People under 60 living in aged care facilities in Victoria

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Abstract

Objective: To describe the characteristics of people under 60 years of age living in residential aged care in Victoria and to examine the occupational participation of younger residents in aged care facilities by measuring their social contact, participation in recreation and community access.

Methods: A survey was sent to the Directors of Nursing at all 803 Commonwealth Department of Health and Aged Care registered aged care facilities in Victoria.

Results: The survey had a 78% response rate and information was provided about the characteristics of 330 people under 60 years with high clinical needs residing in aged care facilities. This sample was extremely isolated from peers, with 44% receiving a visit from a friend less often than once per year. Sixteen per cent of residents participated in a recreation activity less than once per month and 21% went outside less than once per month. Of the sample, 34% almost never participated in any community-based activities such as shopping, leisure or visiting friends and family.

Conclusion: Over one third of younger people in aged care are effectively excluded from life in our community. Most younger residents are socially isolated and have limited opportunities for recreation. Placement of younger people in aged care facilities is inappropriate, and alternative care models and settings are required.

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What is known about the topic?

More than 3500 Australians under 60 years of age live in residential aged care facilities, a situation generally recognised as incompatible with optimal quality of life.

What does this paper add?

This survey documents the isolation, and exclusion from recreational and social activities, experienced by younger residents in aged care facilities in Victoria.

What are the implications?

This study underlines the need to develop alternative settings and models of care for younger people with high clinical needs. The measures of social isolation and exclusion from activity also indicate potential criteria against which alternative approaches to care could be assessed. ◆

THERE ARE ABOUT 3500 people aged less than 60 years of age ("people under 60") residing in aged care facilities in Australia. Of these, more than a quarter (about 1000) are younger than 50 years. (Source: Australian Institute of Health and Welfare. Unpublished data as at 30 June 2003. Adelaide: AIHW, 2004 24 Sep; private communication to author.) There is a critical absence of current information about people under 60 in residential aged care at both the national and state level, other than data on the overall number and proportion of permanent and respite care residents and admissions, by age and gender.[1] We have little information regarding their specific care needs or their participation in occupational roles (including leisure and vocational participation).

Residential aged care facilities are designed to provide accommodation, personal and nursing care to frail older people at the end stage of their life.[2,3] Aged care facilities are not designed or adequately resourced to facilitate the active involvement of younger residents with high clinical needs in everyday activities or support their continued participation in the life of their com-

munity.[4,5] People under 60 living in aged care facilities are at risk of occupational deprivation and the loss of their already limited abilities through lack of use. This group of people are isolated from their peers and often have limited community access.[5]

People under 60 are admitted to aged care facilities typically because more appropriate accommodation is not available. The health and community service system has struggled to respond appropriately to people with acquired injuries who have complex needs.[6] This group has high clinical needs and requires a greater level of care than is generally available through the state-funded disability services. However, once a younger person is placed in residential aged care they are often "lost" in this Commonwealth-funded system. Once placed, they are no longer considered a high priority for a supported accommodation package and are often not registered with the state-funded disability services.[3] Given that aged care beds are funded by the Commonwealth government, there is little incentive for the state disability services to move people under 60 out of aged care facilities.[5] In addition to the people under 60 currently residing in aged care facilities, there is an unknown number of people under 60 with high clinical needs who are at risk of placement in an aged care facility due, for example, to decreasing ability of their parents to provide in-home care as the parents themselves age.[3]

There are two Australian studies,[4,7] which have surveyed nursing homes to describe the characteristics of younger residents. In 1995, Moylan, Dey and McAlpine[7] conducted a national survey to provide an overview of the numbers of people under 60 in nursing homes. Of the 1515 residents under 60 years residing in nursing homes in Australia at the time of the study, 626 (68%) participated in the survey. The researchers collected information about age, sex, primary disability type, other significant disability types, cultural background, previous place of residence, Residential Classification Instrument[8] score (this instrument was superceded by the Residential Classification Scale in 1997) and additional support services received. Information was also obtained for former aged care residents under 60 years of age who had been relocated to other community-based residential options in the 12 months before the data collection. This study found that the majority of residents under 60 had acquired brain injury as their primary disability type and that very few younger people were relocated from an aged care facility to another accommodation option. Although Moylan et al[7] provide a useful methodology for future studies, the data are not current enough to provide a basis for service planning and development.

Cameron et al[4] focused specifically on people with acquired brain injury (ABI) under 65 years residing in nursing homes in Queensland. Their study described the characteristics of 209 residents under 65 years with an ABI. They concluded that while many facilities were attempting to meet the needs of this group, they are simultaneously faced with limited resources, poor funding and inadequate training for this specialist area of care.

More detailed data are required about the population of younger residents currently living in aged care facilities.[3,9] Although it is now generally acknowledged that residential aged care is inappropriate for younger residents,[4] and there is ample anecdotal evidence of the negative consequences of inappropriate placement,[3,5,10] few studies to date have examined consequences such as social isolation, occupational deprivation and exclusion from the community.

This study had two main objectives. The first was to describe the characteristics of people under 60 with high clinical needs living in aged care in Victoria. The second was to examine their occupational participation by measuring their social contact, participation in recreation and community access. This study obtained information about people with both high care (Residential Classification Scale 1–4 or "nursing home" level) and low care needs (Residential Classification Scale 5–8 or "hostel level"[11]). However, this paper focuses on the results of people with high care needs because the characteristics and care needs of these two groups are quite distinct.

Methods

Participants

The respondents in this study were all the Directors of Nursing at certified aged care facilities in Victoria. A list of certified residential aged care facilities was obtained from the Commonwealth Department of Health and Aged Care website (as of July 2004). There were 803 certified facilities listed in Victoria offering a total of 36 058 residential care places.

1 Residential classification scale (RCS) (N = 451)

RCS level	f	Percentage
1	162	36%
2	96	21%
3	60	13%
4	12	3%
5	51	11%
6	48	11%
7	22	5%

Tools

The survey consisted of two questionnaires (Questionnaire A: Facility Data Sheet; and Questionnaire B: Younger Resident Data Sheet). Questionnaire A has four items, takes about 2 minutes to complete and requests information about the aged care facility. Questionnaire B has 24 items, and takes about 10 minutes to complete for each resident under 60. The first half of Questionnaire B covers information about the characteristics of the residents including demographics, disability type and complex care needs. Questionnaire A and the first part of Questionnaire B are based on the surveys utilised in two previous studies which examined younger people residing in aged care facilities.[7,12] The second half of Questionnaire B covers information about the frequency of social contact, participation in recreation and access to the community. These items were developed for this study by selecting relevant items from measures of community integration from the rehabilitation literature[13-15] and modifying them to make them relevant to the aged care facility setting.

A pilot survey was mailed to 40 randomly selected aged care facilities in New South Wales. Respondents were asked to estimate the amount of time each questionnaire took to complete and to comment on any questions that they found to be ambiguous or difficult to answer. The response rate was 45% with 18 facilities returning completed surveys. As a result of the pilot survey, minor modifications were made to five items in Questionnaire B.

Procedure

The project was granted ethics approval by the La Trobe Faculty of Health Sciences Human Ethics Committee. The postal survey was conducted

2 Demographic characteristics of people under 60 years of age with high clinical needs

Chracteristic	No. of people
Sex (*n* = 328)	
Male	160 (49%)
Female	168 (51%)
Language (*n* = 323)	
English speaking background	264 (82%)
Non-English speaking background	59 (18%)
Indigenous status (*n* = 314)	
Aboriginal or Torres Strait origin	5 (2%)
Non-indigenous	309 (98%)
Age (years) (*n* = 327)	
Minimum	8
Maximum	59
Mean (SD)	50.48 (± 8.69)
Length of stay (days) (*n* = 320)	
Minimum	3
Maximum	8535 (23 years)
Mean (SD)	1427.9 (± 1431.7) (3.9 years)

between October 2004 and January 2005. The survey approach and follow up were based on the methods outlined by Dillman,[16] with the aim of maximising the response rate. A pre-survey letter was sent to inform potential participants about the survey. Each aged care facility in Victoria was sent one copy of Questionnaire A and multiple copies of Questionnaire B (depending on the total number of residents in the facility) and a guide to completing the survey. As an incentive to return the survey, potential participants were informed that respondents to the survey would have a chance to win one of two DVD players. Follow-up strategies included a postcard, and a replacement survey.

Data analysis

The characteristics of the residents with high clinical needs were examined by calculating the frequencies for categorical data and the minimum, maximum, mean and standard deviations for continuous demographic data. Social contact, participation in occupation and community access were analysed using frequencies. Incomplete returns were included, and the numbers of people about whom information was available for each data item are specified in the Boxes.

Results

Surveys were sent to the Directors of Nursing at the 803 certified aged care facilities in Victoria. Follow up of non-respondents revealed that three of these facilities had recently closed. Of the remaining 800 aged care facilities, 626 facilities (78%) returned the survey via post. One respondent returned the survey with a note indicating that they did not want to participate in the study.

Respondents provided information about 478 people under 60 residing in aged care facilities. Almost three in four (73% of 451) required a "nursing home" level of care, with high clinical needs as indicated by a Residential Classification Scale score of one to four (Box 1). The results presented below refer to these residents.

Of the residents with high clinical needs, 51% were female (Box 2) and 66% were aged 50–59

3 Age of younger residents (N = 327)

Age range	f	Percentage
< 30 years	13	4%
30–39 years	22	7%
40–49 years	75	23%
50–59 years	217	66%

4 Residence before admission to aged care facility (N = 329)

Variable	f	%
Own home	117	36%
Hospital	73	22%
Rehabilitation facility	45	14%
Aged care facility (high care)	51	16%
Aged care facility (low care)	18	5%
Group home	25	8%

5 Disability type (*N* = 326)

Disability type*	f	%
Cancer	1	0.3%
Muscular dystrophy/atrophy	2	1%
Quadriplegia	2	1%
Motor neurone disease	4	1%
Paraplegia	4	1%
Cerebral palsy	5	2%
Deafness/hearing impairment	5	2%
Other	6	2%
Psychiatric disability	8	2%
Parkinson's disease	9	3%
Dementia	16	5%
Blindness/vision impairment	17	5%
Huntington's disease	22	7%
Intellectual disability	48	15%
Multiple sclerosis	55	17%
Acquired brain injury	122	37%

* Each resident may have more than one disability type.◆

years (Box 3). Eighteen per cent were from a non-English speaking background, with 25 different languages represented (Box 2). Five residents with high clinical needs were of Aboriginal or Torres Strait Islander background (Box 2). The mean length of stay was nearly 4 years with one person residing in an aged care facility for 23 years (Box 2). The place of prior residence of people under 60 with high clinical needs was varied. Thirty-six per cent were admitted from home, 22% were admitted from hospital, 14% were admitted from another aged care facility and 16% were admitted from a high care residential aged care facility (Box 4). This result supports anecdotal evidence that suggests that many young people are transferred from acute hospitals to aged care facilities without receiving rehabilitation services.

The study utilised the disability types and definitions outlined by the Australian Institute of Health and Welfare.[17] Acquired brain injury was the most common disability type (37%): others included multiple sclerosis (17%); intellectual disability (15%); and Huntington's disease (7%) (Box 5). Thirty-eight per cent of the sample had more than one disability (Box 6). The five most common complex care needs identified were: managing challenging behaviour (63%); pressure sore prevention/management (52%); epilepsy management (20%); percutaneous endoscopic gastrostomy (PEG) tube feeding (18%); catheter care (16%); and diabetes management (13%). Seven per cent of the sample did not have a complex care need identified (Box 7).

Many of the people in this sample were socially isolated. While 24% of the sample received visits from a relative most days, 11% received a visit from relatives less often than once per year (Box 8). Family members tended to be the only ones who maintained contact with the people under 60 in aged care. Forty four per cent of the sample was extremely socially isolated from peers, with visits from a friend less often than once per year (Box 8). When we analysed visits from family and friends together we found that 16% of younger residents had visits from family members less than once per month and visits by friends less than once per year.

6 Multiple disabilities (N = 322)

Number of disability types identified	f	%
1	199	62%
2	91	28%
3	26	8%
4	5	2%
5	1	0.3%

7 Complex care needs* (N = 330)

Complex care need	f	%
No complex care need identified	22	7%
Challenging behaviour	207	63%
Pressure area management	172	52%
Epilepsy	65	20%
PEG tube feeding	59	18%
Catheter	53	16%
Diabetes	43	13%
Contractures	6	2%
Extreme obesity	6	2%
Renal failure	3	1%
Ventilator dependent	2	1%
Other	34	10%

* Each resident may have more than one complex care need. ◆

Many of the younger residents did not participate regularly in recreational activities. Twenty-three per cent of the sample participated in recreational activities organised by the aged care facility less often than once per month (Box 9). Fifty-five percent of the sample participated in recreational activities organised independently of the aged care facility less often than once per month (Box 9). This included recreation arranged by the resident, family, friends, volunteers or paid workers. When these two recreation items were examined together we found that 16% of the sample did not participate in either facility-based or independently organised recreation on a

monthly basis. In the sample studied, 10% of participants went outside less than once per week and an additional 21% of younger residents went outside less than once per month (Box 9).

Many of the sample were effectively excluded from the community. Forty-seven per cent of the sample travelled outside the aged care facility less often than once per month (Box 9). Fifty-five per cent of the younger residents went shopping less than once per year (Box 10). Fifty-six per cent of the sample participated in leisure activities such as movies, sports and restaurants, less often than once per year (Box 10). Fifty-eight percent of the sample visited relatives in their home less often than once per year (Box 10) and 83% visited friends less often than once per year (Box 10). When the community access items on the survey were examined collectively, we found that 34% of younger residents almost never participated in any community-based activities such as shopping, leisure or visiting family and friends.

8 How often, on average, residents are visited

	By a relative (N=325)		By a friend (N=324)	
Response options	**f**	**%**	**f**	**%**
Most days	77	24%	12	4%
1–3 times per week	100	31%	54	17%
1–3 times per month	56	17%	47	15%
5–11 times per year	27	8%	23	7%
1–4 times per year	29	9%	46	14%
< once per year	13	4%	30	9%
Never	23	7%	112	35%

Discussion

This study provides current information about demographic characteristics and care needs of people under 60 with high clinical needs, which could be used to assist in the development of more appropriate accommodation options. Although it is widely acknowledged that residential aged care is inappropriate for younger people[3,9] this study provides concrete evidence outlining some specific negative consequences of inappropriate placement. This study also indicates some specific criteria that should be met by community-based living options for people with high clinical needs. Any alternative housing and support options require careful planning, adequate resources, good care models and a commitment to foster social contact with peers and facilitate participation in recreation and community life.

In our sample, 31% of residents went outside less than once per week. It is well established that elderly people in residential aged care are at risk

9 Frequency of participation in activities

	Type of recreation							
	Facility* (N=324)		Other† (N=324)		Outdoor‡ (N=325)		Away from facility§ (N=326)	
Response options	**f**	**%**	**f**	**%**	**f**	**%**	**f**	**%**
More than once per day	43	13%	3	1%	50	15%	5	2%
Almost every day	123	38%	31	10%	82	25%	24	7%
Almost every week	71	22%	77	24%	91	28%	96	29%
Almost every month	13	4%	34	11%	33	10%	49	15%
Seldom/never (< once per month)	74	23%	179	55%	69	21%	152	47%

* On average, how often does the resident participate in recreation activities organised by the aged care facility? † On average, how often does the resident participate in recreation activities organised independently of the aged care facility? (eg, arranged by the resident, family, friends, volunteers or paid workers) ‡ On average, how often does the resident go outside (eg, into the garden)? § On average, how often does the resident travel outside the aged care facility (ie, into the community)? ◆

of vitamin D deficiency,[18-20] and it is likely that this applies to younger people with high clinical needs.

A proportion of young people in aged care are likely to have very limited awareness of their surroundings and have little interaction with other people or their environment. However, given that 63% of the people in this sample had challenging behaviour, it seems that many of them were at least to some extent aware of their surroundings and reacting to events in their environment. High levels of challenging behaviour may reflect significant psychological distress and/or frustration. Triggers to challenging behaviour such as boredom, loneliness and disempowerment may be consequences of limited opportunity to participate in the community or engage in meaningful occupation. It is possible that many of these challenging behaviours would resolve if a more suitable living environment were provided.[21] A limitation of the study is that the detail of the specific contexts of these behavioural reactions was not collected.

Another limitation of this study is that we do not know what the residents themselves, or their families, want in terms of alternative accommodation and support. It is likely that some people are satisfied with their current arrangement, or may be anxious about the prospect of change after several years of institutional living. Future studies need to include the perspective and aspirations of the younger people in aged care as well as their families.

This study provides evidence that aged care facilities do not support younger residents with high clinical needs to participate actively in social, recreational and community activities. It is imperative that alternative housing be developed for this population and that the services address both clinical care needs and occupational participation. Care models need to address the many complex care and clinical needs of this group such as challenging behaviour, pressure sore management and PEG tube feeding. Services also need to be adequately resourced to foster social contact and participation in recreation and community life.

Since this survey was completed, there has been a significant change in the policy environment regarding this issue. The Aged Care Inquiry Report concluded that in most instances it is inappropriate for young people to be living in aged care, as they do not receive adequate support.[22] On 3 June 2005, following the 15th meeting of the Council of Australian Governments (COAG), the Prime Minister announced that a group of senior officials would be set up to report in December 2005 on ways to better integrate health services, including removing young people from nursing homes and setting up national databases.[23] Given the current focus on this issue at the highest levels of government

10 Frequency of participation in external activities

	Type of activity							
	Going shopping* (N=324)		Leisure activities† (N=321)		Visiting relatives‡ (N=322)		Visiting friends§ (N=322)	
Response options	f	%	f	%	f	%	f	%
Never	179	55%	181	56%	186	58%	267	83%
1–4 times	78	24%	64	20%	70	22%	36	11%
5–12 times	28	9%	38	12%	32	10%	8	3%
> 12 times	39	12%	38	12%	34	11%	11	3%

* About how many times a year does the resident usually participate in shopping outside the aged care facility? † About how many times a year does the resident usually participate in leisure activities such as movies, sports, restaurants, outside the aged care facility? ‡ About how many times a year does the resident usually visit relatives in their home? § About how many times a year does the resident usually visit friends in their home (i.e. outside the aged care facility)? ◆

there is a unique opportunity to address this issue over the next decade. However, moving people under 60 out of residential aged care into the community is much more complex than providing bricks and mortar and support packages.

Conclusion

The placement of young people in aged care is a social injustice that needs urgent attention.

Social contact and community participation are basic expectations that most of us take for granted, yet a large proportion of younger people in aged care facilities are effectively excluded from life in our community. Many of the people in this study were socially isolated and deprived of opportunities for engagement in occupation.

The inclusion of people with high care and complex needs in the community requires both the development of infrastructure and practical research on what will work. Given the relatively small numbers of this group in any region, we suggest that a national hub is required to connect people including consumers, families, workers, service providers, agencies and government bodies to provide information and facilitate collaboration. At present, people under 60 living in aged care and their families tend to be isolated[10] and frequently have limited access to information about services and alternative models of care.[3] These people need to be connected with each other through the Internet and newsletters which provide information and opportunities for networking and peer support.[5] The national agency could also collate and maintain databases about current services, local and international models of housing and support, relevant literature and current research projects.

Further research is also required to develop appropriate assessment and planning tools, examine outcome measures and develop and evaluate transitional programs and innovative models of housing and support. The tools currently available are not adequate to capture the complex care needs of people under 60 residing in aged care.[3,22] Although it is now widely agreed that it is inappropriate for younger people to reside in aged care,[9,22,23] and this study highlights some of the consequences, there is little clarity about what we are aiming to achieve by moving younger people out of aged care — how will we know if the transition from aged care to the community has been worthwhile? Further research is required to identify key outcomes of transition from the perspective of consumers. This information could then be used in the development of outcome measures for alternative housing and support models. Action research is also required to develop and evaluate transitional accommodation programs and innovative models of long-term housing and support.[5] Although there have been a number of facilities developed in Australia for people with complex and high care needs,[24,25] there has been limited evaluation of these facilities to determine if these services are meeting the needs and aspirations of consumers.[5,26-28] Comprehensive evaluation of existing and new models of housing and support will direct the development of future models. The development of infrastructure and adequate recurrent funding for service delivery will enable people under 60 with high support needs to be included in the community and live lives with dignity and meaning.

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Competing interests

The authors declare that they have no competing interests.

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