SUMMARY REPORT

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

Dementia Collaborative Research Centre
Assessment and Better Care

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Background

The design of environments in which people with dementia live should be understandable, reinforce personal identity and maintain their abilities. The focus on supporting people with dementia to live well has omitted considering the needs or wishes of those who are nearing the end of their lives. This study explored the views of people with dementia, family carers and professionals on what aspects of the physical environment would be important to support dying well and practicing well.

Methods

A multi-method study, with each method informing the other in an iterative process. A literature review established the evidence base for physical design advocated for people with dementia who are nearing the end of life. Key themes from the literature review informed the topic guide for 3 focus groups. A list of principles derived from analysis of focus group transcripts was distributed to experts in the field and a consensus sought on their appropriateness.

Results

The literature search revealed only 17 papers than met pre-defined criteria for inclusion in the final review. Key design considerations from the review were: environmental factors, practices at end of life and spiritual care. Eighteen people took part in 3 focus groups: 2 with dementia, 11 current or recently bereaved family carers and 5 practitioners. There were differences in opinion on what were important environmental considerations. People with dementia and family carers identified comfort through engagement, feeling at home, a calm environment, privacy and dignity and use of technology to remain connected as important. Practitioners considered practice, design to improve their working lives and institutional influences on their practice. Twenty one experts in the dementia field took part in the survey to agree a consensus on the desirable characteristics derived from analysis of focus group transcripts, with fifteen characteristics agreed.

Conclusions

The following represent the desirable features of the physical environment for the care of people in the final stages of dementia, as determined by a review of the academic literature, a series of focus groups with people with dementia, families of people with dementia in the final stages, and health professionals and consultation with experts in the fields of environmental design for aged care and architecture and palliative and end of life care both in Australia and the UK:
The environment should:

1. Support the continued use of the senses
2. Provide access to the outdoors/natural environment
3. Provide access to nature indoors (e.g. plants, natural light, fresh air)
4. Provide opportunities for engagement with spiritual aspects of life
5. Provide opportunities for social engagement
6. Promote a sense of familiarity and homeliness
7. Provide opportunities to be with family
8. Promote calmness
9. Provide privacy
10. Foster dignity
11. Support safety and security
12. Support staff, residents and visitors to find their way around/know where things are)
13. Enable visual monitoring by staff – via human contact and not through the resident being placed in a public area
14. Reduce physical stress (e.g. provision of appropriate beds/mattresses)
15. Facilitate nursing care (e.g. facilitate bathing, feeding, going to the toilet, lifting)

These characteristics are compatible with the principles currently used in the design of environments for mobile people with dementia. They are offered as a supplement to these that will ensure their applicability to those people with dementia who are less mobile and those who are dying. We suggest that considering these characteristics as part of a continuum of care will support good practice and offer those with dementia and their families a more positive experience in the last days, hours and seconds of their lives together.