher risk of death. Aminoff and Adunsky (2005; 2006), in their study of people with dementia who were dying suggested they experienced a higher degree of suffering, including restlessness and screaming. Although there was no attempt by Aminoff and Adunsky (2005) to look at environmental factors, these may play a role in exacerbating or ameliorating this kind of distress.

Spiritual care

With regard to spiritual care, Keast et al. (2010), in their systematic review of spirituality and dementia in long-term care, identified three themes related to spirituality: preserving a sense of purpose, fostering meaningful connections with the surrounding world and retaining a relationship with God. While not specifically related to end of life, this work illustrates a broader view of spirituality that encompasses connectedness with others. Sampson et al. (2006) however, in their retrospective analysis of 150 sets of case notes of people with dementia admitted to an acute hospital ward in the UK noted that very few had their spiritual needs assessed or addressed while they were dying. Brandt et al. (2005) report nursing home staffs' beliefs that psycho-social and spiritual aspects of care need to be addressed more in the last days of the person's life. This might reflect Bursell and Mayers' (2010) findings of professionals' lack of confidence with spiritual care and their desire for training in how to approach this for people with dementia.

To summarise:

- People with more advanced dementia can express their wishes for end of life care, these include a calm, peaceful environment with access to outdoors and sensory experiences

- There is lack of clarity or awareness of palliative care in dementia
- Professionals are less comfortable delivering psycho-social and spiritual care than physical care
- The focus on design is on meeting the needs of more mobile people with dementia
- People with dementia who are dying appear to experience more physical restraint and more invasive procedures than people without dementia who are dying
- There is some evidence for heightened suffering in people with dementia who are dying
- There is a lack of empirical evidence exploring the design needs of people with dementia who are nearing the end of life.

Focus groups

Tables 1, 2 and 3 present characteristics and roles of focus group participants.

Participants ¹	Gender	Role	Status
P2	Female	Wife	Deceased
P3	Female	Daughter	Long-term care
P4	Female	Wife	Deceased
P5	Female	Wife	Deceased

Table 1. Focus group 1 characteristics

Participants	Gender	Role	Status
P1	Female	Person with dementia	Diagnosed 1999
P2	Male	Husband	Deceased
P3	Male	Husband	Long-term care
P4	Female	Husband	Deceased
P5	Female	Husband	Deceased
P6	Female	Daughter	Deceased
P7	Female	Daughter	Deceased
P8	Female	Wife	Long-term care
P9	Female	Person with dementia	Diagnosed 2008

Table 2. Focus group 2 characteristics

Participants	Gender	Role
P1	Female	Care worker
P2	Female	Care worker
P3	Female	Care home manager
P4	Female	Palliative care nurse/researcher
P5	Female	Dementia care educator

Table 3. Focus group 3 characteristics

All voice files from audio recordings were transcribed verbatim. Transcripts were read thoroughly alongside audio files to ensure accuracy of transcription and to gain

¹ P1 was identified as the first interviewer

a feel for what participants were saying. Transcripts were then read carefully several times by one researcher to identify initial codes and themes based on the topic guides and issues arising during the focus groups. They were then reviewed by the other researcher alongside initial codes and themes to ensure accuracy. Discussions were held on emerging ideas and themes that would inform the development or adaptation of existing design principles. All focus group data were managed using qualitative data management software Nvivo8.

Key themes common to both people with dementia and family carers, although with some differences in emphases, were comfort through engagement, feeling at home/familiar, calm environment, privacy, dignity and useful technology.

Key themes derived from analysis of focus groups with practitioners were: practice at end of life, design to improve working lives and systems and institutional influences. These will be described below and key differences in perspectives will be explored.

Views of people with dementia and family carers

Comfort through engagement

Family carers spoke spontaneously and movingly about how they worked to maintain engagement with the person with dementia they were caring for, up until the end of life. This ranged from engagement with the senses, spiritual engagement and social engagement, with the goal of providing comfort to the person. The two participants with dementia were also clear that being able (and helped) to engage by whatever means was possible would also be important to them as they neared the end of their lives. Participants talked in different ways about how the environment might sooth or comfort the person with dementia. They were clear that attempts must be made to ensure that care was aimed at ensuring comfort through engagement with the senses, even towards the end of life:

Perhaps if they're not well anymore, right at the end, and comfort is something that can be adjusted, adjustable bed with, you know, ventilation and a window nearby and, you know, music nearby, so that if you sense that's what's of comfort to them, would be important. (FG1F4)

This family carer describes how she worked to help her husband engage his senses with the things that had been important to him: bird song, sunshine and the scent of flowers:

We got (husband) out every day that the sun was shining and when it wasn't freezing cold, he came home mid winter and we'd put his beanie on and get him into the recliner wheelchair, I got temporary ramps put in... and we got a few little internal steps in doors because, it's a Gerry built house and got him out over our rickety old cobble stones in the back garden and out into the grass in the garden... lots of garden, lots of birds. He's an ornithologist, loved birds, could tell them all by their sound, you know, and we've got lots of jasmine, and stuff like that, around so, very early spring, like now, the smell of

the jasmine was around and you could see him responding to it. So, in terms of those things, and just feeling the sun, just feeling the warmth of the sun was incredibly important. (FG1F4)

Using outside spaces to facilitate engagement with the senses was seen as very important by carers, even for those who were nearing the end of their lives:

I do think it's... most people like outdoors, there are very few people who don't like looking at the leaves fluttering on the trees and being outdoors, I think, there isn't enough attention and enough space for people to be taken outside, to be able to be taken outside, I think, that's crucial. (FG1F5)

Spiritual engagement was seen in broader terms by a few participants, for example, this participant with dementia viewed spirituality (in its broadest sense) as a way of nurturing her core self:

It depends how you define spirituality, I always say you've got your cognition and then you've got your emotions and then there's the inner you. That could be the herb garden or the music or the pets, or it could be your faith system or all of the above. But I think it does become much more important (near the end of life), because if you can't do all of that remembering and factual things, and you can't do the talking and the emotional, who everybody is, then you really are your true self, and you can be nurtured as your true self. (FG2F1)

The importance of social engagement was raised by several participants and included engaging with family, friends, the community of residents if in long-term care and pets or dolls. For example, this carer was clear that people, regardless of mobility or frailty, should experience the company of others:

But, even, in residential care, I don't think that the focus should be keeping a person in their room, even if they're no longer mobile, they have to get out of that room, I think that's terribly important and I don't know that all facilities are geared for that. (FG1F5)

Others described the sense of peace that can arise with the quiet, gentle, loving company of family:

But, it was having (his son) sitting next to him, holding his hand, talking about some of the things that were there, just, periodically, feeding him, talking some more, just sitting quietly together, just that sense, gentle light in the room, you know, moderate sounds, just, they were the things in terms of the make up of the environment. (FG1F4)

Creating this really, gentle, warm, loving atmosphere. (FG1F2)

In an example of recognising the potential of social engagement for providing comfort, this carer described the comfort her father gained from having the cat sleep on the bed with him:

Something I did with my dad is he used to get up and wander every night and purely by accident one night the cat got stuck in his room, and the next morning, he actually didn't get up that morning, and the next morning when I went into his room the cat was curled up in bed with him. And so from then on for the last two years, every night, I put the cat in bed with him, and he actually died at home with the cat around him. (FG2F6)

As this might not always be feasible, an alternative was suggested by some carers: pretend dogs and cats, which look very realistic and may also meet comfort needs. For example:

I don't know, I was just going to say there was a lady here a few weeks back and her family said she was very restless so as soon as they gave her this little (pretend) cat and a basket or a rug or whatever it was, anyway, she just sat there like this and she was... (FG2F8)

And she began to open up and speak. (FG2M2)

Another participant also recognised the importance of being able to engage socially with who or whatever could provide comfort at that particular time:

I find that where (wife) is, everybody's different and they have different things. One lady has a doll, a big doll, it's almost life-like. I thought it was a doll. Others have dogs and octopuses, all kinds of things. But a lady has a little poodle, and she takes it round to the various ones that she knows loves a dog and puts it in the bed with her. And just to see the reaction on people is just wonderful. (FG2M3)

All of these accounts have one core assumption: that it is possible to provide comfort to people with dementia until they die and that this can be achieved through engaging the person either through whatever senses are possible or appropriate, through spiritual means and through the company of family, friends or other means such as dolls or pets.

Key point

Participants illustrated how aspects of the environment can facilitate the provision of comfort to the person through appropriate engagement with senses, spiritual engagement or through social engagement with significant others.

Feeling at home/familiar

Feeling at home or the sense that the environment or aspects of it were familiar to the person with dementia was seen as important to participants in focus groups 1 and 2. For example:

I tend to think that people with dementia do want familiar; it's the change that is difficult to cope with and the familiar things are personal things, if we're talking about residential care, to bring in personal things of theirs, whether it was his music, I know my husband did a lot of photography as a hobby... and he had the photographs there, we had had them in the room upstairs but when we came down we brought the same things down and when he did go into respite, we took the same pictures, well, not all of them but, you know, some of them, enough to have familiar there, I think, that was important to him. (FG1F5)

This participant with dementia was clear in her wishes for the end of life and referred to the concept of aging in place, where people will live and die in the same familiar place:

Because the last thing I want to happen to me is to be moved. I want to feel at home. (FG2F1)

This carer describes the facility where his wife is and stresses the importance of the familiar feel her own possessions give to it:

Can I just mention, where my wife is at present, she has the most wonderful room, it's an ensuite, incredible facilities for clothing, and they told me when I went there to make it like it was her home. So I brought in some of her paintings and photographs, everything that's all around the wall, TV. And outside she's got a door that opens out into a little porch which has a table on it and two chairs, and she can look straight out into the car park and see me coming in. So it is a really wonderful facility. (FG2M3)

The overwhelming opinion of carers and people with dementia is that care settings must have a homely feel; this will be achieved through having the person's own belongings, ornaments, pictures, television etc in it.

Key point

Participants want the environment to be familiar and homely, with the person's own possessions and whatever is familiar to them.

Calm environment

The importance of ensuring a calm environment was stressed by carers and people with dementia, whether this was at home or in a care setting. This participant with dementia was clear she did not want to be in a noisy environment, what was important for her was calm, peace and quiet:

I think the calm and peaceful environment is...for me, walking into an environment where there's lots of noise and other surroundings going on

seems to affect my coping skills and how I would interact. And I feel that certainly that will stay until the end, the quiet peaceful, serene surroundings seems to be the most important thing, it does impact greatly I feel. (FG2F9)

This participant with dementia also expressed her distaste of noise and overwhelming stimuli:

Nobody seems to understand, but it's visual stuff, visual clutter. When I was visiting last year in a dementia ward, was not only obviously the sound level, the TV and the radio and the staff talking loudly to each other, but it was a smaller area, there were lots of people, lots of tables, people coming in and out and then the occupational therapist had made stuff, which was hanging everywhere and it was just...And then there were loads of those walkers everywhere; it was just visually ... really, really stressful. I would just go there for an hour and I'd be exhausted, And I often think no wonder people in nursing homes are just sitting there like that, because I felt like that when I went in, that I wanted just to sit, close my eyes, because it was too much. (FG2F1)

This was also reiterated by the carers who described how they worked to ensure the environment was calm and peaceful:

So one of the things that I'd do at the...was our thing was, we had the candles, not that he could smell anything, but it was that nice soft light, and we'd have...I'd have the classical music on, which I just left on until he went to sleep at night and, then, I turned it off and it was just all that softness and calm and it's very hard to be calm when you're not a calm person but, for eighteen months we managed because you do need that, you need to have no conflict, totally conflict free, totally and utterly. (FG1F2)

In a similar manner to ensuring comfort through engagement, carers were able to recognise when the person with dementia needed peace, stimulation appropriate to their needs and abilities and an environment free of conflict (excessive noise or visual stimuli).

Key point

Participants want the environment to facilitate varying degrees of stimulation depending on need, ability or wishes, and it should be conflict-free.

Privacy and dignity

While all participants agreed on the need to ensure the person's dignity was respected while carrying out care, there were some differences in opinion on the

necessity of ensuring privacy – ensuite or shared bathroom, single bedroom or shared bedroom.

Carers had mixed views, although these shifted with changing needs of the people they cared for. For example, if the person is confused and not able to find the bathroom, then carers felt there is not such an imperative to have an ensuite bathroom, but as they become more frail and need more care, then the privacy of an ensuite bathroom becomes more important.

Participants with dementia, however, were clear they would want an ensuite bathroom from the outset until the end of life, and they would want to be able to, or supported to use this even when in the public spaces:

But what would you like right now? I mean we need to think, and I think X (other participant with dementia) and I were talking about this, that even in the final stages when we can no longer communicate. But there's still going to be a unique human being with needs like all of you...And we would want an ensuite, we would want to feel private, not wheeled along the corridor to go to the public toilet. (FG2F1)

For carers, privacy also meant private, quiet spaces where they could go to rest or cry. This was an important aspect of the design of a care setting to enable them to keep strong and continue to be psychologically and physically available for the person with dementia:

Is it possible to have a small space, a private space for carers that...Many a time I have to go and stand in the back corridors between two houses to cry sometimes because I'm so upset, because I can't do it where (husband) is. And here I am standing out in a hallway where the laundry comes in. And also a few times there have been a couple of us who've wanted to just chat together, but there's nowhere where we can go, other than to the coffee shop or something like that. So in an ideal world could there be, as they have in hospitals, a small intimate space for families, or you can go and you can have a cry and then go back and face it again. (FG2F8)

From these accounts, respecting dignity and privacy are important and, crucially, become more important as dementia progresses; having ensuite bathrooms ensures that dignity and privacy are maintained when increasing frailty necessitates more personal care.

Key points

Participants want to see privacy and dignity maintained; this becomes more important with increasing cognitive impairment. Family carers want a quiet space to retreat to.

Use of technology

Carers and people with dementia viewed technology as a means of remaining connected to others (family) and of alerting others (practitioners) of a need. For example, one participant with dementia wanted to be able to connect with her husband, and wanted him to be able to check in on her, through a webcam:

Well, when I get to that stage I would like my husband to be able to check on the webcam. (FG2F1)

Technology could also be used to engage with the senses, for example a visual projection onto the ceiling for people who are in reclining chairs or confined to bed was suggested as a useful way to ensure a more interesting experience. Other technology, such as sensor mats or monitoring equipment were also suggested as possible ways of ensuring the person remained safe, particularly in busy settings when staff might not have time to regularly check on people.

There was some discussion about safety, particularly with maintaining the person's safety when they are confined to bed. There was a general feeling that bed rails would be acceptable, if there was a risk the person might fall out of bed, as this participant with dementia said:

Well, I'd be happy to have that for myself rather than fall. And I was happy to have it for my mum because in the last few days she really needed it. (FG2F1)

Technology should, however, be used with awareness of how it might be interpreted or understood by people with dementia, for example a hoist might not be well tolerated, as this carer identified:

Well, the thing with dementia, we know, is that the person's awareness and understanding of their environment, and everything going on in it, is not the same as someone that doesn't have dementia, so they've got a considerably huge burden, I think, of coping with that whole process of losing more, losing more capacities, and so on, when their environment is so confounding for them, for a whole variety of reasons...and (husband) at one point, thought the electronic hoist, in the room, was something that was very fearsome. (FG1F4)

These accounts highlight the ways in which technology can be used to help people with dementia and their families remain connected with each other and to alert professionals of need, yet they also provide a reminder of the sensitivity with which practitioners and families need to approach the use of technology, so that it is understandable and acceptable to the person regardless of cognitive ability.

Key point

Participants suggested that technology can connect people with dementia to others, maintain their safety and alert practitioners of need. It must, however, be used with sensitivity to how it is understood and accepted by people with dementia.

Views of practitioners

Practice at end of life

Practitioners spoke in terms of their practice rather than in terms of their understanding of the needs or wishes of people with dementia as they neared the end of their lives. One practice at the end of life seemed to be the setting up of a syringe driver with morphine and other drugs aimed at sedating the person once it was established they were approaching death:

The drivers really are a great idea. (FG3F5)

This appeared to be instigated because dying was seen to be an uncomfortable process:

Well, dying is not necessarily particularly comfortable. (FG3F1)

But also as a pragmatic response to under-staffing of the setting in which one care worker might be looking after 18 patients on his/her own.

The workload reduces, you're not doing PRNs² every evening. (FG3F5)

Practitioners talked of the consequences of sedating patients as they near the end of life:

...keep it nice and simple, once they get to palliative with a syringe driver, they usually won't hit out, they don't kick, they don't walk, they won't bite, they don't scratch....they are so peaceful and calm and they just lie there, they're basically asleep the entire time... so it really doesn't...the environment around them doesn't matter... (FG3F1)

These accounts indicate that practitioners' understandings of the needs and experiences of people with dementia nearing the end of life appear to be influenced by their practice and the impact of their practice on them, rather than on an understanding of their needs and wishes as individuals. If, as is suggested, syringe drivers containing morphine are used, this will inevitably influence practitioners' views of the experiences of people with dementia as they near the end of life; thus influencing their views on the necessity or otherwise of ensuring the design of the environment meets their engagement, spiritual and social needs.

Key point

Practitioners need to have an understanding of the person with dementia as someone with the potential to engage, regardless of severity of dementia.

² PRN (Pro Re Nata) = 'as needed'. Usually refers to administration of medications.

Design to improve working lives

Practitioners had strong views on the extent to which the design of their work settings was safe for their patients and the extent to which it helped or hindered their work.

I mean I will say, the layout of our dementia floor is ridiculous. Absolutely ridiculous. It just needs to be erased or rebuild a new one. It's just...as a care staff, it's a nightmare. An absolute nightmare. (FG3F1)

Buildings with long corridors and 'nooks and crannies' were deemed unsafe as these meant patients 'wandering'. An ideal design put forward by one participant would be a circle so that people would not arrive at a dead end. Some recounted creative ways to disguise dead ends, such as a mural or other feature to hide an area that was off limits to the person with dementia. Wide corridors and wide doorways were seen as vital for easy access for those with wheelchairs, and electronic beds that would raise and lower were also reported as useful.

Practitioners' ideas for good design were focused on monitoring patients, particularly as they become frailer, and included Florence Nightingale wards (large long wards with beds along each wall) and 'palliative suites' which are rooms that are set up to care for patients reaching the end of life. These were seen as appropriate for delivering good care, although this was viewed more in terms of practicalities rather than in terms of how this might influence the experience of people with dementia and their families. For example:

Palliative care suites are beautiful, I don't know if you've had anything to do with them? They're absolutely delightful. And more often than not, they have more than one room; there's like a bedroom and an associated room, so you have space for both the family and the person. (FG3F3)

Some practitioners also spoke of the preparations they would make when they know the person was dying – they would take out the 'dying box' which contained candles, incense, a vase and objects to create a 'calming atmosphere'.

From these accounts, the design of the building has relevance for practitioners if it can make their working lives easier – if it can allow for easier monitoring of patients, prevent them 'wandering' and ensure their safety. While there was some thought into creating a nice, calm atmosphere for the person at the end of life, this was not central to their views about the design of a care setting, possibly because their practice experience is one of caring for people who are sedated and therefore unable to engage with their environment.

Key point

Practitioners view the design of a care setting in terms of how well it helps or hinders their work. Monitoring patients' safety is a key area of concern.

Systems and institutional influences

A key area of concern for practitioners was lack of staff to provide sufficient care to their patients. There seemed to be a sense of juggling their time between those who were mobile and who needed monitoring and those who were becoming frail and needed more one-to-one care. They recognised the need to have more intensive one-to-one care when someone is dying, but current staffing levels prevent this and this seemed to be a source of frustration for some practitioners.

You don't have the resources to... And if you could take two off to look after the one that was dying... (FG3F2)

Another key area of concern was the funding of aged care and the difficulty of securing enough resources (in a timely manner) to cope with patients' changing needs. This seemed to require a knowledge of the system and strategies to 'play' it. Practitioners described a constant battle to secure resources and if they didn't manage to secure them they would have to do without extra resources (usually more staff) and this inevitably has an impact on the quality of care.

Practitioners' use of language revealed their embeddedness within institutional systems and processes and this was particularly evident when they referred to their patients. The use of words such as 'dementias', 'dementia cases', 'the respites', 'behaviours', 'wheelchairs', 'lifters' indicated they viewed their patients predominately in terms of the tasks required by them, their needs or their disability resulting from dementia rather than as unique individuals. For example:

I was just thinking of two dementia cases that we have; one who, like you were saying, wandering, wandering, still running around.. (FG3F5)

Practitioners' accounts of the constraints of the systems they had to work in illustrate the difficulties of thinking beyond the day to day practicalities of carrying out care. This might explain the difficulty they had thinking about design in relation to the experiences of people with dementia who are nearing the end of life.

Key point

Working within institutional constraints made it difficult for practitioners to think beyond their own day to day practical concerns and beyond the labels applied to their patients.

Summary

Findings from focus groups revealed marked differences in opinion as to what might be important design features to support good practice at the end of life and to ensure optimum experience for those who are dying. Key areas of difference will be discussed below.

4. Discussion and recommendations for design principles

It was clear from the analysis that participants with dementia and family carers differed from practitioners in terms of what might be important design principles in the care of people with dementia nearing the end of life and in ensuring an optimum experience for the person nearing the end of life. People with dementia and family carers placed a strong emphasis on provision of comfort through engaging with the senses, through remaining socially connected (whether through family, friends, pets or soft toys) and through spiritual engagement. These ideas assume some degree of awareness or ability to engage and family carers worked hard to ensure they engaged with the person appropriately and in a way that comforted them. Practitioners seemed to have a different way of offering comfort – to administer morphine through a syringe driver and this had the effect of sedating the person so that they were no longer aware of their surroundings. The implication of this is that there is no need to work to engage spiritually, socially or through the senses and therefore no need to consider how aspects of design might improve their experience.

Participants with dementia and carers were clear they wanted to be, and remain in, a familiar environment, with their own belongings and familiar things. Practitioners, however, liked the idea of a dying room to which they could move a person who is dying and in which they could create an atmosphere of calm. Practitioners also liked the idea of a dying box from which they could select items to create a calming, homely space. The paradox here is, that by moving people who are nearing the end of life, practitioners would be moving them from their familiar space to a space set up to be familiar, but is unfamiliar.

Participants with dementia and family carers were clear they wanted care and an environment that ensured dignity and privacy. Most of them were also clear that the need to ensure this increases with increasing cognitive impairment and this particularly related to having and being able to use ensuite bathrooms. Practitioners were concerned about the balance between privacy and safety – a reflection of their focus on design to improve their working lives. All participants recognised the need for family members to have access to a quiet, private space to rest in and take time out in. The availability of such spaces varies from setting to setting.

Practitioners recognised their practice was constrained by organisational and institutional factors, such as funding arrangements for delivering care, resource and staffing levels and inadequate design of care settings. They also appeared to be unconsciously constrained by unquestioned practices, such as instituting a syringe driver on recognition that someone is dying and the practice of labelling patients according to their needs or levels of impairment. These seemed to influence their perceptions on the importance or otherwise of aspects of the environment for people with dementia nearing the end of life.

Notwithstanding the difference in emphasis between the focus group participants, several main themes emerged concerning the provision of:

1. an environment that supports the continued use of the senses
2. opportunities for social and spiritual engagement
3. calm
4. the means to control levels of stimulation
5. spaces for privacy as well as opportunities for the family to be with the person with dementia
6. the maintenance of dignity by, for example, providing all of the facilities required for personal care
7. opportunities for monitoring of residents by care staff
8. technology, particularly communication technology

While the provision of these characteristics will require the elaboration of some of the ten design principles proposed by Fleming et al. (2003), they do not suggest the need for the addition of new principles. The principle of reducing unhelpful stimulation covers items three and four; the highlighting of important stimuli covers item one; the provision of opportunities for privacy and community covers item five; the provision of all of the facilities required for personal care, item six, to help maintain dignity is encompassed by the principle of being domestic and homelike. The principles of providing unobtrusive safety and good visual access are relevant to item 6 and providing links to the community accommodates item 8.

The possible exception to this is the need to provide opportunities for social and spiritual engagement, item two. In the current formulation of the principles this is covered in the principle dealing with the provision of a variety of spaces, the provision of access to these characteristics within the space available to an immobile person will need to be addressed.

The next stage of the project involves the input of views from a variety of palliative care and environmental specialists. A clear description of each of the eight characteristics will be circulated to them along with a brief summary of their development. They will be asked to comment on and add to the characteristics. Their views will then be used to determine the final set of principles.

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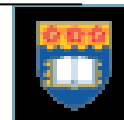
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Appendices

Appendix 1 Articles rated using NHMRC framework

Author Year	Title	Citation	NHMRC level of evidence	Key points
Godwin, B. and Waters, H. (2009)	'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers	Mortality 14(3): 265-285	Level IV	Feasibility and desirability of communication with people with dementia. Contains many clues about the nature of a helpful environment.
Sloane, P. et al. (2008)	Dying with Dementia in Long-Term Care	Gerontologist 48(6):741-751	Level III-3	Reports on excessive use of restraint of people dying with dementia as opposed to people dying without dementia in US
Reid, C. (2008)	Quality of Care and Mortality among Long-term Care Residents with Dementia	Canadian Studies in Population 35(10): 49-71	Not rateable	Fostering spirituality, not related to end of life.
Gallagher, M. and Long, C. (2011)	Advanced dementia care: demystifying behaviours, addressing pain, and maximizing comfort	Journal of Hospice & Palliative Nursing Mar-Apr 13(2): 70-80	Not rateable	Discusses noise
Sampson, E., Gould, V., Lee, D. and Blanchard, M. (2006)	Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study	Age & Ageing 35(2):187-9	Level III-2	Identified lack of attention to spirituality
Aminoff, B. and Adunsky, A. (2005)	Dying dementia patients: too much suffering, too little palliation	American Journal of Hospice & Palliative Medicine 22(5): 344-8	Level IV	Reference to restlessness
Calkins, M. (2009)	Evidence-based long term care design	NeuroRehabilitation 25(3): 145-54	Not rateable	Designing for mobile people with dementia
Bursell, J. and Mayers, C. (2010)	Spirituality within dementia care: perceptions of health professionals	British Journal of Occupational Therapists 73(4): 144-51	Level IV	Spirituality not solely related to religion
Day ,K., Carreon, D. and Stump, C. (2000)	The therapeutic design of environments for people with dementia: a review of the empirical research	Gerontologist 40(4): 397-421	Not rateable	No relevance to end of life
Powers, B. and Watson, N. E. (2008)	Meaning and practice of palliative care for nursing home residents with dementia at end of life	American Journal of Alzheimer's Disease and Other Dementias 23(4): 319-325	Not rateable	Comfort
Allen, R., Burgio, L., Fisher, S., Hardin, M. and Shuster, J. (2005)	Behavioral Characteristics of Agitated Nursing Home Residents With Dementia at the End of Life	Gerontologist 45(5):661-666	Level III-2	Verbal agitation, use of restraints

O'Malley, L. and Croucher, K. (2005)	Housing and dementia care – a scoping review of the literature	Health & Social Care in the Community 13 Issue 6, p570-577	Not rateable	Highlights lack of empirical evidence on end of life care in dementia in UK
Brandt, H et al. (2005)	The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale	Palliative Medicine 19(4) 334-342	Level III-3	More focus required on psycho-social and spiritual care
Aminoff, B. and Adunsky, A. (2006)	Their last 6 months: suffering and survival of end-stage dementia patients	Age & Ageing 35(6):597-601	Level IV	High level of suffering, pressure ulcers
Mitchell, S., Kiely, D. and Hamel, M. (2004).	Dying with advanced dementia in the nursing home	Archives of Internal Medicine, 164(3), 321–326	Level III-2	Excessive use of restraint, invasive procedures US
van der Steen, J. (2010)	Dying with Dementia: What We Know after More than a Decade of Research	Journal of Alzheimer's Disease 22: 37–55	Not rateable	No discussion on environmental factors
Lippa, C. (2008)	Safety, end-of-life issues, and dealing with sexually inappropriate behavior in dementia patients	American Journal of Alzheimer's Disease and Other Dementias 23(4):311-312	Not rateable	No discussion on environmental factors



INFORMATION SHEET

To be discussed prior to focus group

Focus Group to discuss:

Aspects of design to support good care for people in the final stages of dementia

We would like to invite you to take part in this research. Before you decide, we would like to explain why the research is being done and what it involves for you. One of the research team will go through this information sheet with you and answer any questions you may have. This will probably take about ten minutes.

What is this research for?

We have looked at what experts have said about good design for people with memory difficulties and also asked people with memory difficulties themselves what they would like to see in care homes they live in. One area that has not been properly discussed is what aspects of design are important for people with memory difficulties who are nearing the end of life. For this reason, we would like to ask you for your opinions. We would like you to help us identify what experts and planners should think about when designing care homes or hospitals that people with memory difficulties might live in.

What is my involvement in the research?

We would like to meet with you in a small group to discuss what aspects of the design of a building would be important for you if you become frail or ill. Your participation is voluntary. You are also free to withdraw from the study at any time. You may also take part in the research without your family member if you prefer.

What will happen to the information I give?

We would like to tape-record the group discussion. If you are not comfortable with this, but would still like to comment on the research, let us know and we will take notes instead.

All the information we collect during the group sessions with you will be treated in confidence, and only the research team will see it.

We will write a report on our findings and would like to quote you to illustrate the points we make. We will ensure that no-one will be identified in any written report.

Will the research benefit me?

We cannot promise that the research will benefit you directly, but hope our findings will benefit other people with dementia and their families.

Further information

This study has been approved by the University of Wollongong Human Research Ethics Committee. If you have concerns or complaints about the conduct of this study you should contact the University Ethics Officer on (02) 4221 4557.

Should you wish to discuss the study further prior to making a decision the team can be contacted via e-mail or telephone:

Professor Richard Fleming rflaming@uow.edu.au
Telephone: 02 4221 3422

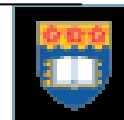
Dr Fiona Kelly fiona.kelly@stir.ac.uk
Telephone: +44 (0)1786 467740

Thank you for taking the time to read this information sheet. If you are happy to take part in this research we will ask you to sign a consent form.

Fiona Kelly
Richard Fleming

Appendix 3. Consent form

University of Wollongong



Consent form

Participant number:

Focus group to discuss:

Aspects of design to support good care for people in the final stages of dementia

Please initial boxes

1. I confirm that I have read and understood the information sheet for the above research and have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3. I understand that all information will be kept confidential.	
4. I agree that the information can be used on condition that it is kept confidential and anonymised.	
5. I understand that all information will be accessed only by the research team and that it will be deleted upon completion of the research.	
6. I give my permission for interviews to be audio-recorded.	
7. I agree to take part in the above research.	
8. I agree that the results of the project may be published.	
9. Any further wishes:	

Researcher Name:

Signature:

Date:

Participant Name:

Signature:

Date:

Appendix 5. Topic guide for people with dementia and family carers

Defining the desirable characteristics of physical environments for the delivery of support and care to people in the final stages of dementia

People with dementia and family carers

Focus Group guide for researchers and topic guide

1. introduction and explanation of aims of focus group
2. reiteration of information sheet, answer questions
3. consent process
4. round table introduction of participants.

Topic guide

What aspects of the design of your house/garden are important to you at the moment?

Prompts: size of space, colour, access to outside space (what kind of outside space?), furniture....

Why are these important?

If you have been in hospital or a medical or nursing setting, can you describe aspects of the design of the setting that you liked and/or disliked?

Explain why

What are the key design differences between a hospital and your home? How do they both make you feel? What changes would you like to make to a hospital setting that would make you feel more comfortable if you are in hospital or other medical setting?

If you become frail or ill, what are the key things that you would like to have in place to help you feel more comfortable?

Prompts: noise levels, freedom to move around, privacy, community, pets...

If you become frail or ill, what aspects of design would you like to see in place to help you feel more comfortable?

Prompts: window/view, familiarity, equipment...

Expand on why they would make you feel better

Expand on aspects of design you think would make you feel worse and why?

Appendix 6. Topic guide for practitioners

Defining the desirable characteristics of physical environments for the delivery of support and care to people in the final stages of dementia

Practitioners

Focus Group guide for researchers and topic guide

1. introduction and explanation of aims of focus group
2. reiteration of information sheet, answer questions
3. consent process
4. round table introduction of participants.

Topic guide

What are the key areas of importance to you when caring for someone with dementia who is frail and/or nearing the end of life?

Prompts: their physical, spiritual, psychological and social needs.

Why?

When someone with dementia is dying, what do you do to care for them?

What are your concerns when caring for someone with dementia who is dying?

From your experience of caring for someone with dementia who is dying, what aspects of the design of the physical environment help or hinder the care you give?

Why?

What aspects of the physical environment would you like to improve when you are caring for someone with dementia who is frail and/or nearing the end of life?

If someone was restless in bed, what would you do to help make them more comfortable? How could the design of the setting help or hinder you with this?