Environments for people in the final stages of dementia

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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.
The process

- Review of the literature
- Identification of themes
- Discussion of themes in focus groups
- Development of survey from focus group results
- Survey of Australian and international experts
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’
Results of literature review

• 164 articles identified as potentially relevant
• 17 empirical articles or systematic reviews found
Overall findings of literature review

• There is a lack of empirical evidence informing the design of environments for people with dementia who are nearing the end of life. The focus is on meeting the needs of more mobile people with dementia.

• 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

• People with dementia who are dying appear to experience more physical restraint and more invasive procedures than people without dementia who are dying.
Key themes

- Key themes arising from the 17 papers reviewed,
  - care practices at end of life,
  - environmental factors, and
  - spiritual care.

- 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.
Focus groups

- Three focus groups were carried out in three NSW cities.
- 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.
- Practitioners were recruited by invitation via NSW/ACT Dementia Training Study Centre mailing list.
Focus group discussions

• Discussion of helpful features of home environment
• Discussion of helpful/unhelpful features of hospital environments in general
• Discussion of specific features needed in hospital when the person is frail or ill.
Focus group results

- Opportunities for families to be with person
- Providing opportunities for social engagement
- Provide privacy
- Support of the continued use of the senses
- Promote a sense of familiarity and homeliness
- Foster dignity
- Promote calmness
- Provide opportunities for engagement with spiritual aspects of life
- Enable staff to visually monitor
- Provide controlled levels of stimulation
- Provision of communication technology
Survey of experts

Translating dementia research into practice
The average number of years experience providing, developing or researching services for people in the final stages of dementia was 13.7 years.
Importance assigned to the features by the expert group.

<table>
<thead>
<tr>
<th>Feature</th>
<th>Importance</th>
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<tbody>
<tr>
<td>Opportunities for families to be with person</td>
<td>4.00</td>
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<tr>
<td>Providing opportunities for social engagement</td>
<td>3.78</td>
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<tr>
<td>Provide privacy</td>
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<td>Support of the continued use of the senses</td>
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<tr>
<td>Promote a sense of familiarity and homeliness</td>
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<td>Foster dignity</td>
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<tr>
<td>Promoting calmness</td>
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<tr>
<td>Opportunities for engagement with spiritual aspects</td>
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<td>Enable staff to visually monitor</td>
<td>3.00</td>
</tr>
<tr>
<td>Means of controlling levels of stimulation</td>
<td>2.95</td>
</tr>
<tr>
<td>Provision of communication technology</td>
<td>1.78</td>
</tr>
</tbody>
</table>
Features emphasised by experts in their comments

- Access to outside and nature
- Safety and security
- Legibility
- Small size
- Facilitate nursing care – bathing, toileting
- Spirituality and sense of purpose
- Familiarity
- Promotes use of senses
The Environmental Audit Tool

Evaluates the environment against the following principles

• Safety
• Size
• Visual Access
• Reduction of unhelpful stimulation
• Enhancement of helpful stimulation
• Provision for ‘wandering’ and access to outside
• Familiarity
• Range of engagement in social interactions
• Links with the community
• Domestic nature
Revised EAT

The EAT has been modified to

• Incorporate the findings of this study
• Take account of an analysis of its use in 100+ facilities that identified some redundant items
• Improve the clarity of the language – eg avoid jargon like ‘Visual Access’

• The inter-rater reliability, test-retest reliability and validity are currently being assessed in another DCRC funded project.