

Dementia:

international comparisons

Summary report for the National Audit Office


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1

Introduction

Dementia: issues

Dementia is a clinical syndrome with multiple aetiology that particularly affects older people. Given the seriousness of the impact of dementia, the ageing of the world's population, and that the prevalence of dementia increases with age, a lot of attention is understandably now focussed on the treatments, care services and support arrangements needed by people with dementia and their families – both today and over the coming decades.

Among the issues raised in relation to dementia, across a number of countries, are

- the impact of demographic change on the numbers of people with the condition;
- the need for better diagnosis; the negative, stigmatising attitudes often expressed about dementia;
- whether service systems are meeting the needs of individuals and families, and especially whether institutional services are appropriate;
- the financing arrangements necessary to secure good quality service systems;
- the roles of families and unpaid carers and how to reduce the burdens that many of them experience; and
- the need for better inter-agency arrangements to improve the efficiency, fairness and affordability of care systems.

Different system responses

Prevalence rates for dementia vary relatively little from country to country, at least among high-income countries. However different health and social care systems identify and diagnose dementia in different ways, identify and assess needs in sometimes distinct ways and at different levels, devote variable amounts of resources to meet those needs, and choose a variety of ways to deliver treatment and support, whether through formal services or by relying on families and other carers. The underlying financing mechanisms also vary. These variations in need, resource base, system response and financing arrangements arise for reasons that include: demographic pressures; socio-economic contexts; macroeconomic capabilities; societal attitudes; cultural and religious orientation; and the political commitment and policy priorities that flow from them.

Aim

The purpose of this report is to draw together information on various aspects of care for older people with dementia, and particularly to make comparisons between countries. This information is summarised under the following headings:

- Demography and prevalence
- Approaches to diagnosis of dementia
- Financing arrangements
- Service range and balance (including services in place especially for older people with dementia)
- Informal care
- Attitudes

Taking England as the reference, we make comparisons with a number of other high-income countries: Australia, Canada, Denmark, France, Germany, Italy, Japan, Netherlands, Norway, Spain, Sweden, USA, and other parts of the UK. This was a desk-based comparative study, and we were not tasked to collect primary data. The information we sought was generally only available for a subset of our target countries, or available only for slightly different concepts or measures.

2 Demography and prevalence

Demographic trends

Numbers of older people (taking the conventional definition as aged 65 or over) – and particularly the numbers of very old people (aged 80 and above) – will increase substantially over the next fifty years in all countries covered by this report, although rates of ageing varies greatly between countries (Table 1). In England in 2005, 16% of the population were aged 65 or over and 4% aged 80 or over. By 2050 it is expected that the number of people aged 65 or over will grow from 8 million to almost 15 million (by which time this number will represent 25% of the projected total population), while the number aged 80 or over will grow from 2 million to just over 6 million (equivalent to 10% of the total population).

The rate of growth of the older population in England is expected to be noticeably higher than in Denmark, Germany, Italy, Japan and Sweden; very similar to projections for France, Netherlands, Scotland and Wales; but a lot lower than projections for Australia, Canada, Ireland, New Zealand, Northern Ireland and the USA. The projected growth in the numbers of people aged 80 or above shows a similar pattern across countries: the expected growth for England of 177% over this 45-year period is a lot less than the 400% growth projected for Australia or New Zealand, and also lower than projections for Northern Ireland and Wales (300%), but rather higher than the expected growth Sweden or France.

However, it is important to exercise caution here. Demographic projections over such a long period carry a substantial degree of uncertainty, and may particularly underestimate numbers of very old people (as has been the case with previous projections when there has been an increase in life expectancy). Moreover,

Table 1: Overview of the projected changes in the size and age structure of the population, in millions (in descending order of projected growth in older population between 2005 and 2050)

	Population (total)			Working age population (ages 15–64)			Older population (ages 65+)			Very old population (ages 80+)		
	2005	2050	Change (%)	2005	2050	Change (%)	2005	2050	Change (%)	2005	2050	Change (%)
Ireland	4.1	6.2	51	2.8	3.7	32	0.5	1.4	180	0.1	0.4	300
Canada	32.3	42.8	33	22.3	25.1	13	4.2	10.9	160	1.1	4.3	291
N Zealand	4.1	5.2	27	2.7	3.1	15	0.5	1.3	160	0.1	0.5	400
Australia	20.3	28.0	38	13.7	16.6	21	2.7	6.8	152	0.7	3.5	400
N. Ire*	1.7	1.8	6	1.1	1.0	–9	0.2	0.5	150	0.05	0.2	300
USA	299.8	402.4	34	200.7	248.4	24	36.8	84.6	130	10.6	30.6	189
Spain	43.4	46.4	7	29.8	24.3	–18	7.3	15.4	111	1.9	5.7	200
Norway	4.6	5.7	24	3.1	3.4	10	0.7	1.4	100	0.2	0.5	150
Netherlands	16.3	17.2	6	11.0	10.1	–8	2.3	4.3	87	0.6	1.8	200
England*	50.4	59.9	19	32.9	35.4	8	8.0	14.8	85	2.2	6.1	177
Wales*	3.0	3.3	10	1.9	1.9	0	0.5	0.9	80	0.1	0.4	300
France	60.9	68.3	12	39.8	39.7	0	9.9	17.7	79	4.6	10.2	122
Scotland*	5.1	4.6	–10	3.4	2.7	–21	0.8	1.4	75	0.2	0.6	200
Denmark	5.4	5.5	2	3.6	3.3	–8	0.8	1.3	63	0.2	0.5	150
Sweden	9.0	10.5	17	5.9	6.2	5	1.6	2.5	56	0.5	1.0	100
Italy	58.6	54.6	–7	38.9	29.5	–24	11.6	17.8	53	3.0	7.3	143
Germany	82.7	74.1	–10	55.2	41.6	–25	15.5	22.4	45	3.6	9.7	169
Japan	127.9	102.5	–20	76.4	45.9	–40	33.7	45.1	34	6.2	15.8	155
GB*	58.5	67.8	16	38.3	40.0	4	9.3	17.1	84	2.6	7.1	173
UK estimates from different sources:												
GAD*	60.2	69.6	16	39.4	41.0	4	9.6	17.6	83	2.6	7.3	181
Eurostat*	59.7	64.2	8	39.2	37.8	–4	9.5	17.0	79	2.6	6.5	150
UN	60.2	68.7	14	39.7	41.0	3	9.7	16.5	70	2.7	6.3	133

Source: UN (2007) except *: <http://www.gad.gov.uk>. UK Eurostat data from ECFIN (2006), p.33.

different bodies come up with different projections, as illustrated by the figures for the UK at the bottom of Table 1 that come from the Government Actuary Service, Eurostat and the United Nations.

Economic dependency ratios

It is also useful to look at how the numbers of younger people are projected to rise over the next few decades, and particularly those aged 15–64 (Table 2). This age group is sometimes called the working age population, although many older people continue to have paid employment or contribute through voluntary work, and indeed there are efforts by many governments to encourage more people to work to a later age.

The ratio of the population aged 65 and older to those aged 15–64 in England – often called the ‘economic dependency ratio’ – is expected to grow from 24% to 30% over just 15 years. If health and social care services for older people are to be financed from tax or social insurance contributions coming mainly from people in the labour force, then growth in this ratio is obviously going to raise questions about the affordability of care in future decades. Countries such as Italy (55%), France (51%) and Japan (51%) are expected to have much higher ratios than England, and Ireland (26%) and Northern Ireland (28%) lower ratios.

Prevalence of dementia

The significance of these demographic changes for the present discussion is made clear by the evidence on prevalence, which increases considerably with age. New prevalence estimates for the UK, from a study supported by the Alzheimer's Society, provide up-to-date estimates (Knapp et al. 2007). The estimated prevalence rates are set out in Table 3.

Table 2: Ratio of the population aged 65 and older to population aged 15 to 64 (in descending order of projected ratio in 2020)

	2005	2010	2015	2020
Italy	44.3	46.7	50.7	54.5
France	37.0	38.9	45.5	51.4
Japan	32.0	37.8	45.3	50.5
Germany	37.5	41.2	42.2	45.2
Sweden	33.5	36.7	41.6	45.5
Spain	36.1	37.4	39.7	42.3
Denmark	28.6	31.6	36.5	40.9
Wales*	27.2	28.7	32.6	35.5
Netherlands	25.3	27.6	32.1	35.3
Norway	26.6	27.5	30.6	33.8
Australia	24.1	26.2	30.5	35.3
Scotland*	24.5	25.9	29.5	32.7
Canada	22.6	24.7	29.0	33.8
England*	24.3	25.1	28.1	30.0
New Zealand	21.3	23.0	27.0	31.3
United States	20.9	22.2	25.1	29.1
Northern Ireland*	20.8	22.5	25.0	27.7
Ireland	21.2	21.6	23.7	26.1
Great Britain*	24.5	25.3	28.5	30.2
UK* (GAD)	24.3	25.2	28.3	30.4
UK (Eurostat)	29.5	31.2	35.5	38.8

Source: OECD (2006), except* data from UK and constituent countries calculated from data available in GAD:<http://www.gad.gov.uk>

Table 3: Dementia prevalence rates

Age group	Population with dementia (%)
65–69	1.3
70–74	2.9
75–79	5.9
80–84	12.2
85–89	20.3
90–94	28.6
95 and over	32.5

Source: Knapp et al (2007). Calculations carried out by Martin Prince, Emiliano Albanese, Cleusa Ferri and Robert Stewart.

There are also some younger people with dementia, although prevalence is very low – the estimated rate being less than 0.1% of the population aged 45–64, for instance.

On the basis of these estimated prevalence rates, it is estimated that there are approximately 684,000 people with dementia in the UK, representing 1.1% of the entire population. Of this total, 562,000 are living in England, 55,000 in Scotland, 36,000 in Wales and 15,000 in Northern Ireland. Because of the demographic changes set out above, the number of people with dementia in the UK is expected to increase to 940,000 by 2021 (a 28% increase) and 1,735,000 by 2051 (a 154% increase).

There have been studies of the prevalence of dementia in other countries, but it is difficult to make comparisons because the methods used for case ascertainment is subject to considerable variation, and it is difficult to disentangle what part of any observed difference is simply due to the methods employed and what reflects a true inter-country difference.

A similar approach to that employed to generate the recent UK figures – a thorough evidence review followed by a Delphi panel of expert epidemiologists – was employed earlier to estimate prevalence by WHO region and five-year age band (Ferri et al 2005). In that part of the European region with the lowest child and adult mortality (effectively Western Europe, and including the UK) the dementia prevalence estimates were 0.9% (of people aged 60–64), 1.5% (age 65–69), 3.6% (age 70–74), 6.0% (age 75–79), 12.2% (age 80–84) and 24.9% (age 85 and above). Applying their prevalence figures obtained for each region to the 2001 world population figures allowed Ferri et al. (2005) to calculate that there were 24.3 million people with dementia globally in 2001.

Projections of prevalence, needs and costs

The PSSRU long-term care projection model looks at the likely future demand for long-term care and its costs (Wittenberg et al. 2006). Given the projected demographic trends and the steady prevalence and incidence rates, not surprisingly, demand for long-term care is expected to increase substantially over the next three decades and beyond. For example, the PSSRU model projects that the number of occupied residential places would need to expand by around 115% to keep pace with demographic pressures. The number of home care hours would need to increase by around 103%.

Long-term care expenditure would need to increase by 325% in real terms between 2002 and 2041 to meet demographic pressures and allow for real rises in unit costs of care. Taking account of the expected expansion of the economy, long-term care expenditure might (conservatively) need to increase from 1.4% of GDP in 2002 to 2.6% of GDP in 2041. These figures do not comprise the total costs of long-term care to society.

This general model has been adapted to make projections of the numbers of older people with cognitive impairment (the proxy for dementia) and the associated costs of their support (Comas-Herrera et al. 2007). The projected number of older people with cognitive impairment in England is expected to rise by more than two-thirds from 468,000 to 855,000 between 2002 and 2031, faster than the increase in numbers of people with functional disability only. Expenditure on long-term care services for older people with cognitive impairment in England is projected to rise from £5.4 billion to £16.7 billion over the same period, equivalent to a rise from 0.60% to 0.96% of GDP. Under present arrangements, a sizeable proportion of this total would be publicly funded, but policy could well change as to the relative contributions of service users and the state. Again, this figure does not comprise the total costs of dementia to society.

Similar projections have been made for some other countries, using a version of this PSSRU model or other approaches. What these projections make absolutely plain is the need for governments to give urgent attention to the needs of an ageing population, how those needs might be met, and how the services that meet those needs can be financed.

3

Approaches to diagnosis

Similarities and differences

Dementia presents a major public health challenge wherever one looks across the developed and the developing worlds, with age structure determining the number of cases and relatively minor (if aetiologically interesting) regional variations in prevalence and incidence (Hendrie 2006; Ferri et al 2005). The nature of the clinical challenge of dementia in terms of behavioural and psychological symptoms, high levels of negative impact on family carers and dependency also varies little between countries (Schneider et al. 1999).

Diagnosis is the gateway for care. No drug or non-drug treatment can be given, and no specific future planning carried out, without individuals receiving a diagnosis. And while there are few differences between countries in the underlying prevalence of dementia, or in its behavioural and psychological symptoms, there are marked differences in the rate of diagnosis, in the rate of treatment, in the roles played by families, and in the care provided by formal health and social services. There is, for example, no international consensus on which specialty within medicine should take the lead in diagnosis and treatment or how such treatment should be delivered.

There *is* consensus that diagnosis should be made as early as possible to enable those people with dementia and their families to benefit from the positive educational, social, psychological and pharmacological interventions that are available and to plan for their future with the illness.

Recognition and diagnosis

There is a widespread reticence among primary care doctors to make the diagnosis of dementia in their patients, and so primary care diagnosis cannot be relied upon (Vernooj-Drassen et al. 2005). This was one of the findings from a consultation exercise with dementia experts drawn from eight EU states (the Netherlands, Belgium, UK, Spain, Italy, Portugal, France and Ireland). The stigma that primary care staff attached to dementia appears to inhibit referrals for diagnostic assessment by a specialist if this would mean disclosing the possible diagnosis of dementia or making a referral to a specialty which they also perceive as stigmatizing, such as old age psychiatry. This generates a culture of ‘concealment, minimisation or ignoring of early signs and symptoms’.

The large majority of people with dementia either do not receive a specialist diagnosis at any time in their illness or do so only late in the disorder or at a time of crisis when it is often too late to prevent harm such as break down of family caring structures or institutionalisation.

OECD comparative study of dementia care

A study by the Organization for Economic Co-operation and Development (OECD) of dementia services across nine states (Australia, Canada, Germany, France, Spain, Great Britain, Japan, Sweden, USA) offers valuable comparative information (Moise et al. 2004). We draw on this material for some of the later sections of this report.

Across the nine countries they found that large proportions of people with dementia do not receive any diagnosis, let alone an early diagnosis, and so have no chance of access to treatment and care. In response to this, many of the countries studied had set in place health care strategies designed to promote early detection of dementia. These can be national, as in the UK National Service Framework for Older People and similar work in France and Spain, or at a sub-national level such as in Ontario in Canada, and in Sweden and the USA. These policy initiatives all share a focus on the importance of the early detection of dementia to help patients and their families prepare for the burden of illness and caring, to enable individuals to express their choices and to prevent future harm.

Memory clinics of some sort were identified in all the countries studied, although there is no precise definition of what constitutes a memory clinic. The balance between clinical work and research in these clinics varies, as does the degree to which they are multi-disciplinary, what sort of clinicians lead the clinic and the involvement of social care professionals. The availability of memory clinics varies very widely both within and between countries, and their capacity to meet the need for diagnosis within the areas they serve has seldom been investigated. However, they appear to reach only a very small proportion of people with dementia in any country.

Specialist old age psychiatric services

The UK is fortunate in having a nationwide structure of specialist old age psychiatric services with the skills to make diagnoses of dementia, and to provide and coordinate treatment and care for people with dementia. The challenge is ensuring that they have the capacity to complete these roles with any but the most complex of cases. Diagnosis and treatment might also be carried out by a geriatrician, a neurologist (sub-specialties of general medicine) or a GP.

Who takes the lead in other countries depends on the development of national health care systems, and professional capacity, interest and financial benefit. In Spain, someone with dementia might first be seen by a neurologist, in France a general psychiatrist, in Australia by a geriatrician, in Norway a GP would be likely to make the diagnosis, while in the developing world traditional systems of medicine might be a first (or simultaneous) port of call. Each specialty has a subtly different paradigm for diagnosis and treatment and the quality issue is perhaps better framed by the provision of good standards of care rather than who does it.

What this plurality undoubtedly does mean is that it can be very difficult to capture all dementia diagnostic and treatment activities within a health system. This limits our understanding of the care provided within countries and our ability to compare services across countries.

4

Financing arrangements

Approaches to financing

There are a number of approaches to the funding of health care (Mossialos et al 2002) and of long-term care for older people (Wittenberg et al. 2002). Usually these are grouped into four main types:

- out-of-pocket payments by service user or family ('user charges'), including from release of housing equity
- voluntary insurance, sometimes called private insurance
- tax-based support, funded from direct and/or indirect taxes, and with services provided on the basis of need
- social insurance, funded through hypothecated contributions linked to employment, with services again provided on the basis of need.

Most countries rely on more than one financing approach, often even within a single service system. In particular, it might be the case that health care financing arrangements differ from those that govern social care, or that there might be differences between these two systems in the financial contributions that have to be made by service users themselves. As is evident from the current debate in England, where health care is free at the point of use while social care is means-tested, this can be a source of considerable tension.

These four main financing approaches differ in various ways, including the balance between private and public (social) funding, the nature and extent of risk pooling, the nature of government intervention, their probable future affordability, their contribution to (say) a government's redistributive policy, and so on. But a number of common patterns and characteristics can be identified; indeed, it is striking how many similarities there are across countries in terms of the challenges to be faced and the approaches now being explored.

Long-term care financing in the UK

There has been a lively debate about how long-term care should be funded in the UK. A Royal Commission (1999) recommended that the costs of nursing and personal care should be met by the state, without a means-test and financed out of general taxation. Implementation of the recommendation varied across the UK, with little change in England. Independent reports have been produced by Institute for Public Policy Research (Brooks et al 2002), Joseph Rowntree Foundation (2006) and the King's Fund. The last of these – the Wanless Review of Social Care (Wanless et al 2006) – recommended increased expenditure on social care for older people and a radical change to the financing system. The authors proposed a non-means-tested entitlement to social care, with government meeting two-thirds of the cost of the care package, and the remainder of the costs

being met half by the user and half by the government, that is, with government meeting five-sixths of the costs if the user agrees to meet one-sixth. This proposal is attracting continuing interest.

Resource commitments and responsibilities

All of the countries we looked at have increased the resources they devote to long-term care over recent years. But they are all also wrestling with the challenge of how to find considerably more resources in the future. Countries such as Germany and Japan have undergone radical overhauls of their long-term care financing systems in recent years, and a lot of international attention is being paid to how the new arrangements perform, even though the wider institutional context – that matters so much – varies greatly between countries.

A common trend is to explore ways to shift the funding balance gradually away from collective responsibility (through taxes or social insurance) to individual and family responsibility (out-of-pocket payments or voluntary insurance). Nevertheless, for the moment at least there remains heavy reliance on pre-payment, collective financing arrangements which are not related to actual or expected service use, and which redistribute in favour of less healthy, poorer and older people. Even if there is a successful move away from collective to individual financing approaches, governments will still carry a heavy responsibility for monitoring or regulating health and long-term care systems (financial regulation, quality assurance, managing care markets and competition), and probably also for financial subsidies (for other financing arrangements) and the provision of ‘safety net’ support for those unable to pay for their own care.

User charges for services are usually income-related.

Self-directed systems

There is also evidence of growing interest in developing self-directed or consumer-directed systems (Ungerson and Yeandle 2007). The Japanese and German financing arrangements are of this kind, and there have been noticeable developments in the Netherlands. In the UK the (slow) growth of direct payments is an example of such an arrangement, while the piloting of the more broadly based and more flexibly deployed individual budgets in England is perhaps a better model for the future. The primary aim is to give more independence and choice to older people, and thereby give them greater control over their lives. There are challenges in giving such powers of decision making to people with dementia, although relatives or others could manage these funds.

Expenditure differences

It is almost impossible to identify health or social care expenditure that is exclusively targeted on people with dementia. However, there some figures for expenditure on long-term care more broadly. The OECD has estimated public and private expenditure on long-term care as a percentage of GDP in 2000, distinguishing home care and institutional care where possible (Table 4). Total expenditure ranges from a low of 0.6% of GDP in Italy, Spain and Ireland to figures in excess of 2% in Scandinavian countries. The estimated figure for the UK in 2000 was 1.37%, close to the average for the 14 countries covered by this OECD study (1.25%).

Table 4: Public and private expenditure on long-term care (home care and institutional care) as a percentage of GDP, 2000 (in descending order of total expenditure)

	Total expenditure			Public expenditure			Private expenditure		
	Home care	Institutional care	Total	Home care	Institutional care	Total	Home care	Institutional care	Total
Sweden	0.82	2.07	2.89	0.78	1.96	2.74	0.04	0.10	0.14
Denmark			2.60						
Norway	0.69	1.45	2.15	0.66	1.19	1.85	0.03	0.26	0.29
Netherlands	0.60	0.83	1.44	0.56	0.75	1.31	0.05	0.08	0.13
UK	0.41	0.96	1.37	0.32	0.58	0.89	0.09	0.38	0.48
Germany	0.47	0.88	1.35	0.43	0.52	0.95	0.04	0.36	0.4
USA	0.33	0.96	1.29	0.17	0.58	0.74	0.16	0.39	0.54
Canada	0.17	1.06	1.23	0.17	0.82	0.99	n.a.	0.24	0.24
Australia	0.38	0.81	1.19	0.3	0.56	0.86	0.08	0.25	0.33
France			1.10						
Japan	0.25	0.58	0.83	0.25	0.51	0.76	0.00	0.07	0.07
N Zealand	0.12	0.56	0.68	0.11	0.34	0.45	0.01	0.22	0.23
Ireland	0.19	0.43	0.62	0.19	0.33	0.52	n.a.	0.10	0.10
Spain	0.23	0.37	0.61	0.05	0.11	0.16	0.18	0.26	0.44
Italy			0.60						
Average*	0.38	0.88	1.25	0.35	0.64	0.99	0.06	0.19	0.24

Source: OECD (2005, p.26)

* Average of: Australia, Canada, Germany, Ireland, Japan, Netherlands, New Zealand, Norway, Poland, Spain, Sweden, Switzerland, United Kingdom and United States.

Public sector spending on long-term care dominated private expenditure in the UK (almost twice as large). This same pattern was generally found across all countries covered by this OECD research, the notable exception being Spain. However, these OECD data only include health-related expenditure and so under-estimate total long-term care spending.

Expenditure patterns generally show a move away from spending on institutional care in favour of community-based services (see section 5 below).

Total cost of dementia

There are now numerous cost-of-illness evidence for dementia, covering most of the countries that we have examined in this report, and indeed endeavouring to cover Europe as a whole (Jonsson and Berr 2005) and worldwide (Wimo et al 2003). Methods used vary hugely from study to study (Moise et al. 2004), and it is not possible to make detailed comparisons of findings (Bloom et al. 2003). However, a consistent finding is that the burden falling on families is substantial.

The recently published *Dementia UK* report offered up-to-date estimates of the overall cost of dementia. Annual costs were calculated for health care, social care, informal care and accommodation, separating older people with dementia living in supported accommodation (including residential and nursing homes) and those living in the community (further sub-divided into three groups according to severity of symptoms). The total annual cost per person was estimated to be:

- £16,689 for someone with mild dementia living in the community
- £25,877 for someone with moderate dementia living in the community
- £37,473 for someone with severe dementia living in the community
- £31,296 for someone living in supported accommodation

Total costs amounted to £17 billion. Accommodation accounted for 41% of the total, health services 8%, social care services 15% and imputed costs for informal

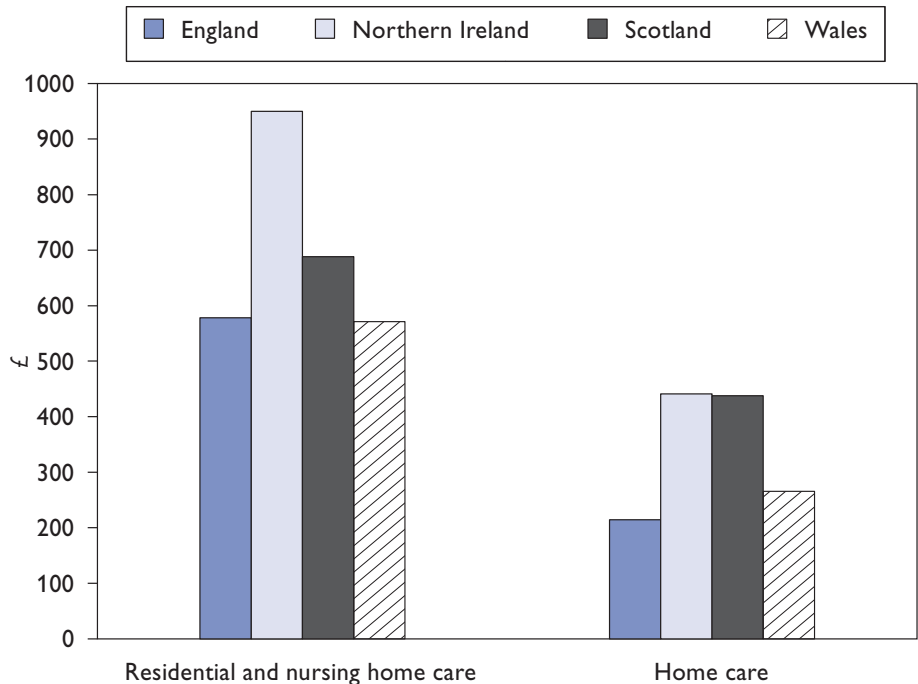
care support and lost employment 36%. (This last element is sensitive to the value placed on informal care.)

Variation within the UK

In most of the countries that we looked at there was evidence of regional or local variation in either financing arrangements (including the extent of co-payments by users or eligibility for public subsidies), levels of expenditure or unit costs. This is certainly the case in the UK. Differences between England and other parts of the UK in per capita expenditure on social care for older people, per capita provision and unit cost for residential and nursing homes, home care and day care are quite marked (Figure 1). For example, expenditure per head of the population aged 65 and over on residential and nursing care was £578 in England in 2004/05, compared to £950 in Northern Ireland, £688 in Scotland and £572 in Wales. Expenditure on home care was no less varied. Within each of these countries there was even greater variation: for example, home care expenditure per head of population aged 65 and over ranged from £62 to £759 per annum across English local authorities.

These figures are for local authority spending on services for all older people. Five years ago the Audit Commission (2002) reported wide variations in NHS funding of continuing care for older people with mental health problems.

Figure 1: Expenditure on (a) residential and nursing home care, and (b) home care for older people – in England, Northern Ireland, Scotland and Wales – per head of population aged 65 or over, 2004/05



5

Service range and balance

Health and social care

The needs of older people with dementia are in part related directly to their deteriorating health and in part to the associated consequences for their ability to look after themselves. Some needs therefore require health care and some are more appropriately met by social care, although the boundaries between these needs are hard to draw. Different patterns of service provision have grown up in different countries, influenced by national culture, financing arrangements, bureaucratic procedures, availability of skilled staff and – usually to a very limited extent – the preferences of service users and families.

The distinction between health and social care has potentially significant implications both for what gets delivered and at what cost (for example, needs may be excessively ‘medicalised’ or specialist treatment underprovided) and for the balance of funding (if different eligibility criteria influence threshold levels of dependence, for instance). In turn, this could encourage cost shifting and the risk of people falling between two systems. The (inconsistently applied) distinction also has implications for international comparisons of spending patterns and provision. Nevertheless, a consistently identified pattern is that, as the severity of dementia increases, social care becomes relatively more important than medical care, except perhaps at the very end of life.

The most important provider of care for older people is the ‘informal’ sector – the families, neighbours and community groups that offer support without funding, without charging and often without recognition. The availability of informal care heavily influences the level and nature of need for ‘formal’ care for which, by definition, funding must be raised in order to employ staff. Informal care becomes relatively less important – compared to ‘formal’ care – as dementia progresses into more severe stages. We discuss informal care in section 6.

Institutional care

The percentage of the older population living in nursing homes and residential care homes in England was 5.5% in 2006, lower than in Northern Ireland (6.8% although this figure refers to 2002), but slightly higher than in Scotland (4.6%) or Wales (5.1%). Looking more widely, the figure for England is rather lower than in Scandinavian countries (for example, 11.8% in Norway and 9.1% in Denmark), but generally not out of line with other countries examined in this study (Table 5).

Most countries have policies to try to reduce this percentage by developing better home-based and community services. Discussions on the appropriate balance of care have included arguments about relative effectiveness, user and family

Table 5: Care home provision

Country	Policy, admission eligibility	Beds	Percentage of population aged 65+ in care homes	Residents with dementia
Australia	Policy aim to shift balance to community care. High level of disability and care needs, assessed by multidisciplinary teams. Incentives to homes to admit people with dementia, but not a specific admission condition. 40% of people with dementia currently receiving care in subsidised aged care homes; proportion is rising	143,000	5.7 (2003)	151,000 beds; estimated to be 46,000 residents with 'probable dementia'
Canada	Policy emphasis on community care. Nursing homes provide LT nursing care. Residential care homes provide support and social care. Community Care Access Centres (CCACs) determine eligibility for, and authorise admissions to all LTC facilities. Some admission barriers for people with dementia, but also a key risk factor.	NA	6.2 (1998)	NA
Denmark	Policy emphasis on community care. Legislation encourages independent specialised housing with care. Admission to based on individual need and appraisal.	91,000	9.1 (2001)	5000 dementia places in 2002. 31% residents with dementia (1990s)
France	Admission based on age. Access to many services is income-related (preference given to poorer individuals). Some barriers for people with dementia. Nursing homes often medicalised – chosen as the last resort. Negative image. Shortages of nursing home places	247,000 places in LT care centres (2000)	6.5 (1997)	'Cantou': special type of small home for people with dementia. No data.
Germany	Short-term, part-time (day or night), or full-time institutional care available. Growth in provision following introduction of LTC insurance system.	621,000 LTC (2000)	3.9 (2003)	60% of residents (c.50,000). Some dementia units
Italy	Low level of provision. Admission depends on dependency and income Expenses of 62% of residents fall entirely upon the family	NA	2.0 (?)	NGO-led initiatives
Ireland	Needs assessment covers housing, family support, social situation, health.	NA	4.6 (2000)	
Japan	People aged 65 and older needing nursing care, who are insured by LTCI can be admitted. Nursing care provided by local government or private providers. Growth of nursing home numbers	NA	2.9 (6.0% incl. hospital) (2003)	30% of nursing home residents had dementia (late 1990s)
Netherlands	Institutions differ by dependency and specialty	NA	8.8 (2003)	
Norway	Policy emphasis on community care. Some shortages of facilities; waiting lists. Dependency influences admission, but income does not		11.8 (2001)	Special units for dementia. Most also have special respite care.
Spain	Most critical factor in admission is availability of informal care. People with behavioural problems can have difficulty getting admission. Varying levels of medical care are provided. Of 3,328 homes, 44% are privately owned and 23% are publicly owned.	4,888 homes	3.8 (2004)	
Sweden	Older people in very extensive need of care and attention. Marked variations across the country. In some municipalities, special dementia care units are integrated within nursing homes.	29,000	7.2 (2003)	25,000 places in group homes
United States	Increasing emphasis on community-based care has tightened up admission criteria. More than half of Medicaid funding spent on institutional care (1999). For-profit sector has largest market share.	1,965,000	4.2 (2000)	About 50%
UK	Policy emphasis on community-based care. Targeting on high-need cases. Threshold for admission to care homes now much higher. Prevalence of dementia in care homes is about 60%			
England (2006 data)		441,335	5.5	
Northern Ireland (2002 data)		16,000	6.8	
Scotland (2005 data)		33,716	4.6	
Wales (2006 data)		26,679	5.1	

Sources: Moise et al. (2004, p. 43), OECD (2005, p. 41), Eurofamcare (p. 88 et seq.), Gibson et al. (2003), national statistics for UK countries.

preferences (themselves influenced by perceptions of quality, availability of informal care, the broader family-centred culture in certain societies and personal cost), and relative cost (in total and distribution between budgets). However, it would be dangerous for policy makers to assume that a shifting balance between institutional and community care will necessarily save money.

One consequence of this shifting balance is that older people tend to get admitted to care homes when already quite dependent, including at later stages of dementia. This can leave families carrying a heavy burden, which is known to be a key factor in institutional admission. Another consequence is that a high proportion of residents in care homes and other highly staffed congregate care settings now have dementia (estimated to be over 60% in the UK).

Home-based and community care

Although there are many differences between countries, there is a common core of (non-family) home-based and community services: needs assessment, counselling and advice, self-help support groups, respite care, crisis management, support centres, day programmes, support for people in their own homes ('home care', including home help, meals, and community nursing), residential and nursing home provision, and – increasingly – a range of housing-with-support services (such as sheltered housing, 'extra-care housing' and some retirement communities).

Comparisons between countries are dogged by definitional differences, but there appears to be wider inter-country variation in home-based and community care than in institutional provision (Table 6). For example, as many as 25% of older people in Denmark receive home care, and Norway (18%), Canada (17%) and Australia (15%) are high providers. In England the figure is 6%, although it is difficult to tell whether this is measuring an equivalent set of services. Nevertheless, there has been a deliberate policy in recent years of targeting state-brokered home care services on a smaller group of older people (with high-level needs). The average weekly number of hours of home care for those in receipt of this service was 8.1 in England in 2004/5. There are very marked variations in patterns and levels of service provision *within* England, just as there are in other countries where there is local autonomy in relation to social care and/or health care policy implementation. Services are being developed that cross the boundaries between institutional and community-based provision, such as extra care housing and extended respite care. There have also been some efforts to integrate housing and health/social care to improve service coordination, promote independence and self-care.

Dementia can be a barrier to access to appropriate care. Specialist dementia services are gradually being introduced but often quite slowly, some in care homes (such as special units within larger facilities or specialist facilities), and some in the community. Voluntary organisations have often taken the lead in developing specialist provision.

Table 6: Home-based and community provision in 2000 (unless stated)

Country	Home care services provided (for all older people)	Percentage of population aged 65+ receiving home care	Specific dementia services
Australia	Considerable expansion since mid 1980s. Targeting on high-need cases	14.7	Information services, education, support groups, counselling, respite support
Canada	Greater emphasis on community care, but slow change in balance of care	17.0	Range of services recommended in Ontario 10-point action plan
Denmark	Ageing in place services. Co-located services in community health centres	25.0	
France	Access depends on age and need but not a right	7.1 (in 2003)	Action plan to improve range of dementia services and carer support
Germany	Growth in home care sector followed introduction of LTC insurance system. Voluntary sector is major provider	7.0	Some dementia units cover spectrum of services in high quality environment. Also group care, day centres, special care units, home visiting helpers, alternative living arrangements, music therapy
Ireland	Range of community services available	c. 5.0	
Italy	Home help and home health care. Wide geographical variations	NA	Specialist services being introduced through voluntary sector initiatives
Japan		8.0	Range of advice and specialist supports provided by voluntary sector
Netherlands	Broad range of home & community services. Coordinated housing and health/social care. Consumer-directed service system introduced	12.3	Some specialist day care for people with dementia
Norway	Home help and home nursing plus wide range of transport, handyman, respite, meals, counselling services.	18.0	'Schools' for carers, resource centres for families, memory clinic
Spain	Community-based care systems not generally well developed yet.	5.2 (2006)	Information, advice, support, advocacy provided by voluntary sector
Sweden	Wide range of community services available, including transportation, home help, meals, technical aids, foot care, security alarms.	8.3 (2003)	Day care for people with dementia. Other specialist services available in some areas
United States	Case management, home maker/home health aid services, personal care services, adult day health, habilitation, respite care, non-medical transportation, home modifications, adult day care.	8.7	Group residential settings, special care units, Alzheimer's disease centres, counselling and information services
UK	Home care (home help), meals services, visiting services, support for carers, day activities, equipment and adaptations to the home, respite care, alarm systems, direct payments.		Range of specialist residential and community-based dementia services, memory clinics, respite care, information for carers
England (2004/5 data)		6.1	
Northern Ireland (2005 data)		2.4	
Scotland (2005 data)		6.9	
Wales (2004/5 data)		4.3	

Sources: Moise et al. (2004), OECD (2005), Eurofamcare (2004), Gibson et al (2003), IMERSO (2006)

Current issues in service provision

As well as the trends and patterns just described, a number of issues recurred when making comparisons between countries.

- Shortages of qualified or skilled staff for long-term care services are reported in a number of countries. Conditions of employment are poor.
- Quality of care has generated concerns, linked in part to staffing difficulties. A number of the countries have recently experimented with new quality assurance arrangements.
- There have been quite marked changes in some countries in the sectoral balance of provision, as in the UK where there are now many fewer local authority services and the private and voluntary sectors have grown considerably.
- Nevertheless, responsibility for strategic coordination and commissioning of care generally still rests predominantly with public sector bodies.

- It is recognised that good inter-agency coordination is imperative if individual and family needs are to be met, which in turn often requires better collaboration in financing. Cost shifting and ‘problem dumping’ between agencies does not help individuals or families.
- ‘Ageing in place’ services are still not very widely developed.
- In most countries there have been high-level policy initiatives focused on dementia or older people’s services more broadly. An example is the Federal Australian Government’s creation of their Department of Health and Ageing, with dementia identified as ‘a national health priority’ and a ring-fenced programme of investment in dementia-specific services, training, and research to support this.

6

Informal care

Carer responsibilities

Most carers provide practical help, companionship, assist the person cared for in going out and provide general supervision. The responsibilities falling to carers increase as dementia progresses, at least until such time as the person with dementia needs full-time ‘formal’ care.

Most carers are women and related to the person being cared for, and cultural obligations can be quite important in this area. Changing demographic patterns, family composition, labour force participation and geographical mobility are all reducing the (potential) pool of family caregivers (Pickard et al 2000). This could be a particular issue for dementia care (Moise et al. 2004). At the same time, the shifting balance of care – away from institutional services and towards community-based care – is increasing the burden on family and other carers. This is particularly the case for dementia.

Carers can incur high costs as a result of their caring responsibilities, particularly through lost employment, reduced salaries, and lost pension entitlements. Less readily observed consequences of caring are impacts on the health, and especially mental health, of carers. Depression is common.

Supporting carers

Adequate and appropriate health and social services provided to older people, both in institutions and at home, are known to be a major factor in supporting the inputs of family carers and reducing the burden of care on their shoulders.

Projections of the future costs of long-term care are consequently sensitive to assumptions made about the future supply of informal care, which is one reason why governments have introduced a range of supports for carers.

Not all countries offer financial support for carers, although this is becoming more common. It can be provided through tax credits (e.g. in Canada, Spain and the US), social security allowances, grants from social care budgets (e.g. in Australia, France and Sweden), pension credits (e.g. in Canada, Germany and the UK), consumer-directed payments (e.g. long-term care insurance in Germany and individual budgets in England), or payments from voluntary sector bodies. Governments need to make a judgement whether it is better to provide financial support to carers or invest the same resources to employ more support staff.

Employment-friendly policies are being introduced in some countries to help carers combine a career with caring responsibilities. For example in Sweden, the 1989 Care Leave Act provided caregivers with a period of paid leave to care for an ill elderly relative. In 1998, an addition was made to the Social Service Act that encouraged local municipalities to support family caregivers.

Educational programmes modestly improve carer wellbeing, but need to be combined with support, counselling and respite services.

Voluntary organisations play important roles in the lives of some carers by providing support, information, advice and advocacy.

Respite care – in a variety of forms – is central to most countries' support programmes for carers. There is some evidence from across a range of countries that group living arrangements are effective and popular (Colvez et al 2002). A recent systematic review found some evidence that respite care can have a small positive effect on carers' perceived burden and their mental and physical health (Mason et al. 2007). However, it did not affect care recipients or delay admission into residential care.

There are marked variations within countries in the nature and availability of support to carers.

7

Attitudes

Attitudes to dementia held by the general public, health and social care professionals, policy makers, relatives and others can influence the ways in which people view this set of conditions, their willingness to pay for medical treatments, and their willingness to see scarce tax or social insurance funds allocated to the support and care of people with dementia.

There are widespread stigmatising attitudes about mental health generally, and negative images of ageing. Dementia sits at the intersection of the two.

The Facing Dementia Survey gathered data from various groups across six European countries in 2004 (Bond et al. 2005):

- Time taken to a diagnosis of Alzheimer's disease after symptoms were first noticed was considerably longer in the UK (32 months) than in France (24), Spain (18), Italy (14) or Germany (10).
- Fewer carers in the United Kingdom (51%) reported that physicians recommended treatment at the time of diagnosis than those in Germany (78%), France (83%), Italy (85%), and Spain (86%).
- The number of carers who believed that governments did not invest enough in Alzheimer's disease was higher in the UK (87%) than in Italy (65%), Germany (77%), France (80%) and Spain (82%).
- Similarly, doctors had lower expectations from the available drug treatments (68% of UK respondents agreed or strongly agreed that early treatment can delay the progression of Alzheimer's disease) than their colleagues in Spain (86%), Germany (87%), Italy (91%) or France (92%).

The same survey found that delayed referral and diagnosis was attributed in part to difficulties in distinguishing when the normal signs of ageing are early symptoms of Alzheimer's, together with individual or familial fear of the condition itself. Health policy makers participating in the survey recognised Alzheimer's as a serious condition, but argued that governments did not give great emphasis to the condition because it did not affect the most productive members of society. Consequently, respondents felt that insufficient funds were being invested in treatment or carer support.

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Dementia: international comparisons

Summary report for the National Audit Office

Given the seriousness of the impact of dementia, the ageing of the world's population, and that the prevalence of dementia increases with age, much attention is understandably now focused on the treatments, care services and support arrangements needed by people with dementia and their families – both today and over the coming decades.

The purpose of this report (commissioned by the National Audit Office) is to draw together information on various aspects of care for older people with dementia, and particularly to make comparisons between countries. This information is summarised under the following headings:

- Demography and prevalence
- Approaches to diagnosis of dementia
- Financing arrangements
- Service range and balance (including services in place especially for older people with dementia)
- Informal care
- Attitudes

Taking England as the reference, we make comparisons with a number of other high-income countries: Australia, Canada, Denmark, France, Germany, Italy, Japan, Netherlands, Norway, Spain, Sweden, USA, and other parts of the UK.