

IN PRACTICE

Young disabled residents in old people's homes

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Abstract

A survey of the status of residents in aged care facilities in the Auckland region conducted in 1988 indicated that almost 9% (645) of the 7516 people studied were under 65 years of age. Rates were markedly higher for people of Maori descent than for those of European descent in this age group. For nonMaori, the rate for men was higher than that for women, but for Maori the opposite was the case. The majority of these young residents (94%) were being cared for in commercial old people's homes. One half were cared for in just 29 of the 223 homes in the region. While most (59%) were admitted after the age of 50, 15% were admitted before they were 40 and must expect to live their lives out in institutions primarily housing elderly residents. Almost half of those in old people's homes had been admitted from a psychiatric hospital. The authors are concerned that so many young people appear to be in old people's homes because of a lack of alternative accommodation which is more suited to their care.

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Introduction

This paper concerns the young disabled who are generally recognised as that group of disabled adults under the age of 65. In the Auckland area a lack of facilities for the rehabilitation and continuing care of these people has meant that for some their rehabilitation has been managed in geriatric facilities and where that has not been sufficient to enable them to return to the community, their continuing care is provided by facilities for the elderly. Geriatricians have therefore had a major role in the health care of these people.

An Auckland wide study of the status of residents in old people's homes and private and public long stay hospitals for the elderly undertaken in 1988, revealed that almost 9% of the population studied was under 65 years of age [1]. This paper presents an analysis of the status of the young disabled in residential care for the elderly using the information gathered in the original study and expanding it in order to highlight the size of the problem of this particular group.

Methods

The details of the methodology for collecting the information have been previously published [2,3]. Briefly, a questionnaire was used to gather key demographic and admission details and dependency ratings for each resident or patient occupying a long term place in an old people's home or a long stay hospital facility. The questions regarding dependency were based on the widely used and validated questionnaire developed by Booth et al [4]. The questionnaires were delivered to the responsible principal nurse, medical superintendent or manager of each institution together with a detailed explanation of the reasons for the study and the way in which the study results would be used. An instruction sheet giving details for the correct completion of each form was also provided. The resident's dependency ratings were to represent his or her condition over the previous two weeks. If the condition varied over this time then the more dependent rating was to be selected. The majority of institutions were surveyed between January and June 1988.

After manual checking of the questionnaire, data were analysed using the SAS package. A computer model was developed to approximate as nearly as possible the composite dependency scale recommended by the Department of Social Welfare for assessing the dependency level of people applying for a rest home subsidy. This scale had previously been used in a nationwide study [5]. The composite dependency scale allocates a score in the range of 1-5 in a variety of activities of daily living and the total score determines the dependency category for each individual. Five categories of increasing dependency are assigned: independent; some dependency - category 1; moderate

dependency - category 2; appreciable dependency - category 3; substantial dependency - hospital care recommended.

Results

The survey covered 288 different care settings, 65 being private long stay hospitals, and 223 old people's homes. Seven thousand, five hundred and sixteen residents were identified of whom 645 (8.6%) were under the age of 65. Five thousand, two hundred and thirteen of the total were resident in old people's homes: of these 486 (9.3%) were under the age of 65.

Of the 486 in old people's homes, 96% were being cared for in commercial homes. A small number of commercial old people's homes catered predominantly for younger residents: in 18 homes more than half of the residents were aged less than 65 years, and between them they cared for almost half of all residents under 65 years. A further 11 homes, all commercial, had over 50% of their residents aged less than 65 at the time of admission, and these cared for a further 11% of those under 65 at the time of survey.

With respect to those residents under the age of 65 resident in old people's homes, there were more men (57%) than women. The majority (59%) had been admitted between the ages of 50 and 65; 23% were admitted between the ages of 40 and 49, and 15% prior to turning 40. Information about age at admission was lacking in 3% of residents.

With respect to ethnic groupings, 11.3% of the younger residents were Maori. For both sexes and in both age groups tested (45-54 years and 55-64 years) the in-care rates per 10 000 population for Maori were higher than in nonMaori (Figure 1). For nonMaori the rate for men was higher than that for women, but the reverse was true for Maori.

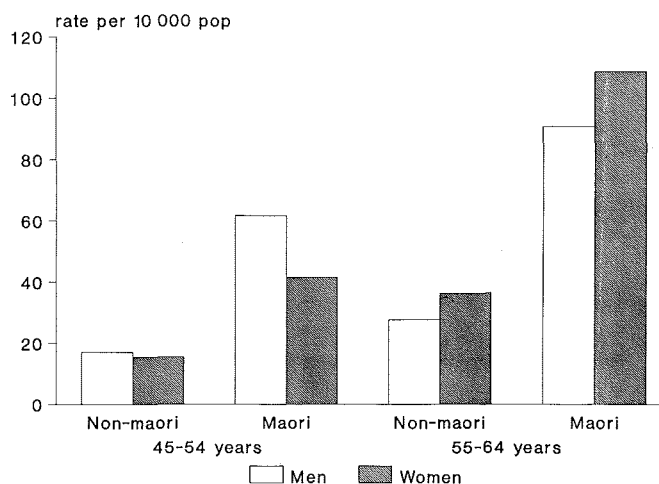


Figure 1. - Young adults in geriatric long term care facilities, by age, sex and major ethnic groups: rates per 10 000 population.

Almost half (48%) of these younger residents were admitted directly from a psychiatric hospital. The remainder were admitted from either a private home (15%), public hospital (9%), an IHC home (3%), or some other source.

Table 1 is an analysis of length of stay of residents based on all residents in old people's homes. It compares three groups: those admitted younger than 65 years of age and still not yet 65 (n=486), those admitted younger than 65 but who were older than 65 at the time of survey (n=258), and those who were admitted after turning 65 years of age (n=4469). Among residents who were admitted prior to turning 65 years but who were over 65 at the date of survey, 44% had been in care for more than nine years compared with 12% and 5%

of people who were younger than or older than 65 years respectively at the time of the survey.

Table 1.—Length of stay for residents in old people's homes

Length of stay	Under 65 at survey date (n=486) %	Admitted under 65, now 65+ (n=258) %	Admitted 65 and older (n=4469) %
<5 years	68	36	82
5 and <9 years	17	20	12
9 years and over	12	44	5
No data	3	0	1
Total	100	100	100

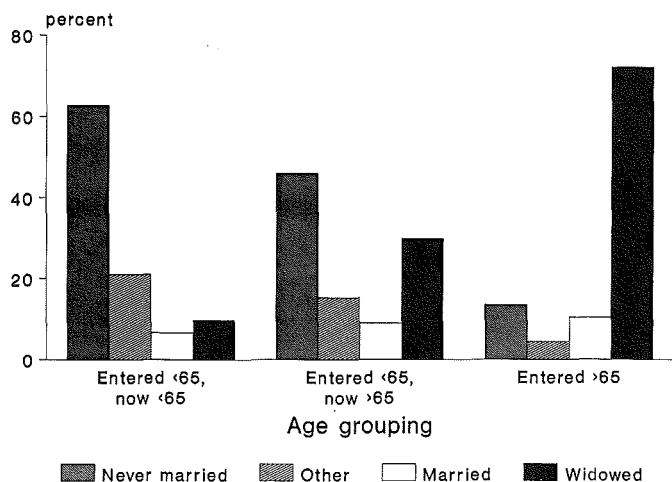


Figure 2.—Marital status of residents of old people's homes, by age grouping.

Figure 2 compares the marital status of residents in the three groups described above. It illustrates the high proportion of the young disabled who have never married. When analysed by sex the proportions of men and women in the younger group living in old people's homes who had never married were remarkably similar. By contrast, as might be expected, there is a very high proportion of widowed people in the 65+ entry age group. Although the majority had family in the Auckland region, a much smaller proportion had regular contact with their families than was the case for older residents.

Residents under 65 years of age at entry to a residential home were more dependent than those admitted after 65 (Table 2). For each of the high categories of dependency—moderate, appreciable and hospital level care—there was a proportionately greater representation of people admitted before age 65 than of people admitted after age 65. This remained true even when the apparently independent groups were excluded from the analysis.

Table 2.—Dependency rates of residents in old people's homes

Level of dependency	Under 65 date of survey (n=486) %	Admitted under 65, now 65+ (n=258) %	Admitted after turning 65 (n=4469) %
Independent	12.6	17.1	24.1
Some dependency	29.6	31.4	32.1
Moderate dependency	34.2	33.3	28.1
Appreciable dependency	18.5	14.7	12.7
Hospital level of care	5.1	3.5	3.0

Discussion

It has long been the contention of geriatricians and social workers in Auckland that the residential care settings occupied by the elderly are not suitable for those in younger age groups. The dependency characteristics of the two groups are different and presumably the social needs of the two groups are also different. The younger residents have appreciably higher dependencies and, because so few have ever married, they are at least in this respect a different social group from the older residents.

We have also shown that a high proportion (48%) were admitted to rest homes via the psychiatric service. By way

of comparison, only 5% of residents who entered long term care after age 65 were admitted from psychiatric hospitals [1]. Given the knowledge that a proportion of this group would have moved from a previous rest home, to which they had originally been referred by the psychiatric services, it is likely that the figures for this latter source of referral are an underestimate.

The fact that so many young disabled in rest homes had been referred by a psychiatric service to old people's homes suggests that more suitable accommodation options did not exist. One of the terms of reference of the Mason committee of inquiry of 1987-8 related to "the extent to which psychiatric care is provided and other facilities for care and rehabilitation (such as half way houses) are available to persons discharged or released in accordance with the Mental Health Act of 1969, and the Criminal Justice Act of 1985" [6]. The committee in fact did not limit its investigation to this group of patients alone, but examined and reported on the psychiatric care and community facilities available to all expsychiatric hospital patients. It appears from the report that old people's homes were not included in the spectrum of accommodation visited by members of the committee. It is possible that it was not even aware of the use of this form of long stay accommodation for expsychiatric patients.

The Mason committee recommended that a range of accommodation be provided in the community for patients discharged from psychiatric facilities. Of the range of models cited in the report none included the concept of physically disabled elderly living on the same premises as younger expsychiatric patients. The development of psychiatric services in Auckland, by the then Auckland Hospital Board, was severely criticised by the committee of inquiry and it seems likely that the situation uncovered by our review is but further evidence of the failure of that hospital board's policies for psychiatric services.

The likely explanation for this high proportion of younger people discharged from psychiatric services to long stay residences for the elderly in Auckland is that, from the mid 1970s, provision was made by the Auckland Hospital Board to discharge residents of psychiatric hospitals to private institutions by using the special rest home subsidy available to those who were "frail ambulant". It was not until 1987 that the Old People's Homes Regulations were amended to remove reference to "infirm" and replace it with a reference to the "aged-frail". This was to ensure that the regulations were in keeping with the needs and concerns of older people, rather than mentally or physically disabled residents of any age. The intent seems to have been that premises catering to younger residents should be licensed under the Disabled Persons' Community Welfare (DPCW) Act of 1975, rather than the Old People's Homes Regulations.

However, as of mid 1990, only two of the old people's homes which our 1988 survey found were catering largely to a younger clientele, had reregistered as DPCW homes; and one currently unlicensed home had applied for registration. Of the remainder, four continued as licensed rest homes, one was licensed as a boarding house by the Local Authority, and the remainder are either currently unlicensed or in the process of having their licences reviewed. The fact that care is being provided in facilities which are unlicensed, and unregistered—perhaps not even meeting fire regulations—must be a cause for concern.

The relatively high proportion of younger Maori residing in old people's homes deserves comment. An earlier analysis of population rates of residents over 65 years of age had shown rates for Maori and nonMaori in residence to be consistent with their proportions in the community at large [2]. It is clear that this is not the case for under 65 year olds. Does this reflect a high proportion of Maori in the mental health services? Does it indicate a breakdown of extended family relationships in urban Maori communities? Special consideration should be given by the area health board to this small but important group of people who might well be able to be returned to a more culturally sensitive and stimulating environment.

The needs of the younger physically disabled adult both for rehabilitation and longer term residence have been a problem

in Auckland for many years. Because the survey on which this analysis is based was constituted on the basis of dependency levels rather than diagnostic categories, it is not possible to identify the major determinants of physical dependence in the population studied. There is unquestionably a need to evaluate further the needs of the younger physically disabled adult – indeed, whereas the services for the psychiatrically disabled in the Auckland area seem to be under continual review, there has never to our knowledge been an inquiry into the board's handling of the needs of younger physically disabled people. Were there to be one, it is likely that a similar state of affairs would be shown to exist: lack of sufficient rehabilitation facilities, lack of sufficient facilities dedicated to long term care, and lack of concern for the needs of yet another group in the community which does not have strong powers of self advocacy.

In its 1986 strategic plan [7], the then Auckland Hospital Board indicated that whereas the Department of Health's guidelines were for 173 places in Auckland for the physically handicapped, the board in fact provided only 125 beds (of which not all were long stay). This figure however failed to take into account geriatric beds in the board's long stay facilities which were occupied by younger disabled patients. At that time we estimate that 10-15% of long stay residents in public geriatric long stay beds were aged less than 65. The majority of these residents were moved into private long stay accommodation in late 1989 and early 1990. Our survey reveals what seems to be a very different assessment of the numbers and needs of the younger physically disabled in

Auckland. If one allows that up to a half of the younger disabled in old people's homes have a history of psychiatric disorders, there remains in excess of 300 other disabled people in long stay residential care designed for the elderly. This figure does not include residents in the spinal unit or the Sutherland unit (a long stay hospital for young disabled), neither of which was included in the survey. It seems obvious that any strategic plan the Auckland Area Health Board seeks to implement for the younger disabled in future will be grossly deficient unless the full extent of the need is recognised.

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