International update

Special Dementia Unit as hostel: a residential care development in Australia

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Abstract

As with many other aspects of health care, specialization has become a feature of residential care. In addition to well-aged units and nursing homes there are two categories of hostel care for older people in Australia. An account is given of the development of the Special Dementia Unit (SDU) in the form of a hostel. The advantages and disadvantages of this facility are mentioned. A close association of geriatric and psychogeriatric services with nursing homes and hostels is necessary to achieve a regional service as well as further development in the several components of institutional care.

Early development of special care

Specialization has been one of the conspicuous features of health care during the present century. The notice "Physician and Surgeon" used to indicate where the local doctor practised. Those names now refer to widely differing specialities, while the local doctor is more confined to the immediate affairs of the family – which is now his or her speciality. Subdivisions abound in many aspects of medical practice: cardiology, oncology, andrology and palliative care, to name only a few. Even residential care for disabled people has followed a somewhat similar trend.

Society's initial reaction to the problem of disability was to build a wall around it with "inmates" kept at a decent distance from the normal populace – hence the asylum. But this institution has now vanished and concern for particular groups has given rise to a number of alternative forms of care. First, children were separated from the conglomeration of the maimed, the crippled and the blind. Mental institutions later provided special attention for people with psychiatric disturbances. But the "aged and infirm" generally remained together. Their home was graced by the word benevolent but there was little attention either to the cause or to the particular needs of their infirmities until the special procedure of geriatric medicine began.

Geriatric medicine

This practice originated in Britain in the 1940s when Dr Marjory Warren and her colleagues refused to accept the notion that the rehabilitation of elderly people was a useless exercise (Warren, 1946). Our local experience began in the early 1960s when the Public Health Department in Western Australia decided to follow the successful British model. It may seem odd that such a department would become involved in an activity that is essentially clinical but it was clear that, while subdivision and specialization were being actively pursued in the main hospitals, it was unlikely that this process would direct special attention towards disabled elderly people. The problem of the "aged and the chronics" had already stimulated the following solution from the *Medical Journal of Australia*: "We plead for special institutions ... where they may be nursed and treated ... it is right that we should do this, especially when we find that they occupy beds in which acutely ill patients should be placed" (Editorial, 1950). There was indeed an element of compassion in this plea; nevertheless, "special" in no way referred to Dr Warren's application of the principle of rehabilitation but to an alternative – the nursing home – designed to counteract what was regarded as "bed-blocking" in the acute hospital. Our alternative had a different purpose, namely to set up an assessment and rehabilitation unit. Because of exclusion from established hospitals we had no choice but to go to an old people's "home" on the outskirts of the city.

The personnel in the geriatric service, mainly physicians, social workers and nurses, made themselves available to general practitioners and hospital clinics to offer assistance and to help plan future care for disabled elderly patients. In spite of our relative isolation from the mainstream of medicine, two considerable advantages – in addition to an opportunity to practise rehabilitation – became apparent. The first advantage was becoming acquainted with people (this included relatives) when care at home had broken down. The second advantage was being confronted by the problems of those living in a permanent care institution – an experience that had largely eluded the physician whose activity had been confined to the acute hospital.

A new form of residential care

Over the ensuing years, an opportunity to study the needs of elderly disabled people led to the development of the conventional hostel[1] as an alternative to the nursing home. The facility proved to have advantages for those who could no longer live in a reasonable manner in the community but who could be supported in the home-like environment of a hostel, cared for by staff who did not have nursing training. More recently, following our encounter with increasing numbers of people with dementia, the concept of the Special Dementia Unit (SDU) in the form of a hostel has evolved.

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Special care unit for people with dementia

It is to the advantage of people with dementia, as well as to their relatives and to the community bearing the cost of residential care, that they remain at home for as long as possible. But for many relatives the burden of care eventually becomes overwhelming. This prompts the question: is a special form of residential care – one that differs both from the nursing home and from the conventional hostel – necessary for people with dementia?

For a selected group of people with dementia there are distinct advantages in creating a Special Dementia Unit (SDU) in the form of a hostel (Lefroy, 1991). The building is on similar lines to the conventional hostel with the added feature of security against wandering away. But because of the necessity for an increase in staff to care for people with cognitive impairment and aberrations of behaviour (four carers and two activity staff members are present during the busy time of the day, while two carers are present from 23:00 to 07:00), an increase in subsidy compared to that available to residents in the conventional hostel is necessary. As with the latter, staff members do not need nursing training; they do, however, need training in dementia care as well as in residential care.

When this concept was introduced to the Commonwealth Government in the 1970s, it did not agree that such a distinction was necessary; an increase in subsidy was refused. Subsequently an approach was made to our State Government. We were then reminded of the division of responsibility between Commonwealth and State governments according to our constitution: while the former takes care of residential services, the latter is responsible for medical services. Accordingly the request was again declined. A third possible avenue was then explored, namely an approach to the voluntary agencies who were operating non-profit (conventional) hostels and relying on the Commonwealth Government for subsidies – providing they possessed some means of meeting the recurrent deficit in maintenance cost that was bound to occur.

It was not surprising that an organization such as Anglican Homes in Perth, with its long experience in residential care, was well aware that the existing situation was often detrimental for people with dementia; the organization also had ample proof that this practice of integration could have disturbing effects on other residents in well-aged units, hostels and nursing homes. Consequently Anglican Homes was enthusiastic about creating an SDU in the form of a hostel for 36 residents, knowing that the Commonwealth Government would provide subsidy both for the building and for at least part of the maintenance costs of the residents. From the Government's point of view, the latter would be classified as hostel residents but their status as needing special attention on account of dementia would not be recognized. The hostel was opened in 1985; a second SDU has recently been opened by the same organization.

It was assumed that after demonstration of this special facility for a year or two, its advantages would be apparent to the bureaucracy and that an appropriate subsidy would be forthcoming. The assumption proved to be wrong. Ten years later the Commonwealth Government is still resisting the concept that residents in a stand-alone SDU in the form of a hostel should attract a special subsidy. The reason is obscure. It is difficult to understand why a department which professes to underscore the rights of the individual continues to deny the right of a person with dementia an opportunity of special care in a segregated unit, as well as the right of a resident in a conventional hostel or nursing home to be free from harassment by those with disturbing behaviour. Notwithstanding this impasse, a number of voluntary agencies throughout Australia have formed SDUs, some of which have already been forced to close on account of the accumulation of financial deficit. Alternatives to this form of SDU have been set up, such as having a separate wing for six to 12 people in a conventional hostel. This goes some way towards making special provision for people with dementia but does not include all of the advantages of the stand-alone segregated hostel.

Advantages of the SDU

Separate or segregated care enables special attention to be given to the person with dementia; it avoids unrealistic expectations but encourages independence within each person's capability and provides support for functions that have diminished, thereby preventing or lessening agitated behaviour. Segregation has advantages not only for a person with dementia but for a resident with normal mental state who is spared the indignity that often results from the integrated care in the conventional hostel or nursing home.

The third group to benefit from such an arrangement are staff members, both those of the SDU and those in the conventional hostel; neither can be expected to attend successfully to the needs of such residents living in the same environment. The phenomenon of "burn out" is negligible when carers are carefully selected, employed part time, trained in dementia care and adequately supported by administration – compared to a situation akin to melt-down that can result from the integration of cognitively impaired individuals with normal elderly people.

A fourth group to benefit from this separation are the relatives, knowing that encouragement and support commensurate with each resident's capability – prosthetic care (Lawton, 1979) – is being provided and that untoward behaviour will receive an understanding and appropriate response.

Lastly, the community stands to benefit. Although care in the SDU hostel (about AUS$ 84 per resident per day) costs more than in the conventional hostel, it is less than in a nursing home (about AUS$ 105 per day) where the residents of the SDU hostel would have otherwise been admitted; this would result in an annual saving in excess of AUS$ 7000 per resident.

One feature essential for the success of an SDU hostel is the careful selection of residents. The diagnosis of dementia must be proven; abnormal behaviour from other causes is not a valid reason for admission. Mistakes of this kind in the past have been one of the reasons for criticism of the special care unit (Norman, 1987). A mild degree of cognitive impairment should not exclude a person from a conventional hostel; more important is whether behaviour is acceptable to other residents. Diagnostic assessment must also include appraisal of physical function. When such acts as mobility or feeding require constant assistance from a relatively small staff, or when medical conditions such as advanced cardiac failure or respiratory insufficiency require attention beyond the capability of the staff, care in a nursing home becomes necessary. (A discussion paper concerning the special hostel unit, with details on the SDU mentioned above, has been prepared by Page (1996).)

Disadvantages of the SDU

Certain disadvantages, some more apparent than real, have hampered the further development of the SDU in the form of a hostel. The absence of a realistic subsidy to cover maintenance costs is the main obstacle. The fact that transfer to a nursing home, a second relocation after leaving home, will be the eventual outcome for the majority of residents admitted

to the SDU, is a relative disadvantage. Nevertheless, our experience over a period of eleven years has been as follows: whereas the total time between admission to the hostel and death (either in a hostel or a nursing home) is 4,7 years, half that period was spent in the hostel (Lefroy, Hyndman & Hobbs, 1997). This would appear to justify admission to the SDU hostel, even though subsequent transfer to a nursing home becomes necessary for the majority of residents. This was the opinion of almost all the relatives of residents transferred from the SDU hostel; they spoke enthusiastically of the advantages following admission to the SDU in spite of the necessity for later transfer to the nursing home.

The necessity for transfer suggests that an SDU hostel should not be run in isolation. A nursing home with about the same number of places as a hostel and capable of caring for people in the advanced stages of dementia should be part of the same administrative complex. In this situation, relatives would be less stressed by the disadvantage of transfer to a second institution.

Regional service

The SDU hostel is not designed to replace either the conventional hostel or the nursing home; it is regarded as an added facility for a *selected* group who would be more appropriately cared for in a hostel. Nor should it exist in isolation. Because continuity, generally over a number of years, is an essential ingredient in the care of people with dementia, a number of institutions, including those for residential care, become involved. At different times during a person's long illness there may well be a need for home-care services or day care as well as for episodes of acute care, rehabilitation and one or more of the three residential institutions already mentioned. It is not easy to correlate these various functions. The general practitioner is the obvious link in the chain of events but he/she needs assistance from time to time. Provision of this assistance, often beginning with the diagnostic assessment and the opportunity of repeating it when necessary, should be one of the responsibilities of the regional geriatric service.

With the principle of continuity in mind, the Anglican Homes SDU has an attached day-care centre and a special section for intermittent (respite) care for people who are still able to remain at home. It would, however, be incongruous to add to this the responsibility of arranging continuing care at home for those who apply but are not selected for admission to the hostel; or for being responsible for the care of residents in the SDU who have acute episodes of illness, requiring reassessment or rehabilitation. Local general practitioners (responsible for day-to-day medical attention) and personnel of the regional geriatric service are vital to the success of the institutions set up for the care of people with dementia. Co-ordination on a regional basis should replace the isolation and separate function of these facilities which all too commonly exist at present.

Postscript

Asylums are now a relic of the past, with the buildings – more appropriately – in the hands of national trusts. Among the special residential developments that have evolved for Australia's older citizens are the conventional hostel – a suitable if less sophisticated mode of living for disabled people who do not need to be in a nursing home – and the Special Dementia Unit hostel for a selected group of people with dementia.

Specialization has also taken place on another plane. The geriatrician, a mutant strain in the evolution of the physician, has generated a service to provide special attention to disabled elderly people. This has been followed by mutation in the psychiatrist, producing the psychogeriatrician. Will the latter, in time, put an end to the geriatrician's involvement in the care of people with dementia?

> *Psychogeriatricians inherited beds in mental hospitals that were vacated as a result of more active management approaches ... Geriatricians, on the other hand, serving the physical and social needs of the elderly, seem to have had dementia thrust upon them* (Gilleard, 1984:115).

Whatever evolves in the continuing metamorphosis of geriatricians and psychogeriatricians, their patients are unlikely to become either bodiless minds or mindless bodies; the thrust observed by Gilleard, and accepted by geriatricians, is therefore likely to continue. The hope is that future specialization will see these two new species of physician combine their efforts in the care of people with dementia – including the final stages when care at home is no longer possible.

Regrettably, a second postscript has become necessary. The Commonwealth Government has recently announced its intention to disband the distinction between nursing homes and hostels (Commonwealth Department of Health and Family Services, 1996). While this decision is no doubt in keeping with economic rationalism, it puts into reverse the trend of specialization which has been in motion during the last three or four decades.

Note

1. A hostel is an establishment accommodating about 40 elderly people with disabilities, built in a normal residential area. The building consists of single rooms with a variety of shared areas designed, as far as possible, according to the principles of domestic architecture. The staff endeavour to provide the degree of autonomy and protection that is compatible with the needs and capabilities of the individual residents.

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