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Towards providing better care planning and environmental design for people with dementia in residential aged care

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Faculty of Science, Medicine and Health
School of Nursing, Midwifery and Indigenous Health
University of Wollongong

**Towards providing better care planning and
environmental design for people with dementia in
residential aged care**

**This thesis is submitted in fulfilment of the requirements for the Award
of the degree of Doctor of Philosophy from the University of
Wollongong**

March 25th, 2013

Richard Fleming, B.Tech. (Hons), Dip. Clin. Psy.

CERTIFICATION

I, Richard Fleming, do hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person, nor material which has been accepted for the award of any other degree or diploma of a University or other Institute of higher learning.

Richard Fleming

March 25th, 2013

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Dr. Belinda Goodenough and Dr.Christopher Magee for their statistical advice.

My wife, Michelle, for her forgiveness of my absence during the long hours of writing the thesis.

PUBLICATIONS CONSTITUTING THIS THESIS

- Fleming, R. (2008). "The reliability and validity of the Care Planning Assessment Tool." *Australasian Journal on Ageing* 27(4): 209-211.
- Fleming, R. and N. Purandare (2010). "Long-term care for people with dementia: environmental design guidelines." *International Psychogeriatrics* 22(7): 1084-1096.
- Fleming, R. (2011). "An environmental audit tool suitable for use in homelike facilities for people with dementia." *Australasian Journal on Ageing* 30 (3): 108-112
- Fleming, R., R. Fay and A. Robinson (2012) "Evidence-based facilities design in health care: a study of aged care facilities in Australia." *Health Services Management Research* **25**: 121-128.

STATEMENT OF VERIFICATION

This statement verifies that the greater part of the work in the above-named manuscripts is attributed to the candidate, Richard Fleming, who took primary responsibility for the study design, and data analysis and prepared the first draft of each manuscript. He then responded to editorial suggestions of co-authors, and prepared the articles for submission to the relevant journals. Details on the contributions of co-authors can be found in Table 1, Preface.

Richard Fleming (PhD candidate)

Professor Patrick Crookes (Primary Supervisor)

27.3.13

OTHER PUBLICATIONS ARISING FROM THIS THESIS

- Davis, S., Fleming, R. and Marshal, M. *Environments that enhance dementia care: issues and challenges*, in *Older people: issues and innovation in care*, R. Nay and S. Garratt, Editors. 2009, Elsevier Australia: Chatswood
- Kanegae, S., S. Koizumi, Fleming, R., Ichimaru, N. Nagashio, T. *Development of a Japanese Version of the Care Planning Assessment Tool*. Australasian Journal on Ageing 2010. 29(1): 27-32.
- Murakawa, K., S. Kanegae, and R. Fleming, eds. *Visually Comprehensible Total Management of Dementia Care: Japanese Version of CPAT*. 2011, Kousei Kagaku Kenkyujo Tokyo.
- Fleming, R. and Kelly, F. *Communicating design research: improving the design of environments for people with dementia*. In *The Routledge Companion to Design Research*, P. Rogers and J. Lee, Editors. In press. Routledge, UK.
- Fleming, R. and K. Bennett. *Environments that enhance dementia care: issues and challenges*. In *Older People: issues and innovations in care*. R. Nay, S. Garratt and D. Fetherstonhaugh, Editors. In press. Elsevier Australia, Chatswood.

ABSTRACT

Introduction

There are more than 84,000 people with dementia in residential care in Australia. This number is increasing by 4% per year. They can benefit from systematic care planning and well-designed environments. The studies presented in this thesis describe and evaluate contributions to these aspects of their care.

Method

Across the six papers presented a mixed methods approach has been adopted.

Chapter 2 describes the quantitative evaluation of the metrics of a care planning tool that assists direct care staff to carry out a comprehensive assessment and prepare for a care planning meeting. Chapter 3 is a review of the literature on environmental design. Chapter 4 describes the quantitative evaluation of the metrics of a tool for assessing the quality of physical environments for people with dementia. Chapter 5 presents the results of a comparison between the theoretical and empirical factors, determined by factor analysis of data from 105 facilities, in the environmental audit tool. Chapter 6 reports the results of a linear regression analysis seeking to determine the relationship between the quality of life of people with dementia and the quality of the environment in which they live. Chapter 7 is a qualitative study using data collected from in-depth interviews to identify the obstacles to the application of the available knowledge on designing for people with dementia.

Results

The studies provide evidence for the availability of a valid and reliable care planning assessment tool, a body of knowledge on good design for people with dementia and the means by which good design can be measured. The quality of physical environments was shown to have a positive relationship

with the self-reported quality of life of people with dementia living in them. The lack of awareness by facility managers of the knowledge on good design was found to be the major obstacle to the application of existing knowledge even when that knowledge was known to the architects involved in the design.

Conclusion

Tools can be developed to assist those involved in caring for people with dementia to take a systematic approach to collecting data that informs care planning and the design of the physical environment. There is still much work to be done in bringing the use of these tools, and the available knowledge, into routine use.

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PREFACE

Chapter Details

Chapters 2–7 of this thesis are empirical work. These chapters are presented in publication format and have either been published in a peer-reviewed journal or have been prepared for submission to a journal. The headings, page numbers and figure numbers of published chapters have been changed for the purpose of achieving consistency throughout the thesis.

Table 1: Publication details

Chapter	Publication status	Authorship
Chapter 1: Introduction	Thesis only	
Chapter 2: The reliability and validity of the Care Planning Assessment Tool	Fleming, R. (2008). "The reliability and validity of the Care Planning Assessment Tool." <i>Australasian Journal on Ageing</i> 27(4): 209-211.	Conceptualisation, design, data analysis, write up by R. Fleming. Data collection by raters trained by R. Fleming.
Chapter 3: Review of the empirical literature on characteristics of the physical environment that support people with dementia	Fleming, R. and N. Purandare (2010). "Long-term care for people with dementia: environmental design guidelines." <i>International Psychogeriatrics</i> 22(7): 1084-1096.	Conceptualisation, design, data analysis, write-up by R. Fleming. Collection of articles by research assistant Shima Sum.
Chapter 4: The reliability and validity of the Environmental Audit Tool	Fleming, R. (2011). "An environmental audit tool suitable for use in homelike facilities for people with dementia." <i>Australasian Journal on Ageing</i> 30 (3): 108-112.	Conceptualisation, design, data analysis, write up by R. Fleming. Data collection by raters trained by R. Fleming.

Chapter	Publication status	Authorship
Chapter 5: The factor structure of the Environmental Audit Tool	Prepared for submission to the <i>Australasian Journal on Ageing</i>	Conceptualisation and write up by R. Fleming. Advice on statistical design and analysis provided by co-author Dr. C. Magee.
Chapter 6: The contribution of the physical environment to the quality of life of people with dementia in residential aged care	Prepared for submission to <i>Dementia</i>	Conceptualisation, design, data analysis and write up by R. Fleming. Statistical advice provided by co-author Dr. Belinda Goodenough.
Chapter 7: The obstacles to the translation into practice of the knowledge on environmental design.	Fleming, R., R. Fay and A. Robinson (2012) "Evidence-based facilities design in health care: a study of aged care facilities in Australia." <i>Health Services Management Research</i> 25 : 121-128.	Conceptualisation, design, data collection, data analysis and write up by R. Fleming.
Chapter 8: Summary and conclusion	Thesis only	

CHAPTER 1: INTRODUCTION

1.1 Overview

*Last scene of all,
That ends this strange eventful history
Is second childishness and mere oblivion;
Sans teeth, sans eyes, sans taste,
Sans everything.*

As You Like It, Act II, Scene vii

Barbara Robb used these words written by Shakespeare to introduce *Sans Everything: A case to answer* (Robb 1967), a book that exposed the awful treatment inflicted on thousands of elderly people in psychiatric hospitals in Britain in the 1960s. The ‘Sans teeth, sans eyes, sans taste’ line was not used as a metaphor but described the practice of taking dentures, spectacles and hearing aids away from the patients – a small example of the disregard for the wellbeing of the patients that was commonplace, but not universal, at that time. I was working as a nursing assistant in a large psychiatric hospital in the north east of England while Robb was writing her book. I had been accepted for entry into university and had chosen to work there during the six months before moving to London. Many of the conditions and events described in her book were familiar to me in my daily experience. To my shame I only objected to one.

The weekly bathing I helped with is clearly described:

Weekly you are led, pushed and pulled through the dipping ritual. A single bath is drawn for all. If you happen to be the last in line, both water and tub are cold and dirty, and other patients may have

defecated or micturated in it previously. By this time the towels are soaking and the floor is flooded. A change of clothing awaits you. But it may, or may not, be your own (Robb 1967, p. 49).

The use of SHB (short hand brush) PRN as a treatment of choice is also described, but I must say that I did not see it used indiscriminately as described below:

The patients feared the staff – especially the older, fully qualified charge nurses. Their fears were justified, as anyone present at 6.55am could vouch for, as they watched the charge nurse go into the assault armed with, for example, a short-handled sweeping brush, and lay about him indiscriminately and with great ferocity (Robb 1967, p. 44).

Robb's book contains many descriptions of the institutionalised cruelties and indignities that were simply taken for granted. The example that stands out in my memory concerns the locking of the dormitories at night. At the end of the afternoon shift I was sometimes given the honour of representing the ward at the daily hand over of keys to the Chief Nurse. This occurred at around 7.30 pm and was a formal affair with the nurses from each ward standing at attention and handing the keys over in turn. It occurred after all of the patients had been locked into the dormitory. The dormitory in my ward had no accessible toilet. When I was on the morning shift my first job was to be present at the opening of the dormitory at 6.30 am and to dress one of the confused patients. The patient was always pleased to see me but his concern with getting to the toilet before he wet himself far outweighed his interest in getting dressed. Sadly, I was not always able to get him there in time.

The only event I objected to was the forced shaving of a moustache that had been carefully grown and tended over a couple of weeks. It was shaved, so far as I could tell, to show the patient who was boss. My hesitant, verbal

report to the charge nurse resulted in a very brief change of attitude in the orderly and nurse who had carried out the shaving. As for the rest, I assumed that they must be acceptable. Robb had not finished her book and, as far as I knew, no one was objecting.

In NSW, Australia, in 1983 David Richmond released his report, *Inquiry into health services for the psychiatrically ill and developmentally disabled* (Richmond 1983). This Inquiry had been established partly as a result of concern expressed by health industry unions about a range of industrial issues, including concerns about the adequacy of patient care and safety (Richmond 1983), and because "It is considered that the Fifth Schedule hospital system has developed a particular ethos which is not conducive to achievement of the service delivery principles the Inquiry considers desirable" (Richmond 1983, p. 30). At the time of the release of the report I had been the head of the psychology department in one of the fifth schedule (mental) hospitals for four years. The clinical role I had selected for myself involved working in the back wards with the elderly patients, many of whom were dementing.¹

Richmond did not get down to describing the problems within the fifth schedule hospitals in the same level of detail as Robb, although I am sure that he would have had access to similar reports. His criticisms were implied rather than stated. However it was clear that his inquiries provided evidence of a profoundly dysfunctional system. I agreed wholeheartedly with

¹ The term 'dementing' may surprise some readers as it strays from the currently accepted term of 'person with dementia'. It is used in the knowledge of the importance of using words that do not stigmatise or disempower people with a diagnosis of dementia, as clearly stated by Sabat et al. (2011). "The 'demented other' or simply 'a person'? Extending the philosophical discourse of Naue and Kroll through the situated self." (quoted in *Nursing Philosophy* 12(4): 282-292.) It has been selected because it accurately describes the process taking place in some of the people living in the wards being described. As Naue and Kroll, in their rejoinder to Sabat et al, (Naue, U. and T. Kroll (2011). "A reply to 'The "demented other" or simply "a person"? Extending the philosophical discourse of Naue and Kroll through the situated self' by John Keady, Steven Sabat, Ann Johnson, and Caroline Swarbrick." *Nursing Philosophy* 12(4): 293-296.) recognise the process "is a *reality* and so are the changes associated with it" and this reality can be justifiably described by words such as demented, provided the context does not lead to an interpretation that is prejudicial to the person with dementia.

Richmond's critique of the mental health services and became heavily involved in the activities of the Richmond Implementation Unit established to put the recommendations of the Inquiry into practice.

The primary operational principles used to guide the implementation were:

1. Fund and/or provide services which maintain clients in their normal living environment; and
2. Progressively reduce the size and number of existing Fifth Schedule Hospitals by decentralising the services they provide (Richmond 1983).

With regard to the specific needs of the confused elderly, the report summarised these:

The dominant theme of submissions to the Inquiry was the importance of comprehensive physical, social and psychological assessment of the elderly person prior to decisions being made about treatment or placement. There is evidence that some of the psychiatric symptomatology in elderly patients is reversible providing full assessment and appropriate care is available. Submissions highlighted the following major problems:

1. Inadequate and inappropriate accommodation – maldistribution of and insufficient nursing homes in some areas; lack of facilities including appropriately designed nursing homes for the containment with dignity of the wandering or behaviorally disturbed patient; and lack of hospital accommodation including appropriate assessment units in general hospitals.
2. Lack of skilled staff trained in assessing and treating the psychiatric disorders of old age.

3. Lack of support services for families who are major 'therapists' for demented people.
4. Lack of services such as laundry, home help, handyman, temporary care facilities, etc., the provision of which could obviate inappropriate nursing home placements.
5. Lack of other community services which would assist in reducing social isolation (Richmond 1983).

I have continued to be heavily involved in these areas since the Richmond Implementation Unit days. The work described in this thesis is related to the first two themes: the provision of a comprehensive physical, social and psychological assessment and the provision of appropriately designed nursing homes for the containment with dignity of the wandering or behaviourally disturbed patient. As the work has progressed the level of understanding of the nature of dementia and the relationships between the illness, the person and the psycho-social-physical environment has deepened. The terms 'containment' and 'patient' have become problematic. When the patient is seen as a person, containment must be changed to maintaining and enhancing personhood (Kitwood 1997).

The fundamental problem with the implementation of the Richmond Report recommendations for improving services to the confused elderly was the lack of a technology. The development of decentralised, normalised services for the younger mentally ill person could be guided by the results of Australian and overseas research (Stein Li 1980; Hoult, Reynolds et al. 1981). This research described the use of crisis teams, living skills centres and group homes. There was some similar information available to guide the development of services for the elderly confused. The Health Commission, for example, had identified the need to have alternatives to Fifth Schedule hospital care for elderly people and recommended that:

1. Only long-stay patients with significant behavioral abnormalities should be cared for in Fifth Schedule system once initial assessment has been carried out.
2. Patients without severe behavioral disturbance should be cared for in nursing homes or in general hospitals (Commission 1982).

The potential for the use of day hospitals to extend the range of available services and provide choice of care had been identified (Skinner 1981) and evaluations of Australian and overseas community based services provided ideas for keeping elderly people out of hospital (Jolley and Arie 1978; Carter 1981; Clarke, Williams et al. 1981; Geeves 1981; Skinner 1981; Commission 1982; Ratna 1982). However there was a paucity of information on what could be done to facilitate the progressive reduction in the population of elderly confused people already in the Fifth Schedule hospitals.

The pressure generated by the Richmond Report would probably have been sufficient in itself to have begun the process of transferring people with dementia from psychiatric hospitals to other locations. When that pressure was intensified by the change in status of people with dementia brought about by the impending proclamation of the 1983 Act, the transfer became inevitable. The 1983 Act provided, for the first time in NSW, a definition of mental illness. In essence the definition stated that mental illness is a disease of the mind and not a disease of the body. Errington (1986) explained the implications of this:

This leads to the somewhat surprising conclusion that a person suffering from senile dementia by reason of arteriosclerotic degeneration, is not a 'mentally ill person' within the meaning of the Mental Health Act.

When a patient in a mental hospital is determined to be not mentally ill he must be discharged. It was clear that the Mental Health Review Tribunal, who were charged with the responsibility of reviewing all continued treatment patients every six months and all informal patients every 12 months, would have no alternative but to discharge a large number of people with dementia requiring continued care. Where were they to go? This context provided an imperative for the development of a new service that would assist the NSW Health Department to implement the Richmond recommendations.

There were developments in the aged care sector that were relevant to this problem. In Western Australia Dr Richard (Dick) Lefroy was the Geriatrician in the Extended Care Section of the Public Health Department. Together with a consistent emphasis on the need for more 'home care', he was advocating for the development of a residential, rather than institutional, character for aged care facilities. This was first explored in the 30-bed Hummerston Lodge hostel for The League of Home Help in West Perth, built in 1971 and consisting of five hubs of six bedrooms, each with its own small and intimate lounge room and pantry, and with access to other communal facilities.

The benefits of smaller group sizes for people with dementia was advocated by Dorothy Eaton and Elizabeth Marshall of the Uniting Church in Victoria. They adapted two existing houses for five or six residents each, one at Sefton Lodge in Hawthorn in 1975, and the other at Dickens Lodge in Fitzroy in 1976. In their publication *Forgetting but not Forgotten* (Marshall and Eaton 1980), these pioneers argued for familiar domestic buildings and small group sizes, involving the residents in helping themselves and each other and providing a simple, familiar environment.

There was a willingness emerging to try alternatives to institutional approaches to the care of people with dementia. With the assistance of a

nursing colleague, John Bowles, I provided the Richmond Implementation Unit with plans for the development of specialised units for the care of confused and disturbed elderly people. These became known as CADE units (Fleming and Bowles 1987; King and Abel 1991; Atkinson 1995; Verbeek, van Rossum et al. 2009) and nine were built in strategic locations across NSW.

The CADE unit programme had three main elements:

1. The assessment of the person in a way that would guide their placement and care
2. The provision of well-designed physical environments that compensate for the problems associated with dementia
3. The provision of a style of care that maximises the involvement of the person with dementia in the ordinary activities of daily living.

This thesis is concerned with the first two of these elements and explores:

1. The development and evaluation of a care planning assessment tool
2. The nature of physical environments that are beneficial to people with dementia
3. The development of a tool to assess these environments
4. The problems with transferring the knowledge gained in the twenty-five years since the beginning of the CADE unit programme into the mainstream of aged care.

It could be described as an exploration of aspects of the technology required to provide high quality residential care to people with dementia. While the origins of this work are certainly in the CADE Unit programme, it will be evident that the impact has extended beyond this and that the work continues to be relevant to today's needs. The motivation behind the work is to improve the quality of life of people with dementia in residential care.

1.2 The area of study and its significance

1.2.1 Dementia

Dementia is an umbrella term for a large number of disorders that affect thinking and memory. Alzheimer's Disease is the most common form and accounts for between 50 and 70 per cent of dementias. The second-most common form of dementia, resulting from small strokes, is Vascular Dementia. Other types of dementia include Lewy Body Dementia and Fronto-temporal dementia. Symptoms have been broadly classified (Burns, 2001) as:

Cognitive impairment: indicated by problems with memory (amnesia), speech or understanding of language (aphasia), a failure to carry out physical tasks despite having intact motor function (apraxia), and failure to recognise objects or people despite having knowledge of their characteristics (agnosia).

Behavioural and psychological symptoms (BPSD): the cognitive impairment may be accompanied by symptoms such as depression, delusions, hallucinations (visual and auditory) – and abnormal behaviours such as wandering, incessant walking or agitation.

Dysfunction in activities of daily living (ADL): In the early stages of dementia these can include more complex difficulties with shopping, driving or handling money. In the later stages more basic tasks are affected such as dressing, eating and bathing.

While the levels of cognitive impairment and the problems with activities of daily living increase as the dementia progresses, the prevalence of behavioural and psychological symptoms (with the exception of passivity) tends to peak in the middle stages (Lövheim, Sandman et al. 2008). The median survival from initial diagnosis has been estimated as 4.2 years for men and 5.7 years for women (Larson, Marie-Florence et al. 2004).

It is important to understand that these symptoms may be due to the circumstances of the person with dementia rather than the dementing process itself. The contribution of the built environment to these circumstances is the main focus of this thesis.

Dementia is predominantly a condition of the elderly with its prevalence increasing steadily as age advances. It has been estimated that the prevalence doubles every 5.1 years post the age of 65 (Jorm, Korten et al. 1987) as illustrated in Table 2.

Table 2: Prevalence of dementia

	Rate (%)		
Age	Males	Females	Persons
0 – 64	0.1	0.1	0.1
65 – 74	3.1	3.4	3.2
75 – 84	8.8	10.4	9.7
85+	24.4	32.3	29.5
65+	7.1	10.3	8.8

Source: (AIHW 2012). (Dementia in Australia. Canberra, Table 2.1)

As a result of declining fertility rates (leading to a lower proportion of young people) and increases in longevity the proportion of elderly people in Australia is increasing (Government 2004). In 1970–71 the proportion of the population over the age of 65 was 8%, in 2001–2 it was 13% and it is anticipated that it will reach 25% by 2045. The combination of an increasing proportion of elderly people, an increasing population and the fact that dementia occurs in the elderly is resulting in the rapid increase of the number of people with dementia.

Table 3: Increasing number of people with dementia

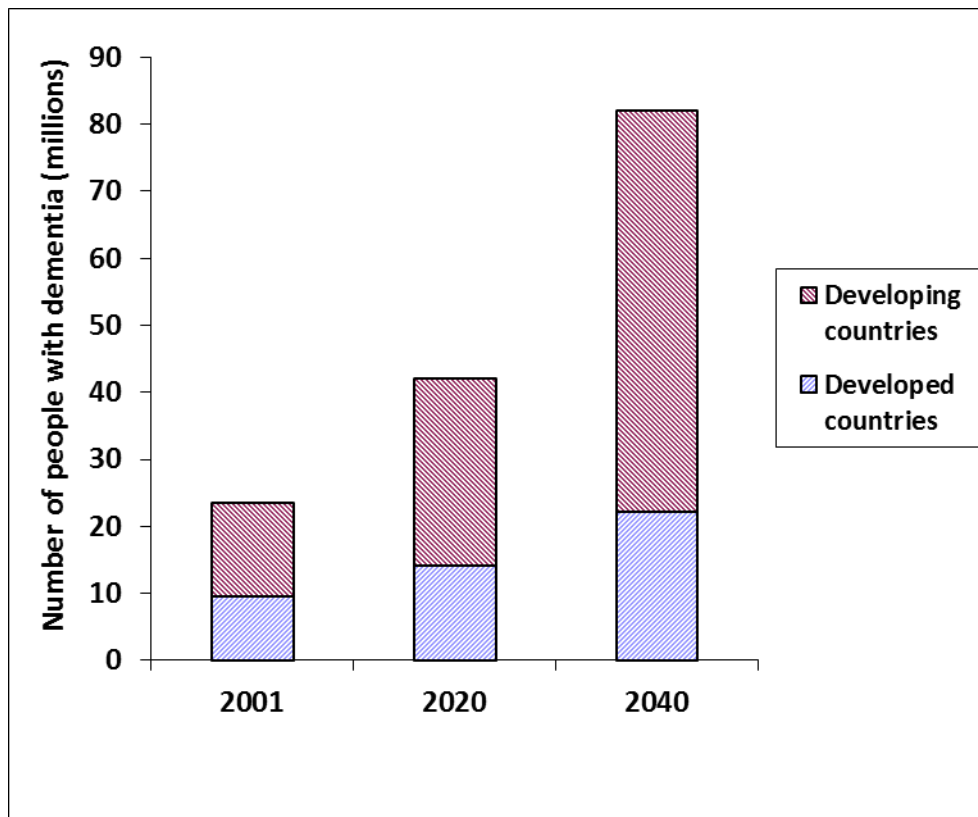
Age	2011	2020	2030	2040	2050	% change: 2011 to 2050
0 – 64	23,900	27,300	29,400	31,500	36,800	53.7
65 – 74	54,100	78,100	93,100	100,400	108,700	101.1
75 – 84	97,400	125,700	192,500	232,700	253,800	160.7
85-94	108,400	142,100	198,700	313,700	393,800	263.4
95+	14,200	26,600	36,600	59,300	98,300	590.0
Total	298,000	399,800	550,200	737,600	891,400	199.1

Source: AIHW (2012) (Dementia in Australia. Canberra, Table 2.3)

This phenomenon is often referred to in the popular press as an ‘epidemic’ of dementia. This is somewhat misleading as dementia is not an infectious disease. The increasing number of people with it is due to the increasing number of elderly people. However the word epidemic portrays the sense of fear that many have as they contemplate the steadily increasing demand for resources that will occur as care is provided to those with dementia. The rapid increase in demand for service is well understood by the Australian Government (Productivity Commission 2011) and has been extensively covered in reports produced by Access Economics for Alzheimer’s Australia (Access Economics 2003; Access Economics 2009).

This problem is not confined to Australia. The graph below is taken from Figure 2 in Ferri et al’s survey of dementia prevalence in each world region (Ferri, Prince et al. 2005).

Figure 1: Numbers of people with dementia in developing and developed countries



Source: Ferri et al. 2005.

1.2.2. People with dementia in residential aged care

The Australian Institute of Health and Welfare (AIHW) recently estimated that 30% of people with dementia live in accommodation in which care is provided (AIHW. 2012).

Information on the dementia status of people in residential aged care facilities (RACF) is collected through the Aged Care Funding Instrument (ACFI) which must be completed on all Australian Government-subsidised RACF residents in Australia. In 2009–10 the ACFI data indicated that approximately 53% (112,139 residents) had a diagnosis of dementia. The demand for residential places for people with dementia is estimated to grow at 4% per annum between now and 2029 (Access Economics 2009).

People with dementia in residential aged care have very high care needs.

The ACFI provides information on care needs in three domains: activities of

daily living (ADL); behaviour characteristics; and complex health care needs. The AIHW report (AIHW. 2012) provides a detailed comparison of the care needs of residents with and without dementia. Residents with dementia are more likely than those without dementia to have been rated with higher care needs in the ADL and the behaviour characteristics domains, but not in the complex health care domain (AIHW 2012). Just over half (52%) of permanent residents with dementia had a 'high' rating in the 'ADL domain' compared with about a third (32%) of those without dementia (Figure 3.8). At the other end of the scale, 19% of those with dementia had a rating of 'low' or 'nil'; this compares with 41% of those without dementia.

About 62% of residents with dementia had the highest possible rating in the 'behaviour characteristics' domain. This is almost three times higher than the proportion of other residents given this rating (22%, Figure 3.7). Relatively few (3%) of those with dementia had a rating of 'nil' for this domain, while 21% of those without dementia did so. These findings are consistent with an earlier estimate of the prevalence of behavioural disturbance in nursing homes in which behavioural and psychological symptoms of dementia were described as ubiquitous, being present in 82% of residents (Brodaty, Draper et al. 2001).

The AIHW report breaks down the behavioural characteristics into the categories of problematic verbal behaviour, physical behaviour and wandering. More than half (55%) of residents with dementia exhibited problematic verbal behaviour twice a day or more, at least six days a week. Problematic verbal behaviours are considered to be: verbal refusal of care, being verbally disruptive, having paranoid ideation that disturbs others, and inappropriate verbal sexual advances. An additional 14% of residents with dementia exhibited such behaviours once a day at least six days a week (A3.14). By comparison, 35% of those without dementia exhibited problematic verbal behaviour twice a day or more, at least six days a week.

Half of all residents with dementia exhibited problematic physical behaviours (that is, physically threatening or harmful behaviour, socially inappropriate physical behaviour and constant physical agitation) twice a day or more, at least six days a week. This is twice the proportion of those without dementia exhibiting such behaviours with the same level of frequency.

In terms of wandering behaviour, the ACFI provides information on repeated attempts to enter areas where the resident's presence is 'unwelcome' or 'inappropriate', and interfering with or disturbing other people or their belongings while wandering. About one-quarter (27%) of residents with dementia displayed this behaviour twice a day or more, at least six days a week compared with 8% of residents without dementia.

The high prevalence of disturbed behaviour must raise concerns about the nature and quality of care being provided to people with dementia in residential aged care. It is clear that pharmacological management has only modest effect, at best. A systematic review of the literature concluded that "Pharmacological therapies are not particularly effective for management of neuropsychiatric symptoms of dementia" (Sink, Holden et al. 2005,p. 596)

This situation was starkly clarified in a report to the UK Minister of State for Care Services by Professor Sube Banerjee (2009) on the use of antipsychotic medication in which he states:

There have been increasing concerns over the past years about the use of these drugs in dementia. The findings of my review confirm that there are indeed significant issues in terms of quality of care and patient safety. These drugs appear to be used too often in dementia and, at their likely level of use, potential benefits are most probably outweighed by their risks overall. This is a problem across the world, not one just restricted to the NHS. It is positive that, with action, we

have the means with which to sort out this problem, quickly and safely.

Looking at the use of these drugs in dementia, it is clear that this is a specific symptom of a general cumulative failure over the years in our health and social care systems to develop an effective response to the challenges posed by dementia (Banerjee 2009, p.2).

This report specifically draws attention to an additional 10 deaths, 18 cardiovascular accidents (50% severe) and 58-94 patients with gait disturbance in every 1,000 people treated (Banerjee 2009, p.27).

The recognition of the risks and limited benefits of the use of medications to assist people with disturbed behaviour associated with dementia have added weight to the view that, at least, medication should be used in conjunction with non-pharmacological approaches (Brodaty 2010) and those that believe the quality of the evidence is mounting to the point that we can consider the replacement of medications with non-pharmacological approaches, including environmental redesign (Gitlin 2010).

It is concern with the quality of care being given to people with dementia in residential aged care that underpins the work described in this thesis. Particularly to assist staff to identify the needs of the residents and to provide a systematic approach to using the physical environment as a tool for meeting those needs.

1.2.3 Significance of the issues

More than 112,000 people with dementia are in residential aged care in Australia alone, and the demand for places is increasing at 4% per year. Every developed and developing country in the world is facing the same issue.

It is known that a high degree of behavioural disturbance (verbal, physical and wandering) is associated with the physical and psycho-social circumstances in which people with dementia live (Lawton, Fulcomer et al. 1984; Lawlor 1996; Kitwood 1997; Brodaty, Draper et al. 2001; Zuidema, de Jonghe et al. 2010). However, despite thirty years of effort, much remains to be done to understand this relationship well enough to be able to build environments that avoid causing behavioural disturbances and that, by their nature, facilitate the delivery of needs-based, person-centred care. The ultimate goal is to maximise the quality of life of people with dementia.

The research reported in this thesis explores the development of assessment tools that help us to understand the needs of people with dementia and the quality of the environments that they live in. It identifies the critical characteristics of the physical environment that are needed to reduce confusion, agitation, social isolation and meaninglessness and provides some clues on how to apply the knowledge we have on a broad scale.

1.3 Structure and approach

The thesis is submitted in fulfilment of the requirements of a Doctor of Philosophy (Journal Article Style). According to the guidelines outlined for higher degree research students of the University of Wollongong (UOW 2011), these articles may be published, submitted for publication, prepared as a manuscript for submission, or any combination thereof. In accordance with these guidelines, this thesis includes the chapters outlined below.

Introductory Chapter: Chapter 1, (this chapter) provides the thesis examiners with a coherent picture of the content of the work, the motivation for carrying it out and how it contributes to the discipline area. It also outlines the structure and approach of the thesis.

Chapters in journal article style: In keeping with the UOW guidelines, chapters have been included in the format of journal articles describing research conducted by the candidate during the period of his candidature. Chapters 2 to 7 comprise six articles, four of which have been published and two of which have been prepared for specific journals and are subject to peer review from the co-authors. Please note, that while the articles are formatted according to the guidelines for each journal, the referencing has been changed to author-date style for consistency in the preparation of the thesis document. Please also note that spelling is consistent with an English (Australian) dictionary, with the exceptions being journal article titles or titles of theories or models referenced within the thesis.

Within each chapter the articles are preceded by a description of their purpose and background and are followed with an extended discussion, a description of their impact, ideas for further research and a conclusion. This format has been adopted to maintain a narrative throughout the thesis and to compensate for the restrictions imposed by the format required by the journals.

Chapter 2: The research begins in Chapter 2 with the evaluation of the metrics of the Care Planning Assessment Tool (CPAT). CPAT was designed by the author of this thesis to assist direct care staff with a minimum of training to collect information to be used in the development of care plans and as a screening tool to bring attention to the need for more detailed assessments in specific areas. CPAT contains 60 questions in eight sub-scales covering the areas of communication, physical problems, self-help, confusion, social interaction, behavioural problems, psychiatric symptoms and dependency on care.

The inter-rater reliability was assessed from the scores obtained by two independent raters assessing 48 randomly selected residents in a large aged care facility. Concurrent validity was assessed by comparison with well-validated measures of cognition and function.

The introduction of a care planning assessment tool to the direct care staff in residential aged care has been shown to improve the quality of care planning. The high inter-rater reliability, validity and ease of use of the CPAT, and its ability to inform decisions on the placement of residents with dementia, have resulted in it being promoted as the assessment of choice by a leading Australian provider of care to people with dementia.

The availability of the CPAT was noticed by Japanese aged care providers who invited the author to work with them on the development and evaluation of a Japanese version. This has been published and endorsed by the Japanese Group Homes Association, the peak body that represents the interests of the 10,000 group homes for people with dementia in Japan.

Chapter 3: The third chapter introduces the effects of the physical environment on people with dementia in residential aged care by systematically reviewing the empirical literature. The literature was searched for articles published after 1980 that evaluated an intervention utilising the physical environment, focused on the care of people with dementia and incorporated a control group, pre-test/post-test, cross sectional or survey design. A total of 156 articles were identified as relevant and subjected to an evaluation of their methodological strength. Of these, 57 articles were identified as being sufficiently strong to be reviewed.

The review clearly indicated that there is a body of knowledge available to inform the design of residential facilities for people with dementia. The review is proving to be useful to a large number of people interested in environmental design for people with dementia, as evidenced by the 900+ downloads from International Psychogeriatrics.

Chapter 4: Chapter 4 introduces the quantification of the quality of the physical environment. It describes the evaluation of the metrics of the Environmental Audit Tool (EAT). The EAT was developed by the candidate and first published in a book commissioned by the NSW Department of Health to assist them with modifying the environments in regional hospitals that were providing long-term care to people with dementia.

The metrics of the EAT were evaluated by the candidate training two raters who independently assessed thirty aged care facilities using the EAT and the most commonly used environmental assessment, the TESS-NH. The data gathered allowed the inter-rater reliability and validity of the EAT to be assessed.

The ability of the EAT to assist with the identification of the strengths and weaknesses of the environment and lead-in to the development of plans for improving it has resulted in it being used extensively across Australia in a

government-funded project aimed at improving the design of new and refurbished facilities for people with dementia.

The ability of the EAT to quantify the quality of the physical environment has resulted in it being used as the primary source of information on the environment in two large Australian National Health and Medical Research (NHMRC) funded projects investigating interventions aimed at improving the quality of life of residents in residential aged care facilities.

It may be concluded from Chapters 3 and 4 that the desirable characteristics of physical environments for people with dementia are known as the result of empirical research and can be quantified in a valid and reliable way that provides practical guidance to those interested in developing environments that will benefit people with dementia.

Chapter 5: Chapter 5 takes the quantification of the quality of the environment further by asking whether or not the sub-scale structure of the EAT, which was initially developed on the basis of experience and anecdotal consensus, can be justified. The investigation also provides an opportunity to improve the EAT through the identification of duplicate and redundant items. This process is an important step in the refinement of every assessment tool. It was made possible by the use of the EAT in three studies: the original study of the metrics of the EAT conducted by the author of this thesis and the two NHMRC investigations mentioned above. The author of this thesis is a chief investigator on the NHMRC studies with particular responsibility for those aspects of the studies dealing with environmental design. Data gathered in these studies provided information on 105 facilities. These data were subjected to an exploratory factor analysis using geomin rotation.

The results of this analysis are informing the development of the next version of the EAT. This is being supported by the Primary Dementia Collaborative Research Centre, funded by the Australian Government.

Chapter 6: Chapter 6 explores the relationship between the quality of the environment and the quality of life of people with dementia living in it. To date there have been very few investigations of this relationship. The great majority of empirical investigations of the influence of the environment have focused on the impact of specific environmental interventions on the behavioural and psychological symptoms of dementia. They have not been able to throw much light on the overarching question: is there a relationship between the quality of the environment and quality of life? The small number of investigations, and their contradictory findings, may be explained by the lack of adequate assessments of both quality of life and quality of the environment.

The study described in Chapter 6 utilises the EAT and the most recently developed assessment of quality of life in people with dementia, DemQoL. It involved the auditing of the environment in 32 facilities and the assessment of the quality of life of 286 people with dementia living in them. The residents were all able to complete the self-report version of the DemQoL. This allowed, for the first time, the investigation of the relationship between the quality of the environment and the self-reported, rather than proxy reported, quality of life of the residents.

The results of this investigation show a clear link between the quality of life of residents with dementia and the quality of their environment when the quality of life is assessed by a direct question put to the person with dementia. This link is sufficiently strong to add urgency to programmes to improve the quality of residential aged care environments and to steps to include people with dementia as agents, rather than objects, in research and the development of services.

Chapter 7: Chapter 7, the final empirical chapter, investigates the reasons for the lack of application of the findings from research on environmental design that have been accumulating for more than thirty years. The study used a model of knowledge translation that specifies the existence of four stages in taking a research finding through to widespread application: awareness, agreement, adoption and adherence.

Ten aged care facilities that had recently been refurbished to make them suitable for people with dementia were audited using the Environmental Audit Tool. Senior managers and architects involved in the facility design were then interviewed to ascertain their knowledge of evidence-based principles of dementia design, their agreement with the principles, and the nature of the obstacles they had encountered in their implementation.

The results of this study have informed the planning and implementation of an Australia-wide, Department of Health and Ageing-funded, ‘timely education’ project that provides one day of consultancy to the management teams and architects involved in planning new, or refurbished, facilities for people with dementia.

Chapter 8: This chapter summarises the impact of the work described in the previous chapters.

This suite of studies has: provided tools that assist with the implementation of a systematic approach to care planning and environmental design for people with dementia; systematised our knowledge of designing environments for people with dementia; identified problems in the usual method of transferring knowledge of environmental design into practice; and informed the development of services across Australia and in Japan.

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CHAPTER 2: THE RELIABILITY AND VALIDITY OF THE CARE PLANNING ASSESSMENT TOOL

Chapter 2 presents an article written by the candidate and published as:

Fleming, R. (2008). "The reliability and validity of the Care Planning Assessment Tool." *Australasian Journal on Ageing* **27**(4): 209-211.

2.1 Aim

The 'Guidelines for Preparation and Submission of HDR Theses' states that a candidate may demonstrate an original and significant contribution to knowledge by having 'developed new techniques for investigating issues'. The aim of this part of the work was to develop an easy-to-use, valid and reliable means of assessing the range of problems of people with dementia commonly encountered as residents of aged care facilities.

2.2 Background

The paper presented in Chapter 2 represents a stage in the development of an assessment tool that occurred within the period of my candidature. The tool helps the staff of aged care facilities to recognise, report and discuss the problems of the residents they care for. This task is regarded as essential to the delivery of good quality care. Davis et al. (2009, p.168) in an editors' comment argue that "the cornerstone of contemporary care of the older person is assessment" (Davis, Dorevitch et al. 2009).

The development of the new tool described in Chapter 2 was preceded in the early 1980s with my development and publication of the Psychogeriatric Rating Scale (PRS) (Fleming 1990). This tool was used in the assessment of all potential residents for the CADE units described in Chapter 1 and in the development of their care plans following admission. I developed a computerised version of the PRS which became the first software-supported

care planning tool to be adopted by NSW Health. It was installed in 10 facilities across NSW.

In the 1990s the PRS was modified to include the Resident Classification Instrument (RCI) used to determine the level of funding provided to residents of Australian aged care facilities. It became the Revised Elderly Persons Disability Scale (REPDS) (Fleming and Bowles 1994). The REPDS was also available in a computerised form and was sold in the UK, Hong Kong and Canada as well as Australia. Approximately 100 services in these four countries had purchased the software by 2000.

In 1996 the REPDS was complemented with a book of model care plans (Fleming, Bowles et al. 1996) designed to provide aged care staff with an easy-to-use source of information that would help them move from the assessment phase of care planning to the development of care plans. The 351-page book contained 'model' interventions for each of the problems assessed by the REPDS. Interventions were provided to match the severity of the problems identified.

The model care plan book was translated into Japanese and published by World Planning, Tokyo in 2002. Experience with the REPDS showed that the inclusion of the RCI funding instrument was having a systematic effect on the assessment results. The raters were overstating the severity of the problems. I decided to develop a new tool that would avoid this bias by not having a direct relationship to the funding instrument. I also took the opportunity to include additional items to provide more information on the social, emotional and spiritual issues that the residents may have been experiencing. The result was the Care Planning Assessment Tool described and evaluated in Chapter 2. A copy of the CPAT is contained in Appendix 1.

The paper follows in sections 2.3 to 2.11.

2.3 Abstract

2.3.1 Objective

The development of a simple, comprehensive, valid and reliable tool to assist aged care services staff to develop and monitor care plans.

2.3.2 Method

An assessment with proven utility in a psychogeriatric setting was modified to improve its relevance to aged care services. Reliability was assessed from the scores obtained from two independent raters assessing 48 randomly selected residents in a large aged care facility. Validity was assessed by comparison with well validated measures of cognition and function.

2.3.3 Results

The Care Planning Assessment Tool has very high inter-rater reliability and good internal consistency. The validity of the sub-scales compared with well validated assessments was very high.

2.3.4 Conclusion

The psychometric properties of the Care Planning Assessment Tool are sufficiently good to allow it to be used with confidence in the care planning process. This is supported by a similar evaluation carried out on the Japanese version.

2.3.5 Acknowledgements

The work described in this paper was supported by the State Street Foundation.

2.4 Introduction

The Care Planning Assessment Tool (CPAT) has been developed to provide the staff of aged care services with a simple to use assessment that results in

a comprehensive overview of the major problems being experienced by their clients. The establishment of such an overview is regarded as being the first step in a care planning process that should identify residents' needs, problems and capabilities, develop interventions and evaluate the responses to the care provided. The availability of a single tool that focuses attention on the common problems of the elderly person receiving care should make it easier to document the information on which a care plan is based and reduce the use of ad hoc collections of assessments.

If the tool is to be used to quantify the severity of the problems, then as well as being comprehensive and simple, it must also be valid and reliable, enabling staff to have confidence in the observations carried out by their colleagues. The availability of comprehensive, valid and reliable information, which is trusted by staff members, is the foundation stone on which a good care plan can be built.

CPAT is the result of a lengthy process of development that began with the Psychogeriatric Rating Scale (PRS) first published in 1990 (Fleming 1990). This scale was heavily biased towards the assessment of people with dementia or psychiatric conditions. Experience of its use in aged care settings, and the introduction of the Resident Classification Scale (RCS) for the funding of residential aged care, brought about the development of a tool that attempted to combine the functions of assessment for care planning and assessment for funding by modifying the PRS questions to better reflect the problems of people in aged care and the incorporation of the RCS questions. The resulting scale, known as the Revised Elderly Persons Disability Scale (REPDS) (Fleming and Bowles 1994) has been used in many aged care services in Australia and abroad since that time.

Experience with the use of the REPDS highlighted two major problems. Firstly the inter-rater reliability of the scale was reduced by the inclusion of the quite complicated RCS questions. Secondly there was a systematic bias

introduced into the scoring, resulting in an apparent increase in dependency, when the REPDS was used to support RCS documentation. The development of the CPAT marks a return to the use of assessment purely for care planning purposes. This is a recognition of the fact that assessment for funding will always be affected by the motivation to maximise returns and that this introduces a significant bias into the process that can have a detrimental effect on assessment for the development and evaluation of care plans.

The transition from the REPDS to CPAT was followed by users in Japan who have conducted their own study of its reliability and validity (Kanegae, Ichimaru et al. 2008) and found it to be satisfactory.

2.5 Description of CPAT

CPAT is designed to be used by direct care staff with a minimum of training. The purpose of using CPAT is to enable these staff to collect and report information that will establish a baseline for future comparisons and either lead directly to the development of specific interventions for the problems identified, or trigger more detailed assessments.

CPAT contains 60 questions in eight sub-scales covering the areas of communication, physical problems, self-help, confusion, social interaction, behavioural problems, psychiatric symptoms and dependency on care. The questions are simply worded and are answered by selecting one of four descriptors that are scored from 0, which indicates no problem, to 3, which indicates a severe problem. The sub-scale score is the sum of the scores in that sub-scale expressed as a percentage of the maximum possible score. As assessment should reflect a holistic and person centred approach (Kitwood 1997) care has been taken to ensure that the 60 questions explore the social, emotional and spiritual needs of the person being assessed as well as the basic physical, behavioural and ADL problems. The Dependency on Care

sub-scale attempts to measure the amount of time required for the delivery of care.

2.6 Method

CPAT, and its predecessor the REPDS, was an integral part of the care planning and QA system of the organisation in which this study took place. As the study did not involve a significant deviation from the normal care practices of the organisation, approval was not sought from an ethics committee.

A sample of residents was selected from the low care, high care, low care dementia-specific and high care dementia-specific units of a large aged care facility in Sydney. The sample was random within units but the number of residents selected in each area was determined by the relative size of the units, with 10 residents selected in each of the low care units and in the non-dementia specific high care while 20 residents were selected in the dementia-specific high care unit. This approach was taken to ensure that a wide range of residents, from the physically quite well and not dementing to the physically frail and dementing, was available.

Two raters, one of whom was experienced in the use of the REPDS and had been involved in the development of CPAT, and one who had a two-hour introduction to CPAT, completed the CPAT independently. The raters worked in each of the areas in turn, observing the residents in that area and familiarising themselves with the problems described in the case notes, talking with the residents and talking with staff about the residents. Their observations were designed to be as like a regular member of the direct care staff preparing for a case reviews as possible. They were free to make notes on their conversations and observations but did so rarely.

The more experienced rater also assessed cognition and functional ADL ability by administering the MMSE (Folstein, Folstein et al. 1975), Barthel Index (Mahoney and Barthel 1965) and Katz Index of Independence in Activities of Daily Living (Katz, Down et al. 1970). The results of these assessments were used in the assessment of the validity of the scale by comparing them with the confusion and self-help scores obtained by the less experienced rater.

The internal validity of the scale was assessed using Cronbach's alpha and the reliability was assessed using the intraclass correlation coefficient (Shrout and Fleiss 1979).

2.7 Results

A total of 48 residents were assessed on all measures. Two of the original sample were not present during the observation period. Of those assessed 19% (9) were male. Ages ranged from 62.2 to 102.9 years, with a mean of 82.6 years.

The mean MMSE score of those in the dementia-specific units was 4.94, standard deviation 7.77; those in the general care areas had a mean MMSE of 19.71, with a standard deviation of 7.63. With the exception of the Psychiatric Symptomatology sub-scale (alpha = 0.68) all of the Cronbach's alpha values were above the generally accepted level of 0.7 (Cronbach 1951) with 5 of them being higher than 0.75. (See Table 4)

The validity of the Confusion sub-scale was assessed by comparing it with MMSE scores obtained within 3 days of the completion of the CPAT. The Spearman's rho correlation of -0.94 (significant beyond 0.01) indicated a very high degree of correlation. The MMSE correlated most highly with the Confusion sub-scale (See Table 4).

Table 4: Reliability and validity data

	Cronbach's alpha	Intraclass Correlation (Type A, single measures, absolute agreement definition.)	Spearman's correlation with MMSE	Spearman's correlation with Barthel	Spearman's correlation with Katz
Communi- cation (4 items)	0.70	0.98	-0.86**	-0.73**	-0.76**
Physical (5 items)	0.74	0.96	-0.42*	-0.70**	-0.67**
Self Help (8 items)	0.91	0.99	-0.79**	-0.93**	-0.91**
Confusion (8 items)	0.88	0.98	-0.94**	-0.63	-0.67**
Behaviour (10 items)	0.83	0.99	-0.61**	-0.43*	-0.46**
Social Interaction (9 items)	0.84	0.98	-0.50**	-0.65**	-0.56**
Psych- iatric Symptoms (7 items)	0.68	0.97	0.06	0.04	0.08
Depend- ency on Care (9 items)	0.75	0.98	-0.78**	-0.72**	-0.76**
		All ICCs significant at 0.000	** Correlation significant at the 0.01 level (2 tailed) * Correlation significant at the 0.05 level (2 tailed)		

The validity of the Self Help sub-scale was assessed by comparing it with the Barthel Index and the Katz Index. The correlations were -0.86 and -0.91 respectively (both significant beyond 0.01) indicating a very high degree of correlation. These correlations were higher than the correlations between these two scales and the other CPAT sub-scales, supporting the validity of the Self Help subscale as a measurement of functional activities of daily living.

Forty-five items (75%) had an Intra Class Correlation (ICC) of 0.9 or above, 55 of the 60 items had an ICC of 0.8 or above and only one item (Auditory Hallucinations) had an ICC below 0.72 (See Table 4).

2.8 Discussion

During the development process the clarity, simplicity, relevance and face validity of the CPAT items and the sub-scales they make up was assessed through a series of discussions with staff from both dementia-specific and mainstream care areas. This resulted in a form of words that was easily understood by these staff and valued by them for providing information of relevance to their concerns and arranged in sub-scales that made sense to them.

This process in combination with the very high correlations between the Confusion and Self Help sub-scales and well accepted measurements of confusion and ADL activities suggests that the validity of the CPAT is acceptable.

The reliability of the scale as assessed by the internal consistency of the subscales is very good in the Self Help, Confusion, Behavioural Problems and Social Interaction sub-scales. The Communication, Physical Problems and Dependency on Care scales have levels of internal consistency that are

at least satisfactory (Cronbach 1951; Streiner and Norman 1995). The internal consistency of the Psychiatric Symptom scale is marginal.

The inter-rater reliability of the sub-scale scores, as assessed by the Intraclass Correlation Coefficient is very high (Table 4). The item by item analysis indicating that 92% of the items have an ICC of more than 0.8 suggests that the use of CPAT will enable staff to have confidence in ratings carried out by others.

However the assessment of auditory hallucinations proved to be difficult. The ICC on this item was almost zero. Each rater identified one person with auditory hallucinations but their selections did not agree with one another. The relative rarity of this condition, combined with the difficulties of recognising it, resulted in the poor inter-rater reliability. This item also contributed to the relatively low Cronbach's alpha (0.68) of the Psychiatric Symptom sub-scale. If it were to be removed the alpha would rise to 0.70 placing it within the range of satisfactory alphas. While the exclusion of the question on auditory hallucinations is easily justified on psychometric grounds, and perhaps should be carried out if the CPAT is to be used for research purposes, it is recommended that it be retained for care planning purposes because of its utility in helping to differentiate between delirium, dementia and depression.

The small sample and use of only two raters limit the confidence that can be placed in these results. However corroborating evidence from the investigation of the Japanese translation of CPAT (J-CPAT) is encouraging. Cronbach's alpha values in each J-CPAT sub-scale were 0.74–0.95. The correlation coefficients between the confusion sub-scale and the MMSE was -0.90 ($p < 0.001$). The correlations between the Physical problems, Self-help skills and Dependency on care subscales in the J-CPAT, and the scale used to assess functional levels the Japanese public long-term care insurance scheme were 0.70, 0.75, and 0.67 ($p < 0.001$) (Kanegae, Koizumi et al. 2010).

2.9 Conclusion

The CPAT has adequate validity and reliability for use in care planning and monitoring. The experiences of those who used it during development and testing strongly suggest that its simplicity, comprehensiveness and relevance make it a valuable tool for direct care staff to use in collecting information that will facilitate the writing of good care plans. The extremely good inter-rater reliability indicates that it will be very useful for helping staff to come to a common understanding of the range and severity of the problems being experienced by those in their care.

The CPAT may be obtained free of charge for use in care planning from www.dementia.com.au .

2.10 Key Points

- There is a need for a single simple, comprehensive, reliable and valid assessment tool that will help direct care staff in aged care homes to develop and monitor care plans.
- The combination of assessment for funding with assessment for care planning introduces a systematic bias into the results and should be avoided.
- The Care Planning Assessment Tool has sufficiently good psychometric properties for it to be used with confidence as an aid to care planning.
- The CPAT may be obtained free of charge for use in care planning from www.dementia.com.au .

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2.12 Extended discussion

The limit on the number of words permitted in the published article prevented the discussion of some important points about the development and use of the CPAT. These are taken up below.

The CPAT is completed on the basis of observations carried out by a care assistant. It does not require the care assistant to ask the resident any questions that would not arise in their normal interactions. This method of data collection was chosen because of the limited interviewing skills of most residential aged care staff and the problems people with dementia have in answering questions. The selection of the care assistant as the assessor was made on the basis of their intimate knowledge of the resident and the desire to provide them with an opportunity to contribute to the care planning process. Pachana succinctly describes this point of view:

Health care workers who are intimately involved in patient care may have a different perspective to nursing managers or visiting consultants. Information systematically collected from persons who have known an individual over an extended period of time may be most instructive in terms of interpreting current behaviours and cognitive and emotional functioning (Pachana, Helmes et al. 2010, p. 1115).

Residential aged care services are usually resource poor. Staff time, training and skills are often limited (De Bellis and Williams 2008). Any assessment tool designed to be used routinely in these circumstances must be easy and quick to use and repay the efforts of the staff by providing them with information that assists them to do their work. The twenty years of experience with the predecessors to the CPAT provided valuable information on the selection and wording of the items.

The CPAT has three main functions:

1. The 60 items provide a prompt to the staff to look for a wide range of common problems. Having identified the presence and severity of the problems the next step is to discuss them in a case review meeting where the experience of colleagues and senior staff will be applied to the development of a care plan. The CPAT provides the structure and language for these discussions and provides a much more thorough exploration and description of the problems than would occur if the staff member was simply asked to contribute her views on the resident's condition and needs using her own words.
2. The CPAT is a screening tool; that is, it is intended that when a certain problem, for example depression, is identified by one or two of the questions, that further assessment is undertaken by an experienced person using a more specialised assessment tool, such as the Geriatric Depression Scale (Yesavage, Brink et al. 1982) or the Cornell Depression Rating Scale (Alexopoulos, Abrams et al. 1988).
3. The CPAT is a measuring tool that quantifies the severity of problems in particular areas (e.g. physical, self-help). This enables measurement over time to monitor the changes in the person. It also enables the establishment of profiles that describe the person and profiles of groups of people, for example those in nursing homes. This allows the matching of a person with a facility.

The use of the CPAT as a measuring instrument requires that it has satisfactory reliability and validity. The CPAT is not a diagnostic tool so the question of its specificity and sensitivity, often measured in evaluations of assessment tools, did not arise (Pachana, Helmes et al. 2010).

It must be borne in mind that the CPAT does not, by itself, provide enough information for the development of a comprehensive care plan. The behaviours of people with dementia, like the behaviours of all of us, are

determined by many factors. The first comprehensive model explaining behaviour in terms of biological, social, psychological and environmental influences was described by Cohen-Mansfield (Cohen-Mansfield 2000). More recently the Newcastle Model (James 2011) has exerted a great deal of influence in the development of assessment services in the UK. This model has extended our understanding of behaviour by explaining the significant causal effects of the beliefs of the person with dementia on their behaviours. The development of these models has encouraged an understanding of the contribution of assessments like CPAT to the biopsychosocial assessment of people with dementia. The results obtained by the use of the CPAT must be combined with information gained from the biography of the person, a knowledge of their medical problems and an understanding of the effects of the social and physical environment on them. (The use of the Environmental Audit Tool described in chapters to follow will assist with the latter.) Only in this way will a comprehensive picture of the causes of the problems being experienced by the person with dementia be revealed and a firm foundation laid for developing effective, needs-based care plans.

2.13 Impact

In addition to the continued use of CPAT in many leading services for people with dementia (e.g. HammondCare), the development of CPAT sparked the interest of the Japanese Group Home Association who supported its translation and evaluation (Kanegae, Ichimaru et al. 2008; Kanegae, Koizumi et al. 2010). This was followed by the publication of a book on care planning for people with dementia that incorporated the Japanese version of CPAT. This was published by Kousei Kagaku Kenkyujo in 2011 (Murakawa, Kanegae et al. 2011).

2.14 Further Research

The development and use of the CPAT is the most recent stage in a lengthy pursuit of ways to engage direct care staff in the care planning process (Fleming and Bowles 1987; Fleming 1989; Fleming 1990; Fleming 1991;

Fleming and Bowles 1994; Fleming, Bowles et al. 1996; Fleming and Kramer 1996). The fundamental problems that make achieving this difficult involve the competition for scarce resources, mainly staff time, and the related problem of giving high priority to the care planning process. From the researchers' point of view one potential answer to these problems would be a research programme investigating the benefits of training staff in the use of screening tools and the indirect effects of this on their view of their role and increases in meaningful communication between staff, residents and family members. From the staff members' points of view, an increase in the number of staff may be more attractive. This could, of course, also be the subject of research.

While the paper presented in Chapter 2 demonstrates the feasibility of providing an easy-to-use, valid and reliable assessment tool it does not provide any information on the clinical effectiveness of its use or how it performs in comparison with other broadly based assessment tools that have attracted international attention (Morris, Hawes et al. 1990; Elzinga and Meredith 2001; Orrell and Hancock 2004; Hirdes, Ljunggren et al. 2008). Such an evaluation, focussing on the practicality of use as well as psychometric properties, could provide important guidance on the features required in an assessment tool designed to assist with screening, care planning and research.

2.15 Conclusion

The paper presented in Chapter 2 reports on a significant development in the provision of an easy-to-use, valid and reliable assessment tool that has a contribution to make to screening, care planning and research in the care of people with dementia in residential accommodation.

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CHAPTER 3: LONG-TERM CARE FOR PEOPLE WITH DEMENTIA: ENVIRONMENTAL DESIGN GUIDELINES

The paper presented in Chapter 3 was written by the candidate and co-authored by Dr. Nitin Purandare who provided information on noise levels in long-term care and contributed to the style of the article. Research Assistant Shima Sum helped in sourcing the articles and the Forbes rating. It was published as:

Fleming, R. and N. Purandare (2010). "Long-term care for people with dementia: environmental design guidelines." International Psychogeriatrics 22(7): 1084-1096.

3.1 Aim

The purpose of writing this paper was to provide as firm a foundation as possible for the provision of advice on the design of environments for people with dementia.

3.2 Background

The paper was written as part of my contribution to the International Psychogeriatric Association Task Force on Mental Health Services in Long-Term Care Facilities efforts to develop a suite of resources to improve the care of people in residential aged care facilities.

The availability of 156 relevant articles, 63 of which were of sufficient methodological strength to be included in the review, is an indication that the field has made modest progress since the days of the CADE units described in the introduction.

The paper follows in sections 3.3 to 3.8.

3.3 Abstract

3.3.1 Background

A large and growing number of people with dementia are being cared for in long-term care. The empirical literature on the design of environments for people with dementia contains findings that can be helpful in the design of these environments. A schema developed by Marshall in 2001 provides a means of reviewing the literature against a set of recommendations.

The aims of this paper are to assess the strength of the evidence for these recommendations and to identify those recommendations that could be used as the basis for guidelines to assist in the design of long-term care facilities for people with dementia.

3.3.2 Methods

The literature was searched for articles published after 1980, evaluating an intervention utilising the physical environment, focused on the care of people with dementia and incorporating a control group, pretest-posttest, cross sectional or survey design.

One hundred and fifty-six articles were identified as relevant and subjected to an evaluation of their methodological strength. Fifty-seven articles were identified as being sufficiently strong to be reviewed.

3.3.3 Results

Designers may confidently use unobtrusive safety measures; vary ambience, size and shape of spaces; provide single rooms; maximise visual access and control levels of stimulation. There is less agreement on the usefulness of signage, homelikeness, provision for engagement in ordinary activities, small size and the provision of outside space.

3.3.4 Conclusions

There is sufficient evidence available to come to a consensus on guiding principles for the design of long-term environments for people with dementia.

3.4 Introduction

Globally it is estimated that 24.3 million people have dementia, with 4.6 million new cases of dementia every year. The number of people affected will double every 20 years to 81.1 million by 2040. Most people with dementia live in developing countries (60% in 2001, rising to 71% by 2040) where the design and building of residential services is, at best, embryonic. In these countries the rate of increase is higher than the average; numbers in developed countries are forecast to increase by 100% between 2001 and 2040, but by more than 300% in India, China, and their south Asian and Western Pacific neighbours (Ferri, Prince et al. 2005).

It is estimated that in Australia there are 230,000 older people with dementia (Access Economics 2009). Of these 44% are in cared accommodation, mainly residential care but some in health facilities (AIHW 2007). The proportion of people with dementia who live in households decreases with age – 79% of people with dementia aged 65–74 still live in the community, but for those aged 85 and over the proportion decreases to 36%. Most people with mild dementia live in households in the community (96%) and most people with moderate or severe dementia are in cared accommodation (91%).

If the Australian figures are applied to the global figures the result suggests that by 2040 about 36 million people with dementia will require residential care. It may well be that a focus on community services or developments in pharmacology will reduce this number but it seems clear that a great many

people stand to benefit from well-designed facilities for people with dementia.

In her influential statement on designing environments for people with dementia (Marshall 2001) Professor Mary Marshall of the Dementia Services Development Centre in the University of Stirling, Scotland, recommended that dementia-specific residential facilities should be designed in a way that compensates for disability, maximises independence, reinforces personal identity, enhances self-esteem/confidence, demonstrates care for staff and welcome relatives and the local community.

To achieve these results she recommended that residential facilities for people with dementia:

- Be small in size;
- Control stimuli, especially noise;
- Enhance visual access, i.e. ensure that the resident can see what they need to see from wherever they spend most of their time;
- Include unobtrusive safety features
- Have rooms for different functions with furniture and fittings familiar to the age and generation of the residents;
- Have single rooms big enough for a reasonable amount of personal belongings;
- Be domestic and home like;
- With scope for ordinary activities (unit kitchens, washing lines, garden sheds);
- Provide a safe outside space;
- Provide good signage and multiple cues where possible (e.g. sight, smell, sound);
- Use objects rather than colour for orientation.

The aims of this paper are to assess the strength of the evidence for these recommendations and to identify those recommendations that could be used

as the basis for guidelines to assist in the design of long-term care facilities for people with dementia.

3.5 Methodology

A report on the empirical evidence available to guide the design of facilities for people with dementia has been conducted for the Primary Dementia Collaborative Research Centre in Australia (Fleming, Crookes et al. 2008). This paper extends the findings of this report with the inclusion of additional and more recent papers.

The major databases (Medline, Cinahl, PsycInfo, Embase, Central, ProQuest, Pubmed, Google Scholar and Cochrane), were searched electronically and reference lists in earlier reviews, related published articles and books were checked by hand.

The search terms were based on those used by Day et al. in their comprehensive review of the literature (Day, Carreon et al. 2000). They were 'dementia', 'physical environment', 'home', 'nursing home', 'assisted living', 'day care', 'hospital', 'residential care', 'public places', 'resident room', 'SCU', 'privacy', 'security', 'safety', 'behavioural changes' and 'behavioural modifications'.

The titles, key words, abstracts and where necessary the methodology, discussions and/or conclusions of the papers identified by the electronic and hand searches were screened for potential relevance by one of the researchers. This was an over-inclusive process designed to eliminate only papers that were obviously irrelevant. Three hundred and thirty-two papers were identified as potentially relevant. The over-inclusiveness was tested by both researchers assessing the first 39 papers available to both of them. They agreed that 32 of them were relevant. All seven of those for which there was disagreement were rated as relevant by the junior researcher, who

was carrying out the screening, and judged as being not relevant by the senior researcher. There was no occasion in which the screening researcher excluded an article that would have been included by the senior researcher. On completion of the screening by the junior researcher, 242 articles remained.

These papers were assessed for relevance by two researchers resulting in the identification of 148 articles as relevant. Eight additional papers were identified during the internal peer review process (see acknowledgement). Papers that were identified as relevant were then subjected to an assessment of their validity using the model provided by Forbes (Forbes 1998).

The Forbes approach to the validation of the papers was chosen in the absence of any well accepted alternative contender. The Forbes approach involves an assessment of external validity (design, inclusion, and attrition), internal validity and statistical validity resulting in the allocation of a rating of strong, moderate, weak or poor. The most recent comprehensive review of the environmental design literature (Day, Carreon and Stump 2000) did not attempt any systematic validation, while in the area of psycho-social research the Forbes approach has been used in recent reviews (Opie, Rosewarne et al. 1999); (O'Connor 2007). While the Forbes approach is not finely tuned to the methodologies used in the environmental design literature, an adaptation of it was used in the Cochrane review on bright light therapy (Forbes, Morgan et al. 2004) and its use provides an opportunity for a future comparison between the strength of the environmental design literature and the psychosocial intervention literature.

Table 5: Summary of strong and moderately strong papers

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Ancoli-Israel, S., P. Gehrman, et al. (2003). "Increased light exposure consolidates sleep and strengthens circadian rhythms in severe Alzheimer's disease patients."	Randomized control trial with 3 treatment groups. Sleep patterns measured	Strong	92 patients nursing home residents with dementia	Control of stimuli	Morning bright light, evening bright light or morning dim red light.	Increasing light exposure throughout the day and evening is likely to have the most beneficial effect on sleep and on circadian rhythms in patients with dementia.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Baker, R., S. Bell, et al. (2001). "A randomized controlled trial of the effects of multi-sensory stimulation (MSS) for people with dementia	Randomised control trial	Strong	Fifty patients with diagnoses of moderate to severe dementia .	Control of stimuli	Multi-sensory stimulation compared with activity group.	Both interventions brought about improvements. MSS significantly better in increasing attentiveness to environment, mood and behaviour.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Cohen-Mansfield, J. and P. Werner (1995). "Environmental influences on agitation: An integrative summary of an observational study."	Time-sampling recording of behaviour in various locations and conditions.	Strong	24 residents from three units Unit 1 was an Alzheimer's unit and the other two units included a mixture of cognitively impaired and physically ill residents.	Control of stimuli	Physical environmental, social environment, activities and level of stimulation varied naturally during the course of the day and evening.	Increasing strange movements in the dark, pacing more frequently under normal lighting. Increasing agitation behaviours with high levels of noise, perceived cold, and being physically restrained.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Cohen-Mansfield, J., & Werner, P. (1998). "The effects of an enhanced environment on nursing home residents who pace.	Multiple single subjects, pre-test post-test design with measures of agitation, mood and exit seeking.	Strong	27 nursing home residents who were rated as pacing /wandering at least several times a day.	Domestic and homelike,	Visual, auditory, and olfactory stimuli were added to the nursing home corridors to simulate a home environment and an outdoor nature environment.	Residents spent more time in the enhanced environments and showed increased pleasure.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Phillips, C. D., Sloan, P.D., Howes, C., & Koch, G. (1997). "Effects of residence in Alzheimer disease special care units on functional outcomes.	One year longitudinal study with multiple measurements, using MDS, of locomotion, transferring, toileting, eating, dressing, ADLs, continence and weight.	Strong	Data on 841 nursing home residents in 4 states with 48 SCUs	Domestic and homelike,	Life in a variety of residential aged care settings including SCUs.	No statistically significant difference was observed in the speed of decline for residents in SCUs and traditional units in cognitive and behavioural status.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Reimer, M. A., Slaughter, S, et al. (2004). "Special Care Facility Compared with Traditional Environments for Dementia Care: A Longitudinal Study of Quality of Life.	A prospective, matched-group design with assessments of QoL every 3 months for 1 year	Strong	185 residents From 24 long-term care centres and 4 designated assisted living environments 62 in the intervention SCU group and 123 in the traditional groups.	Small size, Domestic and homelike, scope for ordinary activities,	The provision of an environment that encompasses a vision of long-term care that is more comfortable, more like home, and offers more choice, meaningful activity, and privacy than traditional settings.	The SCU group demonstrated fewer declines in ADL, more sustained interest in the environment, and less negative affect. There were no differences between groups in concentration, memory, orientation, depression, or social withdrawal.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Sloane, Philip D, M. M., P. Christianna S. Williams, et al. (2007). "High-Intensity Environmental Light in Dementia: Effect on Sleep and Activity."	A cluster-unit crossover intervention trial measuring night time sleep and day time activity	Strong	66 residents	Control of stimuli	Ambient bright light delivered through a low-glare lighting system installed in the dining and activity areas. Participant exposure averaged 2.5 to 3.0 hours for the morning and evening interventions and 8.4 hours for the all-day intervention.	Night-time sleep increased significantly in participants exposed to morning and all-day light. The overall strength of day and night activity rhythms did not change significantly under any treatment condition.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Wells, Y. and A. F. Jorm (1987). "Evaluation of a special nursing home unit for dementia sufferers: a randomised controlled comparison with community care.	Randomized control trial measuring cognitive status, behaviour, QoL, psychological problems of caregivers pre-admission and at 3 month follow up.	Strong	12 people with dementia admitted to dementia specific facility, 10 in community care control group.	Domestic and homelike, safety features, , rooms for different functions, outside space, single rooms of an adequate size	Applicants for a newly opened special unit for dementia sufferers were randomly allocated to full-time care in the unit or placed on a waiting list and offered periodic respite care in the meantime.	Admission of dementia sufferers to full-time care in a special unit appears to be of great benefit to the psychological health of their care-givers and has no adverse effects on the dementia sufferers themselves.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Zeisel, J., N. M. Silverstein, et al. (2003). "Environmental correlates to behavioural health outcomes in Alzheimer's special care units.	Cross sectional survey utilizing hierarchical linear modelling controlling for cognitive status, ADLs, medication use, amount of Alzheimer's staff training, and staff-to-resident ratio. Measurement of aggression, agitation, social withdrawal, depression, and psychotic problems	Strong	427 residents from 15 SCUs	Small size, domestic and homelike, rooms for different functions, single rooms of an adequate size, and control of stimuli	Life in various forms of SCU.	Privacy and personalization in bedrooms, residential character, understandable environment associated with reductions in aggression, agitation and psychological problems. Camouflaged exit doors and rooms that vary in ambience associated with reduced depression, social withdrawal, 76 misidentification and hallucinations.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Annerstedt, L. (1993). "Development and consequences of group living in Sweden: A new mode of care for the demented elderly.	One year follow-up of residents in a group living unit and a control group in traditional care. Measurements made of motoric functioning, intellectual and emotional ability, symptoms of dementia, behavioural disturbance and ADLs.	Moderate	28 group living patients 31 patients living in traditional institutional care	Small size, domestic and homelike, and safety features	Homelike group living housing; supervision by trained registered nurses; staff training, and relatives' active role in the caring task	Group Living environment produced better motoric, emotional and intellectual functions, and less Psychotropic medication; less psychological strain among the relatives; improved competence and satisfaction among staff ; and decreased the total cost of care

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Bellelli, G., G. Frisoni, et al. (1998). "Special care units for demented patients: a multicenter study."	Pre-admission, 3month and 6 month post admission assessment of health status, medication and restraint use.	Moderate	55 patients with dementia transferred to 8 SCUs	Control of stimuli	Admission to SCU.	In 6 months follow-up, behavioural disturbances progressively improved despite the psychotropic drug load and physical restraints use decreased.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Bianchetti, A., P. Benvenuti, et al. (1997). "An Italian model of dementia special care unit: Results of a pilot study."	Pre-admission, and 6 month post admission assessment of functional status, cognitive status, behavioural symptoms, medication and restraint use.	Moderate	16 patients transferred from traditional ward to a SCU.	Safety features, good signage and control of stimuli	Admission to SCU	Significant reduction in behavioural disturbances after relocation in SCU; no improvement in cognitive status or functional ability.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Bowie, P. and G. Mountain (1997). "The relationship between patient behaviour and environmental quality for the dementing.	Cross sectional survey comparing 5 environmental characteristics and patients behaviour in wards paired to systematically maximize differences in environmental characteristics.	Moderate	All patients with a dementing illness on 7 wards.	Small size and good signage	Life on wards with varying characteristics	Institutional character and lack of RO cues associated with behavioural abnormalities, Poor ward condition paradoxically associated with better self-care and fewer behavioural problems. Small versus large physical size not associated with differences in behaviours.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Cleary, T. A., C. Clamon, et al. (1988). "A reduced stimulation unit: Effects on patients with Alzheimer's Disease and related disorders."	Pre-test / Post-test measurements of functional ability, agitation, food consumption, continence, sleep, use of restraints, weight and medication use taken before and 3 months after admission.	Moderate	11 low stimulus unit residents with dementia.	Control of stimuli	Admission to low stimulus unit.	Reducing patients weight loss, agitation, physical restraint use. Increased relative's satisfaction.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Cox, H., I. Burns, et al. (2004). "Multisensory environments for leisure: promoting well-being in nursing home residents with dementia."	Cross over (within subjects) design with measurement of affect under 3 conditions.	Moderate	24 residents with dementia	Outside space and control of stimuli	Residents experienced three activities (living room, garden, Snoezelen room) during three individual 16-minute sessions.	Some evidence of increased pleasure in the Snoezelan room and garden.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Dickinson, J. I., J. McLain-Kark, et al. (1995). "The effects of visual barriers on exiting behaviour in a dementia care unit."	Pre-test post-test measuring exit attempts	Moderate	7 residents with dementia and history of exiting attempts.	Control of stimuli	Installation of a blind and cloth cover panel over panic bar on door.	Visual barriers serving to camouflage the panic bar or door knob are effective and cost-efficient controls for wanderers' exiting.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Hewawasam, L. C. (1996). "The use of two-dimensional grid patterns to limit hazardous ambulation in elderly patients with Alzheimer's disease."	Pre-test/post-test measuring exit attempts.	Moderate	10 patients with dementia	Good signage	Black insulation tapes in two different grid configurations were laid out in an attempt to prevent patients ambulating through exit doors.	The use of a horizontal grid reduced exit door contact up to 97% for four of these patients.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Leon, J. and M. G. Ory (1999). "Effectiveness of Special Care Unit (SCU) placements in reducing physically aggressive behaviours in recently admitted dementia nursing home residents."	Stratified cluster samples entering SCUs and traditional nursing homes compared on levels of agitation over the 6 months post admission.	Moderate	695 residents; 495 entered SCUs and 200 were admitted to non-SCU facilities.	Small size,	Admission to SCU.	<p>SCU placement showed no positive or negative effect on the frequency of aggressive behaviours.</p> <p>A reduction in physical aggression attributed to increased use of psychotropic medications and the reduction in the use of physical restraints.</p>

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Mayer, R. and S. J. Darby (1991). "Does a mirror deter wandering in demented older people?"	Pre-test post-test measurement of exiting behaviour.	Moderate	9 severely demented residents	Good signage	3 experimental conditions, a full-length mirror placed in front of the door, the mirror reversed and no mirror.	The presence of mirror in front of an exit cues the response not to touch, reducing exit attempts by 50%.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Melin, L. and K. G. Gotestam (1981). "The effects of rearranging ward routines on communication and eating behaviours of psychogeriatric patients."	Pre-test post-test measurement of communication and eating behaviours in control and experimental groups.	Moderate	21 patients on a psychogeriatric ward	Scope for ordinary activities,	Introduction of eating at tables rather than from trays attached to chairs set around the walls.	The frequency of communication increased in the experimental group.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Morgan, D. G. and N. J. Stewart (1998). "Multiple occupancy versus private rooms on dementia care units."	Pre-test post –test measurement of time spent in various locations plus qualitative observations from staff and family.	Moderate	46 SCU residents 9 staff caregivers and 9 family members	Single rooms of an adequate size	Residents moved from 2-bed or 4-bed rooms to private rooms in SCUs.	Following the move to the new SCUs to promote sleep at night. Perceptions of staff and family members about person-environment interaction model were positive.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Satlin, A., L. Volicer, et al. (1992). "Bright light treatment of behavioural and sleep disturbances in patients with Alzheimer's disease."	Pre-test/ post-test measurement of agitation, sleep patterns, restraint use and PRN medications.	Moderate	10 residents with sundowning behaviour and sleep disturbances.	Control of stimuli	Patients received 2 hours/day of exposure to bright light for 1 week.	Clinical ratings of sleep-wakefulness on the evening nursing shift improved with light treatment in 8 patients. The relative amplitude of the circadian locomotor activity rhythm increased.

Study	Methodology	Forbe's rating	Sample	Strongest relevance to Marshal's design features	Intervention	Outcomes
Thorpe, L., J. Middleton, et al. (2000). "Bright light therapy for demented nursing home patients with behavioural disturbance."	Repeated measures ABA design measuring agitation and disruptive behaviours.	Moderate	16 residents with dementia	Control of stimuli	Bright light (2,000 lux) administered for 30 minutes during breakfast.	Bright light therapy has modest efficacy in reducing agitation, with possible concurrent improvement in positive behaviours.

In practice the Forbes approach required a great deal of discussion between the two raters to come to a consensus on the ratings and resulted in the description of some important work, particularly that of Namazi (Namazi and Johnson 1991a; Namazi and Johnson 1991b; Namazi and Johnson 1992a; Namazi and Johnson 1992b; Namazi and Johnson 1992c; Namazi and Johnson 1992d; Namazi and Johnson 1992e) as weak or poor because of the descriptive nature of the statistical analysis and/or because of high attrition rates which are sometimes impossible to avoid in research on very elderly people.

The methods used in 93 papers were judged to be “poor” as per the Forbes criteria (Forbes, 1998) and were excluded from the review. Additionally two papers were excluded as we were unable to obtain sufficient details to apply Forbes criteria, leaving 63 papers which were of sufficient quality (Forbes rating: 9 strong, 14 moderate, 40 methods weak but sufficient) are included in the current review. The findings of these papers are reported below under headings based on Marshall’s schema.

3.6 Results

3.6.1 Size of the care home

Perhaps the most influential combination of principles in recent decades has been that of small and homelike. Their frequent combination makes it virtually impossible to tease out the individual contributions of the principles. While there is evidence supporting the proposition that small size, that is, a small number of residents, is associated with a variety of positive outcomes for people with dementia (Annerstedt 1993; Sloane, Mitchell et al. 1998; Reimer, Slaughter et al. 2004) it is impossible to quantify the contribution that the size of the unit makes in comparison with the other environmental factors that are commonly associated with a purposely designed, small unit, for example home likeness, safety and familiarity (Reimer, Slaughter, Donaldson, Currie and Eliaszew 2004). The relationship between size and positive outcome is not always evident. No significant correlation was found between facility size - large or small – and physically aggressive behaviours in a sample of 695

residents of SCUs and traditional nursing homes (Leon and Ory 1999). However this study defined large facilities as those with more than 150 beds, a definition that may have swamped the effects of genuinely small facilities. A recent study carried out in Holland found no relationship between neuropsychiatric symptoms and the number of residents per SCU or per living room in 25 nursing homes of regular sized SCUs (Zuidema, de Jonghe et al. 2009) and in smaller-sized group living homes there was no difference in behavioural problems compared to traditional, larger-sized nursing homes (te Boekhorst, Depla et al. 2009).

The relationship between behavioural disturbance and the size of the space in which the group lives has been investigated in two studies (Bowie and Mountain 1997; Elmstahl, Annerstedt et al. 1997) and the findings suggest a lack of association between the amount of space available in a ward and the level of behavioural disturbance.

3.6.2 Optimum level of stimulation

People with dementia have difficulties in dealing with high levels of stimulation. Their ability to screen out unwanted stimuli appears to be reduced. They can become more confused, anxious and agitated when over stimulated (Cleary, Clamon et al. 1988.). Common causes of over stimulation are busy entry doors that are visible to patients, clutter, public address systems (Cohen 1991; Brawley 1997.), alarms, loud televisions (Hall 1986.; Evans 1989.), corridors and crowding (Nelson 1995.). The careful optimisation of levels of stimulation is well supported (Cleary, Clamon, Price and Shullaw 1988.; Cohen-Mansfield and Werner 1995; Zeisel, Silverstein et al. 2003). Methods of dealing with specific elements of the environment that cause overstimulation, such as hiding or disguising busy entry doors that provide a view to the outside, providing two wardrobes so that the resident accesses one that has only a manageable range of clothing in it, have been thoroughly investigated and found to be effective (Namazi and Johnson 1992b; Dickinson, McLain-Kark et al. 1995)

While it is necessary to reduce unhelpful stimulation, care must be taken to optimise helpful stimuli. There is good evidence to show that increasing levels of illumination

beyond that which is usually considered to be normal can improve sleep patterns and reduce behavioural disturbance (Satlin 1992; Thorpe, Middleton et al. 2000; Ancoli-Israel, Gehrman et al. 2003; Sloane, Christianna et al. 2007). The introduction of multi-sensory stimulation has been shown to improve mood and behaviour as much as the introduction of an activity group (Baker, Bell et al. 2001).

Studies involving the combination of reduced stimulation with other environmental and care practice manipulations have been shown to reduce behavioural disturbance (Bianchetti, Benvenuti et al. 1997; Bellelli, Frisoni et al. 1998) .

Residents in care homes are exposed to a variety of different noise sources including man-made noise and noise from household/electrical equipment. Repeated measurements in nursing homes in the US revealed that noise levels reached 55–70dB, comparable to busy road traffic noise (Bharathan 2007). One group videotaped nursing home residents, to identify antecedents of agitated behaviour and it appeared that unwanted music or interruption to pleasurable music can lead to agitated behaviour (Ragneskog 1998). Noise has been recognised as a possible contributing factor to poor sleep. However interventions in nursing homes to reduce night time noise have not improved sleep time (Ouslander 2006), although another study using non-pharmacological interventions including decreasing noise levels to increase night-time sleep found a modest benefit (Alessi 2005). Furthermore, Alessi et al. (1999) established that a combination of increased physical activity during the day and reduced noise levels at night can lessen agitation in nursing home residents (Alessi, Yoon et al. 1999).

3.6.3 Total Visual Access

The observation that people with dementia stand a better chance of finding something if they can see it from where they are led to the idea of 'Total Visual Access' which was incorporated into the design of the NSW Health units for the confused and disturbed elderly CADE units (Fleming and Bowles 1987). It resulted in a very simple, corridor-free environment. The evidence for the incorporation of good visual access on the unit level scale is not strong (Elmstahl, Annerstedt and Ahlund 1997;

Passini, Pigot et al. 2000) but the dramatic effect of making an important amenity, the toilet, easily seen provides good supporting evidence for the concept (Namazi and Johnson 1991a).

3.6.4 Unobtrusive safety features

The level of safety and security in facilities designated as providing care to people with dementia is higher than in other facilities (Morgan, Stewart et al. 2004). One of the most common problems associated with caring for people with dementia in an environment that has not been designed for their use is that of keeping them safe from the danger of wandering away and perhaps getting lost or run over (Rosewarne, Opie et al. 1997). The most obvious response to this problem is to provide a secure perimeter, preferably one that allows for safe wandering and access to an outside area.

Positive effects have been found when unobtrusive means are used to provide a secure perimeter (Zeisel, Silverstein, Hyde, Levkoff et al. 2003). Depression was negatively correlated with exits that were well camouflaged and had silent electronic locks rather than alarms. Zeisel hypothesised that residents try to elope less in such settings and that caregivers, believing that such environments are safer, give residents greater independence of movement. Residents who experience this greater freedom have less conflict about trying to leave and feel a greater sense of control and empowerment, leading in turn to less depression (Zeisel, Silverstein, Hyde, Levkoff et al. 2003).

Placing a horizontal grid of black tape in front of an exit reduced contact with the door by up to 97% in four people with Alzheimer's disease (Hewawasam 1996). The presence of a mirror in front of an exit cued the response not to touch, reducing exit attempts by 50% (Mayer and Darby 1991) and hiding the latch behind a cloth panel reduced the number of attempts to exit (Dickinson, McLain-Kark and Marshall-Baker 1995; Dickinson and McLain-Kark 1998) .

The beneficial effects of unobtrusive safety features, particularly in relieving depression, were noted in an early RCT (Wells and Jorm 1987; Zeisel, Silverstein, Hyde, Levkoff et al. 2003). The need for security to be unobtrusive and to avoid restraining people with dementia who, while confused, are not likely to abscond, is supported by the finding that harmful behaviours, particularly risk taking and passive self-harm, were associated with more security features (Low, Draper et al. 2004). The possibility that an emphasis on safety reduces enjoyment of activities and the feeling of being able to control the environment is made in a UK study (Torrington 2006).

3.6.5 Availability of rooms to suit varying functions or specific purpose

The provision of rooms for different functions has been shown to differentiate SCUs from non-SCUs in a state-wide survey involving 436 Minnesota nursing homes (Grant, Kane et al. 1995). The strongest evidence for its importance comes from Zeisel's well controlled study that provides some certainty about the contribution of the individual factors to the wellbeing of the residents (Zeisel, Silverstein, Hyde, Levkoff and al 2003). It contains findings of direct relevance to the principle, concluding that the degree of privacy–personalisation in the SCUs studied was negatively correlated with patient scores on the Cohen-Mansfield total aggression scale. Residents in facilities with more rooms that are individual and more opportunities for personalisation tend to experience less anxiety and aggression. The provision of common areas that vary in ambiance is associated with reduced depression, social withdrawal, misidentification and hallucinations.

A well conducted cross sectional study involving 38 homes and 452 residents (Barnes 2006) showed that gradation of space is associated with resident quality of life, highlighting the necessity for design guidance to emphasise a variety of spaces.

The availability of private rooms has been shown to reduce irritability and improve sleeping patterns in people with advanced Alzheimer's disease and other related disorders (Morgan and Stewart 1998).

3.6.6 Social environment (homeliness, activities and outside space)

The problem of an intricate relationship between the social/professional environment, that is, philosophy of care, staff skills, good management practices, and the physical environment appears again when assessing the impact of providing a homelike environment, especially in the case of people with advanced dementia. However there is good evidence that it reduces aggression (Zeisel, Silverstein, Hyde, Levkoff et al. 2003). A very well controlled investigation of the effects of introducing a few of the most basic elements of a homelike environment into a very institutional nursing home (Cohen-Mansfield and Werner 1998) showed that residents chose to spend time in a corridor containing comfortable chairs, pictures, a coffee table, books and the aroma of citrus in comparison with a normal corridor. There was a weak trend to reduced agitation, pacing and exit seeking in comparison to behaviour in a normal corridor but this positive trend was stronger when, instead of a domestic setting being provided, a setting reminiscent of a natural outdoor setting was provided. The differences between the two enhanced settings were small.

If it can be assumed that home-likeness is a feature of SCUs in the USA, and there is some doubt about this (Chappel and Reid 2000), then the findings of the four-state study of 800 facilities (Phillips 1997) are relevant. This showed that SCU residents declined at the same rate as non-SCU residents matched for baseline cognitive status, behavioural problems, age, sex and length of stay.

The provision of opportunities to engage with ordinary activities of daily living is often associated with the principle of home-likeness (Verbeek, van Rossum, Zwakhalen, Kempen and Hamers 2009). There is moderately strong evidence for the beneficial effects of providing people with dementia with an environment that gives them this opportunity (Melin and Gotestam 1981; Reimer, Slaughter, Donaldson, Currie and Eliaszew 2004) However it is very difficult to differentiate the contribution of the physical environment from that of the staff encouragement and support.

Similarly there is little evidence for the benefits of outside spaces by themselves but good evidence of benefits when combined with staff interaction (Cox, Burns et al. 2004).

3.6.7 Signage and orientation cues

Perhaps surprisingly the evidence for the beneficial effects of signage is not strong (Hanley 1981; Namazi and Johnson 1991b) and weak empirical support was found for the use of the display of personal memorabilia as aids to orientation (Namazi, Rosner et al. 1991).

3.7 Conclusion

Marshall's schema provides a useful framework for organising the existing literature. The items in it are broad but sufficiently detailed to inform a literature search and to help identify areas of strength and weakness in our knowledge base. The available research suggests that designers and architects may be confident about using unobtrusive safety measures; varying the ambience, size and shape of spaces; providing single rooms; maximising visual access to important features; and providing for stimulus control with the periodic availability of high levels of illumination.

There is less agreement on the usefulness of signage of various sorts and the quality of the research is sufficiently high to suggest that we should not be placing much emphasis on this area. The response to the identification of other areas where there is limited empirical support, such as homelikeness, provision for engagement in ordinary activities of daily living, small size, provision of outside space, should perhaps be different. These are areas where there is a great deal of anecdotal and experiential evidence to suggest that they are highly desirable. They are worthy of more research before concluding that they are unimportant and the research must be designed to control for the confounding effects of changes in staff attitudes and skills.

Most of the research has been carried out in special care units, a generic term that covers a wide range of facilities but tends to focus on the relatively physically robust person with dementia. There is little research on the impact of dementia on people in the final stages of the disease where physical frailty is very common. It is therefore clear that we are not in a position to provide a formula for the design of an environment that will suit the needs of everyone. The evidence does not exist to support the description of a well-designed environment for the person with dementia who is in the final stages of palliative care and, perhaps more importantly, there is a consensus that while common elements may be identified there cannot be one optimal environment. The environment should, as far as possible, meet the individual needs of the resident and as these will vary even within the one facility, every environment will be a compromise.

Designing for dementia in isolation from other common problems encountered by the elderly, such as sensory deficits and falls, is far from ideal but the evidence base for designing for combinations of problems is very small indeed. There is also the issue of designing for the person caring for the person with dementia, both the professional carer and the relatives who visit. How can the needs of these people be met by the physical environment?

It may yet be too early to argue for the provision of definitive guidelines for the design of long-term care units for people with dementia. While progress has been made since 1980 the evidence base is still not strong. Yet there are some aspects of design that we can have some confidence in and the need to offer guidance in this large and expanding area of service provision is great. The following suggestions are offered as a contribution to the process of determining guidelines. Perhaps the next step in this process should be a consensus statement. They are offered as an update on those that have already been offered (Day, Carreon and Stump 2000; Marshall 2001).

The empirical evidence supports the advice that long-term facilities for people with dementia should be designed and constructed so that:

1. Where it is necessary to provide for the safety and security of the residents by confining them within a secure perimeter this is achieved by means of unobtrusive security measures that maximise the feeling of control over the environment.
2. The part of the facility which is accessible to the residents contains within it a variety of spaces that provide the residents with differing ambience, size and function.
3. The resident has the opportunity to have a single room and to personalise that room.
4. The resident can see the features most important to him, or her, from the location(s) where they spend most of their time.
5. The levels of stimulation are adjusted to minimise unhelpful stimulation and optimise helpful stimuli with the periodic availability of high levels of illumination.

It is desirable that the facility:

6. Be small
7. Have a homelike appearance
8. Provide opportunities for engagement with the ordinary activities of daily living, and
9. Have an outside space that is accessible to the resident in accompaniment with a member of staff.

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3.9 Extended discussion

It is interesting to apply the knowledge gained over the last twenty-five years to a critique of the original design of the CADE units, not because I am obsessed with CADE units but to get a bearing on the major changes in our thinking on environmental design over the last twenty-five years.

The CADE units provided 16-bed units comprising two eight-bed wings that were run independently from each other during the day but supervised from a common staff room at night. The care was based on the philosophy of involving the residents in the ordinary activities of daily living as much as possible and the environment was designed to be domestic in nature to provide the facilities and atmosphere required to achieve this. The layout was extremely simple so that residents could always see where they wanted to go and wayfinding was assisted by highlighting useful features such as the toilet, and disguising those features that might lead the resident into trouble, such as cleaners' cupboards. Eight principles were used to guide the design (Fleming and Bowles 1987). These principles were picked up by Marshall and incorporated into her recommendations for the essential features of good design (Marshall 2001) that were used as the framework for the paper presented in Chapter 3.

The paper shows that the empirical support for most of these environmental design features is quite strong but it calls into question the wisdom of having small, isolated units. It also reports a lack of evidence for the benefits of providing a domestic environment. The recent work of Verbeek on the effects on residents of living in small, domestic environments has enriched the debate on the usefulness of these characteristics by identifying a wide range of pros and cons (Verbeek, van Rossum, Zwakhalen, Kempen and Hamers 2009; Verbeek, Zwakhalen et al. 2012).

On balance it appears that the weakness of the CADE unit design lay in their size, isolation and lack of opportunities for involvement in activities other than those focussed on daily living. While there is little empirical evidence yet available for the idea of facilities for people with dementia being integrated into dementia-friendly communities, thereby offering opportunities for a wide range of social interactions

and activities, there is growing support for this development (Keady, Campbell et al. 2012).

It is becoming clear that designing environments for people with dementia should entail not only an understanding of how they respond to their immediate physical environment but also how they respond to, and can be assisted by, the wider community.

3.10 Impact

Research Online reported in January 2013 that the paper presented in Chapter 3 had been downloaded 917 times. Scopus reported in December 2012 that it had been cited 12 times.

The paper has been used as the foundation for educational resources on environmental design for people with dementia developed by the author for the NSW/ACT Dementia Training Study Centre and delivered across Australia in conference and workshop presentations. A variation on the paper has been published by the University of Stirling Dementia Services Development Centre in their environmental audit resource (Dementia Services Development Centre 2012).

The paper has been used as the foundation for a chapter in a major textbook on caring for the elderly (Fleming and Bennett In press).

3.11 Further Research

The paper has informed the development of research in areas identified in it as requiring further attention, namely investigating the relative contribution of personal care and environmental factors to the wellbeing of residents with dementia (Chenoweth, King et al. 2011) and the identification of environmental features that support the wellbeing of people in the final stages of dementia. The author is a chief investigator in the NHMRC-funded project investigating the former and principal investigator in a UNSW, Dementia Collaborative Research Centre project investigating the latter.

The paper is limited by its focus on residential care. It does not deal with the design of acute care facilities which are dealing with large numbers of people with dementia.

This area is now receiving increasing attention (Harwood, Porock et al. 2010; Dementia Services Development Centre 2012; Waller 2012) and would benefit from rigorous research into the benefits, or otherwise, of applying the residential aged care findings to the totally different acute care setting.

A growing number, and proportion, of people with dementia in Australia are being cared for at home (AIHW. 2012). The paper could be improved by either incorporating the very limited research on helpful characteristics of domestic homes or by identifying this as an area for future research. As mentioned in the extended discussion, there is also a need for investigation of the characteristics of the physical environment that will contribute to the development of dementia-friendly communities. This will involve breaking down the barriers between residential care and community life. Success has already been demonstrated in making modifications to dementia-specific units to make them places that families enjoy visiting (Edwards, McDonnell et al. 2012). The related challenge is making places in the community places that people with dementia can enjoy (Keady, Campbell, Barnes, Ward, Li, Swarbrick, Burrow and Elvish 2012).

3.12 Conclusion

The paper presented in Chapter 3 has informed the work of many and laid a firm foundation for current and future research.

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CHAPTER 4: AN ENVIRONMENTAL AUDIT TOOL SUITABLE FOR USE IN HOMELIKE FACILITIES FOR PEOPLE WITH DEMENTIA

The paper presented in Chapter 4 was written by the candidate and published as:

Fleming, R. (2011). "An environmental audit tool suitable for use in homelike facilities for people with dementia." Australasian Journal on Ageing **30** (3): 108-112.

4.1 Aim

The purpose of writing this paper was to examine the metrics of a tool designed to measure the quality of environments for people with dementia so that it could be used with confidence as a research and consultancy tool.

4.2 Background

I developed the Environmental Audit Tool (EAT) with the assistance of two architects to enable us to evaluate the strengths and weaknesses of wards in small, regional hospitals that were being used to accommodate people with dementia for long periods while they waited for placement in residential care (Fleming and Bowles 1987). NSW Health wished to improve the quality of the service being provided to these people and had commissioned me to provide them with advice.

The EAT was based on the eight principles used in the design of the CADE units plus two introduced by one of the architects, Kirsty Bennett, namely safety and the provision of opportunities for privacy and community.

The EAT was seen primarily as a consultancy tool, designed to identify problems in the design of the physical environment and to provide a framework within which they could be understood and discussed. The potential to use the EAT as a measuring tool, able to quantify the quality of the environment, was recognised but not considered

central to its use for some years. The adoption of the EAT as the means of measuring the quality of the environment in two large-scale National Health and Medical Research projects (Chenoweth et al. 2011; Goodenough, Low et al. 2012) made it imperative that the metrics of the tool be established. A copy of the EAT is included in Appendix 2.

The paper follows in sections 4.3 to 4.11.

4.3 Acknowledgement

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4.4 Abstract

4.4.1 Objective

This paper compares an assessment tool developed for use on contemporary homelike environments, the Environmental Assessment Tool (EAT), with the gold standard assessments for residential facilities for people with dementia, the Special Care Unit Environmental Quality Scale (SCUEGS) and the Global Score of the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH).

4.4.2 Method

Thirty facilities were assessed with the EAT and the TESS-NH by two raters working independently.

4.4.3 Results

The average absolute agreement on individual items using the EAT was 87.1% and 84.4% for the TESS-NH. Inter-rater reliability of the SCUEGS was 0.84, the TESS-NH Global Score .93, the EAT final score .97. The EAT was described by raters as easier and slightly quicker to use.

4.4.4 Conclusion

The EAT offers a valid and reliable alternative to the TESS-NH and appears to be more suitable for the assessment of the less institutional facilities favoured by Australian aged care services.

4.5 Introduction

Although the evidence for the beneficial effects of environments specifically designed or modified for people with dementia is growing in strength (Fleming, Crookes and Sum 2008), “instruments for assessing physical environment remain in a relatively primitive state” (Lawton, Weisman et al. 2000). Understanding good environments and their relationship to good outcomes for people with dementia are likely to be improved by the use of measurement instruments that provide an indication of the quality of the environments, allow comparison of one environment with another, enable weaknesses in the environment to be identified, and describe changes made in the environment in attempts to make them more suitable for people with dementia.

4.5.1 Frequently used environment assessment scales

The systematic assessment of residential care environments for people with dementia has a 25-year history beginning in earnest with the publication of the Multiphasic Environmental Assessment Procedure (MEAP) (Moos and Lemke 1984). Only a handful of quantitative assessment tools have been published since (Grant 1994; Zeisel, Hyde et al. 1994; Cutler, Kane et al. 2006).

The Multiphasic Environmental Assessment Procedure (MEAP) (Moos and Lemke 1984) has been described as “the most established instrument” (Sloane, Mitchell et al. 2002). The scales of this procedure were designed to assess planned residential environments for older people ranging from congregate housing to nursing homes. It is a very detailed assessment which is not suitable for use by non-researchers. Its scoring is biased toward larger, more institutional settings (Moos and Lemke 1984).

These limitations were addressed in the development of the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH) (Sloane et al. 2002). The TESS-NH contains 84 discrete items that cover 13 domains plus one global item. The domains include exit control, maintenance, cleanliness, safety, orientation/cueing, privacy, unit autonomy, outdoor access, lighting, noise, visual/tactile stimulation, space/seating, and familiarity/home likeness. Problems with the internal consistency of some of the domain scores make it impossible to sum the sub-scale scores into an overall total score. This has been overcome by the identification of items from several domains that make up the Special Care Unit Environmental Quality Scale (SCUEGS).

The Professional Environmental Assessment Protocol (PEAP) (Lawton, Weisman, Sloane, Norris-Baker, Calkins and Zimmerman 2000) was developed to supplement the TESS. It is designed to be completed by raters who possess substantial knowledge and expertise in person-environment design research. There is a strong relationship between the TESS-NH and the PEAP scores (Norris-Baker, Weisman et al. 1999).

The choice between these scales is reasonably clear when the environment being assessed is a residential unit for people with dementia. The MEAP does not address some of the environmental issues that are considered to be important in dementia care and its scoring is biased toward larger, more institutional settings. The TESS-NH yields results that correlate well with the PEAP, takes half the time and can be used by a research assistant after eight hours of training (Sloane et al. 2002).

In summary the TESS-NH has a practical edge over both the PEAP and the MEAP and has become the gold standard for assessment of environments for people with dementia. However the TESS-NH has some severe limitations. While the 84 items cover a wide variety of relevant environmental features they do not combine to form a scale and therefore do not enable a simple summary of the quality of the environment to be obtained. This is left to the single item global rating scale, which is in Likert format with responses ranging from 1 (low, distinctly unpleasant, negative, and non-

functional) to 10 (high, quite pleasant, positive and functional) and the less than comprehensive SCUEGS.

The single-item global rating scale completed by the rater at the conclusion of the assessment appears to be quite robust. It correlates highly (0.71, $p > 0.01$) with the PEAP total score (Lawton et al. 2000) but is, essentially, a subjective assessment. The SCUEGS score brings together a comprehensible number of defined items. However, of the 18 SCUEGS items, four deal with maintenance matters, three with cleanliness, and two with odour from bodily excretions. That is, 50% of the scale is of dubious relevance to the specific care of people with dementia in the context of contemporary environments (Judd, Marshall et al. 1998).

There has been a significant movement in Europe and Australia over the last 20 years towards providing homelike environments for people with dementia requiring residential care (Verbeek, van Rossum, Zwakhalen, Kempen and Hamers 2009).

The question then arises as to whether or not there is an assessment that is better suited to the understanding of these environments than the current gold standard, the Tess-NH.

The Environmental Audit Tool comprises 72 items selected to exemplify a set of design principles first used in the development of the units for the Confused and Disturbed Elderly (CADE Units) built by the NSW Department of Health in the late 1980s and early 1990s (Fleming and Bowles 1987; Fleming 1989; Atkinson 1995) and extended in the publication of a manual to guide the modification of hospital wards (Fleming, Forbes et al. 2003). When originally formulated (Fleming and Bowles 1987) these principles were based on expert opinion, however strong empirical evidence to support them has accumulated over the last twenty years (Fleming, Forbes and Bennett 2003; Fleming, Crookes and Sum 2008). The items are grouped by the 10 principles:

The environment should:

1. Be safe and secure
2. Be small
3. Be simple with good visual access
4. Have unnecessary stimulation reduced
5. Have helpful stimuli highlighted
6. Provide for planned wandering
7. Be familiar
8. Provide opportunities for a range of social interactions from private to communal
9. Encourage links with the community
10. Be domestic in nature providing opportunities for engagement in the ordinary tasks of daily living.

The majority of questions are answered either Yes or No, some have a Not Applicable option and some provide for extra points in certain circumstances, for example, if the safety feature is unobtrusive. Each principle is considered to be a sub-scale with a score expressed as a percentage of the available score to ensure that all sub-scales have equal weight. The total score is the mean of the sub-scale scores.

Both the TESS-NH and the EAT are observational tools requiring the assessors to move through the environment and look for specific, defined features. There is no need for the assessors to question or interact with residents. While this simplifies the ethics of the assessments it is also an indication of a weakness in both tools that is becoming increasingly apparent as the full extent of the call to be person-centred is understood (Kitwood 1997). They make no attempt to take into account the views of the residents.

4.6 Methodology

The minimum size of the sample of facilities was determined by the Walter et al. formula (Walter, Eliasziw et al. 1998). This indicated that a sample of 18 would provide a power of 80% with an expected Intra Class Correlation coefficient (ICC) of 0.93; that is, the ICC describing the inter-rater reliability of SCUEGS (Sloane et al.

2002). A larger convenience sample comprising 22 Dementia Specific Units (DSUs) and eight units accommodating people with a variety of diagnoses was utilised. All facilities were located in metropolitan or regional centres within 80 kilometres of Sydney.

Two raters were employed for the EAT and TESS-NH observations. One had many years of experience as a consultant on the care of people with dementia and the other was a first year PhD candidate with a degree in psychology. They were provided with the assessments and supporting manuals and spent three hours reading them and in discussion with the author of the tool. They then assessed two facilities (not included in the sample) in collaboration, discussing the interpretation of questions and the method of completing the tools as they went. Their assessments were scored by the author of the tool and items which were not scored the same were discussed in detail with the two raters to arrive at an agreement on how they were to be scored in future. The training process took approximately eight hours.

The order of assessments was varied at each visit to a sample site to control for the contamination of one assessment tool by the provision of information from another tool. The raters worked independently in each facility, helped by a staff member who identified the boundaries of the unit and provided them with access to the required areas.

Following the assessment of all facilities the raters were asked to make written comments on their experience of completing the evaluation tools. They were specifically asked to comment on ease of use and time taken.

Quantitative data were analysed using SPSS 17.

4.7 Results

The majority of the residents in the mixed units (66.1%) had a diagnosis of dementia. The mixed units were significantly larger than the DSUs and scored significantly lower on the three measures of environmental quality.

Table 6: Comparison of bed numbers and assessment results in mixed and dementia-specific units.

		Number of beds	TESS- NH SCUEG total	TESS- NH Global Rating	EAT Total Score
Mixed units	Mean	36.13*	27.75*	5.13*	41.98**
	SD	12.93	4.65	1.46	7.58
Dementia Specific Units	Mean	23.18*	32.36*	7.18*	61.53**
	SD	12.06	4.88	2.20	16.06

*difference sig at 0.05

** difference significant at 0.01

Both the EAT and the TESS-NH were found to discriminate between the DSUs, which are likely to have some environmental features that are helpful to people with dementia, and the mixed diagnosis units, see Table 6.

The average percentage of absolute agreement between the two raters using the TESS-NH was 84.4% (range 43% to 100%). ICCs ranged from -0.07 to 1; 18.1% of items had ICCs of less than 0.4 and 39.8% of the ICCs were greater than 0.70. The

inter-rater reliability of the SCUEGS was 0.84 (Pearson's r , significant at 0.000). The internal consistency of the subscales was assessed using Cronbach's alpha following the recommendations of Bland (Bland and Altman 1997). Four of the subscales have a Cronbach's alpha below the usually acceptable level of 0.6, two were not calculable and seven were above the acceptable level.

The average percentage of absolute agreement between the two raters using the EAT was 80.2% (range 53% to 90%). ICCs ranged from -0.05 to 1; 13.8% of items had ICCs of less than 0.4 and 54.2% of the ICCs were greater than 0.70. The inter-rater reliability of the total score was 0.97 (Pearson's r , significant at 0.000). Two of the subscales (Highlighting of helpful stimulation and Familiarity have a Cronbach's alpha below the usually acceptable level of 0.6 (Bland and Altman 1997). Cronbach's alpha was not calculated on two subscales (Size and Community Links) because they are based on a single item.

Table 7: Pearson's correlations between TESS-NH Global Score, SCUEGS and EAT Final Score

	TESS-NH Global Score	SCUEGS	EAT Final Score (Figures in brackets refer to revised EAT)
TESS-NH Global Score	1	0.92*	0.82* (0.83*)
SCUEGS		1	0.85*(0.85*)

*Significance (2 tailed) 0.000

The written comments on the experience of completing the assessments obtained from the raters at the conclusion of the study clearly indicated that both raters found the EAT to be significantly easier and slightly quicker to complete than the TESS-NH.

4.8 Discussion

The TESS-NH was developed in the USA in the early 1990s before much of the useful literature on environmental design was published. It reflects an institutional approach to the residential care of people with dementia and does not capture the person-centred, small-scale, domestic philosophy of care that has informed developments in Australia and the United Kingdom (Fleming, Crookes and Sum 2008). The EAT has been developed within that philosophy and is informed by the recent literature.

The item-by-item inter-rater reliabilities of the scales are very similar. The average level of absolute agreement between raters across all items is 84.4% (TESS-NH) and 87.1% (EAT). The original report on the validity of the TESS-NH (Sloane et al. 2002) records that the average percentage of agreement between two raters was 86.7 (range 41.7% to 100%). The very similar level of agreement found in the current study suggests that the raters were able to use the TESS-NH at an appropriate standard.

The inter-rater reliability (ICC) of the items has a greater spread with only 39.8% of TESS-NH items having an ICC in excess of 0.7 while 54.2% of EAT items exceed this standard. There were three instances of negative correlations in TESS-NH and one in the EAT. Whether this was due to a disagreement about the meaning of the questions or differences in conclusions based on observation is not known. It should be noted that the original TESS-NH ratings included one with a zero correlation.

Neither scale achieved the desired standard of having all of the sub-scales reach the benchmark of internal consistency (i.e. a Cronbach's alpha of 0.6). Seven of the 13 TESS-NH scales achieved this, and six of the 10 EAT scales.

The low Cronbach's alphas in the Highlighting of helpful stimulation and the Familiarity sub-scales of the EAT can be improved by eliminating items that have

zero variance or low correlations (0.2 or below) with the sub-scale totals. This would reduce the Highlighting scale to five items with a Cronbach's alpha of 0.6 and the Familiarity Scale to three items with an alpha of 0.62. The remaining two subscales are single items and therefore do not require an evaluation of internal consistency. All subscales in the EAT would then have acceptable internal consistency. The correlations between the revised total EAT score and the TESS-NH Global Score and the SCUEGS remain significant, see Table 7. The inter-rater reliability of the EAT Total Score remains unchanged by the modifications at an ICC of 0.97.

The inter-rater reliability (ICC) of the SCUEGS, the TESS-NH Global Score and the EAT Total score were all high with the EAT being the highest.

The correlation between the EAT and the TESS-NH Global Rating was 0.82. If the correlation had been low, below 0.7 for example, there would be concern that the scales had little relationship to each other and, as the TESS-NH Global Rating has been established as a gold standard, being used as the criterion for checking the validity of the PEAP and the SCUEGS for example (Lawton et al. 2002), doubt would be thrown on the validity of the scales. If on the other hand the correlation was exceptionally high there would be doubt about the new scales being sufficiently different from the TESS-NH to warrant a change to using them. The same argument applies to the correlations of 0.85 (EAT) with the SCUEGS. It is high but there is room for the new scale to add value.

The differences in mean scores of the mixed units and the DSUs was significant for all three measures and largest for the EAT. Assuming that some effort has been made to ensure that the environments for the DSUs are better suited for people with dementia than general purpose units, these differences are a strong indicator of the validity of the three scales. However the assessment of the true validity of these scales awaits an attempt to calibrate them against the views of residents with dementia and of the staff caring for them.

While it is suggested that the EAT offers an improvement in the assessment of homelike environments, there is no doubt that reliance on a single score from an assessment scale to describe the suitability of a physical environment for people with dementia, does not do justice to the complexity of the needs and problems experienced by them. The next generation of assessments might utilise the profiling of subscale scores to measure the suitability of the environment for differing groupings of people with dementia (e.g. mobile and disturbed, immobile and disturbed, mobile and apathetic). So that the fine tuning of group size, levels of stimulation and opportunities for social interaction, for example, can be matched against the needs of specific groups.

In summary the EAT item-by-item inter-rater reliability compares favourably with the TESS-NH, the EAT has better internal consistency in its subscales and the validity of the EAT is established by the strong correlation with the TESS-NH Global Score and the SCUEGS and its ability to discriminate between DSUs and mixed diagnosis units. The raters were in no doubt that the EAT provides an easier way to assess the physical environment than the TESS-NH.

Details of the results of the psychometric evaluation of the EAT and a copy of the EAT form are available from the author of this paper.

4.9 Conclusion

The EAT is a quick, easy-to-use, viable alternative to the TESS-NH in the type of aged care settings commonly found in Australia. While more extensive testing with the revised scale is necessary, the indications are that the EAT, with the Highlighting and Familiarity sub-scales shortened, is a valid and reliable tool for assessing the quality of environments for people with dementia.

4.10 Key Points

1. The importance of providing a well-designed physical environment for people with dementia is now well supported by the research literature.
2. The most commonly used tools for assessing the quality of environments for people with dementia reflect an institutional approach.
3. The Environmental Assessment Tool is easy to use, psychometrically robust and is capable of quantifying the quality of the physical environment used for the care of people with dementia in a homelike environment.

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4.12 Extended discussion

While the paper presented in Chapter 4 provides assurance that the EAT is sufficiently valid and reliable to be used as a research tool as well as a consultancy tool, there remain many questions that can, and should, be asked about it.

Overseas there has been a growing awareness of the potential benefits to people with dementia of maintaining their integration within the broader community. In Japan this has included training 1,000,000 volunteers to recognise a person who is having problems that may be due to dementia (e.g. wayfinding, confusion), and to be able to assist them. This is only part of a vigorous effort to make it possible for people with dementia to maintain a position within society (Takeda, Tanaka et al. 2010).

In the UK the government has announced a similar scheme as part of their National Dementia Strategy (Health 2009; Banerjee 2010). This strategy, as elaborated in the UK Prime Minister's 2012 'Dementia Challenge', includes an emphasis on the development of 20 dementia-friendly communities by 2015. Cities like Stirling in Scotland and Newcastle in England have taken up this challenge.

The movement towards dementia-friendly communities calls into question the emphasis placed in the EAT on a secure perimeter, albeit an unobtrusive perimeter. During a tour of Norwegian residential facilities for people with dementia in 2011, I was repeatedly shown fences that marked the boundary of the facility but did not confine residents. I was told that, as citizens, the residents with dementia had a right to leave the facility. Should they do so, and be thought to be at risk, they would be accompanied by a member of staff.

The focus on a secure perimeter in the EAT is a direct result of its development from the CADE unit work. The CADE units were designed to replace very secure, psychiatric hospital facilities. Fortunately those days have passed. Rather than being designed to record the presence of a secure perimeter as an unequivocal boundary, the EAT should be redesigned to allow this as an option in certain circumstances but to

prompt a question about the need for a secure perimeter at the time, and in the place, of assessment.

Empirical work has only just begun on identifying the physical characteristics of a neighbourhood that will assist people with dementia to live to their full potential (Mitchell and Burton 2010). As this work continues it will be possible to refine the EAT questions on a secure perimeter so that they gather information about the interface of the residential facility with the neighbourhood.

Many of the questions in the EAT focus on the presence of desirable characteristics but not their use. The exceptions are questions about domestic activities involving residents. This inconsistency can be resolved by either changing the domestic activity questions so that they only refer to the presence of the amenities required for engagement with domestic activities, or by introducing another aspect of measurement wherever relevant throughout the EAT – that is, whether the desirable feature is actually accessible and used. The effect of this is easy to see in relation to the questions about access to the outside. All of the desirable features may be available outside, but if the door to the outside is locked, then it is hard to justify giving the facility the points associated with them.

Introducing a change towards capturing information on the use of the physical environment, as well as its physical characteristics, would begin to include the examination of the relationship between the physical environment and its users, both staff and residents, into our evaluations. This may enrich our understanding of how to develop the role of the physical environment as a tool to support the care of people with dementia.

It is clear that the EAT, like all other assessment tools, carries within it a set of assumptions. These assumptions need to be challenged from time to time.

4.13 Impact

The paper presented in Chapter 4 has been cited in a recent publication as describing one of four internationally recognised assessment methods for residential care environments (Topo, Kotilainen et al. 2012). The inclusion of an inexperienced rater in the evaluation of the metrics demonstrated that it can be used with very little training. This has paved the way for the widespread use of the EAT. It is now, thanks to funding from the Australian Department of Health and Ageing, available as a free iPhone app.

The paper has been extended in a project led by another researcher that investigated the ability of the EAT to discriminate between mainstream aged care facilities and specifically designed, dementia facilities (Smith, Fleming et al. 2012). The study showed that the EAT can identify the differences. This study has provided norms that are now used to assist users to compare their EAT scores with average scores for dementia specific and mainstream facilities.

4.14 Further Research

The evaluation of physical environments for people with dementia is still in its infancy. There remains work to be done in defining and measuring the physical characteristics of a good environment – that is, an environment that compensates for the problems associated with dementia. This is particularly so in the specialised areas of end-of-life and acute care where the available tools lean heavily on the research that has been carried out in residential aged care. The author is leading a project on the evaluation of end-of-life environments for people with dementia that has been funded by the UNSW Dementia Collaborative Research Centre.

Perhaps a more exciting area of research is how we measure the quality of the building from the point of view of its users. Pioneering work on this has been carried out in Australia (Davis, Byers et al. 2009) in a study that sought the views of people with dementia and their carers about the environmental features that contribute to the

person with dementia being an active participant in life rather than simply a recipient of care. This area of study has been expanded in Finland by applying affordance theory (Gibson 1977) which specifically refers to the positive or negative possibilities for action that are provided by an environment and are situated in the interaction between the person and the environment (Topo, Kotilainen and Eloniemi-Sulkava 2012). The authors developed a tool for evaluating the presence of desirable features and the affordances they provide: the Residential Care Environment Assessment Tool (RCEA). Four of the six sub-scales are derived from an assessment tool developed for assessing the affordances of the outdoor environment for children. These were revised using items from existing dementia-oriented scales, including the EAT, and two additional sub-scales were developed.

The RCEA is a complex tool to use and no data on its reliability and validity have yet been offered. Nevertheless it is an exciting example of a new (to dementia care) paradigm of environmental assessment and it opens up new areas of research that will require the development of more tools.

It is essential that this new paradigm influences the design of the tools for evaluating acute care and end-of-life care settings mentioned above. There is ample evidence to show that the perspectives of people with dementia and those who are trying to speak on their behalf are not always in accord when it comes to describing the important aspects of services (Bamford and Bruce 2000; O'Connor, Phinney et al. 2007). Practical, valid and reliable tools that will give designers access to the views of the users are needed.

4.15 Conclusion

The paper presented in Chapter 4 has contributed significantly to the confident use and widespread acceptance of the Environmental Assessment Tool.

A critical examination of the assumptions underlying the EAT leads on to an awareness of fresher ways of looking at the nature of a quality environment for people with dementia. These will take us well beyond the CADE unit paradigm.

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CHAPTER 5: THE FACTOR STRUCTURE OF THE ENVIRONMENTAL AUDIT TOOL

The paper presented in Chapter 5 was written by the candidate with statistical guidance provided by co-author Dr. Christopher Magee. Co-authors Professor Henry Brodaty and Professor Lynn Chenoweth provided access to data collected in their research projects. It will be submitted to the *Australasian Journal on Ageing* under the title ‘The factor structure of the environmental audit tool’.

The paper follows in sections 5.1 to 5.6.

5.1 Aim

The purpose of this study was to investigate the fundamental assumption underpinning the EAT, that there are ten principles (factors) that adequately describe the data.

5.2 Background

The principles underpinning the EAT were described , essentially, on the basis of experience and a knowledge of the literature (Fleming and Bowles 1987; Fleming, Forbes and Bennett 2003). They provided a rational framework for guiding the evaluation of a facility and the discussion of its strengths and weaknesses. However there was little in the way of empirical evidence to support their existence as organising factors.

The investigation revealed the existence of four factors, not five, and the conclusion was that the observed factor structure showed moderate concordance with the five symptom clusters proposed in the original CSDD, leaving the way open for the continued use of the CSDD.

The paper presented below in sections 5.3 to 5.9 is therefore an important step towards ensuring that the EAT can make a meaningful contribution to the field of environmental design.

5.3 Introduction

Abstract

Objectives

To investigate the relationship between the Environmental Audit Tool's (EAT) sub-scales and its factor structure.

Methods

An exploratory factor analysis was conducted on data from 105 residential aged care facilities

Results

The factor analysis revealed nine factors. Six of these were highly correlated with the sub-scales.

The factors suggest new ways of organising the EAT items when assessing and determining the optimal design of new or refurbished facilities. The EAT factors challenge current ways of conceptualising the characteristics of residential aged care design.

Redundant items were discovered in the EAT and this provided the basis for the construction of a shortened version.

Conclusion

Two shortened versions of the EAT are now available, one organised around the original sub-scales and the other around the nine factors.

Key points

- The description of the built environment requires a multi-factorial approach.
- The current EAT sub-scales offer an understandable framework for describing the environment.
- There is a high correlation between the EAT sub-scales and six of the factors revealed by factor analysis.
- The EAT is now available in a shortened form.

Introduction

The Environmental Audit Tool (EAT) (Fleming, Forbes and Bennett 2003) was developed to provide an objective measure of the quality of residential physical environments used by people with dementia. Its psychometric properties have been investigated (Fleming 2011; Smith, Fleming et al. in press) and found to compare favourably with the most widely accepted environmental assessment tool, the TESS-NH (Sloane al. 2002).

The EAT comprises 72 items and is organised around the ten principles of design described in Table 10. These have been fully described elsewhere (Fleming and Bennett In press) and a summary of them is available on the web (Burton, Fleming et al. 2012). They were developed from the practical experience of designing facilities for confused and disturbed elderly people (Fleming and Bowles 1987) and refined by the accumulation of research findings on desirable characteristics in environments for people with dementia (Fleming and Purandare 2010). However there was little empirical evidence to support their existence as organising factors. This is not an uncommon situation in the development of assessment tools. The Cornell Scale for Depression in Dementia (CSSD) (Alexopoulos, Abrams, Young and Shamoian 1988), for example, categorises the signs and symptoms of depression into five content areas but it was ten years after its introduction that the existence of these clusters was investigated (Harwood, Ownby, Barker and Duara 1998) by the application of factor analysis, in order to “better understand what the scale measures overall, what the individual items measure, and whether the logical groupings of items suggested by the scale’s authors exist empirically” (Harwood, Ownby, Barker and Duara 1998, p.

213). This investigation revealed the existence of four factors, not five, in the CSDD and the conclusion was that the observed factor structure showed moderate concordance with the five symptom clusters proposed in the original CSDD.

If the factor structure had been found to be quite different from the clusters proposed in the original it is unlikely that the CSSD would have become the most commonly used assessment of depression in people with dementia. In Australia the CSDD is the required measure of depression in Australian residential aged care facilities to receive funding for the management of depression (Davison, Snowden et al. 2012).

The EAT has similarly continued to be improved through continuous testing, including in two recent large-scale Australian studies investigating interventions to improve the quality of life of people with dementia living in residential care (Chenoweth 2011; Fleming 2011; Goodenough et al. 2012). The use of an environmental assessment tool in these studies reflects a growing interest in the contribution the physical environment makes to the wellbeing of people with dementia. The choice of the EAT as the assessment of the physical environment indicates a recognition of its value. This recognition signals the imperative to explore its metrics to ensure that it is a robust tool that will assist researchers to understand the role of the physical environment in delivering care to people with dementia.

The EAT is also being used in an Australian Government-funded, nationwide, consultancy service aimed at improving the quality of the physical environments in residential aged care (Fleming 2012). Its use in consultancy brings a different, but related, set of requirements. While it must be a sound measuring instrument it must also facilitate communication about the strengths and weaknesses of the environment so that plans can be made to improve inadequate environments.

Objectives

This psychometric investigation into the EAT is aimed at identifying the number and characteristics of the constructs underlying the EAT item variance and comparing them with the framework of principles used in the development of the sub-scales. This will provide guidance for the refinement of the EAT as a research and consultancy tool.

Methods

The EAT has been used in three large-scale studies (Chenoweth et al. 2011; Fleming 2011; Goodenough et al. 2012) referred to below as the initial psychometric, SMILE and PerCen studies. The combination of the data from these studies has provided a sample of 105 residential aged care facilities located in NSW Australia. Data from the SMILE and PerCen studies reported here was collected at baseline. This is particularly important for the PerCen data as this study involved making environmental modifications to a sub-sample of the facilities. Each study was conducted independently and included the express intent of not including facilities that were engaged in other studies.

Ethics approval was obtained for all studies from the relevant university research ethics committees.

Because the EAT items are ordinal in nature the exploratory factor analysis was conducted with Mplus version 6 using geomin rotation and WLSMV as the estimator. The analysis was terminated after the extraction of ten factors.

Results

The sample of 105 facilities comprised 30 from the initial psychometric study, 36 from SMILE and 39 from PerCen. The average number of beds was 30 (S.D. = 19.05), 55 were described by their managers as being used specifically for the care of people with dementia.

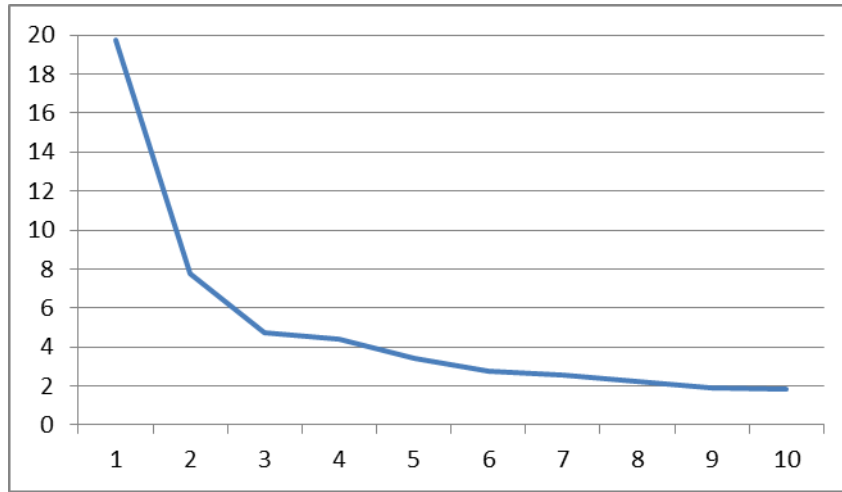
The exploratory factor analysis revealed that 14 items were redundant because they either always scored the same or were so correlated with another item that they added no information. Mplus could not complete the analysis until they were removed. These items are described in Table 8.

Table 8: Redundant items

Safety	Stimulus Reduction	Stimulus Enhancement	Engagement Path	Activities of Daily Living
If the kitchen is used by residents is there a lockable knife draw in the kitchen?	Does the doorbell attract the attention of the residents?	Is the dining room looked into from the lounge room or clearly marked with a sign or symbol?	Does the path take residents past a toilet?	Have a significant involvement in main meal preparation?
If the kitchen is used by residents is the cooker a gas cooker?		Is the lounge room either looked into from the dining room or clearly marked with a sign or symbol?		Have constant and easy access to a lounge?
If the kitchen is used by residents is there a master switch that can be turned off quickly?		Are toilets visible as soon as the toilet/bathroom door is opened?		Have constant and easy access to a dining room?
Is the temperature of the water from all taps accessible to residents limited so that it cannot scald?		Is the artificial lighting bright enough in all areas?		
If residents are involved in meal preparation are the pots and pans used small enough for them to lift easily?				

The analysis of the remaining items revealed ten factors with eigenvalues ranging from 19.71 to 1.866

Figure 2: Eigenvalues for sample correlation matrix



The goodness of fit of the factors was evaluated using CFI, TLI and RMSEA.

Table 9: Goodness of fit indices

Model	X ² (df)	CFI ^a	TLI ^b	RMSEA ^c
1	2924.24 (1595)*	0.813	0.806	0.089
2	2222.74 (1538)*	0.904	0.897	0.065
3	1911.39 (1482)*	0.94	0.933	0.053
4	1706.42 (1427)*	0.961	0.954	0.043
5	1524.09 (1373)*	0.979	0.974	0.032
6	1436.39 (1320)*	0.984	0.980	0.029
7	1359.53 (1268)*	0.987	0.983	0.026
8	1288.48 (1217)	0.990	0.986	0.024
9	1221.12 (1167)	0.992	0.989	0.021
10	1155.06 (1118)	0.995	0.992	0.018

* p<0.05

^a Comparative Fit Index

^b Tucker Lewis Index

^c Root Mean Square Error of Approximation

The significance of the difference between the factors was evaluated using chi square and revealed that all factors up to factor 8 added significantly to the model. The significance of the difference between factor 8 and factor 9, 0.0512, was marginally beyond the usually accepted cut off of 0.05.

Examination of the eigenvalues (Figure 2), Goodness of Fit indices (Table 9) and the significance of the difference between factors resulted in acceptance of the nine factor solution. The nine factors and the items comprising them, are listed in Tables 10a to 10d.

Table 10a: The factor structure of the Environmental Audit Tool – Safety, Size and Visual Access

EAT sub-scales and items	Safety	Legibility and Familiarity	General visibility	Frequency of kitchen stimulation	Visibility of toilet	External pathway	Domestic activities	Places for social interaction	Places for small gatherings
SAFETY									
Secure garden	0.653	0.523	0.034	0.101	0.591	0.481	0.148	0.098	0.279
Secure front door	0.872	0.553	0.197	0.015	0.497	0.261	0.105	0.095	0.051
Secure side doors	0.855	0.499	0.201	0.024	0.536	0.417	0.094	0.022	0.150
Bedroom windows secure	0.582	0.404	0.076	0.139	0.452	0.445	0.148	0.070	0.361
Easily supervised garden	0.687	0.609	0.063	0.191	0.255	0.664	0.192	0.177	0.585
Access to kitchen only for people who are safe in a kitchen	0.677	0.242	0.060	0.294	0.213	0.381	0.057	0.326	0.578
Floor areas safe from being slippery when wet?	0.170	0.372	0.176	0.362	0.118	0.515	0.550	0.036	0.390
Lounge room easily supervised from the point(s) where the staff spend most of their time?	0.609	0.823	0.123	0.089	0.447	0.323	0.176	0.008	0.513
Areas used by residents well lit?	0.368	0.869	0.178	0.005	0.275	0.221	0.337	0.217	0.202
SIZE									
Size of unit	0.212	0.308	0.267	0.598	0.000	0.032	0.299	0.083	0.199
VISUAL ACCESS									
Visibility of bedroom doors	0.209	0.608	0.650	0.175	0.058	0.292	0.222	0.037	0.146
Visibility of lounge room from bedrooms	0.194	0.595	0.727	0.155	0.037	0.329	0.297	0.004	0.215
Visibility of dining room from bedrooms	0.281	0.562	0.643	0.301	0.135	0.365	0.238	0.093	0.227
Visibility of door to garden from lounge room	0.242	0.593	0.133	0.453	0.109	0.565	0.186	0.055	0.307
Visibility of dining room from lounge room	0.255	0.473	0.051	0.473	0.072	0.212	0.181	0.334	0.177
Visibility of kitchen from lounge room	0.323	0.557	0.062	0.766	0.097	0.607	0.427	0.053	0.120
Visibility of kitchen from dining room	0.157	0.747	0.021	0.763	0.113	0.424	0.514	0.295	0.359
Visibility of a toilet from dining room	0.356	0.345	0.239	0.053	0.775	0.121	0.318	0.091	0.118
Visibility of a toilet from lounge room	0.245	0.418	0.125	0.001	0.961	0.060	0.425	0.008	0.230
Visibility into lounge from point where staff spend most of time	0.577	0.783	0.009	0.259	0.396	0.343	0.095	0.162	0.563

Note: Loadings in bold identify EAT items used to form factor subscales. These items had high loadings relative to other items.

Table 10b: The factor structure of the Environmental Audit Tool – Stimulus Reduction and Stimulus Enhancement

EAT sub-scales and items	Safety	Legibility and Familiarity	General visibility	Frequency of kitchen Reduction in stimulation	Visibility of toilet	External pathway	Domestic activities	Places for social interaction	Places for small gatherings
STIMULUS REDUCTION									
Too much noise from kitchen	0.142	0.335	0.032	-0.523	0.410	0.087	0.062	0.107	0.151
Doors to dangerous areas easily seen	0.108	0.181	0.370	0.255	0.204	0.040	0.021	0.003	0.221
Wardrobe full of too many clothes	0.212	0.685	0.127	0.659	0.314	0.059	0.185	0.171	0.028
Deliveries made across public areas	0.137	0.194	0.030	0.298	0.061	0.152	0.288	0.514	0.036
Intrusive public address or paging system	0.310	0.217	0.058	0.555	0.459	0.013	0.060	0.213	0.208
Front entrance easily visible	0.702	0.296	0.039	0.109	0.412	0.145	0.251	0.241	0.085
Service entry easily visible	0.685	0.169	0.058	0.424	0.260	0.063	0.030	0.314	0.131
STIMULUS ENHANCEMENT									
Individual identification of bedrooms	0.474	0.473	0.019	0.370	0.217	0.341	0.779	0.231	0.156
Shared bathrooms/toilets clearly signed	0.228	0.440	0.336	0.096	0.365	0.145	0.352	0.340	0.033
Kitchen easily seen or signed	0.032	0.322	0.198	0.811	0.133	0.298	0.509	0.092	0.268
A lot of natural light in lounge room	0.245	0.657	0.256	0.110	0.153	0.470	0.381	0.208	0.126
Lighting is free from glare	0.202	0.689	0.005	0.067	0.290	0.239	0.303	0.118	0.299

Table 10c: The factor structure of the Environmental Audit Tool – Engagement Path and Familiarity

EAT sub-scales and items	Safety	Legibility and Familiarity	General visibility	Frequency of kitchen Reduction in stimulation	Visibility of toilet	External pathway	Domestic activities	Places for social interaction	Places for small gatherings
ENGAGEMENT PATH									
A clearly defined and <u>easily</u> accessible path in the garden that guides the resident back to their starting point?	0.286	0.369	0.176	0.070	0.379	0.756	0.197	0.247	0.457
Path passes alternatives to wandering	0.291	0.658	0.173	0.090	0.437	0.838	0.304	0.378	0.323
Path within a secure perimeter	0.178	0.128	0.377	0.461	0.256	0.895	0.066	0.130	0.247
Path easily supervised by staff	0.469	0.536	0.095	0.095	0.175	0.813	0.239	0.266	0.500
Seats available along path	0.165	0.080	0.224	0.230	0.045	0.887	0.004	0.263	0.279
Sunny and shady areas along path	0.214	0.199	0.224	0.175	0.048	0.890	0.118	0.332	0.186
Path clearly continues inside back to starting point	0.349	0.647	0.392	0.045	0.617	0.479	0.231	0.374	0.360
Internal path provides access to activities other than wandering	0.127	0.625	0.436	0.119	0.480	0.447	0.211	0.534	0.284
FAMILIARITY									
Colours are familiar	0.260	0.824	0.131	0.122	0.487	0.196	0.219	0.132	0.095
Taps, light switches etc are familiar	0.074	0.843	0.083	0.090	0.263	0.074	0.321	0.332	0.222
Furniture in lounge area is familiar	0.041	0.815	0.070	0.145	0.094	0.298	0.445	0.380	0.056
Furniture in bedrooms is familiar	0.164	0.768	0.013	0.062	0.165	0.218	0.816	0.264	0.057
Residents have own ornaments/photos in bedroom	0.213	0.987	0.180	0.039	0.405	0.351	0.721	0.156	0.303
Residents have own furniture in bedrooms	0.053	0.233	0.267	0.478	0.023	0.303	0.647	0.316	0.299

Table 10d: The factor structure of the Environmental Audit Tool – Privacy, Social Interaction, Community Links and Domestic Activities

EAT sub-scales and items	Safety	Legibility and Familiarity	General visibility	Privacy of kitchen Reduction in stimulation	Visibility of toilet	External pathway	Domestic activities	Places for social interaction	Places for small gatherings
PRIVACY AND SOCIAL INTERACTION									
Small areas available for conversation	0.010	0.181	0.006	0.208	0.208	0.426	0.504	0.805	0.139
Small areas have pleasant views	0.076	0.312	0.001	0.141	0.090	0.502	0.530	0.837	0.068
Opportunity for small group activities	0.027	0.270	0.097	0.358	0.036	0.205	0.611	0.092	0.747
Opportunity for small groups to eat together	0.256	0.236	0.066	0.121	0.154	0.165	0.260	0.257	0.773
Opportunity for people to eat alone	0.258	0.591	0.030	0.310	0.498	0.263	0.244	0.137	0.487
COMMUNITY LINKS									
Area for dining with families/friends	0.067	0.393	0.150	0.086	0.208	0.382	0.300	0.833	0.443
Is this area familiar and reassuring	0.056	0.492	0.010	0.010	0.253	0.487	0.305	0.903	0.469
DOMESTIC ACTIVITIES									
Access to kitchen	0.162	0.169	0.211	0.472	0.613	0.006	0.619	0.159	0.114
Involvement in making snacks	0.390	0.492	0.252	0.068	-0.706	0.407	0.528	0.002	0.175
Involvement in keeping bedroom tidy	- 0.454	0.050	0.322	0.120	0.386	0.095	0.440	0.282	0.293
Involvement in personal laundry	- 0.434	0.021	0.054	0.198	0.131	0.006	0.421	0.369	0.263
Involvement in gardening	0.224	0.397	0.313	0.079	0.281	0.299	0.472	0.208	0.259

Pearson's r correlations were calculated to investigate the relationships between the factors and the original sub-scales. They are reported in Table 11.

Table 11: Pearson's r correlations between factor scores and sub-scale scores.

	Safety	Legibility and Familiarity	General visibility	Visibility of kitchen Reduction in stimulation	Visibility of toilet	External pathway	Domestic activities	Places for social interaction	Places for small gatherings
Safety	.951**	.726**	.461**	.117	.394**	.550**	.195*	.285**	.215*
Size	.188	.194*	.331**	.684**	.056	.046	.285**	.059	.068
Visual Access	.558**	.656**	.922**	.356**	.304**	.471**	.344**	.114	.208*
Stimulus reduction	.185	-.126	.112	.332**	-.125	.047	.225*	.327**	-.002
Stimulus enhancement	.424**	.671**	.381**	.412**	.309**	.273**	.492**	.144	.224*
Engagement path	.578**	.569**	.443**	.134	.240*	.951**	.244*	.440**	.284**
Familiarity	.366**	.785**	.396**	.284**	.342**	.350**	.589**	.444**	.241*
Privacy and community	.300**	.432**	.148	.232*	.177	.432**	.487**	.853**	.606**
Community links	.320**	.368**	.129	.028	.176	.380**	.265**	.814**	.230*
Domestic	-.116	-.031	.036	.408**	-.126	.069	.847**	.291**	.298**

*Significance at 0.05

** Significance at 0.001

The internal reliability of the two shortened forms of the EAT – that is, the original with the redundant items extracted organised around the original sub-scales, and the factors was investigated using Cronbach’s alpha and reported in Table 12.

Table 12: Internal reliability of factor scores and sub-scale scores (short form)

	Safety	Visual Access	Stimulus reduction	Stimulus enhancement	Engagement path	Familiarity	Privacy and community	Domestic
Cronbach’s alpha	0.891	0.805	0.158	0.555	0.855	0.774	0.662	0.544
	Safety	Legibility and Familiarity	General visibility	Visibility of kitchen Reduction in stimulation	External pathway	Domestic activities		
Cronbach’s alpha	0.89	0.86	0.828	0.713	0.842	0.695		

5.4 Discussion

The Mplus analysis revealed a substantial number of items that were almost always scored one way, such as the question on the limitation of the temperature of the water, which is controlled by regulation in Australia; or items that were synonymous with other items. This gives rise to questions about the need for them in the scale. The decision on their exclusion must take into account the purpose of the scale. Is the EAT to be used purely as a measurement tool or as a tool to inform a discussion on the strengths and weaknesses of the physical environment? If it is the latter then a certain amount of redundancy in the scale can be tolerated when it enriches discussion of the problems of the environment and ways in which these problems can be overcome.

The distribution of factor loadings in Table 9 and the high correlation with the six items from the original safety subscale suggests that Factor 1 can continue to be called ‘Safety’. Factor 2 appears to be an omnibus factor combining items that

concern visibility and familiarity, with three items from the original visual access scale, three from stimulus enhancement and four from the familiarity scale. It correlates highly with Safety, Visual Access, Stimulus Enhancement, the presence of an engagement path and Familiarity. Factor 3 is very highly correlated with the original visual access scale but it also correlates significantly with safety, size, stimulus enhancement and the presence of an engagement path. Factor 4 is mainly about the visibility of the kitchen but it is also highly correlated with size. Factor 5 items are exclusively about the visibility of the toilets but the score correlates highly with safety. Factor 6 contains six items from the original Planned Wandering subscale and no other items. Not surprisingly it correlates very highly with the engagement path sub-scale but it also correlates highly with safety and visual access. Factor 7 contains five items from the original Domestic Activities subscale and correlates very highly with it. It also contains a question on the identification of the residents' bedroom. Factor 8 combines two items from the Privacy and Community subscale and two from the Community Links subscale to give a factor that describes the provision of social areas. Factor 9 describes opportunities for small groups to sit together and does not correlate well with other sub-scales.

The factor analysis confirms the large number of factors required to describe the physical environment. The best statistical description requires nine factors. Examination of table three shows the high level of agreement between six of the factors and the original principles (safety, legibility/familiarity, general visibility, engagement path, privacy/community and domestic activities).

There is a substantial number of highly significant correlations across the factors indicating that neither the original sub-scales nor the identified factors are independent constructs. For example while the dominant influence on some of the Safety subscale items is from items in the Safety factor, there are also items dominated by the Legibility and Familiarity factor. Furthermore, items on the Safety subscale that were dominated by legibility, and the familiarity factor also had small-to-moderately sized loadings on the Visibility of the Toilet and the External Pathway factors. Examination of Table 11 will reveal other examples of this.

The combination of the items called for by the factor analysis does, however, result in the establishment of scales that have higher internal consistency than the sub-scales based on the original principles, as shown in Table 12.

Combining size of the unit with items from the Visual Access, Stimulus Reduction and Stimulus Enhancement scales, for example, makes sense. A smaller unit is likely to provide better visual access, a reduction in unwanted stimulation and greater opportunities to see the kitchen. Nevertheless, while justifiable on statistical grounds, the combination of items in the factors where there is not strong agreement with the original sub-scales does not increase the clarity of the scale. Abandoning the separate consideration of size, visual access, stimulus reduction and stimulus enhancement seems a high price to pay for statistical coherence.

The identification of a strong environmental legibility and familiarity factor (Factor 2) is very interesting. However the combination into one omnibus scale of items from safety, visual access, stimulus reduction, stimulus enhancement, engagement path, familiarity and variety of spaces is difficult to understand. There is no conceptual framework that brings all of these things together. While the sub-scale will give a score that indicates how well an environment has been designed against these items, it is difficult to know what this means. It may be better to consider this factor as an overarching description of desirable characteristics of the physical environment, while use of the existing framework provides an easy way of communicating strengths and weaknesses of an environment to those who wish to improve it.

The concept of construct validity is related to this decision; it is a concept that has changed its focus from whether an assessment measures what it is intended to measure (Kelley 1927; Cattell 1946) to an understanding that assessments always exist in a broader context and therefore must be evaluated from the perspective of this context. The evaluation can include the question of whether the relationships between test scores match theoretical relationships (Cronbach and Meehl 1955) and whether interpretations and actions based on the scores are justified with respect to the social consequences of their use (Messick 1989).

The development of this approach has led to intense debate with one commentator strongly objecting to the development that has resulted in a situation where

validity theory has gradually come to treat every important test-related issue as relevant to the validity concept and aims to integrate all these issues under a single header (Borsboom, Mellenbergh et al. 2004, p. 1061).

A recent review described the debate on construct validity as being very strong in the late 1980s and early 1990s but as having come to an unresolved stalemate in recent years (Wolming and Wikström 2010).

This debate provides a context in which it is justifiable to leave open the choice of the format of the EAT. The results of this analysis provide the data necessary for the construction of two variations on the original EAT: first, a shortened form maintaining the original structure with 14 statistically redundant items deleted and, secondly, an EAT structured around the nine factors identified in this study. The latter will have better internal reliability and be consistent with an empirically derived factor structure. As the items are the same, both scales will collect the same data, take the same time to complete and have the same ease of use. The difference will lie in the ease of explanation of the results.

It is suggested that the level of agreement between the statistically derived factors and the original principles is sufficient to justify the continued use of the original principles in circumstances where ease of communication about the strengths and weaknesses of facilities is paramount, for example in consultancy and educational activities. However the factor structure revealed by this analysis should not be neglected. In particular the meaning of Factor 2 demands investigation. What construct brings those disparate items together? Indeed, discussions about the grouping of the items in the factors discovered here may lead to a new way of looking at what constitutes good design for people with dementia.

The original form of the EAT, containing the 14 statistically redundant questions, may still be preferred by users who prioritise a comprehensive exploration of the characteristics of the environment over saving time or adhering to a statistical grouping of items.

5.5 Conclusion

The analysis of the large data set provided by combining the data from three studies has resulted in the identification of nine factors that provide a different way of organising data on the design of physical residential care environments for people with dementia. The factor structure is, however, difficult to interpret from a theoretical point of view. It has led to the development of a shortened form. The shortened form is available in the original format, based on ten principles, and also formatted according to the nine factors identified in this study. The use of the original format is recommended for educational and consultancy purposes while the meaning of the revealed factor structure is examined further. The original and shortened forms of the EAT are available free of charge from the first author.

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5.7 Extended discussion

The factor analysis revealed that nine factors were necessary to explain the variation in the data without adding in non-significant factors. This is a reassuring finding as it justifies a multi-dimensional view of the quality of physical environments. The alternative, finding that only one or two factor explained the variation, would have called into question the need for ten principles of design.

The themes of most of the nine factors can be seen in the ten principles. The most striking exception is Factor 2 which draws together:

1. Lounge room easily supervised from the point(s) where the staff spend most of their time
2. All areas used by residents well lit
3. Visibility of door to garden from lounge room
4. Visibility of dining room from lounge room
5. Visibility into lounge from point where staff spend most of time
6. [Not] Too much noise from kitchen
7. Shared bathrooms/toilets clearly signed
8. A lot of natural light in lounge room
9. Lighting is free from glare
10. Internal path provides access to activities other than wandering
11. Path clearly continues inside back to starting point
12. Colours are familiar
13. Taps, light switches etc. are familiar
14. Furniture in lounge area is familiar
15. Residents have own ornaments/photos in bedroom
16. Opportunity for people to eat alone.

It is difficult to conceptualise this range of themes (visibility, stimulus reduction, stimulus enhancement, provision of walking path, familiarity, opportunity for privacy) as a single dimension. Nevertheless the analysis tells us quite clearly that they cluster together.

When the EAT is used simply as a checklist of desirable features this clustering poses no problems. The analysis tells us that these items are important and should be included in the assessment. The problem comes when we are looking for explanatory concepts.

The Visual Access items in the original EAT are grouped together because of the belief that it is beneficial to people with dementia for the environment to be organised so that they can see the spaces and things that they need to access. The Familiarity items are grouped together because it is believed that people with dementia are more comfortable with, and more able to use, objects that were familiar to them early in their life because recent memory is impaired by dementia.

There is empirical evidence to support both of these groupings: visual access (Namazi and Johnson 1991a; Elmstahl, Annerstedt and Ahlund 1997; Passini, Rainville et al. 1998.), familiarity (Greene and Asp 1985; Annerstedt 1997).

The question is, what is the explanatory concept that brings the items together in Factor 2? The ability of factor analysis to raise this type of heuristic question is another reason for carrying out this type of investigation. It not only provides information on the current structure of the EAT but points towards future theoretical and empirical developments.

While this research is going on the paper presented in Chapter 5 suggests that there is still value in using the ten principles as the framework for organising and communicating the information. While the factor analysis tells us that this must be done with caution, as the fit between the nine factors and the ten principles is far from perfect, the benefits of being able to communicate via a framework that has some conceptual strength seems to the author to outweigh the benefits of moving immediately to a statistically sound, but conceptually weak, framework for communication.

This conclusion is similar to that of those who investigated the factor structure of the CSSD:

Our results suggest that the subscales indicated by the authors of the CSSD should be interpreted with caution. Without replication, our findings should also be interpreted cautiously, but these empirically derived item groupings may eventually prove useful in understanding patterns of depressive symptoms among AD patients' (Harwood, Ownby, Barker and Duara 1998, p. 218).

For the time being there is no need to abandon the principles that were used in the design of the CADE units.

5.8 Impact

As the paper presented in Chapter 5 is yet to be published it has had no impact outside of the team working on developing the EAT. Within that team the identification of redundant items has been very useful in the development of the end-of-life version of the EAT that is being undertaken with funding from the UNSW Dementia Collaborative Research Centre.

5.9 Further research

There is a need for replication inherent in all investigations of this type, particularly a confirmatory factor analysis on another sample.

The paper identifies an omnibus sub-scale that appears to be very important in the measurement of the quality of environments for people with dementia. This sub-scale is difficult to place in any conceptual framework known to the author. One way of trying to understand this sub-scale is to examine it through the eyes of the users, people with dementia and staff, as described in the previous chapter. Perhaps they can offer an explanation of how the items hang together. Does an environment high on these items produce a particular feeling – calmness, competence, freedom for example? Does it afford particular opportunities – independence, stimulation, participation for example?

The study provides an impetus for trying to re-conceptualise quality in physical environments. The challenge is to find the methodology that will help us do this.

5.10 Conclusion

The paper presented in Chapter 5 presents support for the multi-dimensional approach to understanding the quality of physical environments for people with dementia.

There was moderate agreement between the ten principles used in the original EAT and the nine factors empirically identified. However, the study also provides evidence for an omnibus factor that includes items from most principles. This challenges the current conceptual framework and requires further exploration that may lead to another view of what constitutes a high quality environment.

5.11 References

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CHAPTER 6: THE RELATIONSHIP BETWEEN THE QUALITY OF THE CARE HOME ENVIRONMENT AND THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA.

The paper presented in Chapter 6 was written by the candidate with statistical supervision provided by the co-author Dr. Belinda Goodenough. Co-authors Professor Henry Brodaty and Dr. Lee-Fay Low commented on the manuscript and provided access to data from the SMILE study. The paper has been written for the publication *Dementia* under the title ‘The relationship between the quality of the care home environment and the quality of life of people with dementia’.

The paper follows in sections 6.1 to 6.13.

6.1 Aim

The purpose of this study was to investigate the relationship between the quality of the environment and the quality of life of people with dementia.

6.2 Background

I was fortunate to be invited to join a team of researchers, led by Professor Henry Brodaty, who wished to look into the effects of introducing humour therapy into residential aged care facilities (Goodenough, Low, Casey, Chenoweth, Fleming, Spitzer, Bell and Brodaty 2012). My contribution to the team was to provide the tools and expertise required to measure the quality of the physical environment so that this could be controlled for in the evaluation of the impact of the therapy.

The study involved the audit of 35 facilities using the Environmental Audit Tool and the collection of data on levels of depression, agitation, psychiatric symptomatology and quality of life. The paper presented in Chapter 6 examines the relationship between the quality of the environment and the quality of life of the residents with dementia.

6.3 Abstract

While there is considerable evidence on specific design features and their impact on specific problems associated with dementia, the link between the quality of the built environment and quality of life of people with dementia is largely unexplored. There has been progress in the design of quality of life and quality of the environment measurement tools. This study utilised relatively new quality of life and quality of environment measurement tools in an exploration of the environmental and personal characteristics that are associated with high quality of life in people with dementia living in residential aged care. Data were obtained from 275 residents of 35 aged care homes taking part in the Sydney Multisite Intervention of LaughterBosses and ElderClowns (SMILE) study and analysed using linear regression. The results indicated that the quality of the built environment is significantly associated with the quality of life of the resident when it is measured by simple self-report. The features associated with higher quality of life are the facilitation of engagement with a variety of activities both inside and outside, familiarity, the provision of a variety of private and community spaces, and the amenities and opportunities to take part in domestic activities. This information is of practical use to the designers and managers of aged care homes.

6.4 Introduction

There is an emerging literature on the relationship between quality of life (QoL) and dementia. The link between QoL and levels of cognitive functioning and ADL functioning in care homes has been explored and found to be significant (Edelman, Fulton et al. 2005). Variations in levels of QoL that may be attributable to dementia sub-type have been found (Thomas, Lalloue et al. 2006). Effects of gender on QoL treatment responses (Woods, Thorgrimsen et al. 2006) and ethnic background have been identified (James, Xie et al. 2005). Differences in QoL have been associated with differences in care settings (Zimmerman, Sloane et al. 2005) and the presence of psychiatric disorders has been linked to poorer QoL (Banerjee, Smith et al. 2006).

However the research is still in a very early stage and there is a great deal of debate on how to conceptualise and measure QoL (Banerjee, Samsi et al. 2009).

There is also a literature on designing facilities for people with dementia. It has accumulated over the last thirty-five years (Fleming and Purandare 2010) and provides support for the inclusion of a number of features into care homes that accommodate people with dementia. This literature, like the QoL literature, includes various points of view on how quality can be measured.

To date the application of the quality of the environment literature to the understanding of the impact of the built environment on the quality of life of people with dementia has been limited and has not provided a clear picture of the relationship. This may be attributable to the problems of measurement in both areas. The investigation reported here uses an approach to the assessment of the built environment that is more broadly based and empirically supported than previous measures and looks at QoL as measured in four, interrelated, ways. The aim is to find a way to explore and describe the relationship between QoL and the quality of the environment that the environmental design literature suggests should be there.

6.5 Background

While the evidence for the beneficial effects of designing the physical environment to meet the needs of people with dementia in residential care has been mounting for more than 25 years, there have been few studies that have directly addressed the relationship between the nature of the environment and the quality of life of the people with dementia living in it. The effect of the setting in which care is provided, that is, community versus residential, has been subject to some research (González-Salvador, Lyketsos et al. 2000) but there are no consistent data on the differences in quality of life across them (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam and del Valle 2009).

An evaluation of the impact of the quality of the immediate physical environment on quality of life has been attempted in two studies. The earliest (Zimmerman, Sloane et

al. 2005) examined the relationships between a wide variety of measures of the structure and processes of care in 35 residential facilities and the quality of life of 421 residents using linear mixed models controlling for facility type, resident age, gender, race, marital status, length of stay and cognitive, ADL, number of comorbid conditions, depressive and behavioural symptoms. Quality of life was measured from the viewpoint of the resident, the viewpoint of the staff and by direct observation. Quality of the environment was evaluated using the Therapeutic Environment Screening Survey for RC/AL, an assessment developed from the Therapeutic Environment Screening Survey for Nursing Homes (Sloane 2002) to provide ratings for dementia-specific areas (Special Care Unit-Environmental Quality Score, SCU-EQS) and non-dementia-specific areas (Assisted Living Environmental Quality Score, AL-EQS). The findings were mixed. Hierarchical Linear Modelling revealed a significant negative association ($p < 0.05$) between quality of the environment and staff-rated quality of life as measured by the Quality of Life – Alzheimer's Disease, QOL-AD (Logsdon, Gibbons et al. 2000) but a significant positive ($p < 0.01$) relationship with quality of life assessed by direct observation using the Dementia Care Mapping protocol (Bradford Dementia Group 1997). The relationship with resident-rated quality of life as assessed by the QOL-AD was positive but did not reach significance ($p < .1$).

A more recent study (Bicket, Samus et al. 2010) utilising the same environmental assessment, the TESS-NH, but a different quality of life measure, the Alzheimer's Disease Related Quality of Life (Rabins, Kasper et al. 2000), reported a positive correlation between the quality of the physical environment and quality of life. However, this association was no longer significant after controlling for age, gender, education and dementia status.

The lack of definitive evidence of a link between the quality of the environment and the quality of life of people with dementia living in that environment is somewhat surprising given the evidence that is available on the beneficial effects of specific environmental interventions (Day, Carreon and Stump 2000; Fleming and Purandare 2010). The current study utilises an environmental assessment tool that collects data

on a wider range of features than the TESS-NH covers and that are theoretically and empirically related to high quality environments: unobtrusive safety features, small size, good visual access, enhancement of helpful cues, reduction of unhelpful stimulation, familiarity, provision of an interesting internal and external pathway, links to the community, provision of space to be alone and with others and provision of opportunities to engage in the ordinary activities of daily living.

The study tests the hypothesis that the quality of the environment thus measured is predictive of the quality of life when controlling for variables that have been shown to have the potential to influence quality of life: age, marital status, ethnic background, cognitive functioning, psychiatric diagnosis, number of medications taken, level of daily living functioning.

The tool used to measure quality of life provided four scores: a global rating based on a single question put to both the resident and the proxy, and a detailed assessment utilising multiple questions put to both the resident and proxy. This provided the opportunity to investigate the effect different approaches to quality of life measurement have on attempts to reveal the relationship with the quality of the environment. It was hypothesised that the self-report of the person living in the environment would provide a better chance of identifying the relationship should that relationship exist.

The study falls into two parts: the investigation of the link between the overall quality of the environment and quality of life as measured by self-report and proxy measures; and an analysis of the specific features of the environment that contribute to quality of life.

6.6 Subjects and methods

6.6.1 Setting

The opportunity to examine the relationship between quality of the environment and quality of life was afforded by the collection of data for the Sydney Multisite

Intervention of LaughterBosses and ElderClowns (SMILE) study. This involved 35 aged care homes in the greater metropolitan area of Sydney, Australia, not catering for a particular ethnic or minority group, or medical condition except for dementia (Goodenough et al. 2012; Low, Brodaty et al. 2013). Australian residential aged care facilities are classified as either low or high care depending on the severity of the physical frailty and behavioural disturbance of the residents. Fourteen homes were low care. Fifteen of the aged care homes involved in the study had more than 31 beds, 12 had between 17 and 30, and 8 had 16 or less.

6.6.2 Sample

The sample comprised residents over the age of 50, not being so disturbed that they presented a risk to study personnel, having at least a limited ability to communicate, not acutely ill, not floridly psychotic, living in a discreet area of the nursing home and having someone able to consent to inclusion in the study on their behalf. A total of 497 residents were considered to be potentially eligible for inclusion and screened, 83 were found to be not eligible, consent was not obtained for six, three withdrew prior to assessment, data could not be obtained on seven, and one or both self-report or proxy quality of life assessments could not be obtained in 123 cases, leaving a final sample of 275, 77% female, average age 84.3 (SD 8.68) and time in care 2.84 (SD 4.5 years).

6.6.3 Measures

All data reported in this study were collected at the baseline of the SMILE study. Information on resident demographics (age, gender, ethnicity), time in care, medications, diagnosis of dementia and other neurodegenerative disorders (e.g. Parkinson's disease), psychiatric diagnoses (e.g. depression, anxiety, psychosis) and illness co-morbidity (e.g. diabetes, cardiovascular disease) was obtained from case notes; current functioning was assessed using the Barthel Index (Mahoney and Barthel 1965); psychiatric symptomatology was assessed using the Neuropsychiatric Inventory-Nursing Home version (NPI-NH) (Cummings, Mega et al. 1994) total score and cognitive impairment was evaluated using the Global Deterioration Scale (Reisberg, Ferris et al. 1982).

The study utilised an environmental assessment tool that has at its foundation a set of principles that have substantial empirical support (Fleming 2011) . The Environmental Audit Tool (EAT) comprises 72 items arranged into 10 sub-scales to reflect these design principles. The inter-rater reliability of the EAT, ICC 0.97 (sig. 0.000) and the validity, as measured by its correlation with the TESS-NH (Sloane et al. 2002) of 0.82 (sig. 0.000) are very satisfactory. The validity of the EAT has also been demonstrated by its ability to discriminate between dementia-specific and mainstream facilities in Australia (Smith, Fleming, Chenoweth, Jeon, Stein-Parbury and Brodaty 2012). The EAT data was collected by a single assessor visiting all facilities.

6.7 The principles underpinning the EAT

Provide unobtrusive safety features: The confusion which accompanies dementia determines the need for a variety of safety features to be built into the environment. They include the provision of a secure perimeter (Rosewarne, Opie, Bruce, Ward and Doyle 1997). The residents may respond negatively to the security if it obviously impedes their freedom (Low, Draper and Brodaty 2004; Torrington 2006). This can be mitigated by providing unobtrusive safety features (Annerstedt 1997; Zeisel, Silverstein, Hyde, Levkoff and al 2003).

Provide small units: The development of special care units for people with dementia has been influenced by the view that larger facilities increase agitation and are confusing for residents (Sloan 1998; Hagglund and Hagglund 2010) and high quality care is easier to provide in small groups (Annerstedt 1993; Reimer, Slaughter, Donaldson, Currie and Eliaszew 2004). The findings reported in the literature are hard to interpret however as there is no accepted definition of small, which has been defined as up to 150 beds (Leon and Ory 1999). Small size is almost always accompanied by approaches to the delivery of care and staff training that differentiate small units from traditional units (Sloan 1998) and there are contradictory findings. Zeisel, for example, found less social withdrawal in larger units (Zeisel, Silverstein,

Hyde, Levkoff et al. 2003). No link has been found between small size and neuropsychiatric symptoms (Zuidema, de Jonghe, Verhey and Koopmans 2009). The evidence tends to suggest that the best outcomes occur when the resident lives in a small unit but has access to a larger social network.

Maximise visual access: Confusion may be reduced by caring for the confused person in a simple environment. The simplest environment is one in which the resident can see everywhere that she wants to go to from wherever she is. Being able to see the kitchen, dining room, lounge room and the person's own room is particularly important. This principle defined the plans of the units for the confused and disturbed elderly built by the NSW Department of Health in the late 1980s which were shown to improve self-help, socialisation and behaviour (Fleming and Bowles 1987) and is associated with improved orientation (Passini, Rainville, Marchand and Joannette 1998.). Disorientation has been found to be less pronounced in L-, H- and square-shaped units where the kitchen, dining room and activity rooms were located together (Elmstahl, Annerstedt and Ahlund 1997) and where the straight layout of the circulation system, without any change of direction, provided good visual access (Hagglund and Hagglund 2010).

Evidence of the importance of being able to see what you need to see when you need to see it is provided in a study that investigated the effects of making the toilet visible rather than hiding it away (Namazi and Johnson 1991a). When the toilet was visible to residents with dementia it was, on the average, eight times more likely to be used than when it was not easily seen.

Reduce unnecessary stimulation: As the person with dementia experiences difficulties in coping with a large amount of stimulation, the environment should be designed to reduce the impact of stimulation that is unnecessary for the wellbeing of the resident (Cleary, Clamon, Price and Shullaw 1988.) There is strong evidence that residents are less verbally aggressive where sensory input is more understandable and where such input is more controlled (Zeisel, Silverstein, Hyde, Levkoff and al 2003). Aggressive behaviours increase with high noise levels (Cohen-Mansfield and Werner

1995). Busy entry doors pose particular problems for staff and patients. They are a constant source of over stimulation and a temptation to escape. These problems can be significantly reduced by reducing the stimulation (Namazi 1989.; Dickinson, McLain-Kark and Marshall-Baker 1995).

Enhance useful stimulation: The reduction in unnecessary stimulation should be balanced by highlighting stimuli that are important to the residents. The provision of signs and aids to wayfinding is integral to the design of many special environments for people with dementia (Grant, Kane and Stark 1995; Passini, Pigot, Rainville and Tetreault 2000) and have been associated with a reduction in behavioural symptoms (Bianchetti, Benvenuti, Ghisla, Frisoni and Trabucchi 1997). The placement and nature of the signs is important; signs placed low and using words rather than pictograms are most effective (Namazi and Johnson 1991b).

There is some evidence that the use of colour to distinguish the doors to residents rooms has a beneficial effect (Lawton, Fulcomer et al. 1984) and the display of personal memorabilia outside the room may be of some benefit (Namazi, Rosner and Rechlin 1991; Nolan, Mathews et al. 2001).

Provide for wandering: Wandering is sometimes a feature of the behaviour of the person with dementia. It can be significantly reduced by the provision of a path that guides people past opportunities to engage in activities other than wandering. The provision of a walking path has been shown to be associated with lower levels of agitation (Zeisel, Silverstein, Hyde, Levkoff and al 2003). Access to an outside area is associated with reduced sadness and increased pleasure (Cox, Burns and Savage 2004).

Provide a familiar environment: The person with dementia recalls the distant past more easily than the recent past. This may explain the beneficial effects associated with them being in a familiar environment (Cohen 1991; Chandler 2007; Smith, Lamping et al. 2007; Access Economics 2009). To ensure that their experience of their surroundings is in keeping with their mental state the decor should be such that

it would have been familiar to the residents in their early adulthood. The opportunity to increase the familiarity of the surroundings by the resident bringing in their own belongings has been associated with the maintenance of activities of daily living and reductions in aggression, anxiety and depression (Annerstedt 1997).

Provide spaces for both privacy and social interaction: People with dementia require a range of opportunities for social interaction and privacy. The provision of rooms for different functions has been shown to differentiate SCUs from non-SCUs in a statewide survey involving 436 Minnesota nursing homes (Grant, Kane and Stark 1995). The strongest evidence for its importance comes from Zeisel's well controlled study (Zeisel, Silverstein, Hyde, Levkoff et al. 2003) which indicated that residents with the opportunity to enjoy privacy were less anxious and aggressive, and those who had access to a variety of common spaces with varying ambiance were less socially withdrawn and depressed. The time residents spent in active behaviour has been shown to be associated with the provision of a variety of spaces (Barnes 2006).

Provide amenities that encourage links with the community: In an early statement of the principles of good design for people with dementia (Fleming and Bowles 1987) it was stated that facilities should be placed close to the community of origin of the person because the identity of a person who has lost their recent memories can be more easily supported by familiar sights and visits from friends and relatives when they are living close to that community. This view has been supported (Chiarelli, Bower et al. 2005) but no empirical investigations of the advantages have been found. The importance of a community to the wellbeing of people with dementia is an emerging field of research (Keady, Campbell, Barnes, Ward, Li, Swarbrick, Burrow and Elvish 2012).

Provide a domestic environment with opportunities to engage in activities of daily living: The environment should be as homelike as possible as, in the absence of a treatment for dementia, the goal of care is to maintain the person's abilities for as long as possible. This requires that they have access to all of the normal household facilities and encouragement to use their abilities (Scott, Ryan et al. 2011). The

introduction of a small number of homelike features into an institutional environment resulted in a reduction in pacing, agitation and exit seeking (Cohen-Mansfield and Werner 1998) and improved social interaction and eating behaviour (Melin and Gotestam 1981.)

Access to a homelike environment has been associated with reduction in anxiety and an increase in interest in the surroundings as compared with levels found in residents of traditional nursing homes (Reimer, Slaughter, Donaldson, Currie and Eliaszew 2004). Higher levels of agitation were also found but interpreted as an indication of the greater freedom available to the residents in a homelike environment. Lower levels of aggression have been found in residents of more residential type units than in more institutional settings (Zeisel, Silverstein, Hyde, Levkoff et al. 2003).

Residents in group homes providing engagement with the ordinary activities of daily living have less need for help with Activities of Daily Living, more social engagement, more sense of aesthetics and the opportunity to do more than residents in traditional nursing homes (te Boekhorst, Depla, de Lange, Pot and Eefsting 2009). Support for environmental approaches to encouraging residents to take part in domestic activities have been well described (van Hoof, Kort et al. 2010) in a summary of more than 20 studies.

Quality of life (QoL) of the residents was assessed using the proxy and self-report versions of the DEMQOL (Smith, Lamping, Banerjee, Harwood, Foley, Smith, Cook, Murray, Prince, Levin, Mann and Knapp 2007). The self-report version of this scale contains 28 specific questions: thirteen questions on feelings, six on worries about memory and nine on worries about everyday life, such as getting help when needed. Responses to these questions are summed to provide a total score. Question 29 “We’ve already talked about lots of things: your feelings, memory and everyday life. Thinking about all of these things in the last week, how would you rate your quality of life overall?” provides an overall score. The response can be very good, good, fair or poor. This question is treated as a global rating of quality of life. The proxy version follows the same format.

6.8 Data analysis

Statistical analysis was carried out using IBM SPSS 19 for Windows ®. Variables associated with the quality of life of people with dementia in previous studies were entered into a linear regression model to determine their influence on DemQol scores. The variables were entered in order of probable significance based on previous studies (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam and del Valle 2009). The EAT score was entered last.

Following the identification of a successful model, the EAT subs-scales making a significant contribution were identified by repeating the linear regression using the subscale totals as the final variable to be entered

6.9 Results

Data were available from 275 residents for whom both the self-reported and proxy versions of the DemQol were available. While 27.3% of these people did not have a formal diagnosis of dementia the Global Deterioration Scale scores indicated that all participants had at least subjective complaints of memory loss and 60% had moderate to moderately severe dementia. Table 13 reports the details of the assessments.

Table 13: Descriptive statistics of the measures (n=275)

	Frequency count (%)	Range	Mean	Standard Deviation
Age		53 -101	84.33	8.66
Time in care (years)		0.08 - 58	2.84	4.51
Gender				
Male	64 (23.3)			
Female	211 (76.7)			

	Frequency count (%)	Range	Mean	Standard Deviation
Ethnicity				
Australian	170 (6.18)			
UK, US, Canada or English speaking country	44 (16.0) 25 (9.1)			
European	5 (1.8)			
Asian	16 (5.8)			
Other	15 (5.5)			
unverified				
Marital status				
Married/Partnered	40 (14.5)			
Separated/Divorced	30 (10.9)			
Single	42 (15.3)			
Widowed	162 (58.9)			
unverified	1 (.4)			
Diagnosis of dementia				
Nil	75 (27.3)			
Alzheimer's Disease	51 (18.5)			
Dementia with Lewy Bodies	1 (.4)			
Front-temporal dementia	1 (.4)			
Huntington's disease	1 (.4)			
Korsakoff's syndrome / alcohol	11 (4.0)			
Parkinson's disease	5 (1.8)			
Vascular	29 (10.5)			
Mixed	13 (4.7)			
Unspecified "dementia"	86 (31.3)			
MS	2 (.7)			

	Frequency count (%)	Range	Mean	Standard Deviation
Global Deterioration Scale				
Subjective complaints of mild memory loss	10 (3.6) 45 (16.4)			
Mild Cognitive Impairment (MCI)	55 (20.0)			
Early dementia	67 (24.4)			
Moderate dementia	98 (35.6)			
Moderately severe dementia				
Cognitive Rating		0-21	9.77	6.12
Barthel Index –Total Score		0-100	46.22	24.39
Physical Incapacities (speech, sight, hearing) (max = 45)		15-45	36.36	7.48
Psychiatric Diagnoses				
0	119 (43.3)			
1	100(36.4)			
2	48 (17.5)			
3	7 (2.5)			
4	1 (.4)			

	Frequency count (%)	Range	Mean	Standard Deviation
Number of regular medications				
0	8 (2.9)			
1	17 (6.2)			
2	20 (7.3)			
3	34 (12.4)			
4	42 (15.3)			
5	40 (14.5)			
6	38 (13.8)			
7	27 (9.8)			
8	26 (9.5)			
9	5 (1.8)			
10	4 (1.5)			
11	8 (2.9)			
12	2 (.7)			
13	1 (.4)			
14	2 (.7)			
15	1 (.4)			
EAT Total score (%)		13.39- 63.39	34.73	10.97
DemQol Global Rating - self report (Q29)		1 - 4	2.27	0.83
DemQol Global Rating – proxy (Q32)		1 - 4	2.36	0.89
DemQol Total –self report		33 - 112	90.05	14.31
DemQol Total -proxy		61 - 113	97.75	7.99

Table 14: Correlations between QoL measures

DemQol results	Total score self-report*	Global proxy	Total proxy
Global self-report (qu. 29)	-0.519**	0.288**	-0.015
Total score self-report		-0.293**	0.054
Global proxy (qu. 32)			0.015

*Scored oppositely to the total score, hence negative correlation

Linear regression was performed using DemQol self-report global rating, proxy global rating, self-report total score and proxy total score as the dependent variable. Table 15 shows the significance of the regression models and the predictive power of the variables in the final model. Only the model utilising the DemQol self-reported global rating reached significance, accounting for 14.6% of the variance. The best predictor of quality of life in this model is the Barthel Index total score, a measure of the resident's capacity to engage in the activities of daily living. The quality of the environment as measured by the EAT total score was the second-most significant predictor.

Table 15: Results of linear regression analyses (n=275)

	Global self-report (Q29)			DemQol Total self-report			Global Proxy (Q32)			DemQol Total proxy		
	B _{in}	B _{end}	r ²	B _{in}	B _{end}	r ²	B _{in}	B _{end}	r ²	B _{in}	B _{end}	r ²
High or Low Care	-0.123	0.000	0.015	0.097	-0.025	0.009	-0.033	0.059	0.001	0.089	0.084	0.008
Gender	0.279	0.135*	0.026	-0.118	-0.139*	0.044	0.166	0.156*	0.031	0.029	0.007	0.021
Age	-0.001	0.009		0.053	0.025		0.040	0.046		0.055	0.051	
Time in care (yrs)	-0.011	-0.101		0.082	0.078		-0.059	-0.074		-0.066	-0.082	
Marital status	-0.001	-0.079		0.107	0.096		-0.032	-0.026		-0.033	-0.016	
Ethnic background	0.000	0.042		-0.076	-0.048		0.073	0.052		0.082	0.066	
Dementia type	0.011	0.032	0.051	-0.047	-0.015	0.046	0.117	0.091	0.073*	-0.005	-0.005	0.033
Global Deterioration Score	-0.012	-0.009		0.027	0.032		0.158	0.162		-0.132	-0.117	

	Global self-report (Q29)			DemQol Total self- report			Global Proxy (Q32)			DemQol Total proxy		
Cognitive rating	0.003	-0.044	0.118*	-0.030	-0.006	0.122*	-0.043	-0.056	0.096	0.039	0.017	0.039
Barthel Index - Total score	-0.009	-0.219*		0.320	0.274*		-0.124	-0.084		-0.004	0.014	
Physical Incapacities	-0.003	-0.042		-0.064	-0.058		-0.073	-0.081		-0.077	-0.086	
Number of Psychiatric Diagnoses	0.102	0.117		-0.148	-0.152*		0.167	0.172*		-0.033	-0.026	
Number of regular medications	-0.006	-0.027	0.127	-0.130	-0.128*	0.166*	0.042	0.040	0.126*	-0.021	-0.024	0.040
EAT total %		-0.159*	0.146*		0.047	0.168		-0.057	0.129		-0.078	0.045

B_{in} standardised partial regression coefficient on step that variable was entered into the model;

B_{end} standardised partial regression coefficient after all variables entered, $r^2 = R$ -Squared

* $p < 0.05$ (note: for r^2 , * denotes statistically significant change in r^2 since previous step in analysis.

Linear regression of the same variables using the DemQol self-reported global score as the dependent variable was repeated with each of the EAT sub-scale total scores being entered as the final variable. This process revealed that the provision for alternatives to wandering (R^2 0.143, sig 0.03), familiarity (R^2 0.149, sig 0.01), provision of spaces for privacy and social interaction (R^2 0.143, sig 0.028) and provision of opportunities for engagement in domestic activities (R^2 0.142, sig 0.032) are the significant environmental characteristics that contributed to self-reported quality of life.

6.10 Discussion

This study provides support for the hypothesis that there is a positive relationship between the quality of the built environment and the quality of life of the people living in it. It also supports the hypothesis that the relationship between quality of life

and quality of the environment is best revealed by seeking information directly from those living in the environment.

These findings are in contrast to a previous investigation which concluded that higher environmental quality was significantly and negatively associated with quality of life of residents as rated by staff and not significantly related to resident ratings of quality of life (Zimmerman, Sloane et al. 2005). Another investigation showed that environmental quality was not associated with quality of life as measured by the proxy rated ADRQL (Cheng, Cruysmans et al. 2009). The evaluation of the environment in both of these studies was carried out with a variation of the TESS-NH (Sloane et al. 2002).

The lack of association between quality of the environment and quality of life of the residents in these studies is surprising given the large number of studies that have found positive relationships between specific characteristics of the environment and the reduction of problems associated with dementia (Day, Carreon and Stump 2000; Fleming and Purandare 2010). It is suggested that these findings are due to problems in the measuring tools.

There is a lack of agreement on the most appropriate method to assess the quality of life of people with dementia. Problems with recall, time perception, insight and communication raise concerns about the validity of self-report measures (Rabins, Kasper, Kleinman, Black and Patric 2000) and have led some to the conclusion that ratings should be made by proxies, for example family members or caregivers (Whitehouse 1999). However, more recent research has drawn many to the conclusion that “clinicians should give importance to the person with dementia’s rating of quality of life. Informant ratings of QoL (by both staff and family carers) should be interpreted cautiously, as they do not directly represent patients’ perceptions, needs and aspirations” (Beer, Flicker et al. 2010). This issue is explored in detail in the reviews of (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam and del Valle (2009) and Ettema et al. (2005).

Difficulties also exist with the measurement of the quality of the environment. The tool used in the studies described above rates 15 environmental items: facility maintenance, cleanliness, handrails, call buttons, light intensity, light glare, light evenness, hallway length, home-likeness, room autonomy, telephones, tactile stimulation, visual stimulation, privacy, and outdoor area. It is heavily biased towards an institutional view of what characterises a high quality environment and may, again, not reflect the residents' perceptions, needs and aspirations.

It is suggested therefore, that investigations of the relationship between the quality of the environment and the quality of life of residents, require a sharper focus on the views of the residents themselves and environmental characteristics that have a firm link with the reduction of problems associated with dementia and the enhancement of engagement with life.

The modest, though significant, correlation between the DEMQOL overall rating and total score suggests that these scores are measuring different aspects of quality of life. It has been noted that the DEMQOL questions are heavily weighted towards worries of various types (Jenkinson, Peters et al. 2011, p. 90). This raises the question of whether people with dementia themselves, define the quality of their lives in terms of concerns with specific aspects of life.

The term 'disability paradox' (Albrecht and Devlieger 1999) has been coined to describe the phenomenon of people with serious and persisting disabilities reporting that they experience a good quality of life. The individual problems that they experience do not seem to define their lives. This phenomenon has been used to explain the discrepancy between proxy and self-reports of quality of life (Banerjee, Samsi, Petrie, Alvir, Treglia, Schwam and del Valle 2009). While the proxy, putting themselves in the place of the person with dementia, describes the quality of life as poor based on their experience, the person with dementia, having gone through a process of adaptation, takes a more positive point of view.

This process sometimes results in the disabled person finding a new way to evaluate their life. This seems to depend on them finding “a balance between body, mind and spirit and on establishing and maintaining an harmonious set of relationships within the person’s social context and external environment” (Albrecht and Devlieger 1999, p. 977).

This raises the possibility that the simple, single question ‘Thinking about all of these things...’ provides a better chance for the person to express this balance, or lack of it, than answering 28 separate questions.

This study reports findings from the use of both the DEMQOL proxy and self-report assessments. Given the existing findings in the literature and the comments above it is not surprising that the proxy measure of quality of life did not show any significant relationship with the quality of the environment.

However, the linear regression modelling revealed a significant association between global rating of quality of life provided by the residents and the quality of the environment as measured by the EAT. The model accounted for a modest 14.6% of the variance. The variable most predictive of self-rated quality of life was the total Barthel Index score which measures the resident’s ability to engage in the basic activities of daily living (e.g. grooming, walking and dressing). The quality of the environment was more predictive of quality of life than age, time in care, marital status, level of cognitive functioning, medication usage and level of psychiatric disturbance.

The second part of the investigation revealed that the most important features of the environment were the provision of a range of opportunities to engage with objects and activities (facilitated by an external and internal path guiding the resident past them), familiarity, the provision of a variety of spaces allowing for privacy and social interaction and access to ordinary activities of daily living.

The results suggest that when the environment is able to provide a range of opportunities for engagement with daily living and when the resident has the ability to use them, quality of life can be expected to be higher. The finding of a positive relationship between quality of life and the provision of opportunities to follow an interesting path that guides the resident from inside to outside and back again, a familiar environment with opportunities for privacy and social interaction, and the possibility of being involved in ordinary activities of daily living have some congruence with the idea of finding the balance described above.

The findings of this study suggest that the quality of physical environment is very important to people with dementia and they provide a strong foundation for the provision of advice to managers and architects who are engaged in refurbishing or designing environments for them.

However a major limitation of this study, which has not yet been overcome in any study reported to date, must be noted. The study did not control for quality of care. There is evidence to suggest a close association between quality of care and the quality of the environment (Sloan 1998) but the relative contributions await the completion of a longitudinal randomised control trial comparing the results of residence in facilities differing on quality of care and quality of the environment (Chenoweth, King, Luscombe, Forbes, Jeon, Parbury, Brodaty, Fleming and Haas 2011)

It must also be noted that the sample of residents was not random but chosen for their suitability for the SMILE study. It is not known whether or not they are representative of the population of residential aged care residents.

6.11 Conclusion

At its simplest, this study suggests that when a person with dementia is asked a straightforward question about how they rate the quality of their life, that rating is heavily influenced by the quality of the environment in which they are living. Higher

quality of life is associated with living in an environment that is familiar and that provides opportunities for engagement with objects and activities, privacy and social contact along with the amenities and opportunities to take part in domestic activities. However, definitive proof requires the inclusion of a quality of care measure with the other control variables using a randomised controlled trial, preferably longitudinal in nature to demonstrate cause and effect.

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6.13 Extended Discussion

While the amount of the variance explained by the model was very modest, it was significant and indicated that the built environment is more important to the quality of life of people with dementia than many other variables. The fact that the variable that was more important was the ability to engage in ordinary activities of daily living, as measured by the Barthel Index, may be pointing to the interrelationship of the opportunities provided by the building and the resident's ability to take advantage of them. Clearly both are necessary for engagement to occur, and hence quality of life to be produced (Wood, Harris et al. 2005). However, as mentioned in the paper, there is a third variable that needs to be taken into account: the quality of the care provided by the staff. Just as it has been shown that the provision of an attractive outdoor space has very little effect if staff are not involved in its use (Cox, Burns et al. 2004), so it is likely that the effects of a well-designed building will be mediated by the presence of staff who use the amenities it provides to engage the residents.

The absence of a measure of quality of care may well explain the modest size of the explained variance. It is suggested that when a measure of the quality of care is added to the model the amount of explained variance will increase. This is currently being investigated in a research project funded by the NHMRC, led by Professor Lynn Chenoweth, with the candidate as a chief investigator (Chenoweth, King et al. 2011).

Perhaps the most satisfying aspect of this investigation, even though I am heavily invested in exploring the impact of the built environment, is the highlighting of people with dementia as the source of the best information, when they are asked in a manner that is sensitive to their needs. This study utilised a self-report measure of quality of life. Other measures have been proposed, for example structured and semi-structured interviews, observation and focus groups (Cheston, Bender et al. 2000). One of these methods, focus groups, was used in a recent UK study investigating the extent to which the environment of care homes met the requirements of the residents (Popham and Orrell 2012). The authors claimed that this was the first study to investigate in depth the views of people with dementia about the suitability of their living environments. It is clear that much needs to be done to bring the views of people with dementia into consideration in our research.

6.14 Impact

As this paper has not yet been published it has had no widespread impact. However it is helping to guide the analysis of the Chenoweth data.

6.15 Further Research

The demonstration that the investigation of the impact of the physical environment on quality of life of residents using a broadly based environmental assessment and a simple question addressed directly to the residents is likely to spark more research. A similar approach could be taken to investigating the relationship between the quality of the environment and depression, for example. The single item Geriatric Depression Scale might provide the data for the dependent variable (Gori, Appollonio et al. 1998). It may be possible to use other simple single-item scales to explore the relationship between the built environment and, for example, happiness (Abdel-Khalek 2006) or anxiety (Davey, Barratt et al. 2007). They would, of course, have to be validated on a sample of people with dementia.

6.16 Conclusion

This chapter advances our understanding of the relationship between the built environment and people with dementia who live in it, and offers suggestions for sensitive, and respectful, ways to engage in further investigations.

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CHAPTER 7: EVIDENCE-BASED FACILITIES DESIGN IN HEALTHCARE: A STUDY OF AGED CARE FACILITIES IN AUSTRALIA

The paper presented in this chapter was written by the candidate. Co-author Professor Roger Fay assisted with data collection and commented on the manuscript. Co-author Professor Andrew Robinson commented on the manuscript. It was published as:

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7.1 Aim

The purpose of undertaking this study was to try to understand the reasons for the slow uptake of the knowledge on designing physical environments for people with dementia so that effective programmes for translating this knowledge into practice could be devised.

7.2 Background

Chapters 1 and 3 of this thesis have outlined the accumulation, over a thirty-year period, of a significant body of knowledge on the design of environments for people with dementia. Yet there are still many ‘dementia-specific’ facilities being built that appear to have been designed without reference to this information.

This situation is known to the Department of Health and Ageing (DoHA) in Australia. DoHA assigned responsibility for doing something about this to the NSW/ACT Dementia Training Study Centre (DTSC). As director of this centre I set about developing a number of interrelated projects aimed at addressing this issue. They included the development of the EAT iPhone app, the provision of workshops in every state and territory on environmental design, the introduction of designing for people with dementia to undergraduate architectural studies in four universities and

the introduction of a consultancy service targeting organisations that were actively involved in designing facilities for people with dementia.

While it is satisfying to be involved in trying to do something about an unsatisfactory situation, it is more satisfying, and possibly more effective, to understand some of the problems that make the situation unsatisfactory.

The opportunity to investigate the problems was provided by the availability of funding from the UNSW Dementia Collaborative Research Centre and the Tasmania-based Wicking Trust.

The paper follows in sections 7.3 to 7.8.

7.3 Summary

Many facilities for people with dementia have been built with little translation of the substantial body of evidence available to inform design. Knowledge translation has been described as a four stage process, awareness, agreement, adoption and adherence. This paper identifies where knowledge translation fails in the design of aged care facilities for people with dementia.

Ten aged care facilities were audited using the Environmental Audit Tool (EAT). Senior managers and architects involved in the facility design were then interviewed to ascertain their knowledge of evidence-based principles of dementia design, their agreement with the principles and the nature of the obstacles they had encountered in their implementation.

All architects claimed at least partial awareness of the design principles. Five facility managers claimed full awareness. Those facilities designed with the input of managers who were fully aware of the principles were of significantly higher design quality. There was little agreement on the significance of other obstacles.

Once aged care providers are aware of the principles they appear to find ways to implement them. If the next generation of residential aged care facilities is to be suitable for people with dementia, the facility managers must be made aware of the available design principles, architects encouraged to be more active in sharing their knowledge and ways found to improve the exchange of knowledge between the parties.

7.4 Introduction

In 2009–10 it was estimated that there were over 84,000 people with dementia in residential aged care facilities across Australia (Access Economics 2009) and it is estimated that the demand for these places will grow at 4% per annum between now and 2029 (Knapp and Prince 2007). This reflects a worldwide phenomenon. The number of people with dementia in the UK is currently estimated at 700,000 and will double within 30 years (Fleming and Purandare 2010). The scale of the demand for residential facilities for people with dementia directs attention to the need for these facilities to be well designed.

There has been a substantial amount of empirical research into those aspects of the physical environment that can assist people with dementia by reducing confusion, agitation and depression while improving social interaction and engagement with the activities of everyday living. This research has been used to develop a set of principles that inform the design of residential aged care facilities for people with dementia (Howard, Ballard et al. 2001; Marshall 2001; Fleming, Forbes and Bennett 2003; van Hoof, Kort, van Waarde and Blom 2010). The importance of the design in supporting quality of life for people with dementia has been recognised in guidelines published by the *International Journal of Geriatric Psychiatry* (Howard, Ballard, O'Brien, Burns and Manage 2001), the American Academy of Neurology (Doody, Stevens et al. 2001), the American Geriatrics Society and the American Association for Geriatric Psychiatry (Ouslander, Bartels et al. 2003) and the Australian Alzheimer's Association (Alzheimer's Australia 2004).

While there are examples of good design to be found in Australia and elsewhere (Judd, Marshall and Phippen 1998) the results of an audit of 30 aged care facilities in Sydney, Australia showed that many have been designed in a way that does not reflect the application of the evidence-based principles (Fleming 2011). This gap between the actual design of facilities and the evidence base highlights a problem in the translation of dementia design knowledge into practice.

The steps involved in the process of translating knowledge into practice in health care have been analysed in several ways. The transtheoretical model (Prochaska and Velicer 1997), dealing with change at the level of the individual, suggests that health behaviour change involves progress through six stages of change: pre-contemplation, contemplation, preparation, action, maintenance, and termination. Rogers (Rogers 2003) looking at the broader picture, conceptualised them as stages in the decision-innovation process and in their very influential paper Pathman and colleagues (Pathman, Konrad et al. 1996) provided a useful, four-stage framework for exploring the issues around knowledge translation on a large scale. They suggest that if knowledge is to be translated into practice the potential knowledge users must first become aware of the existence of the evidence, for example by reading an article or a conference presentation. In the second stage Pathman suggests the user must evaluate the new knowledge and come to the conclusion that it is credible and that they agree with it. In the third stage the knowledge must be adopted into practice and in the fourth stage, adherence, the new application becomes business as usual, often as the result of the development of regulations to ensure compliance with accepted good practice.

The idea that knowledge translation in the area of the development of medical services is a simple linear process has, however, come under criticism. Newell et al. (2003) have drawn attention to the role of 'process knowledge' as a facilitator in the transfer and application of 'product knowledge'. This approach recognises that the characteristics of the relationships within a project team will have a profound impact on the uptake of the available knowledge. McDonnell (2009) has investigated this in the area of client–architect relationships and, while not using the language of

knowledge transfer, has come to similar conclusions. Analysing conversations between architects and building users, she describes the interchanges in a collaborative planning meeting and reports that “a priori designations of the roles of building user, client, designer ... are also to some extent continually negotiated during conversation” (p. 49). McDonnell goes on to suggest that in the context of such negotiations, it is important not to “overprivilege nor to under-rate expertise” but rather acknowledge the expertise of others and their right to assert their expertise when the situation demands as “a practical way to get things done ... a consensual act without implying power inequality” (p. 49).

This study applies Pathman’s model of knowledge translation to the exploration of obstacles that frustrate the application of the existing knowledge on good design for people with dementia. It also calls on the insights of Newell and McDonnell to help explain the lack of knowledge transfer that occurred in some teams even when the knowledge was available, when there was a failure to achieve “a practical way to get things done”.

Table 16: Principles to guide the design of environments for people with dementia

1. Safety and security	The confusion that accompanies dementia determines the need for a variety of safety features to be built into the environment. They include a secure perimeter, hot water control and safety switches in the kitchen. As obtrusive attention to safety and security increases anxiety and agitation, unobtrusive measures are to be preferred.
2. Small	The larger a facility the more confusing it is likely to be for residents. High quality care is easier to provide in small groups.

3. Simple with good 'visual access'.	Confusion may be reduced by caring for the confused person in a simple environment. The simplest environment is one in which the resident can see everywhere that she wants to go to from wherever she is. This principle limits the inclusion of corridors in the design and results in the staff being able to see the residents almost all of the time. This reduces anxiety in both staff and residents.
4. Reduced unwanted stimulation	The person with dementia experiences difficulties in coping with a large amount of stimulation. The unit must be designed to reduce the impact of stimulation that is unnecessary for the well-being of the resident, e.g. entry and exit doors used for deliveries, staff movements etc. should not be visible to the residents. Noise must also be minimised.
5. Highlighting of important stimuli	Stimuli that are important to the residents should be highlighted. These include toilet doors, exit to safe outside area, aids to recognition on bedroom doors.
6. Provision for wandering.	Wandering is sometimes a feature of the behaviour of the person with dementia. The design should allow it to take place safely but not encourage it. The wandering path should provide an opportunity for the person to go outside and take them past areas of interest in the expectation that they will provide the person with an alternative to repetitive wandering.
7. Familiarity	The person with dementia recalls the distant past more easily than the recent past. It follows then that their experience of recent furniture designs and decors must be less congruent with their present mental state than their experience of decors that they enjoyed in their younger days. To ensure that their experience of their surroundings is in keeping with their mental state the decor should be such that it would have been familiar to the residents in their early adulthood.

8.Privacy and community	People with dementia require a range of opportunities for social interaction. Spaces are needed for sitting quietly alone, with one or two intimate friends, and in larger groups.
9. Links to the community	The chances that the residents will continue to be part of their social network after admission should be maximised by providing for their care in small units in their community. These units should provide amenities that encourage visitors so that links with families and friends are not broken.
10. Domestic	The environment should be as homelike as possible, recognising that the primary problem is often dementia, not an acute illness. In the absence of a treatment for dementia the goal of care is to maintain the person's abilities for as long as possible. This requires that they have opportunities, facilities and encouragement to use their abilities. So, all of the facilities found in an ordinary house need to be provided, these include a kitchen, laundry, bathroom etc.

7.5 Methods

7.5.1 Recruitment

This Australian study involved five facilities in the state of Tasmania and five in the state of NSW. In Tasmania a convenience sample of facilities that had been either built or renovated within the last five years was accessed. The NSW sample was selected to ensure that the facilities had been built within the last two years. They were identified by randomising a comprehensive list of aged care facilities in the greater Sydney area, using the Microsoft Excel randomisation function, and telephoning facilities in order. The question “Have you completed the construction of any new wings, units, facilities in the last two years?” was asked of the most senior person available. If the answer was affirmative the question, “Were any of the units specifically designed for people with dementia?” was asked. When both questions were answered in the affirmative the study was described and the respondent asked if they would participate. If this question was answered in the affirmative the consent process was initiated.

Calls were made to 269 NSW facilities. Contact could not be made with twelve, 244 did not meet the criteria, and 13 facilities (4.8%) met the criteria. Of these 13 facilities, three declined to take part in the study immediately, two showed interest in the study but took too long deciding whether or not to participate, three took information about the study via phone or email but did not return any further emails and five completed the consent process.

7.5.2 Data Collection and Analysis

The study involved undertaking an audit of each facility using the Environmental Audit Tool (EAT) (Fleming 2011). This tool provides information on the degree to which the ten design principles described in Table 16 have been applied. The audits were carried out by two auditors with extensive experience in the use of the EAT. The data gathered was used in the production of a report that highlighted the gaps between the design of the facility and the optimum design as defined by the principles underpinning the EAT. This report was provided to the aged care facility

representatives who had been involved in the design process and to the architects. The aged care facility managers and the architects were then interviewed by the first author by telephone, separately, using a semi-structured interview designed to guide the respondent through a discussion of their awareness, acceptance and adoption of the principles of design that underpinned the audit. Particular attention was given to the exploration of the reasons for the gap between the ideal, as defined by a perfect score on the EAT, and the actual environment.

Facility managers were identified in all cases, but in one case the architect could not be identified, and in another the architect repeatedly cancelled the interview and could not be interviewed before the end of the project. All interviews were audio taped and transcribed.

The semi-structured interview questions were developed to guide the interview through the stages of knowledge transfer described above. The development of the questions relating to difficulties with the adoption of the knowledge, i.e. the application of design principles to dementia facilities was informed by a discussion with the participants in a workshop at a dementia conference attended by a broad cross section of managers, researchers and direct care staff (Judd, Zeisel et al. 2008). These included the potential impact on the application of the design principles of regulations, costs, family preferences and corporate policies. Their relevance to the design of facilities for people with dementia was checked by searching the literature from 2000. Key words used for the search were: Australia, long-term care, nursing homes, standards, regulations, costs, family, policies and administration in the CINAHL, Medline and Art & Architecture data bases. The review identified four papers of relevance to factors that may have an influence on environmental design. These provided support for the inclusion of standards (Grenade and Boldy 2002) and family preferences (Cheek and Ballantyne 2001; Cheek and Ballantyne 2001; Edwards, Courtney et al. 2003; Cheek, Ballantyne et al. 2007). The remaining topics were included in the interview on the basis of the views of the cross section of aged care service providers involved in the conference workshop. The interview was

completed with open ended questions to elicit any other factors that the architects and managers considered relevant.

The thematic analysis of the data was conducted by the first author in keeping with the process described by Braun and Clarke (2006). All of the transcripts were read to ensure a complete familiarisation with the data, a ‘theoretical’ thematic analysis was conducted to ascertain the ideas embedded in the answers to the specific questions contained in the interview protocol, and an inductive analysis was conducted of the spontaneous comments and answers given to general questions (e.g. ‘can you think of anything else?’). Responses were manually coded and then assigned to potential themes. When all of the responses had been coded and collated their relevance to the themes was checked and the themes modified if required.

The themes generated and the responses used to identify them were then scrutinised by the other two authors. This resulted in the clarification of the themes and the support for them.

Ethics approval was obtained from the ethics committees of the University of Tasmania and the University of Wollongong .

7.6 Results

Six facilities were specifically designed for people with dementia, three were refurbished to accommodate people with dementia and one was a generalist facility that admitted people with dementia. The Environmental Audit Tool total scores ranged from 57.4 to 79.9 with a mean of 67.9 and a standard deviation of 8.34. The professional backgrounds of the managers and the architects are described in Table 17.

Five of the aged care facility managers clearly described an awareness of the principles contained in the report provided to them. One claimed to “have read them in the past” and four responded that they were not aware of the principles of design.

All of the managers who were aware of the principles stated that they agreed with them.

Table 17: Experience and views of aged care facility representatives and architects

<i>Years of dementia experience and Professional background of facility managers</i>	<i>Conscious awareness of principles</i>	<i>Agreement with principles</i>	<i>Years in practice and specialization of architect</i>	<i>Conscious awareness of principles</i>	<i>Agreement with principles</i>	<i>EAT Score</i>	<i>Tension between manager and Architect</i>	<i>Site restrictions</i>
25 years Registered Nurse (RN) - psych and general	Yes	Yes	30 yrs Specialist in dementia design	Partial	Partial	78.3		Yes
8 years Insurance, finance, local government	No		30+ yrs Specialist in dementia design	Yes	Yes	62.8	Yes	
14 years RN with Masters in Health Service Management	No		40 yrs Not a dementia design specialist	Yes	Yes	58.5		Yes
13 years Accounting and business management	No		Not available			59.6		

<i>Years of dementia experience and Professional background of facility managers</i>	<i>Conscious awareness of principles</i>	<i>Agreement with principles</i>	<i>Years in practice and specialization of architect</i>	<i>Conscious awareness of principles</i>	<i>Agreement with principles</i>	<i>EAT Score</i>	<i>Tension between manager and Architect</i>	<i>Site restrictions</i>
12 years Business management	No		30+ yrs Specialist in dementia design	Yes	Yes	70.8	Yes	
25 years RN	Yes	Yes	10 yrs Specialist in dementia design	Yes	Yes	69.4	Yes	Yes
25 years RN and registered geriatric nurse	Yes	Yes	Not available			79.9	Yes	
25 years Hospital and aged care management	Yes	Yes	35 yrs. Specialist in dementia design	Yes	Yes	66.1		Yes
15 years RN	Yes	Yes	20 yrs Specialist in dementia design	Yes	Yes	76.1		

<i>Years of dementia experience and Professional background of facility managers</i>	<i>Conscious awareness of principles</i>	<i>Agreement with principles</i>	<i>Years in practice and specialization of architect</i>	<i>Conscious awareness of principles</i>	<i>Agreement with principles</i>	<i>EAT Score</i>	<i>Tension between manager and Architect</i>	<i>Site restrictions</i>
20 years RN with Masters in business administration	Partial	Partial	19 yrs Specialist in dementia design	Yes	Yes	57.4	Yes	Yes

One of the architects expressed only partial awareness of, and partial agreement with, the principles. the remainder described themselves as being aware of the principles and agreeing with them.

The mean EAT scores of the facilities where the manager was aware of the principles was 73.96, significantly higher (t test, sig. 0.01) than the mean EAT score of 61.82 for those facilities where the managers described themselves as unaware or only partially aware of the principles. Analysis of the differences between the EAT subscale scores revealed that the difference in the overall quality of the environment, as represented by the total EAT score, was brought about by higher mean scores in eight out of the ten EAT subscales in those facilities where the managers were fully aware of the principles. See Table 18.

Table 18: Comparison between environments planned by managers with and without knowledge of design principles

EAT sub scales	Mean EAT score in facilities where managers were fully aware of principles (%)	Mean EAT score in facilities where managers were not fully aware of principles (%)	Significance of difference (t test, 2 tailed)
Safety	73.02	73.52	NS

EAT sub scales	Mean EAT score in facilities where managers were fully aware of principles (%)	Mean EAT score in facilities where managers were not fully aware of principles (%)	Significance of difference (t test, 2 tailed)
Size	63.82	26.66	0.08
Visual Access	59.36	37.26	0.07
Stimulus Reduction	85.28	45	0.003
Stimulus Enhancement	85.02	71.14	NS
Planned wandering	82.78	80.02	NS
Familiarity	74.86	78.32	NS
Privacy and Community	78.66	65	NS
Links to community	78.68	100	NS
Domestic	51.68	41.28	NS
Total Score	73.96	61.82	0.01

The analysis of the response to the specific questions concerning the application of the principles, stage three in Pathman's model, is summarised below.

1. Regulations as an impediment to applying the principles

Two managers identified regulations as being an obstacle to the implementation of the principles. The responses of the others suggested that while regulations have to be considered, there was always room for negotiation.

You'd have to argue with people. I know the [CEO]... has done that at [facility X] ... they've got rid of the hand rails in their new designs, and still got accreditation (Manager 7).

Regulations were of more concern to the architects with four reporting that contending with regulations restricted the application of the principles, particularly with respect to making facilities seem more homelike.

Most of our challenges in our office are basically dealing with authorities. It depends on how the standards are written. Sometimes they are ridiculous requirement (Architect 2).

2. Cost as an impediment to applying the principles

Cost was identified as a major obstacle to the application of the principles by three managers. Capital and operating costs were differentiated. One manager reported that their dementia-specific facility was built in the knowledge that residents would have to pay more than the usual amount for a bond and that the residents would make additional payments under the extra service provisions for funding residential aged care. However others argued strongly that good design was not an additional cost in terms of capital outlay and that it led to a reduction in operating costs.

There's no falls, the people exercise, they're happier. So cost per person and the [decrease in] staff [turnover], there's no turnover here ... [means] it actually works better on costs.

There was no consensus on the theme of cost from the point of view of the managers. Three architects were of the opinion that the application of the principles resulted in greater capital costs because the separation of resident spaces from service spaces and the lower number of residents in individual units resulted in a larger overall building. However the other architects did not support this view.

[The application of] those principles doesn't really jump out as putting a rather large burden on a budget ... building that we produced there would've been ... a little dearer than the other residential units that we provided, but not unreasonably and certainly it did not worry the client (Arch. 3).

3. Family Member views impede the application of the principles.

There was little evidence for the existence of consensus on the importance of the views of family members in determining the nature of the design of facilities. Two

managers expressed the view that relatives choose the residential facility not the resident and one of them was particularly concerned that the choice is made on the basis of their preference for a hotel-like environment.

Yeah of course they [family members] choose and when relatives come, even though mum has a diagnosis of dementia, they don't want her to have a bed in [facility] because it looks different. It doesn't look as hotel-like as the rest of the building (Manager 5).

The architects were divided on the importance of this issue.

4. Corporate policies override design principles

Corporate policies, for example the centralised preparation of meals, were seen by only two managers as overriding the application of principles. One manager reported that his application of the principles had been so successful that it had changed corporate policies. The architects were more likely to see corporate policies as an obstacle but again, there was no consensus on this issue. For example, one architect highlighted the influence of corporate policies on food preparation:

Well, I mean obviously they [the aged care facility] want to operate how they want to operate the food preparation ... [yet] in your report you sort of say residents don't have access to the kitchen area. Well, that was intentional [on the part of the organisation] (Arch. 4).

However, overall there was no evidence of strong, consistent themes describing obstacles to the application of the design principles emerging from the specific questions raised during the interviews.

Analysis of the managers' spontaneous comments and responses to general questions, such as 'Can you think of anything else?' identified a number of themes. The strongest was site restrictions followed by weakly supported themes of industrial relations, practicality, lack of clear identification of people with dementia as being the target group, conflict with the operational model and lack of understanding of the principles by the architects. One manager summarised her dissatisfaction with what she saw as a common approach to the planning process :

You just can't say we've got four houses, and just put a lock on the door of that fourth house for [residents with] dementia, and basically the floor plan is exactly the same (Manager 7).

The architects also nominated site restrictions but their main concerns were clashes between the ideals implied by the design principles and the practical operational issues. One architect's response to a question on his awareness of the design principles "Yes, as principles but sometimes principles can't be put into practice" (Architect 8) was made understandable by the description of the brief given to him: "The overall brief, if you like, the brief of the board of directors was to get as many beds as you can in this site as cheaply as possible" (Manager 10).

Architects were also concerned with inconsistencies in the client team leading to conflicting instructions and an unclear original brief:

Where they [managers] have competing views or views that are very sort of dogmatic, that you may not agree with. ... that's where it's harder because you really don't have any room to move. You can sort of have the argument [to try to convince them], but that's not to say you're going to win (Arch. 4).

In five cases these types of difficulties caused some tension between the architects and the clients.

7.7 Discussion

Table 17 shows that the managers who took part in this study had considerable experience in services for people with dementia. Five of them were fully aware of the principle and five were not. They had commissioned architects who, with one exception, claimed to be fully aware of the principles that were presented to them. The exception was an architect who claimed partial awareness. Notwithstanding the architects' claims regarding their awareness of the principles, there was a significant difference in the quality of the environments that resulted from the involvement of a manager who was aware of the principles in the planning as compared with

environments that were refurbished when the manager reported little knowledge of the principles. The mean EAT score of the five facilities designed with the input of a manager who was aware of the principles, 73.96, was significantly higher (t test, $p=0.01$) than the mean score of the facilities whose design was influenced by managers who were not fully aware of the design principles, 61.82.

Table 18 shows that this difference is largely attributable to the better facilities having fewer beds, good visual access and, most significantly, improved reduction of unhelpful stimulation. These characteristics are important, having been shown to be associated with better outcomes for the residents (Passini, Pigot, Rainville and Tetreault 2000; Zeisel, Silverstein, Hyde, Levkoff and al 2003; Torrington 2006; Productivity Commission 2011)

There is practically no literature to assist us to understand the nature of the obstacles to ensuring that the next generation of residential aged care facilities is suitable for people with dementia. This study highlights the difference that having a manager who is aware a basic set of design principles makes to the quality of the environment. As all of the managers who were aware of the principles agreed with them, the problems associated with putting the knowledge into practice cannot be described as occurring in Pathman's second stage of knowledge translation (i.e. establishing agreement).

The managers did see a number of obstacles in the adoption stage but no consensus emerged from the analysis. The weak themes explaining the lack of application of the principles comprised operating and capital costs and the restrictions imposed by the site. Only a small minority of managers saw regulations, pressure from relatives, corporate policies, industrial relations issues, and mismatches between the design and the operational model as impeding the application of the principles.

A minority of the architects identified site restrictions, regulations, operating costs and difficulties in coming to an agreement with the client on the brief as the major obstacles. The significance of the difficulties in establishing a clear brief and restrictions in the sites were assessed by comparing the mean EAT scores of those

facilities where there were no problems to those where problems were present. There were no significant differences in the t test results, suggesting that these difficulties did not have as great an impact on the quality of the environment as the level of the manager's awareness.

The lack of the presence of any consensus between the managers and architects on significant obstacles to the adoption of the principles once they are known, suggests that there are no common impediments to the application of the design principles. The impediment that has the greatest impact occurs in the first stage of Pathman's model, awareness, and is particularly relevant to managers. Once the managers are aware of the principles they tend to agree with them and find ways to implement them – and produce higher quality facilities.

The presence of a very high-scoring facility in which the manager was fully aware of the principles while the architect only described himself as partially aware, further supports the conclusion that the manager's awareness of the design principles is a key to their application. This is corroborated by the negative example, illustrated above, where the manager, who was not fully aware of the principles, briefed an architect who claimed awareness, to put as many cheap beds on the site as possible. The result was a poor quality environment.

It is unreasonable to place all of the responsibility for the application of evidence-based design principles on the aged care managers. The lack of influence of architects, who claimed awareness of the principles, must raise questions about the willingness of architects to take on an active role as educator and professional guide. The data suggests that on at least three projects there was the opportunity for the architects to raise the awareness of the managers. If they tried they were not successful and followed the directions of inadequately informed managers.

However, the data suggests that the fundamental problem lies not with either the managers or the architects but with their combined failure to establish an effective project team. Newell (Newell, Edelman, Scarbrough, Swan and Bresnen 2003) has

highlighted the vital role that the exchange of knowledge within the project team plays in achieving best practice outcomes. Successful project teams are characterised by a willingness to interact, debate and go through a process of sense making in which the members try on the perspectives of the others involved in the process. The presence of tension between architects and managers in 50% of the projects described here may well be an indication of the difficulty of establishing a successful team and the resultant problems in realising “a practical way to get things done”. The architects’ concerns about the quality and consistency of the brief are noteworthy and suggest the lack of a common understanding of the knowledge base, or principles, that can be used as a foundation for the exchange of ideas that is necessary to achieve a common, well informed view of the project.

The lack of impact of the expertise of the architects may be explained in McDonnell’s terms. It appears that either the architects have over-privileged the expertise of the building users, or the building users have underrated the expertise of the architects. In either case the result is an inability to make use of knowledge that is available to the team.

The relatively poor outcomes in the five homes where the managers were not fully aware of the principles of design may therefore be explained in two ways. The first is a failure in Pathman’s first stage of knowledge transfer; the existing evidence-based information had not been brought to the attention of the managers, and they were simply not aware of it. Secondly, the tensions between the architects and the clients described in three of these homes are probably an indication of the failure to establish a cohesive team characterised by mutual respect and the ability to hear other points of view, negating the availability of the knowledge from the architects.

An alternative explanation, in some cases, is that producing positive outcomes for the residents by applying evidence-based principles is not a priority. The availability of the knowledge needed to bring this about is irrelevant when the brief does not include them.

In Australia the need to provide assistance to facility managers and the architects has been recognised and a national programme aimed at making information available to them during the planning process has commenced through the activities of the five Dementia Training Study Centres established by the Australian Government. This project involves a day-long meeting between the managers, architects and a consultant who provides a systematic explanation of the principles of design and an audit of the existing facility and assists with starting a planning process based on a common understanding of the principles.

The capital cost of providing one residential aged care place in Australia is estimated at \$200,000–\$240,000, \$109,000 of which is provided by the Commonwealth Government (Productivity Commission 2011). While the number of places that will be provided in the coming years will be determined by the interplay of the many factors, such as the speed of development of community services and the changes in funding mechanisms now being considered, it has been estimated that in Australia 9,000 new beds per year for the next 20 years will be required for people with dementia (Access Economics 2009). The lack of awareness of well-established design principles must be recognised as a major obstacle to meeting their needs and obtaining the best outcome from the capital expenditure. It is essential that the knowledge that is available on how to design for people with dementia be provided to both the managers and the architects and that attention be given to facilitating discussions between them.

The study is limited by the small size of the sample and the possibility that the experiences of those that chose not to be audited may be different from those that did. It is further limited by reliance on the self-reporting of the managers and architects in relation to their awareness of the design principles. Future research should involve larger sample sizes and an objective measure of awareness of the design principles.

7.8 References

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7.9 Extended discussion

The route from research finding to practice can be very long and complex. The vital importance of hand washing in the control of infection has been known since 1847 (Semmelweis and Carter 1983) yet rates of compliance with guidelines have been measured to be only 26% in intensive care units and 36% in other acute care areas (McGuckin, Waterman et al. 2009). The problem extends beyond hand washing. Despite wide promulgation, clinical practice guidelines are limited in their effect on behaviour. A study reviewing the reasons for this identified 293 potential barriers to physician guideline adherence (Cabana Md et al. 1999).

The analysis of the obstacles to the application of empirically supported design principles contained in the paper presented in Chapter 7 sketches out a limited view of the issues. It is clear that this topic alone could be the subject of a thesis.

A broad view of the problem of translating knowledge about the care of people with dementia into practice suggests that effective knowledge translation (KT) has four features:

1. A simple compelling message
2. Use of interpersonal contact and roles
3. An emphasis on 'know-how'
4. The provision of support and resources for KT (Draper, Low et al. 2009).

The analysis of the obstacles contained in the paper identifies the negative impact of the managers who were not aware of the principles of design and the architects who were not prepared, or able, to insist on the application of empirical evidence. It also identified the need for developing constructive dialogue between the architects and the managers. It may be useful to look at these issues through the lens of the four features identified above.

Is one of the problems that the managers who were unaware of the principles had not been exposed to a simple compelling message? It has been said that:

The basic principles of knowledge translation are integration and simplification. Methods for integration include: narrative review, systematic review, meta-analysis, meta-database, inventory of best practices, and public health observatory. After integration, information must be simplified to a level that can be understood and used by the users (Choi 2005, p. 93).

Chapter 2 provides one example of integration but where is there an example of simplification and where are the channels for getting the simple message out to those who need it?

These are issues that are unresolved in Australia and elsewhere. It is clearly simplistic to believe that the researchers will, or should, pick up this role. High level research skills do not always go hand in hand with the ability to communicate simply and there are few incentives for researchers to engage in time consuming discussions with, or presentations to, potential users of their findings. The incentives drive them to applying for another research grant rather than sharing the knowledge from the previous one. Too often knowledge translation is nodded to by the publication of a paper in a learned journal, or a presentation to a conference attended by other researchers.

If the managers who were unaware of the principles are to be helped then a new group of people are going to have to take on the responsibility for integrating and simplifying the available research and new channels of communication between the researchers and the users must be developed.

While these issues are unresolved they are being worked on. The NHMRC has recently established the Faculty of Knowledge Translation represented by 2,500 members made up of NHMRC-supported Chief Investigators and NHMRC Fellows (NHMRC 2012). The activities of the five DoHA-funded Dementia Training Study Centres are making a contribution to the simplification and dissemination of information of direct relevance to the professional carers of people with dementia (DTSC 2012). One of these activities has been the launch of the *Australian Journal of*

Dementia Care (AJDC 2012). This publication is explicitly intended to put the results of current research into the hands of practitioners like the managers described in the paper. It is not a learned journal but a means of providing a clear, and hopefully stimulating, picture of the implications of research for their practice. The paper refers to the need for a constructive conversation and identifies the negative results that occur when this conversation is not present. This falls under the feature of interpersonal contact and roles.

A conversation requires at least two parties and if it is to be constructive in the sense required here, then one of them must know about good design for people with dementia. The architects knew about good design but did not bring about a change in the behaviour of five of the managers. Was this only because of the power of the client–contractor relationship wherein the client gets what he wants because he is paying? No doubt this played a part but conversations with architects about the results of this study have led me to the conclusion that it is also a matter of confidence and commitment to bringing about change. Perhaps the mental set of the architects was such that they did not believe that they could influence the managers. If architects are to successfully occupy the role of change agent, [they need] both to perceive the need for change, and to possess the belief that they can effect it – that they can make a difference (Crookes 1998).

This brings into the discussion the role of individual differences in KT. It is clearly not a mechanistic process. How are we to give architects the confidence that they can make a difference, and perhaps just as importantly, that they should make a difference?

One of the ways in which the architect may be helped is to give them tools that place an emphasis on ‘know-how’. One way of doing this is to change the nature of the conversation from a dialogue about knowledge, as something that is embedded into the background and experience of each expert and is therefore highly idiosyncratic, to a conversation about data, that is, a series of observations or measurements that are relatively impersonal and factual. This approach has been well described in relation to

the role of information and communication technologies in improving the transferability of knowledge (Roberts 2000). It has the effect of reducing the interpersonal relationship issues and individual differences that can impede communication.

In this context the use of tools like the EAT in the hands of the architect could provide managers with an objective picture of the strengths and weaknesses of an existing building, or a plan, and provide the foundation for a constructive conversation. This has certainly been my experience.

Of course nothing is going to work if the available support and resources are insufficient. The managers must provide support by being “open to evidence-based practice, they must acknowledge that they can and should learn from those around them, that they neither have, nor need to have, the answer to every problem” (Crookes 1998). If knowledge about good environments for people with dementia is to be transferred then the resources for renovations and/or buildings must also be available and under the control of the manager involved in the conversation.

7.10 Impact

The results of this research have informed the development of an Australia-wide consultancy service being offered by the NSW/ACT DTSC. As a result of this research the service is deliberately designed to:

1. Raise awareness in the minds of service providers and architects of the evidence base.
2. Provide a summary of the evidence base.
3. Obtain agreement with the findings in the evidence base and agreement between the architects and service providers of its utility.
4. Assist in the application of the evidence by applying it to weaknesses identified by the use of the EAT in the plans, when a new building is being designed, or in the existing building when a refurbishment is taking place.

In short, the service is designed to establish the conditions in which well-informed service providers and their architects can engage in a conversation aimed at deciding on ‘a practical way to get things done’ (McDonnell 2009).

This service has impacted on more than 60 aged or health care services to date. This will be doubled in 2013. The impact of the paper will be increased in 2013 with the publication by Routledge of a chapter based on it in *Design Research* edited by Professor Paul Rogers and Dr. Joyce Lee of Northumbria University’s School of Design.

7.11 Further Research

The research on knowledge translation is continuing under the joint funding of the NSW/ACT DTSC and the UNSW DCRC. It has been widened to include projects from all five of the Australian Dementia Training Study Centres. The goal in the first round of funding is to identify successful knowledge translation projects and, using the Pathman model used in this paper, to investigate and describe the methods used to obtain awareness, agreement and adoption.

7.12 Conclusion

It is clear that KT is tricky and our understanding of the structures and processes required to bring it about is embryonic. Even the use of the label ‘Knowledge Translation’ implies a certainty about the activity that is not reflected in the literature where there are more than 90 terms used to describe it (Straus, Tetroe et al. 2009).

Perhaps it should be a pleasant surprise to find that five of the ten facilities were designed with evidence-based principles in mind. When compared with the progress made on establishing effective hand hygiene it is a good result.

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CHAPTER 8: SUMMARY AND CONCLUSION

The growth in the number of people with dementia, which is occurring internationally, is resulting in increasing numbers of residents in aged care facilities. There has been a steady development in our knowledge of how to care for these people. Attention has been focussed on the need for comprehensive assessment that informs care planning and the provision of well-designed environments as major factors in the suite of interventions that they require.

This thesis began with an agenda for exploration of:

1. Better ways to undertake care planning
2. The nature of physical environments that are beneficial to people with dementia
3. Better ways to evaluate the quality of the built environment
4. The problems with transferring the knowledge gained in the twenty-five years since the beginning of the CADE unit programme into the mainstream of aged care.

I believe that the first three items have been addressed by:

1. The development of a comprehensive care planning assessment tool with good inter-rater reliability and validity that has been welcomed by significant sections of the Australian, UK and Japanese aged care industries
2. The provision of a review of the literature dealing with the characteristics of good design for people with dementia that has informed the work of many academics and practitioners and laid a foundation for the development of services funded by the Australian Government
3. The development and provision of a tool that enables the systematic evaluation of the quality of environments for people with dementia. This tool

is central to the consultancy service being provided in every Australian state and territory through the activities of the NSW/ACT Dementia Training Study Centre. The demonstration of the validity and reliability of this tool has allowed it to be used with confidence in two large-scale research projects led by international experts. Its use has contributed to the clarification of the relationship between the quality of the environment and the quality of life of people with dementia living in that environment.

The final item has been addressed in the exploration of the problems involved in ensuring that the available knowledge is applied in practice. It is clear that even when the knowledge is available to the team developing the facility, it is not always utilised.

This leads to the conclusion that while there remains a need to further develop the strands of research identified in this thesis, the overriding challenge is not ‘How can we add to human knowledge?’ but ‘How can we apply the knowledge we have?’.

It is, perhaps, fitting to look back on the journey represented by the research reported here through the lens of Pathman’s stages of knowledge translation. In the early days there was not even awareness of the problem, just a slightly troubled perception that all was not right. The years of responsibility as a senior member of the clinical staff in a large psychiatric hospital certainly made me aware of the plight of people with dementia. The problem was to gain agreement that the problem existed. The publication of the Richmond Report certainly assisted with that and, with the continuous input of Alzheimer’s Australia and other like-minded organisations, the awareness of the problem has persisted. The next problem was to discover and decide what to do about the problem. In the absence of a great deal of competing views it was relatively easy to decide on a better model of care. The task was then to gain agreement that this was a sensible way to go. The opportunity provided by the reforms initiated by David Richmond and continued by the Barclay report made that possible. The rest of the journey is really about adoption, getting the model into practice. The initial opportunity was provided by the development of the CADE units

but the generalisation of the model had to wait until the mid-90s when HammondCare adopted the ideas and provided a platform for their implementation and promotion. Currently the ideas are being implemented across Australia, in residential and healthcare facilities, through the activities of the UOW based NSW/ACT Dementia Training Study Centre.

The next stage, the final stage in Pathman's model, is that of making the ideas common-sense, business as usual. As well as this occurring simply through familiarity with the ideas this will occur when principles of designing for people with dementia are used in the development of the standards and regulations that govern the construction of such buildings.

Help for the processes of adoption and adherence is coming from a source that was unthinkable in the 1980s, the people with dementia themselves. Calls for the involvement of people with dementia in planning their own care began in the 1990s (Smale, Tilson et al. 1993; Adams and Clarke 1999) and were taken up and expanded to include the involvement of people with dementia in making decisions on research in the context of the development of the Relationship Centred Care model (Nolan, Ryan et al. 2002).

These ideas moved from the theoretical to the practical in the UK with the publication of a pilot study involving 15 people with dementia in applying an approach developed in the US that was designed to empower the person with dementia in relation to his, or her, GP (Ariss, Grant et al. 2006). This approach focussed on improving the preparation for the appointment and the communication style of the person with dementia, thereby enabling them to exercise more control within the consultation.

While the research on the characteristics and effectiveness of involving consumers in directing their own care is embryonic, being described as having the lowest quality of evidence in a systematic review of different models of home and community care services (Low, Yap et al. 2011), there have been substantial developments in this area. Alzheimer's Australia now has a significant number of consumer

representatives, people with dementia and their carers (Skladzien 2010), who provide input on decisions about funding research and the development of programmes and consumer directed care is being trialled in 500 aged care packages by the Australian Government's Department of Health and Ageing (Department of Health and Ageing 2010; Low, Chilko et al. 2012).

I am hopeful that this movement, largely the result of demands from consumers (Low, Chilko et al. 2012), will highlight the need for higher quality in building design and care planning. This should establish the context for more research into the views of people with dementia on what they consider quality design and quality care and oblige us to refine our methodologies for exploring these views. In a rational world the results of this research would find their way into the regulatory system so that high quality design becomes the norm. This would complete my journey. It hasn't happened yet, but it is beginning to be a possibility.

Insofar as the work described in this thesis has made a contribution to the care of people with dementia, the major part of that contribution lies in the provision of tools that help people to think more clearly about the task that is before them. The need to focus on the mechanics of the development and impact of these tools in writing this thesis may have obscured the purpose of the activity. So I would like to conclude by contrasting the Shakespearian view of the externalities of old age and dementia I began with, a view that resonated with the services being provided in the '70s and '80s, with a contemporary view that describes the personal, internal experience of a person with dementia, a description that allows us a glimpse of the essence that our services should aspire to protect:

[A]s this disease unwraps me, opens up the treasures of what lied within my multifold personality, I can feel safe as each layer is gently opened out.

The fullness of who I once was will be seen in the simplicity of who I am within, surrounded by layer upon layer of memories. These memories form the kaleidoscopic perspectives of all the many expressions of my being over my lifetime: as a child, daughter, granddaughter and sister, as a student and

young adult, as a wife and a mother, as a friend, as a researcher, an editor, an information officer, policy manager and senior public servant, as a member of St. George's church and a Cursillo team member, and a writer of this book.

In each of these aspects of my life, the centre of my being was always there within, expressing itself in these many forms of me. This unique essence of 'me' is at my core, and this is what will remain with me to the end. I will be perhaps even more truly 'me' than I have ever been (p. 63)

– Christine Bryden *Who will I be when I die?* Jessica Kingsley.

8.1 References

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APPENDICES

Appendix 1: The Care Planning Assessment Tool

**Care Planning Assessment Tool
(CPAT)**

The assessment tool below has been removed for copyright reasons, if you wish to view this appendix in full contact Library staff.

Appendix 2 The Environmental Audit Tool

The Environmental Audit Tool

"Design of the physical environment is increasingly recognised as an important aid in the care of people with Alzheimer's disease and other dementias.Design is regarded as therapeutic resource to promote well being and functionality among people with dementia."

Day, Carreon and Stump, 2000, The Therapeutic Design of Environments for People with dementia: A Review of the Empirical Research, *The Gerontologist*, Vol 40, No.4.

Until the final stages of dementia rob them of all of their abilities to engage with their surroundings, people with dementia will either be helped or harmed by the environment in which they live. This observation is now backed by more than 25 years of research into the design of prosthetic environments for people with dementia. While the research is wide ranging it can be simplified into the application of 10 principles without artificially constraining the findings.

The principles can be summarised :-

An environment that is to be used to provide care aimed at maintaining the abilities of people with dementia should

- | | |
|--|--|
| 1. Be safe and secure | The confusion which accompanies dementia determines the need for a variety of safety features to be built into the environment. They include a secure perimeter, hot water control and safety switches in the kitchen . |
| 2. Be small | The larger a facility is the more confusing it is likely to be for residents. High quality care is easier to provide in small groups. |
| 3. Be simple and have good 'visual access'. | Confusion may be reduced by caring for the confused person in a simple environment. The simplest environment is one in which the resident can see everywhere that she wants to go to from wherever she is. This principle limits the inclusion of corridors in the design and results in the staff being able to see the residents almost all of the time. This reduces anxiety in both staff and residents. |

- | | |
|---|---|
| 4. Reduced unwanted stimulation | The person with dementia experiences difficulties in coping with a large amount of stimulation. The unit must be designed to reduce the impact of stimulation that is unnecessary for the well being of the resident, e.g. entry and exit doors used for deliveries, staff movements etc. should not be visible to the residents. Noise must also be minimised. |
| 5. Highlight important stimuli | Stimuli that are important to the residents should be highlighted. These include toilet doors, exit to safe outside area, aids to recognition on bedroom doors. |
| 6. Provide for planned wandering. | Wandering is sometimes a feature of the behaviour of the person with dementia. The design should allow it to take place safely but not encourage it. The wandering path should provide an opportunity for the person to go outside and take them past areas of interest in the expectation that they will provide the person with an alternative to repetitive wandering. |
| 7. Be familiar. | The person with dementia recalls the distant past more easily than the recent past. It follows then that their experience of recent furniture designs and decors must be less congruent with their present mental state than their experience of decors that they enjoyed in their younger days. To ensure that their experience of their surroundings is in keeping with their mental state the decor should be such that it would have been familiar to the residents in their early adulthood. |
| 8. Provide opportunities for privacy and community | People with dementia require a range of opportunities for social interaction. Spaces are needed for sitting quietly alone, with one or two intimate friends and in larger groups. |
| 9. Provide links to the community | The chances that the residents will continue to be part of their social network after admission should be maximised by providing for their care in small units in their community. These units should provide amenities that encourage visitors so that links with families and friends are not broken. |
| 10. Be domestic | The environment should be as homelike as possible, recognising that the primary problem is often dementia, not an acute illness. In the absence of a treatment for dementia the goal of care is to maintain the persons abilities for as long as possible. This requires that they have opportunities, facilities and encouragement to use their abilities. So, all of the facilities found in an ordinary house |

need to be provided, these include a kitchen, laundry, bathroom etc.

Date:

Time:

Facility

Unit:

Number of residents when full:

Observer:

Safety	N/A	NO	YES	Add 1 if Unobtrusive	Score
1 Is the garden secure, <i>i.e.</i> are residents prevented from getting over/under fence or out of the gate without the assistance of a staff member?	N/A	0	1	1	
2 If the front door leads out of the unit, is it secure?	N/A	0	1	1	
3 Are all side doors leading out of the unit secure?	N/A	0	1	1	
4 Are bedroom windows restricted in the extent to which they open so that residents cannot climb out?	N/A	0	1	1	
5 Is the garden easily supervised from the point(s) where staff spend most of their time?	N/A	0	1	1	
6 Is there a way to keep residents who are not safe with knives and/or appliances out of the kitchen?	N/A	0	1	1	
7 If the kitchen is used by residents, is there a lockable knife drawer in the kitchen?	N/A	0	1	1	
8 If the kitchen is used by residents, is the cooker a gas cooker?	N/A	0	1		
9 If the kitchen is used by residents, is there a master switch that can be turned off quickly?	N/A	0	1		
10 Is the temperature of the water from all taps accessible to residents limited so that it cannot scald?	N/A	0	1		
11 If residents are involved in meal preparation are the pots and pans used small enough for them to lift easily?	N/A	0	1		
12 Are all floor areas safe from being slippery when wet (water or urine)?	N/A	0	1		

13	Is the lounge room easily supervised from the point(s) where the staff spend most of their time?	N/A	0	1	1
14	Are all areas used by residents well lit?	N/A	0	1	

Total

Size		10 or fewer	11-15	16-30	30+	Score
1	How many people live in the unit?	3	2	1	0	

Visual Access Features							Score
1	What proportion of confused residents can see their bedroom door from the lounge room?	N/A	0 Score 0	25% Score 1	50% Score 2	75% Score 3	100% Score 4
2	What proportion of confused residents can see the lounge room as soon as they leave their bedroom?	N/A	0 Score 0	25% Score 1	50% Score 2	75% Score 3	100% Score 4
3	What proportion of confused residents can see the dining room as soon as they leave their bedroom?	N/A	0 Score 0	25% Score 1	50% Score 2	75% Score 3	100% Score 4
4	Can the exit to the garden be seen from the lounge room? If there is more than 1 lounge room answer with reference to the one most used by most confused residents.	N/A		NO Score 0		YES Score 1	
5	Can the dining room be seen into from the lounge room? If there is more than 1 dining room or lounge room answer with reference to those used by most confused residents.	N/A		NO Score 0		YES Score 1	
6	Can the kitchen be seen into from the lounge room? If there is more than 1 lounge room answer with reference to the one used by most confused residents.	N/A		NO Score 0		YES Score 1	
7	Can the kitchen be seen into from the dining room? If there is more than 1 dining room answer with reference to the one used by most confused residents.	N/A		NO Score 0		YES Score 1	

8	Can a toilet be seen from the dining room? If there is more than 1 dining room answer with reference to the one used by most confused residents.	N/A	NO Score 0	YES Score 1
9.	Can a toilet be seen from the lounge room? If there is more than 1 lounge room answer with reference to the one used by most confused residents.	N/A	NO Score 0	YES Score 1
10.	Can the lounge room be seen into from the point(s) where staff spend most of their time?	N/A	NO Score 0	YES Score 1

Total Score

Stimulus reduction features		Yes	No	Score
1	Does the doorbell attract the attention of the residents?	0	1	
2	Is the noise from the kitchen distracting for the residents?	0	1	
3	Are doors to cleaner's cupboards, storerooms and other areas where residents may find danger easily seen (i.e. not hidden or painted to merge with the walls?)	0	1	
4	Is the wardrobe that the resident uses full of a confusing number of clothes?	0	1	
5	Are deliveries of food, linen etc. taken across public areas such as the lounge or dining room?	0	1	
6	Is there a public address, staff paging or call system in use that involves the use of loud speakers, flashing lights, bells etc?	0	1	
7	Is the front entry to the unit easily visible to the residents?	0	1	
8	Is the service entry (where food, linen etc. is delivered to) easily visible to the residents?	0	1	

Score is number of **NO** responses

Highlighting useful stimuli		NO	YES	Score
1	Is the dining room looked into from the lounge room or <u>clearly</u> marked with a sign or symbol?	0	1	
2	Is the lounge room either looked into from the dining room or <u>clearly</u> marked with a sign or symbol?	0	1	
3	Do bedrooms have a sign, symbol or display that identifies them as belonging to a particular individual?	0	1	
4	Are the shared bathrooms and/or toilets <u>clearly</u> marked with a sign, symbol or colour coded door?	0	1	
5	Is the kitchen either looked into from the lounge or dining room or <u>clearly</u> marked with a sign or symbol?	0	1	
6	Are toilets visible as soon as the toilet/bathroom door is opened?	0	1	
7	Is there a lot of natural lighting in the lounge room?	0	1	
8	Is the artificial lighting bright enough in all areas?	0	1	
9	Is the lighting free of glare, e.g. from bare bulbs, off shiny surfaces?	0	1	

Score is number of **YES** responses

Provision for wandering and access to outside area		NO	YES	Score
1a	Is there a clearly defined and <u>easily</u> accessible (i.e. no locked exit) path in the garden that guides the resident back to their starting point without taking them into a blind alley?	0	1	
1b	Does the external path allow the resident to see into areas that might invite participation in an appropriate activity other than wandering?	0	1	
1c	Is the path within a secure perimeter	0	1	
1d	Can this path be easily and unobtrusively surveyed by staff members?	0	1	
1e	Are there chairs or benches along the path where people can sit and enjoy the fresh air?	0	1	
1f	Are there both sunny and shady areas along the path?	0	1	

1g	Does the path take residents past a toilet?	0	1
2a	Is there a clearly defined path inside that takes the resident around furniture and back to their starting point without taking them into a blind alley?	0	1
2b	Does the internal path allow the resident to see into areas that might invite participation in an appropriate activity other wandering?	0	1

Score is number of **YES** responses

Familiarity		Many	A few	None	Score
1	Are there any colours in the furnishings or the decoration that would <u>not</u> have been familiar to the majority of residents when they were 30 years old?	0	1	2	
2	Are there any taps, light switches, door knobs that are to be used by residents that are of a design that would <u>not</u> have been familiar to the majority of residents when they were 30 years old?	0	1	2	
3	Are there any pieces of furniture in the lounge room or the dining room that are of a design that would <u>not</u> have been familiar to the majority of residents when they were 30 years old?	0	1	2	
4	Are there any pieces of furniture in the bedrooms that are of a design that would <u>not</u> have been familiar to the majority of residents when they were 30 years old?	0	1	2	
5	How many residents have their own ornaments, photos in their bedroom	2	1	0	
6	How many residents have their own furniture in their bedroom	2	1	0	

Total Score

Privacy and Community					Score
1	Are there small areas (nooks) that provide opportunities for casual interaction and quiet chats?	None Score 0	1 Score 1	2 Score 2	3 or more Score 3
2	How many of these areas or nooks have views of pleasant or interesting scenes (outside, the living room, the nursing station)?	None Score 0	1 Score 1	2 Score 2	3 or more Score 3
3	Do the shared living areas support small group activities (4-6 people) without re-arranging the furniture?	N/A	NO Score 1	YES Score 2	
4	Does the dining room provide opportunities for residents to eat in small groups (2-4)?	N/A	NO Score 1	YES Score 2	
5	Does the dining area provide opportunities for people to eat alone?	N/A	NO Score 1	YES Score 2	

Total Score

Community links		NO	YES	Score
1a	Is there an area or room somewhat removed from the main dining room where families can share meals with their relatives?	0	1	
1b	Is this room/area domestic and familiar in nature, to reassure family members and friends and encourage them to visit and to participate in the care of the resident?	0	1	

Score is number of **YES** responses

DOMESTIC ACTIVITY			Up to 50%	More Than 50%	
Record the percentage of residents who:-		None			Score
1	Have access to a kitchen	0	1	2	
2	Have a significant involvement in main meal preparation	0	1	2	
3	Have a significant involvement in making snacks or drinks	0	1	2	
4	Have a significant involvement in keeping bedroom clean and tidy	0	1	2	
5	Have a significant involvement in personal laundry	0	1	2	
6	Are involved in gardening	0	1	2	
7	Have constant and easy access to a lounge?	0	1	2	
8	Have constant and easy access to a dining room?	0	1	2	

Total Score

Summary of Scores

	Possible Score	Actual Score	Percentage
Safety	22		
Size	3		
Visual Access	19		
Stimulus Reduction	8		
Stimulus Enhancement	9		
Wandering and access outside	9		
Familiarity	12		
Privacy and community	12		
Community access	2		
Domestic activities	16		
Total	112		