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REVIEW

Long-term care and dementia services: an impending crisis

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Abstract

Background and Objectives: since the transfer of long-stay care to the independent sector, provision of places in care homes in the United Kingdom has varied in response to market trends, and has shown a consistent fall in the past 10 years. People with dementia constitute the largest diagnostic group affected by these changes, and are also likely to be the group that will determine future need. We therefore estimated the number and proportion of older residents in care homes who suffer from dementia relative to all those with dementia in the United Kingdom and projected future levels of demand on the basis of this data.
Design and Method: the number of dementia cases in long-stay care was estimated from a random sample survey in south-east England and compared with data on age-specific prevalence. Projections of future demand were based on UK population projections for the next 40 years.
Main Result: over half of all people with dementia in the United Kingdom are in care homes. The number of available long-stay places in care homes has fallen by one-sixth over the past decade. Projection of future demand suggests that well over double the present total places in care homes would be required by 2043 to maintain the present ratio of institutional to community services for dementia.
Conclusion: this finding suggests an impending crisis of availability. A more realistic scenario calls for investment in affordable domiciliary care of good quality, but it will also depend on the acceptance of the fact that the main function of long-stay care for old people is now to provide for advanced cases of dementia, with consequent requirement for improvement in staff ratios and training.

Keywords: *care homes, dementia, elderly, long-stay provision, old-age psychiatry, service projections*

Over the past 30 years, provision of long-stay care for the 'elderly mentally infirm' (EMI) in the United Kingdom has undergone a radical change as a consequence of a number of social and political developments. First, as Roth [1] predicted, community lines of defence began to crumble and demand for institutional care-provision began to grow because of increased population ageing, longer survival of dementia sufferers and alterations in household and employment patterns. Secondly, the number of hospital beds available for long-stay care declined rapidly following a change in national policy. Old-age psychiatry services, which in the mid-1980s had, on an average, 3–4 long-stay beds per 1,000 population aged over 65 years, have been reduced by 65–70%, and so also geriatric long-stay beds. Indeed, some areas now have no such beds. Thirdly, the contribution of local authorities was increasingly restricted to purchasing residential and community services in a free-enterprise economy, with overt disincentives for direct provision of services.

These changes are documented in the annual field market reviews [2, 3]. During the 1980–90 decade, the number of places in residential homes run by the local authority fell steeply, but both this decrease and the decrease in long-stay hospital beds were compensated by the expanding care-home industry. In 1979, 16% of the long-stay care establishments worked 'for profit'. Voluntary agencies managed 20% of the homes and 64% were homes managed by the local authority. However, by 2005, 76% of the homes were 'for profit'; 15% voluntary and only 9% under local government. Total

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capacity for long-term care increased steadily to a peak in 1996 with approximately 575,000 beds, of which 78% were located in private or voluntary care homes. However, the number of care homes and the total number of beds available in them began to decline since then and have fallen steadily to date—a trend ascribed to diminishing profits and difficulty in meeting statutory requirements [4].

Old people with Alzheimer's disease or other forms of dementia comprise the largest group affected by these changes. Early mental health surveys of older people served to demonstrate that a great majority of dementia sufferers were not found in institutions but in the wider community. Forty years ago, a pioneering study in Newcastle upon Tyne [5] reported that only 13.5% of the older people with severe organic brain syndromes (senile and arteriosclerotic dementia) were in any form of institutional care, and when milder brain syndromes were included, this proportion fell to 11.4%. These and similar results encouraged specialists in the field to focus their attention on community-based treatment and care. 'Two-thirds of people with dementia', declared the London-based Alzheimer's Society in 2003, 'whatever their impairment, live at home' [6]. Meanwhile, the number of cases in care homes and their proportions, grew steadily [7, 8]. In 1996, the replication of a survey of care homes for older people in England, which was carried out 10 years earlier, found that the proportion of residents with severe cognitive impairment had risen in the interim from 21 to 44% in nursing homes, and there was increase in all forms of residential care [9]. Unfortunately, recognition rates of dementia in these settings are very low [10]. It therefore seemed useful to estimate, as accurately as possible from published data, the number of old persons who suffer from dementia and currently residing in care homes in the United Kingdom and to assess the proportion of all cases in the older population who are in care homes. In view of the crucial importance of care homes to the success of the NHS Plan [11], we attempt to predict the future demand for places in care homes, particularly for old people with dementia.

Aims and method

The mean prevalence of dementia among residents of non-EMI care homes—i.e. all those not specifically designated for the 'EMI'—was estimated from findings of a recent survey in Southeast England, which drew a 10% random sample from residents [12]. The definition of 'EMI', though opaque [13], is for practical purposes largely synonymous with dementia accompanied by behavioural problems. Cognitive function was screened using the Mini Mental State Examination (MMSE) and the predictive value of this instrument checked by independent use of the Geriatric Mental Status (GMS) interview [14] in low and high scorers. Positive and negative predictive values were then applied to the main sample to derive an estimate of dementia frequency. We linked these survey data to the total number of older people in care homes and the prevalence of dementia among the United Kingdom population, as well as to the projection of the number of dementia cases and their long-term care needs up to 2043.

Findings

The current situation

Prevalence of dementia in care homes

The investigated sample consisted of 445 residents drawn at random from a total of 4,243 in 157 non-EMI nursing homes [12]. On screening by means of the MMSE, 195 (43.8%) scored in the range 0–17 (moderate or severe dementia) and 96 (21.6%) scored in the range 18–23 (mild dementia). Applying positive and negative predictive values for screening yielded a probability estimate of 74.0% (95%CI 62–83) for the prevalence of dementia, of which two-thirds would be moderate or severe and one-third would be mild. Comparable findings for the United Kingdom are sparse, but an older survey of 21 care homes in England found that 67% of the residents had significant cognitive impairment on admission [15].

Number of older care-home residents

UK statistics on care homes are not available from a single source. Since a place in a care home can be registered for more than one category of resident, calculation of the number of residents in any specific category is not possible. Census data have also been questioned because of uncertainty as to whether residential staff members were wrongly counted as residents. The most comprehensive data are those from the annual market reviews by Laing and Buisson [2, 3] which are based on systematic surveys. According to the most recent of these, the number of places available in the United Kingdom for old people's long-stay care, including places in care homes and those provided by NHS but excluding NHS homes for younger people with dementia, stood at 475,200 in 2005.

Number of people with dementia in care homes

Here, one must distinguish between specialist EMI units and non-EMI homes, which have differing prevalences of dementia. Data for England indicate that 22% of places in care homes for older people are in the former category and 78% in the latter (Commission for Social Care and Inspection, personal communication 2005).

Table 1 is based on the assumption of a linear growth in the prevalence of dementia in EMI homes from 80% in 1988 to 90% in 2005 and in non-EMI homes from 66% in 1989 to 74% in 1997 [12], with no further increase assumed thereafter. These figures include NHS 'psychogeriatric' homes, NHS 'geriatric' homes and community hospitals, the latter two have the same dementia prevalence and occupancy levels as non-EMI nursing homes. Overall, it appears from Table 1 that approximately 368,000 people with dementia resided in care homes in the United Kingdom in 2001. Of this total, three-quarters were in non-specialist care homes, suggesting

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Table 1. Estimated number of older care-home residents in the United Kingdom, and of those suffering from dementia (2001)

Type of care home	No. of places available	No. of elderly residents (occupancy 91.1%)	Prevalence of dementia (%)	Residents with dementia
EMI homes	119,272	108,646	88	95,600
Non-EMI	404,628	368,669	74	272,800
Combined	523,900	477,315	77	368,400

Table 2. Estimated number of dementia cases according to age-group in the population older than 65 years in the UK in 2001

Age-group	Population (in thousands) [18]	Prevalence [16] (%)	Cases
65–74	4,947	2.0	98,700
75–84	3,296	8.9	291,800
85+	1,130	25.4	287,100
65+	9,373	7.2	677,600

that there is now a close functional overlap between the two types of establishments. However, there may be significant variations in the degree of overlap among different regions or countries. Scotland, in particular, has a higher proportion of institutional care within the NHS.

Number of people with dementia in the older population

To estimate the total number of older people with dementia in the United Kingdom, age- and sex- specific prevalence ratios were derived from the MRC six-centre Cognitive Function and Ageing Study [16], in which the diagnosis of clinical dementia required a rating of 3+ on the GMS organicity scale and a moderate or severe degree was defined by a Mini Mental State score of 17 or less. The resulting estimates were applied to the population data of 2001 UK Census, to the population projections by the Government Actuary's Department (GAD) [17] and to projections of future demand for long-term care for older people provided by a number of sources (see below).

In Table 2, data for the population older than 65 years at the 2001 Census [18] are computed against age- and sex-specific prevalence estimates for dementia from the MRC Cognitive Function and Ageing Study (CFAS), giving an approximate total of 677,600 cases. The MRC-CFAS project supplied no estimates for the 60- to 64-year-olds. Assuming a 1% prevalence ratio in this age-group [19] would add an additional 29,000 cases and bring the total to 706,600. This is still a fairly conservative figure, being appreciably lower than the 774,600 cases cited in a recent press release by the London-based Alzheimer's Society [20].

Proportion of all old people with dementia who are in care homes

Data from Tables 1 and 2 suggest that the proportion of people over 65 with dementia who were in care homes in 2001 was approximately 368,000/677,600 or 54%.

Figure 1, based on similar calculations, shows the estimated proportion of people with dementia who were in care homes for each year from 1989 to 2004. Even after allowing for the increase in prevalence of dementia within the care homes, the overall contribution of care homes to care of dementia in the United Kingdom appears to be falling after it peaked at just under 60% in 1993, even though there may be national or regional variations to this trend.

Long-stay care: future demand and expenditure

Projections of future demand for care homes and expenditure can be summarized briefly under three headings.

Projections based on population ageing alone

According to population projections for the next 40 years, the number of persons aged 60 or more will show an increase over the 2003 baseline of around 64%. However, the corresponding projections of demand for long-stay care must be based on age-specific groups, since the expected rates of increase will be disproportionately high among the very old. The recent OFT market survey [21], projecting demand from 2003 onward in this way, concluded that an increase of 60% could be expected by 2023 and 150% by 2043.

Projections based on dependency rates

In a model developed by the Personal Social Services Research Unit (PSSRU) [22], dependency on other factors, rather than age, is assumed to be the best predictor of need for care and is measured by reported difficulties in activities of daily life. When care-home distributions by age-band, gender, previous type of household care and previous household care tenure were included in a multivariate analysis, this technique yielded a more moderate estimate, with an increase of 58% in the numbers of institutionalised old people between 2001 and 2031.

Increased provision of community services

A Department of Health analysis in 2000 considered the issue of community alternatives to acute hospital admission, some of which are also alternatives to care-home placement [11]. Of the three alternatives they examined, the first (though not the most favoured) was to 'maintain current direction', in which an increase in primary care services beyond that required to meet the demographic pressure was to be complemented by a shift from institutional to domiciliary settings. Resident numbers, it affirmed, would then increase in line with demographic change 'less a shift of 5 to 15%

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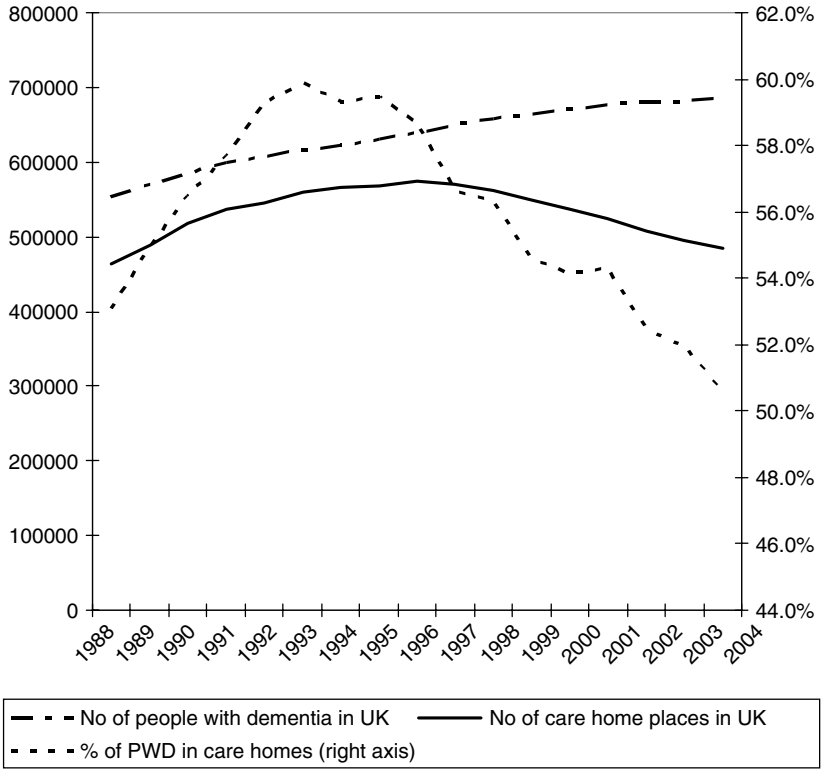

Figure 1. Number of people over 65 with dementia in the United Kingdom (left hand axis), total number of places in all the care homes in the United Kingdom (left hand axis) and estimated percentage of all people over 65 in the United Kingdom with dementia in any type of care home (right hand axis) 1998–2004. Number of people with dementia has been estimated from MRC [16] using population data from ONS [18]. Number of places in care homes and fluctuations in occupancy rate have been taken from Laing & Buisson [3]. Percentage of all people with dementia in care homes has been calculated using prevalence estimates based on linear growth from 80 to 90% in EMI homes over this period and from 66% in 1989 to 74% in 1997 in non-EMI homes [10], with no further increase assumed thereafter.

(central assumption 10%) from institutional to home care by 2019.' No statistical projection based on empirical data has been presented in support of this conclusion. However, the PSSRU research cited above also suggests that the proportion of dementia sufferers with spouses will increase [23], a shift that may increase the contribution of informal care.

Future impact of dementia on long-term care resources

The above scenarios do not consider the specific question of late-life dementia despite its critical importance for national care resources. Estimates for the United Kingdom over the period 2003–2043 are given in Table 3, in which age-specific prevalence ratios [16] are applied to national population projections [17]. (Here again, the prevalence of dementia in the 60–64 year age-group has been estimated as 1%.) Table 3 indicates that, if age- and sex-specific prevalence ratios remain constant, the overall number of dementia cases will increase over the next decade by 20% and over the next 40 years by 122%.

These estimates are broadly supported by the PSSRU group's study of the same question using their multivariate projection model but limiting the inquiry to England [22]. Although their report refers throughout to 'cognitive impairment', it appears to relate more directly to moderate and severe dementia. They concluded that from 1998 to 2031 the number of affected persons could be expected to rise from 461,000 to 765,000 (i.e. 66%), and the cost of long-term care for dementia sufferers from £4.6 to £10.9 billion (i.e. 137%). These estimates may err on the conservative side because of underestimation of the total prevalence of dementia and the special burdens it imposes on care services [24].

Figure 2, based on occupancy levels of 90%, maps the increase in care-home places as required by the three scenarios (all based on a notional 50% of people with dementia residing in care homes).

- Assuming a fixed 50% of persons, aged 60 and over, with dementia in care homes, with a mean 80% prevalence of dementia in the homes from 2003 until 2043, the total number of places required would be around 740,000 by 2023 and well over one million by 2043.
- Combining the above option with the Department of Health's 'current direction scenario' for shifting 10% of the old people with dementia from residential to non-residential forms of long-term care [11] would mean

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Table 3. Expected increase of dementia cases among those aged over 60 years in the United Kingdom for 2003–2043. On the basis of (a) GAD population projections [17] and (b) age-specific prevalence rates [16].
(Cases are rounded to nearest 100 for each group and year)

Age-group	Dementia prevalence %	2003 pop (in thousands)	Cases	2013 pop (in thousands)	Cases	2023 pop (in thousands)	Cases	2043 pop (in thousands)	Cases
60–64	1.0	2,943	29,000	3,522	35,000	4,075	41,000	3,753	37,000
65–74	2.0	5,005	100,000	6,018	120,000	6,535	131,000	7,118	142,000
75–84	8.8	3,401	299,000	3,635	320,000	4,682	412,000	6,314	556,000
85+	25.3	1,105	280,000	1,471	372,000	1,923	487,000	3,300	835,000
60+		12,454	708,000 (100%)	14,646	847,000 (120%)	17,215	1,071,000 (151%)	20,485	1,570,000 (222%)

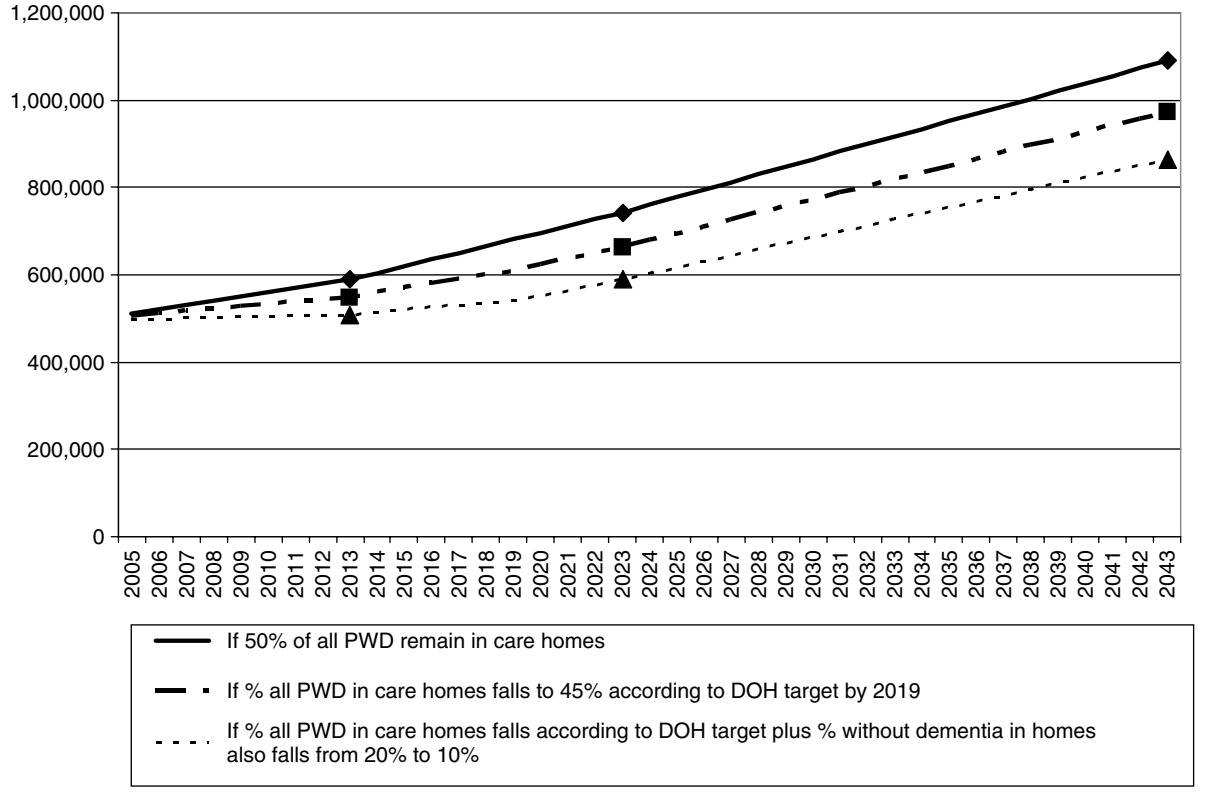

Figure 2. UK Projections, based on occupancy levels of 90%, of the increase in care-home places necessary (a) to maintain half of all people with dementia aged 60 and over in care homes, with a prevalence rate of 80% for dementia in care homes, (b) reduce the proportion of people with dementia aged 60 and over in care homes from 50% to 45% over 10 years from 1999 [11], with a prevalence rate of 80% for dementia in care homes, and (c) same as for (b) but also reducing the percentage of people without dementia in care homes from 20 to 10% over the same period. Population projections from GAD [17]. Number of people with dementia based on age band specific rates (MRC-CFA) [16].

a 35% rise in the number of care-home places to 660,000 by 2023.

- Such a general shift towards community care, combined with a reduction in the proportion of non-demented care-home residents to 10%, would further reduce the increase in the requirement for places to 590,000 by 2023: an increase of just under 20% in 20 years. This scenario, however, calls for both increased provision of affordable domiciliary care of good quality and for the acceptance that the main function of long-stay facilities for old people in the 21st century must overwhelmingly be to provide care for advanced cases of dementia: a policy that, while fundamentally realistic, would require additional funding for training and enhanced staff costs.

Discussion

This study is subject to two principal limitations of methods. To begin with, it relies on extrapolation of data on dementia frequency in care homes from one region of the United

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Kingdom to the data for the United Kingdom as a whole. The extent of countrywide variation needs to be examined, either by a national survey or by comparable smaller studies in some regions, particularly in Scotland, where there are important differences in infrastructure and funding arrangements. Secondly, projections of future demand for services must always be treated with caution because, as 'sensitivity analyses' demonstrate, they can vary widely with changes in any of the independent variables in question [22, 23]. In the case of dementia, future levels of demand may be affected by both more effective treatments and changes in the community lines of defence (e.g. 'extra care' housing).

Nonetheless, making allowance for differing diagnostic criteria, population coverage and time periods, the various statistical projections outlined above broadly agree in pointing to a massive increase in demand for long-stay care in the decades ahead. As pressure on the available care-home places mounts, cases of dementia are bound to require high priority because of the frequency of incontinence, behaviour disorders and wandering among these patients, and hence they are increasingly likely to become the predominant occupants in care homes. Moreover, unit costs of nursing and residential care for dementia are higher than the costs for most other medical conditions [24]. In short, the evidence suggests that future growth inthe demand for long-term residential care and expenditure on it will be driven primarily by growth in the number of old people with dementia.

Currently, however, the number and proportion of those suffering from dementia in care homes are falling as care-home places continue to disappear, while at the same time the total prevalence of dementia continues to rise, in step with population ageing. Moreover, the reduction in available care-places is taking place against the background of increased cost for domiciliary care [25]; this cannot readily be attributed to improved community services.

These conflicting trends presage a national crisis in the provision of long-stay care. Great concern has been expressed by care professionals, consumer groups and voluntary bodies such as Age Concern, but this concern has been mainly directed towards the underfunding of care-home places by the local authority, with calls to upgrade care-home fee-scales (bluntly stated, to throw in money for the problem). Would this remedy alone resolve the problem? The care-home industry is already under attack for failures that are unlikely to be made good simply by increasing fees. A report commissioned by the Royal Colleges of Physicians and Nursing, together with the British Geriatrics Society [26], considered the present standards of care grossly unsatisfactory on a number of counts and set out a list of recommendations, including population-based planning and provision, better clinical assessment and documentation, individual care planning, a specialist qualification for geriatric nurses, a specialist pharmacist service for care homes, additional training and qualification for care-home GPs, re-engagement of geriatric and old-age psychiatric consultants in the home sector and development of 'teaching nursing homes'. These are all eminently sensible proposals, but the report gives no indication of how they might be implemented within a care-home system that is now mainly located in the private sector, and how the proposals could be achieved in practice without radical changes to the infrastructure.

Many would consider that this projected increase in the need for care-home places simply because of the rising prevalence of dementia is unfeasible, even if the DOH target of a shift of 10% towards community provision is achieved by 2019. However, the rise necessary with this increase in community resources, combined with the acceptance that dementia care is the prime function of homes, is much more modest, although the costs of such a strategy must include those of training and staffing requirements for appropriate and good quality dementia care in care homes.

Long-term care is now largely controlled by venture capital and has a current market value of over £9 billion a year. In 2005, 90% of nursing home beds and 80% of residential care beds were operating for profit. In the boom period of 1979–90, the number of residents in independent sector homes who were on income support rose from 11,000 to 281,000 and the annual cost to the public purse rose from £10 million to £2.6 billion [27]. The recent OFT market survey estimated that 68% of care-home residents were being paid for wholly or partly out of public funds [21].

Nonetheless, the industry has steadily shrunk in recent years. Since 1996, the number of long-stay places for old people has diminished by nearly 43,000 in the independent sector, with an overall decrease of nearly 100,000 [3], despite many local protests against the closure of care homes. As occupancy rates have risen to over 90% in this period, it seems clear that the decline in the provision of care homes in the independent sector has not been due to any fall in public needs or demand, or indeed due to improvement in community services, but rather due to restricted profit margins. In the words of one market review: 'Where local market conditions for elderly care remain difficult, there may be opportunities to reposition to serve other client groups where demand is more buoyant and pressures on margins less severe. Continued repositioning in the future will help raise occupancy rates in the remaining care homes for the elderly and improve overall profitability of the sector' [3].

If the future of health care and social care for demented old people is to be determined in this fashion by the 'invisible hand' of market forces, all the signals will be set for a crisis in the provision of places in care homes in the years ahead.

Key points

- We set out to estimate, from institutional and prevalence survey data, what proportion of people with dementia in the United Kingdom are in long-stay care.
- Despite a falling trend in the number of places available in care homes, just over half of all such cases are to be found in care homes.
- Taking the proportion of 50% as standard, we then estimated future need for places in care homes on the

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basis of the rising figures for dementia and three different projection scenarios from 2003–23. The present trend indicates an increase of around 50%; a policy shift of 10% in favour of community care could reduce this to around 35%, and combining this community care with increased specialisation in the homes for dementia care further reduces it to 20%.

- We suggest that the latter 20% limited increase could prove sufficient, but only if better regulation, staff training and support in dementia care for homes are provided.

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Dr Nori Graham had raised relevant questions (to which the first part of this paper is the answer) and has commented on drafts of the paper. Rob Darton and Professor Ann Netten have helped with advice and access to PSSRU data and publications and Graham Booth has kindly made data available from CSCI.

Competing interests

AM is an ex officio member of Horizon Housing Association, which provides not-for-profit NHS continuing care for patients with dementia and behavioural problems. BC has no conflict of interests to declare.

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