Keynotes

Needs for continuing care of demented people: a model for estimating needs

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The way in which residential and other forms of continuing care have developed in the United Kingdom has been reviewed (Lewis & Wattis, 1988). It has been a story of unclear policy and confusion, especially in respect of people with dementia. At present there is a lack of clarity about who is responsible for providing continuing care for demented people. Traditionally, their care was shared between social services Part III (including EMI - for the 'elderly mentally infirm') homes and NHS psychogeriatric and geriatric beds.

Since 1985, with changes in social security funding for private care, there has been a massive increase in the private sector and a corresponding decline in the local authority and health service provision relative to the continuing increase in the number of very old people who are the chief consumers of this kind of care. Care in the private sector is spread between private residential homes, private nursing homes and private mental nursing homes. There are relatively few beds provided in this country by the churches and other charitable institutions.

Community care has been politically fashionable, although this has not always been reflected in funding! The Association of British Pharmaceutical Industries report (Laing & Hall, 1991) states:

"Though caring for people as long as possible in their own homes remains an aim to which all political persuasions subscribe, the fact is that most state and private financial resources are spent in one sort of residential setting or another - and the high cost of caring for the most dependent groups of elderly people in their own homes means this is unlikely to change in the foreseeable future. The private sector is now the main provider of long term nursing and residential care which is in line with the prevailing government ideology ... Policy changes from a new Labour Government would probably be limited to ring-fencing government grants to local authorities and scrapping the present government’s plans to place financial penalties on local authorities which place old people in authority-run homes."

At the same time as the government has decided to put all funding for residential and nursing home care in the hands of social services, a House of Commons report has stated that people placed in private nursing home care from hospital should be paid for by the NHS and that health authorities are still obliged to provide continuing nursing care for those who cannot or do not wish to pay for it.

A model for estimating care needs

If we are to avoid endless buck-passing, grave risk to old people who need continuing care and serious embarrassment to acute hospital (including psychiatric) services it is essential to arrive at rational policies which are not, like present policies, apparently in conflict with each other. In many areas, surveys have been done on residents in different long-stay settings. This paper is based on a previous small-scale survey into dementia and disability in residential and nursing homes in Leeds, a city of approximately 700,000 people with around 100,000 over the age of 65 years, and on supplementary surveys of the disability levels in long-stay psychogeriatric and registered mental nursing home beds. Patients in long-stay geriatric medical care have been excluded since there was no easy way of identifying them. It has been possible to construct a model which gives the likely levels of dementia and disability across all the varied settings and enables the numbers of people in each category to be estimated for the city. More accurate estimates could be made on the basis of more extensive surveys and the model could be refined to include geriatric medical beds. It should prove easy to develop similar models for other areas.

The model uses a computer spreadsheet program to list the percentages of people with dementia and with different levels of disability in different settings and to multiply this by the number of people in
each setting within the city. The Clifton Assessment Procedure (CAPE (Pattie & Gilleard, 1979)) has been used to assess levels of dependency. The scale is well validated. In the hospital, the Crighton Royal Behaviour Scale (Robinson, 1961) was used and scores were converted to CAPE scores using a nomogram devised from the original study where both scales had been used.

The following illustrations are based on this model and should be interpreted in the light of the following notes.

(a) The number of local authority and NHS beds is based on 1990-91 estimates and is set to decline. The private sector continues to expand.

(b) The registered mental homes, Part III homes, and EMI homes disability figures are derived from one example of each kind of home only. The hospital figures derive from two wards in one hospital and the private residential and private nursing home figures from two homes in each case.

(c) The CAPE dependency scales have not been analysed in terms of physical v. psychiatric disturbance so that it is impossible to say what proportion of highly dependent patients would have been classed as 'geriatric' and what proportion as 'psychogeriatric' in the system pertaining up to 1985.

(d) Long-stay beds for geriatric medicine have not been included in the equation as it was impossible to identify these clearly.

**Cape dependency grades**

A = No impairment: independent elderly – comparable to those living without support in the community.

B = Mild impairment: low dependency – likely to include those needing some support in the community, warden supervised accommodation and the better residents in residential accommodation.

C = Moderate impairment: medium dependency – people functioning at this level are likely to need residential care or considerable support and help if at home.

D = Marked impairment: high dependency – it is within this category that there is the greatest overlap between those in social services accommodation and those in hospital care.

E = Severe impairment: maximum dependency – this level is most often seen in psychogeriatric wards and the ones who remain in community homes/EMI hostel often present considerable problems to staff in terms of their demands on staff time.

These data show the very high levels of dependency found, especially in the hospital and local authority EMI homes. Dependency is also high in the private mental nursing homes and to a lesser extent in the general nursing homes and residential homes. It is worth noting that scores on dependency scales relate to the environment as well as the individual. Dependency may increase when a patient is moved into a facility where less care is available. For example, patients who are occasionally incontinent in an environment where they are regularly reminded to go to the toilet may become incontinent if moved to a setting where these reminders are not provided or where the toilet is less accessible.

The following table illustrates the model as it applies in Leeds with available data. (See Figure caption for key).

Some general conclusions can be drawn from these data, although they can only be confirmed by more detailed study. There are very few people in any care setting whose disability levels would suggest they should be in 'community care', CAPE grades A and B are only found in about 12% residential/nursing home patients and in none of the registered mental nursing home, hospital or EMI facilities.

The number of people in CAPE dependency grades D and E probably represents those who definitely need some form of nursing care. This represents around 3,400 people who, according to the House of Commons report, could claim free nursing care from the NHS. At an estimated cost of £250 per person per week, or £12,000 per annum, this gives a total cost of nearly £40,000,000 for Leeds. Even a more conservative figure, based on the 2,100 people in CAPE dependency grade E gives a cost of £25,200,000.

The model can be refined by getting more up-to-date figures for dementia prevalence and dependency from a wider range of homes and in particular by analysing separately for physical and psychiatric disability, though it must be conceded that the majority of patients/residents have both. The model can also be refined by feeding in more accurate/up-to-date figures for the numbers of beds in different care settings.
Needs for continuing care of demented people

Model for continuing care needs in Leeds health district

| PMNH | PGNH | PRH | LARH | LAEM | PGHOS |
|------|------|-----|------|------|-------|
| % with dementia in each setting | 93 | 74 | 59 | 80 | 97 | 97 |
| % in each dependency grade in each setting |
| % CAPE A | 0 | 5 | 2 | 3 | 0 | 0 |
| % CAPE B | 0 | 8 | 10 | 10 | 0 | 0 |
| % CAPE C | 17 | 22 | 22 | 25 | 3 | 3 |
| % CAPE D | 21 | 25 | 26 | 29 | 6 | 13 |
| % CAPE E | 62 | 40 | 36 | 34 | 91 | 84 |
| Number of beds in each setting | 277 | 1330 | 1487 | 1631 | 171 | 180 |
| Numbers with dementia in each setting | 258 | 984 | 877 | 1305 | 166 | 175 |
| Totals | 3765 |
| Numbers in each dependency grade in each setting | CAPE A | 0 | 67 | 30 | 49 | 0 | 0 | 146 |
| CAPE B | 0 | 106 | 149 | 163 | 0 | 0 | 418 |
| CAPE C | 47 | 293 | 327 | 408 | 5 | 5 | 1085 |
| CAPE D | 58 | 333 | 387 | 473 | 10 | 23 | 1284 |
| CAPE E | 172 | 532 | 535 | 555 | 156 | 151 | 2101 |

Nevertheless, even with this crude model, it can be seen that from April 1993 an enormous challenge is posed by providing care for these vulnerable people when responsibility is apparently to be placed clearly with the health service and equally clearly with social services (who will also receive a non ring-fenced grant).

The idea that there are vast numbers of people in residential or nursing care who do not need to be there has little truth in it. At most, in Leeds, we might hope to find 400–500 people in this category and it is likely that many of these, if their needs were examined using more sophisticated techniques, would be found to be appropriately placed in a residential home setting.

It is essential to define which, if any, of the more severely disabled residents/patients require continuing care in the NHS and who decides which patients receive free care from the NHS and which have to go into means tested care administered by local social services authorities. Psychiatrists working in the field generally identify the need for some longer stay hospital beds to cope with the most severely disturbed people with dementia and for some beds to act as a 'buffer' between the acute wards and long-stay care outside of hospital. The Royal Colleges of Physicians and Psychiatrists suggest 3 beds per 1,000 population over the age of 65 for this sort of purpose (Royal Colleges of Physicians and Psychiatrists, 1989). In 1985 many services had more than this (Wattis, 1988). Although there has been no recent survey, anecdotaly the figure is now much lower. What is workable clearly depends on what volume and quality of care is available in other settings. If this decreases because of cash limits then the need for hospital care will correspondingly increase.

The average age of patients in this survey was 83 years. The ageing of the elderly population, with an increasing proportion of people over 80 years, has not been incorporated into this model but it will tend to increase rather than decrease the need for continuing care.

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A full list of references is available on request to the author.