Adelina Comas-Herrera, Raphael Wittenberg, Linda Pickard, Martin Knapp

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Cognitive impairment in older people: future demand for long-term care services and the associated costs.

Ms Adelina Comas-Herrera
Personal Social Services Research Unit, London School of Economics and Political Science.

Mr Raphael Wittenberg
Personal Social Services Research Unit, London School of Economics and Political Science.

Ms Linda Pickard
Personal Social Services Research Unit, London School of Economics and Political Science.

Professor Martin Knapp
Personal Social Services Research Unit, London School of Economics and Political Science.

MRC CFAS: Medical Research Council Cognitive Function and Ageing Study; Address for Correspondence: Professor C. Brayne, Institute of Public Health, Forvie Site, Robinson Way, Cambridge CB2 2SR.

Address for correspondence:

Adelina Comas-Herrera
Personal Social Services Research Unit
London School of Economics and Political Science
Houghton Street
London WC2A 2AE

Tel. +44 (0)20 7955 7306
Fax: +44 (0)20 7955 6131
Email: a.comas@lse.ac.uk

Abstract

Background
Projections are presented of future numbers of older people with cognitive impairment (CI) in England, their demand for long-term care (LTC) services and future costs of their care. The sensitivity of the projections to factors that are likely to affect future LTC expenditure is explored. These factors include future numbers of older people, prevalence rates of CI, trends in household composition, informal care provision, care service patterns and unit costs.

Methods
A macrosimulation (or cell-based) model was developed to produce the projections, building on an earlier PSSRU model. Base case assumptions are made about trends in key factors expected to impact on future LTC expenditure, and variant assumptions about the key factors are introduced to test for sensitivity.

Results
Expenditure on LTC services for older people with CI is projected to rise from 0.60% of Gross Domestic Product (GDP) (£5.4 billion) in 2002 to 0.96% of GDP (£16.7 billion) in 2031, under base case assumptions. Under variant assumptions, the projection for 2031 ranges from 0.83% to 1.11% of GDP. These figures do not include the opportunity costs of informal care.

Conclusions
Sensitivity analysis shows that projected demand for LTC is sensitive to assumptions about the future numbers of older people and future prevalence rates of CI and functional disability. Projected expenditure is also sensitive to assumptions about future rises in the real unit costs of services. (227 words)

Introduction

Estimates for England project that between 2002 and 2031 the number of people aged 65 or over will rise by 63%. The numbers aged 85 or more are projected to rise faster, by 123% (GAD, 2005). The numbers of older people with cognitive impairment are also expected to rise: Wancata et al (2003) project that the number of people with dementia in Europe will grow from 7.6 million prevalent cases in 2000 to 16.2 million in 2050.

Cognitive impairment has substantial impacts on quality of life for individuals, families and other caregivers. It also has major implications for health and social services, in turn generating high costs (Souêtre et al, 1999, McNamee et al, 1999 and 2001, Kavanagh and Knapp, 2002, Schneider et al, 2003). It is clearly important, for strategic planning purposes, to estimate likely future service requirements. It is also important, in the context of debates about how to fund long-term care (LTC), to project the associated expenditure.

This paper presents projections, for the next 25 years, of future numbers of older people with cognitive impairment in England, their demand for formal LTC services and associated expenditure under a range of assumptions. The assumptions relate to trends in factors that affect future LTC expenditure, including trends in numbers of older people, prevalence rates of cognitive impairment, household composition, informal care provision, care service patterns and unit costs.

Projections cover residential and community-based services, both long-term health services and social services. Informal care is also considered. Expenditure projections cover public expenditure by health and social services and private expenditure by individuals. Informal care costs are not included nor are general living costs of people living in the community.

The projections were produced using a macrosimulation (cell-based) model, based on the LTC projections model constructed by the Personal Social Services Research Unit (PSSRU) as part of its Department of Health -funded programme (Wittenberg *et al* 1998, 2001, 2006).

Methods

Data

The model requires data on older people's characteristics, including health status and socio-economic situation, their use of LTC services and the associated costs. No single dataset in England has all the information needed, so we used data from a range of sources chosen on the basis of quality and coverage.

The model uses GAD projections of the numbers of older people in England to 2031 by age band and gender taking 2002 as the base year (GAD, 2005), and marital status and cohabitation projections to 2031 from a 2003 base (ONS, 2005).

The model employs data on prevalence of cognitive impairment and physical disability, use of services and other characteristics of people with cognitive impairment from the MRC CFAS study. This study collected information about incidence and prevalence of cognitive decline and dementia, identified factors associated with the risk of dementia, and evaluated the degree of disability associated with cognitive decline and the service needs generated (MRC CFAS, 1998a). It found no heterogeneity between different sites, which gave the MRC CFAS team confidence to generalise their prevalence estimates. In four sites (Cambridgeshire, Nottingham, Newcastle, Oxford) the resource implications of functional or cognitive frailty were investigated in the Resource Implication Study (RIS) (McNamee *et al*, 1999 and 2001), based on a sample of 10,377 people aged 65 years and over, 1,446 of whom were classified as disabled, and for 1,391 of whom the RIS collected service monitoring data.

Our model uses GHS data on household composition, functional disability, receipt of informal help and receipt of formal non-residential services. The 2001/2 GHS included 3,356 people aged 65 years and over in private households in Great Britain. Of these, 3,213 provided information on ability to perform tasks and on use of community care services (Walker et al, 2003).

For numbers of people in residential homes and nursing homes we use Department of Health (2003) data. Data on age, gender, cognitive impairment, previous household composition and previous housing tenure of care home residents are taken from PSSRU surveys (Netten et al, 1998 and 2001 and Darton et al, 2006). We also use data from the 2001 Census for information about people in hospitals for long-stays.

Finally, information from the PSSRU annual unit costs volume (Curtis and Netten, 2004) and from Laing and Buisson (2004) is used to cost services. Information about housing tenure by age, gender and household composition was obtained from the 2002 Family Resources Survey.

We sought to use best available data for each part of the model, as detailed below. In general, more recent sources, such as the GHS, are used as the primary data source, with less recent sources, such as CFAS, used for more detailed subdivisions of service users.

Overview of the model

The model makes projections for England to 2031 of three key variables: expected number of older people with cognitive impairment, their likely level of demand for LTC services and costs associated with meeting this demand.

The model has three parts: the first divides the projected older population into cells by age, gender, cognitive impairment and/or functional disability, household composition and housing tenure; the second focuses on receipt of LTC services by attaching a probability of service receipt to each cell; the third estimates expenditures on services.

The model makes projections under different scenarios. It should be stressed that *we do not aim to make forecasts about what will happen in the future*. Rather, we make *projections*, rooted in the present demand and use of services, that investigate the impact of specific assumptions about future trends. The approach involves simulating the impact on demand of specified changes in demand drivers, such as demographic pressures, changes in household composition, or specified changes in patterns of care, such as more support for informal carers. We do not forecast future policies or care patterns.

Older people with cognitive impairment and their characteristics

Cognitive impairment and functional disability

The numbers of older people by age and gender projected by GAD (2005) are split into those with cognitive impairment only, those with combined cognitive impairment and functional disability (defined in terms of ability to perform activities of daily living), those with functional disability only and those with neither cognitive impairment nor functional disability. The model uses, for this purpose, data on prevalence from the four CFAS RIS sites (Melzer *et al,* 1999). People were classified as disabled in this study if they were identified as functionally[1] or cognitively frail. People were considered to be cognitively impaired as assessed by a score of three or more on the Automated Geriatric Examination Computer Assisted Taxonomy (AGECAT) (Copeland *et al* 1986). They were considered to have functional disability if they scored seven or less on the modified Townsend Disability Scale (MRC CFAS, 1998b). Table 1 presents the prevalence estimates[2] used in the model.

Table 1 here

Household composition and informal care

Household composition is an important structural correlate of informal care (Pickard *et al,* 2000). Informal care is combined with household composition in a four-fold classification: living alone without informal help; living alone with informal help; single, widowed or divorced (*de facto* single) living with others; and married/cohabiting couple (including couples living with others). Household compositions where older people live with others have not been broken down between those with and without informal carers

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[1] Melzer and others (1999) refer to having difficulties with activities of daily living as having "physical" frailty. We use the term "functional" disability, as difficulty in performing activities of daily living can also stem from severe cognitive impairment.

[2] People who, because of their advanced cognitive impairment, were not able to answer the activities of daily living (ADL) questions are included in the combined disability group, following Melzer et al (1999).

because those living with others have a potential carer and most of those who are disabled have an actual carer[3]. To split the population by age, gender and disability into household composition/informal care groups, data from the 2001/2 GHS and RIS CFAS were used for people in households. Data from the Census 2001 and the PSSRU 1996 residential care survey (Netten et al, 1998 and 2001) were used to divide those in care homes according to previous household characteristics.

Housing tenure

The model includes, for people in private households, a simple breakdown by housing tenure between owner-occupied tenure and rented accommodation. Housing tenure is included as a proxy for socio-economic group and because home owners are less likely to move to care homes than those in rented accommodation (Hancock et al., 2003).

Proportions of older people, by age band and household composition, living in owner-occupier and rented tenure were derived by analysis of the 2002 Family Resources Survey. Projected rates to 2022 are from projections by Hancock et al (2006), derived from a microsimulation model, assuming that housing tenure remains constant after 2022.

Projected demand for long-term care services

The second part of the model projects volumes of services demanded. Outputs of the first part of the model (numbers of older people by disability, household composition/informal care and other characteristics) were combined with functions that assign receipt of services to each sub-group.

The model includes key formal non-residential social services (home care, day care, meals) and health services (day hospital, community nursing, chiropody). Private domestic help is included, though this should be treated with caution as it may not relate to care needs. Residential, nursing home and long-stay hospital care are included.

The probability of receiving each service by age, gender, household composition, disability and housing tenure was estimated separately for non-residential and residential services. For non-residential services the primary data source was GHS 2001/2. First, the probability of receipt of each service was estimated through multivariate (logistic regression) analysis: independent variables were age, gender, level of functional disability, household type/informal care and housing tenure. Estimates from the analysis were then applied to the population to estimate overall numbers of older people receiving each service by age group, gender, functional disability, household type/informal care and housing tenure.

RIS CFAS data were used to split the recipients of each service according to type of disability (cognitive impairment and/or functional disability). This analysis was conducted by age and gender[4]. Table 2 shows the proportion of recipients of non-

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[3] In the 2001/2 General Household Survey (GHS), over 90% of functionally disabled older people living with others reported receiving informal help with domestic tasks.

[4] For users of each service, logistic regression analysis was conducted with dependent variable being whether the person had cognitive impairment. Explanatory variables were age, gender, household type/informal care and housing tenure. For most services the proportion of service recipients in the RIS data with cognitive impairment varied with age and gender but not with other variables.

residential services (except for chiropody) by disability type. Most service recipients belong to the group with functional disability only, reflecting the higher prevalence of functional disability (see table 1).

Table 2 here

Data for residential services from the Department of Health (2003) were used to estimate numbers in care homes. Data from PSSRU residential care surveys in 1996 and 2005 (Netten et al, 1998, 2001; Darton et al., 2006), the 2001 Census and RIS CFAS data for institutional care were used to split care home residents according to their characteristics (Comas-Herrera et al 2003).

The estimated proportion of each sub-group (defined by age, gender, household composition, disability, housing tenure) receiving each service was then held constant for future years. This means that projections are based on recent care patterns, except where changes in these patterns are specifically investigated.

Projected aggregate expenditure on LTC services

The third part of the model projects total expenditure, at constant 2002 prices, on formal services. Projected levels of services are multiplied by their estimated unit costs. Estimated expenditure on home care and community nursing services has been grossed up broadly to match official data. Separate expenditure projections were produced for services for older people with and without cognitive impairment. We include public and private expenditure on long-term health and social services.

Projections for future years should take account of expected rises in real unit costs of care, which are likely to be affected by factors such as future real wages and other input prices, efficiency and quality of care. As LTC services are highly labour-intensive, future real wages are probably the key factor. We assumed, as a base case, that real unit costs will rise annually by 2%, in line with the Treasury's assumption for real rises in earnings. Real Gross Domestic Product (GDP) is assumed to rise in line with Treasury assumptions of 2% p.a. in the medium to long-term (HM Treasury, 2005).

Base case assumptions and projections

The base case assumptions are summarised in box 1 (Wittenberg et al., 1998). This base case is a starting point for examination of the assumptions used in the model, not a prediction of the future. It is a point of comparison when assumptions are subsequently varied in alternative scenarios. The assumptions keep most policy-related variables constant and use Government assumptions for demographic changes.

Box 1: Main base case assumptions

- The older population changes in line with the GAD 2004-based principal population projection.
- Age/gender-specific prevalence rates of cognitive impairment and functional disability remain unchanged.

> - Marital status rates change in line with GAD 2003-based marital status and cohabitation projections.
> - There is a constant ratio of single people living alone to single people living with others.
> - The proportion of older people receiving informal care, formal community care services and residential and nursing home care remains constant by age, disability, household composition and other needs-related circumstances.
> - Health and social care unit costs rise by 2% p.a. in real terms. Real GDP rises in line with Treasury assumptions.
> - Formal care supply will adjust to match demand[5] and demand will be no more constrained by supply in the future than in the base year.

The model projects that, under these base case assumptions, between 2002 and 2031 the numbers of people with cognitive impairment in England will rise from 468,000 to 855,000 (83% increase), 430,000 of whom will also have functional disability. The number of hours of home care arranged by local authorities for older people with cognitive impairment would need to rise by 91% to keep pace with these demographic pressures. The numbers of people with cognitive impairment in care homes would rise by 88%, from an estimate of 205,000 in 2002 to 385,000 in 2031.

Expenditure on LTC for older people with cognitive impairment in England[6] is projected to rise from £5.4 billion in 2002 to £16.7 billion in 2031 at constant 2002 prices (Figure 1), under base case assumptions. This amounts to a rise from 0.60% to 0.96% of GDP[7] (Table 3).

Table 3 here.

The estimate for 2031 of £16.7 billion for LTC expenditure for people with cognitive impairment produced using this updated version of the model is substantially higher than the £10.9 billion estimate projected by a previous version based on year 2000 data (Comas-Herrera et al. 2003). This difference is due, mostly, to a new GAD population projection (which assumes a greater increase in numbers of older people), an increase in the proportion of people in care homes with severe cognitive impairment (Darton et al., 2006), and especially a revised assumption about future growth in unit costs. The earlier estimates were comparable to those obtained by McNamee et al (2001). Their demographic model estimated the projected costs of formal care for people with cognitive impairment to be £11.2 billion, but they included acute health service costs, as well as using a different methodology.

Sensitivity analysis

Changes in numbers of people with cognitive impairment

One of the main influences on demand for LTC for older people and associated expenditure will be the number of older people with cognitive impairment. This depends on future mortality and prevalence rates. Figure 2 shows projected long-term care

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[5] The model effectively assumes that the real rise in unit costs of care is sufficient to ensure that supply at least meets demand.

[6] In 2002/3 prices, i.e. with expected real increases but not nominal changes in care costs.

[7] Used as an indication of the economy's capacity to meet expenditure.

expenditure in England as a percentage of GDP under different assumptions. The second and third columns show the impact of using high and low life expectancy variants: the impact on future expenditure is relatively small[8].

The fourth column shows the impact of an annual 1% decline in prevalence of cognitive impairment only, and the last column shows the impact of an annual 1% decline in prevalence of combined cognitive impairment and functional disability. This latter assumption illustrates the impact of a delay in progression of cognitive impairment to more severe stages. A decline in prevalence of combined cognitive impairment and functional disability of this magnitude would have a substantial impact on projected expenditure, as it would reduce substantially the numbers in care homes or using very intensive home care packages.

Changes in informal care availability and formal care patterns

Demand for LTC services depends partly on availability of care by family and friends. Figure 3 shows projected LTC expenditure in England as a percentage of GDP under different assumptions about informal and formal care provision.

The model takes into account the effects of future changes in marital status on informal care and household composition. Whereas there is likely to be an increase in spouse carers of disabled older people, there is considerable uncertainty about future provision of intensive informal care by children (Pickard et al, 2000). The second column in figure 3 shows the impact of a hypothetical decline by one third in the proportion of single disabled older people living with others by 2031. It assumes that older people who no longer move in with their children instead move into residential homes. The impact is slight, primarily because the number of older people co-residing with their children is already small.

The third column shows the potential impact of a larger fall in informal care supply, where it is assumed that people currently living with others have the same probability of going into an institution as those living alone. The impact of this assumption is more substantial. Expenditure on LTC for those with cognitive impairment is projected to represent 1.11% of GDP in 2031 under this scenario, compared with 0.96% under the base case.

There may also be changes affecting future patterns of formal care. The fourth column in Figure 3 shows the impact of increased formal support to carers. This assumption investigates the implications of giving older people with combined cognitive impairment and functional disability who live with others the same packages of non-residential services as received by those living alone (a so-called 'carer-blind' assumption). The impact is modest.

Changes in unit costs

Expenditure projections over an extended period are inevitably sensitive to assumptions about real rises in unit costs. The model assumes, as a base case, that unit costs of care will rise in line with the projected rate of earnings growth in the overall economy (using

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[8] Due to the relatively narrow assumed range of life expectancy at birth explored in these projections.

HM Treasury assumption of 2% per year). The first variant assumption examined was that the real rise in unit costs would be lower, at 1.5% per year. This could occur if improvements could be achieved in the efficiency of care services. Under this assumption LTC expenditure for older people with cognitive impairment would represent 0.83% of GDP in 2031. The second variant assumption is that real unit costs rise faster than expected earnings, by 2.5% per year. This assumption illustrates a possible impact of increases in real costs as a result of, for example, improvements in service quality or higher labour costs due to workforce shortages. Under this assumption LTC expenditure for people with cognitive impairment would represent 1.11% of GDP in 2031.

Projected future LTC expenditure is clearly highly sensitive to the assumed rate of growth in real unit costs.

Discussion

Limitations

The model's projections are as good as the data used; as no single recent data source contained all necessary information, we drew on a number of sources. Some data covered different populations, collected at different points of time. We have tried to address the resultant comparability issue by primarily using nationally representative, recent sources (to estimate, for example, total service use at baseline) and older sources as second-line (mostly to split service users between those with cognitive impairment and those with other types of disability).

Our expenditure projections do not cover the total societal costs of cognitive impairment. That would require inclusion of a wider range of costs (such as housing, medicines and the opportunity costs of informal care). This would produce substantially higher estimates. Including the opportunity costs of informal care would be challenging given the difficulties of measurement (McDaid, 2001).

No allowance has been made for changes in public expectations about the quality, range or level of care. The base case projections assume an unchanged relationship between receipt of care and age, gender, disability, household composition and housing tenure. Rising expectations, associated with rising real incomes of older people, could clearly have a substantial impact on future LTC demand, resulting in substantially higher expenditure estimates.

Future mortality and prevalence rates and rises in unit care costs, which are inevitably uncertain, have substantial implications for future LTC demand and associated expenditure. This is on the basis of univariate sensitivity analysis, where each factor is considered separately. Multivariate sensitivity analyses, in which variant assumptions are tested for two or more factors together, could show even greater variability in projected expenditure. We are conducting further research into the sensitivity of these projections to multivariate scenarios chosen by a panel of experts.

Social and policy implications

The model projects that, unless more effective treatments for cognitive impairment are developed and made widely available, the numbers of older people with cognitive impairment will rise significantly over the next 30 years. Substantial increases in formal services will therefore be required. The model also shows that, if current or future treatments were to reduce prevalence rates of combined cognitive impairment and functional disability by 1% per year, this would nearly offset expected demographic pressures. One implication is that investment in developing, and making widely available, better treatments to slow down the progression of dementia could substantially reduce expenditure growth.

Informal carers provide much of the support for older people with cognitive impairment living at home. We did not estimate or project the value (or costs) of such informal care, although the model allows expenditure projections as a result of a possible future decline in informal care supply. The projections suggest that such a decline, resulting in increased admissions to residential care, could have substantial financial consequences. The projections also suggest that the financial consequences of providing more support for carers in the form of home-based services provided on a 'carer-blind' basis would be lower than the costs of a decline in informal care resulting in increased institutionalisation. This illustrates the value of developing services to support informal carers as well meeting the needs of older people.

The projections show that the proportion of GDP required to fund LTC services will rise significantly. Improving the efficiency of services would help to limit rises in unit costs, though the scope for this may be limited. More generally, improving the cost-effectiveness with which needs are met would obviously be attractive.

Our projections also highlight the importance of promoting the sustainability of funding for long-term care for older people (Wittenberg et al, 2002). Since the Royal Commission (1999) report there has been a lively debate about the long-term care financing in the UK, to which the Wanless Review of Social Care (Wanless and Forder, 2006) contributed significantly by recommending radical changes to the financing system.

Acknowledgments

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Table 1 Estimated prevalence of cognitive impairment and/or functional disability among older people in England and Wales, by age group, sex, and type of disability, in percentages:

	65-74		75-84		85 or more		All 65 and over	
	Men	Women	Men	Women	Men	Women	Men	Women
Functional only	3.31	5.03	7.69	14.84	17.27	32.18	5.70	12.54
Cognitive only	1.56	1.20	4.22	3.29	8.03	8.46	2.88	3.01
Combined	0.68	0.45	2.44	3.29	10.84	13.73	2.02	3.42
All with cognitive imp.	2.24	1.65	6.66	6.58	18.87	22.19	4.90	6.43

Source: Melzer *et al*, 1999 and personal communication from B. McWilliams, from the MRC CFAS team.

Table 2. Users of non-residential services by type of disability: percentages.

	CI only	ADL only	Combined	Total
Male				
65-74	13	72	15	100
75-84	22	58	20	100
85+	20	51	29	100
Female				
65-74	7	85	8	100
75-84	11	74	15	100
85+	10	69	21	100

Source: Analysis of the RIS-CFAS dataset.

Table 3 Projections of the future numbers of people with cognitive impairment, their future demand for services and associated expenditure. England, 2002-2031.

	2002	2031	% increase between 2002 and 2031
Numbers aged 65 or more	7,890,000	12,785,000	63%
Numbers aged 85 or more	955,000	2,135,000	123%
Numbers with CI only	240,000	425,000	78%
Numbers with CI and ADL	230,000	430,000	88%
Numbers with ADL only	775,000	1,325,000	71%
All with CI	470,000	855,000	83%
Numbers with CI receiving home-based services	110,000	210,000	91%
Numbers with CI in care homes	205,000	385,000	88%
Total LTC expenditure, £bn at 2002 prices	12.4	35.4	186%
of which by people with CI	5.4	16.7	207%
LTC expenditure as % of GDP	1.36%	2.04%	
of which due to CI	0.60%	0.96%	

Source: PSSRU CI model estimates, 2002 base.