Title: Architecture and dementia care: An exploratory study of nursing homes and their spatial environment.

Original Objectives: To explore design features evident in government funded private and voluntary nursing homes where dementia care is provided and to examine the extent to which Irish features comply with an international consensus on best practice for dementia care.

Deviations from original objectives: While the key focus of the research was on design, other data pertaining to costs of care, contract beds, staff ratios and other indicators of care standards were also collected. Only data pertaining to design is presented in this report.
**Methodologies:** This exploratory study had two phases, each employing a distinct research methodology, namely in-depth interviews and focus groups. In phase one, a sample of forty directors of nursing was randomly drawn from an Alzheimer Society of Ireland sampling frame of 251 private and voluntary nursing homes known to provide dementia care. The sample was stratified according to nursing home location (urban/rural) and management type (matron owned, matron managed, and homes run by voluntary bodies). A semi-structured questionnaire consisting of fixed choice and open-ended questions was designed to collect quantitative and qualitative data. The instrument was pre-tested in five pilot interviews and revised accordingly.

In-depth interviews lasted approximately 1.5 hours and were conducted in Irish nursing homes between August 2001 and May 2002. A high response rate (85%) was achieved. Thirty-four (85%) of the interviews were taped. Phase two of the study involved conducting focus groups with family caregivers. Eight participants were recruited to the focus group through the Alzheimer Society of Ireland and the social work departments of St. James’ and St. Vincent’s Hospitals. An interview guide was developed to collect data on issues previously explored with directors of nursing in phase one. Participants were relatives of people with dementia who had placed their relatives in private or voluntary nursing homes, one of which was a dedicated dementia care home. Five women and three men (4 daughters, 2 sons, 1 sister and 1 husband) participated in the two-hour focus group held in May 2002. Quantitative data was analysed using SPSS computer software. Content analysis was conducted on the qualitative data.

**Findings (Phase One): Interviews with Directors of Nursing**

Detailed below are key findings on the design features found in the Irish nursing homes surveyed. Results are presented in accordance with the international consensus on design. This consensus suggests that dementia-friendly environments should be small, domestic, accessible, welcoming, safe, have visual access and scope for everyday activities, offer different rooms for different functions, employ signage, orientation cues and have controlled stimuli. An important feature of design is that persons with dementia should have their own private, en-suited bedroom. **Small size** - The optimum number of residents in any given specialist dementia unit is between eight and fourteen. In the current study, a total of 1402 men and women were residents of nursing homes surveyed and about one third (n=541) were identified as having dementia. Homes ranged in size from the smallest having only 10 beds to the largest having 142. The mean number
of residents per home was 36. There was only one specialist dementia unit in the sample. The majority of residents with dementia lived in integrated rather than segregated environments.

**Familiar, domestic and homely** - While most staff agreed that homely environments were beneficial to people with dementia, in the majority of nursing homes surveyed, no access to normal domestic activities was allowed. For example, residents had access to a kitchen in only 18% of cases and to laundry rooms in 36%. Only about one third of nursing homes lit a traditional living room fire. A large majority of directors of nursing reported they had an open door policy and in almost all nursing homes surveyed (95%) visitors made some contribution to the social activities. Interestingly, in 43% of cases, residents had frequent or occasional contact with pets, in most of these cases the proprietor or staff member had a pet that lived in or visited the home. Alcoves or clusters of chairs outside the main living areas, arranged to encourage socialisation and stimulation, were available in 58% of homes.

**Ordinary activities** - While all homes offered residents some therapeutic activities (e.g. music, exercise, art and reminiscence), with almost half (42%) offering at least three weekly, involvement in everyday activities was extremely limited. For example, residents with dementia helped to set the table in only one third of nursing homes and in only eight facilities were they encouraged to wash dishes. There was only one nursing home where residents with dementia helped to prepare food.

**Safety** - Overwhelmingly, safety emerged as a concern in most nursing homes surveyed and was a key reason why residents were excluded from kitchen and laundry activities. Overall, 97.5% (n=39) of participants stated that the internal nursing home environment was extremely safe, very safe or safe. In one long established urban nursing home, housed in two converted adjoining private residences, the director of nursing reported that the internal environment was very unsafe. Hazards here included many stairs and steps on corridors and split level arrangements on floors. A further consequence of this inadequate design was the restriction it placed on residents’ ability to negotiate their own environment, to exercise or “to potter”.

Different methods were used in the nursing homes surveyed to promote safety and avoid residents leaving the facility unaccompanied. In 48% of cases normal locks were used, in another 30% door supervision, 15% used combination locks, 10% used closed circuit television and electronic tagging was used in just 3 cases. Interestingly, no nursing homes used methods to
disguise or detract attention from exit or entry points. A very small number of homes (n=3) utilised passive safety devices such as temperature controls on hot water taps, automatic cooker safety switch-off and flood detector. Also of some interest is the finding that non-slip and safety features were reasons for choice of floor covering in as few as 5 homes.

**Different rooms for different functions** - Recreational and social activities for residents generally took place in living or dining room areas and few homes (15%) had separate activity rooms. A quiet room was available to residents in less than one third (28%) of participating homes.

**Safe outside space** - All but four nursing homes had gardens or outdoor courtyard areas available to residents. Gardens varied from some (47%) being purpose-built to others (21%) where only a small area of garden was accessible to residents with mobility difficulties. Not all gardens were considered safe. For example in 20% of cases, the external environment was considered unsafe for residents. Lack of security, with gardens opening onto sometimes busy roads was the most common reason cited for places being unsafe. Respondents’ comments tended to reflect an appreciation of the benefits that residents with dementia gain from using gardens in terms of stimulation, sense of freedom, fresh air and change of scene. Interestingly, outside noise was reported as being a problem in as few as 3 nursing homes.

**Single rooms big enough for personal belongings** - Internationally, single bedrooms are considered a critical component of best practice in dementia care, however results from this study show that only 37% of residents with dementia had their own single room and just 40% of these rooms were en-suited. High levels of personalisation were reported in 73% of homes as evidenced by items of personal belongings, such as photographs, ornaments and bed linen in bedrooms. Although most respondents commented on the meaning residents attach to their belongings in terms of identity reinforcement and homeliness, a small number saw no benefit in this.

**Good signage and multiple cues** - While the literature demonstrates that much can be done to aid orientation through appropriate signage, cues and visual access, these design features were not in evidence in the majority of nursing homes surveyed. For example, signage to aid orientation was reported in less than half (n=16). Colour for orientation was used in only 5
homes, carpeting in 2 and texture in another 2 homes. Visual aids such as pictures and photographs to enhance orientation were used in just one home.

**Findings (Phase Two) - Focus group with family caregivers**

Phase two of the study consisted of a focus group with eight family caregivers (see page 1 for carer composition). The focus group discussion covered many issues raised by directors of nursing in phase one. New topics of interest to family caregivers were also explored. The results are presented in themes below:

**Personalisation** - Level of personalisation depended, according to some participants, on the size of bedrooms and/or on the presence or absence of nursing home’s own furniture. Only one family caregiver was actively encouraged to personalise a relative’s space by bringing in photographs and furniture. In another case, a family caregiver recounted her frustration when her efforts to personalise her sister’s bedroom were undermined by cleaning staff who stored away in cupboards items such as framed photographs that she had put on display. Some participants expressed concern about how personal items brought into the nursing home such as clothing and jewellery often went missing. A couple of participants referred to the de-personalising experience of seeing their relative dressed in someone else’s clothing. While a few participants believed that personalisation had little benefit for their relatives whose dementia was advanced, several others reported it was fundamental to maintaining the individual’s identity; As one participant stated: “I think it’s important because we are talking about people who are losing so much in themselves that if they are losing things they don’t need to lose like their personal possessions. It’s the one thing that...may help them...to have their identity around the place.”

**Design**

*Privacy:* Five of the eight focus group participants had their relatives placed in private bedrooms. These caregivers reported they valued the privacy this provided and the enhanced control it allowed over daily living. In one unusual case, a son caregiver spoke of the peace of mind his mother experienced since moving to a shared room. He believed having company helped reduce her anxiety. Interestingly, a special room for visits was provided in only one home but this was reported as being too cold to sit in and instead visits took place on the corridor, affording little privacy. In another, the living room was large and at peak visiting times packed with visitors. The situation was reported as not being conducive to privacy.
Mobility: A number of participants stated that poor spatial design resulted in their relative developing an acquired dependence. Lack of opportunity to exercise due to poor or non-existent gardens and lack of encouragement to maintain mobility were blamed for inability to walk in two cases. A couple of homes were reported to have sold off most of the garden for development, or to have built resident accommodation on it, leaving very little outdoor space for residents’ use. In other cases, where outdoor access was available, participants saw great value in the nursing home gardens when visiting. The only purpose-built dementia unit included in the study was reported to afford ample opportunity to exercise both indoors and outdoors by virtue of very creative design.

Safety: Family caregivers were not overly concerned about safety features in nursing homes and appeared very satisfied with same. It was suggested by a number of participants that care providers face a real challenge in trying to balance homeliness with safety for residents.

Staffing - Although participants identified some weaknesses, on the whole, family caregivers were satisfied with staffing levels available. In particular, staff efforts to reduce residents’ anxiety and to understand life stories were highlighted as examples of good practice. Staff shortcomings included the lack of one-to-one psycho-social care required by people with dementia (particularly at meal-times), inadequate staff ratios for staff to just take time with residents beyond meeting their physical needs and staff rotas driving residents’ routines such as bedtimes. A couple of participants reported that their relatives’ other health needs had not been met due to their dementia. For example one resident had a back injury that was left unattended.

Protocols for nursing home admission - Family members voiced much dissatisfaction about the lack of and poor quality of community care services available to their relative prior to admission but, in contrast, reported that respite and day care services had been very helpful. One respondent commented: “The local health nurse didn’t want to know anything about her. Her own doctor didn’t want to know anything about her “Ah, she’s getting old, she’ll be grand””. In terms of finding an appropriate nursing home placement, some participants (n=4) aided by hospital departments had little difficulty while others without assistance experienced real problems finding affordable appropriate care close to home. Of the eight participants, six had their relatives placed in private nursing home beds whilst in the other two cases relatives were placed in contract beds paid for by the health board. Meeting the costs of care was described as very stressful for many family caregivers. Identifying resources such as subvention and tax
relief was difficult: “It’s the best kept secret”. Some participants felt finding the correct information depended on luck. Two families had experience of the Ward of Court process and found it very demoralising and upsetting. The health board practice of refusing applications for subvention until family resources were depleted to a level that would pay for just weeks of care was a cause of great distress to a small number of families and undermined their security in the long-term care placement. Many family members viewed the statutory policies and procedures affecting the financing of long-term care as a significant disincentive to saving and wealth accumulation.

**Plans for Future Development:**

*Current findings will be used to*

- Develop guidelines on accommodation and design for private nursing homes offering dementia care
- Recommend that guidelines be incorporated into nursing home inspections
- Ensure that all new specialist dementia units comply with guidelines on best practice and dementia care

*Future development*

- A proposed new study investigating design standards in Health Board funded nursing homes offering dementia care
- The development of a Care Standards Act
1 One interview was conducted with a senior staff nurse, another with a non-nursing director as the director of nursing was unavailable at the time of interview