Costs and cognitive disability: modelling the underlying associations[†]

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Background The high support needs of elderly people with cognitive disability raise questions about the cost-effectiveness of different treatments. Associations between costs and cognitive disability could be influenced by other factors, particularly comorbidities.

Aims To examine the links between costs and cognitive disability in the context of covariates.

Method Secondary analyses of data from the UK Office of Population Censuses and Surveys disability surveys for over 4500 elderly people living in households were used to examine associations between cost and cognitive disability.

Results Costs varied considerably, and were associated with severity of disability along a number of dimensions. The cost-raising effects of cognitive disability were smaller when the analyses controlled for levels of disability in other domains.

Conclusions Cognitive disability is significantly associated with higher costs, but these analyses highlight the need to examine a range of disabilities.

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[†]See editorial, pp. 97–98, this issue.

Dementia has a considerable impact on the quality of life of the patients themselves, their families and other caregivers. It also has major health service and social care implications, in turn generating high costs. Of course service needs and costs are not uniform across the elderly population. In particular, there are links between cost and both cognitive disability and behavioural problems (Ernst *et al*, 1997; Jönsson *et al*, 1999; Kavanagh & Knapp, 1999; McNamee *et al*, 1999; Souêtre *et al*, 1999). With the development of treatments that might slow the rate of cognitive decline or reduce behavioural disturbance, attention has turned to whether service needs are reduced and cost-effectiveness gains achieved. Unfortunately, few studies have examined both cognitive disability and comorbidities when considering the resource consequences of new treatments. That is our aim in this paper.

METHOD

The household sample

The most complete and informative UK population-based data-set on disability is still provided by the Office of Population Censuses and Surveys (OPCS) disability surveys conducted in the mid-1980s (Martin *et al*, 1988). The OPCS conducted separate national surveys of disability among adults in communal establishments (in 1986) and private households (in 1985). For households, a random sample of 100 000 addresses received an initial 'sift' questionnaire. Eleven thousand people identified as possibly having a disability (or their carers) were subsequently interviewed. Where possible OPCS interviewed the person with the disability; otherwise proxies were interviewed. The survey included 5699 elderly people with disabilities in private households. In 4782 cases (85%) interviews were with the elderly subjects themselves, in 441 cases (8%) with the subject and a proxy interviewee, and in 439 cases (8%) with just a proxy interviewee. (These percentages are weighted for sampling fractions.) The greater the degree of cognitive disability the greater the likelihood of a proxy interview. The survey methods have been detailed elsewhere (Martin *et al*, 1988).

The survey of communal establishments did not overlap with the household survey. The analyses in this paper focus exclusively on the household sample. We also exclude people aged under 65 years, and those with a learning disability ('mental handicap' in the surveys). For a small number of people there was an anomaly in that although they were reported as being 'mentally incapable' of being interviewed, their cognitive disability score was coded as 0 ('no disabilities'). In our previous work with these survey data these people were recoded as having 'severe cognitive disability' in a threefold classification (Kavanagh & Knapp, 1999). In these new analyses we exclude these people because of the difficulties of assigning disability scores when using the full scales for analyses.

Disability

Disability was measured across 13 domains: locomotion, reaching and stretching, dexterity (holding), seeing, hearing, continence, communication, personal care, behaviour, intellectual functioning (cognitive disability), consciousness (fits), digestion and disfigurement. In developing the instrument to assess disability, to be administered by a non-clinically trained interviewer in the interviewee's own home, OPCS sought the views of carers' organisations, staff and researchers. The OPCS disability instrument has good interrater reliability; it is highly correlated with the Barthel Index (Collin *et al*, 1988) but is more comprehensive. The measure has previously been used, *inter alia*, to estimate the prevalence of cognitive disability among elderly people (Opit, 1990) and to structure predictions of growth in the number of people affected as a reult of demographic change (Melzer *et al*, 1997).

The behaviour sub-scale was scored hierarchically in terms of the following eight descriptions (ratings in parentheses): 'gets so upset that hits other people or injures him/herself' (10.5); 'gets so upset that breaks or rips up things' (7.5); 'feels the need to have someone present all the time' (6.5); 'finds relationships with

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members of the family very difficult' (6.0); 'often has outburst of temper at other people with very little cause' (4.0); 'finds relationships with people outside the family very difficult' (2.5); 'sometimes sits for hours doing nothing' (1.5); 'finds it difficult to stir him/herself to do things, or often feels aggressive or hostile towards other people' (0.5).

The communication sub-scale has five levels, scoring 12 for 'is impossible for people who know him/her well to understand; or finds it impossible to understand people who know him/her well'; 8.5 for 'is impossible for strangers to understand; or is very difficult for people who know him/her to understand; or finds it impossible to understand strangers; or finds it very difficult to understand people who know him/her well'; 5.5 for 'is very difficult for strangers to understand; or is quite difficult for people who know him/her well to understand; or finds it difficult to understand strangers; or finds it quite difficult to understand people who know him/her well'; 2.0 for 'is quite difficult for strangers to understand; or finds it quite difficult to understand strangers'; and 1.0 for 'other people have some difficulty understanding him/her; or has some difficulty understanding what other people say or what they mean'.

The intellectual functioning (cognitive disability) sub-scale is a weighted measure of the number of problems from the following set of descriptors: 'often forgets what was supposed to be doing in the middle of something; often loses track of what is being said in the middle of a conversation; thoughts tend to be muddled or slow; often gets confused about what time of day it is; cannot watch a half-hour television programme all the way through and tell someone what it was about; cannot remember and pass on a message correctly; often forgets to turn things off such as fires, cookers or taps; often forgets the name of people in the family or friends seen regularly; cannot read a short article in newspaper; cannot write a short letter to someone without help; cannot count well enough to handle money'. Scores range from 0 to 13.

In our previous analysis, we distinguished three groups of elderly people with disabilities on the basis of their cognitive disability score, based on the typology of Opit (1990):

(a) no or indiscernible cognitive disability (scores of 0–2);

(b) mild to moderate cognitive disability (3–6);

(c) severe cognitive disability ($\geqslant 7$).

In this paper we conduct analyses using the full cognitive disability sub-scale as well as full scores on other disability sub-scales.

Service utilisation

The household survey asked detailed questions about the number of in-patient stays (days), out-patient appointments and general practitioner consultations during the previous year. For other community or domiciliary services, multiple choice questions asked whether service use was daily, two or three times per week, once per week, once per month, or less than once per month. People were also asked whether they regularly went somewhere such as day centres and clubs for training or social activities. We defined 'respite care' as a stay in a nursing home, residential home or hostel during the previous year, excluding holidays with family or friends.

Unit costs

Unit cost estimates for services were taken from the annual Personal Social Services Research Unit (PSSRU) compendium (Netten & Dennett, 1995). These unit cost figures are nationally applicable in the UK and include not only revenue expenditure but also capital elements and overheads. Where information was not available from this PSSRU source, we assumed that domestic visits took 40 minutes, half of which time was spent on travel and administration. We used these (now slightly dated) unit cost figures in order to ensure comparability with earlier economic analyses of these OPCS data (Kavanagh & Knapp, 1999). To uprate these 1994/95 unit costs to present-day prices, a multiplier of 1.16 should be applied (Netten *et al*, 1999).

The caregiver data collected in the OPCS surveys were too narrow to allow costing of informal care. More detailed questions were asked only of people needing help with personal care such as bathing and toileting. In addition, because it is also difficult to attach monetary values to informal care inputs we were forced to limit our estimates to the direct costs of services.

Analyses

Our earlier examination of the association between cognitive disability and costs included people in private household and communal establishments, and distinguished three severity groupings for disability, as described above. Our aim in this paper is to conduct more searching analyses, but at the same time to restrict attention to people in private households. The principal reason for excluding people in communal establishments from these analyses is that the survey did not collect individualised charge or cost data for people in public sector settings, so that we do not have complete variability in the dependent variable. We wished to determine the extent to which variations in costs for people in households were associated not only with cognitive disability, but also with other disability and health problems and with other personal characteristics.

We used multivariate statistical methods, taking the total cost of services as the dependent variable. The explanatory variables were: age and gender, whether the person lived alone, severity of disability in each of the 13 domains covered by the survey, and an indicator variable taking the value 1 if the reported condition underlying the primary disability had occurred within the previous 2 years, and the value 0 otherwise.

The survey estimation routines of STATA (Release 5; StataCorp, 1997) were used for the multivariate analyses to allow for the complex survey design employed by OPCS. The probability weights supplied with the data-set were used to correct for aspects of the survey such as different sampling probabilities and non-response. In the case of regression analyses, weighting ensures that the calculated regression coefficients are unbiased. Furthermore, the standard errors of the coefficients are adjusted to correct for the effects of clustering and stratification. The survey estimation uses robust regression methods (Huber, 1981).

A problem common to many economic studies in health care is that the distribution of cost variables is skewed with a long tail to the right, which in turn often results in regression models where the residuals are also non-normal and skewed to the right. Plots of the residuals in our analyses showed them to be indeed non-normal and heavily skewed to the right. The residuals were tested using the Shapiro–Francia W test for normal data and the Jarque–Bera test (Shapiro & Francia, 1971; Jarque & Bera, 1987), and were found to be statistically different to the normal distribution for all the estimated regressions ($P<0.001$).

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Table 1 Variables used in the regression analyses

Variable	*n*	Mean	s.d.	Min.	Max.
Total cost of services, excluding housing and personal consumption (£, 1994/95 prices)	4531	34.16	58.45	0	870.96
Gender (1, male; 0, female)	4531	0.37	0.48	0	1
Age at time of interview (years)	4531	76.37	6.81	64	99
Living alone (1, yes; 0, no)	4531	0.40	0.49	0	1
Locomotion disability score (range 0–11.5)	4531	4.14	3.45	0	11.5
Holding (dexterity) disability score (range 0–10.5)	4531	2.16	3.49	0	10.5
Reported morbidity with hearing (1, yes; 0, no)	4531	0.39	0.49	0	1
Behaviour disability score (range 0–10.5)	4531	0.68	1.99	0	10.5
Cognitive disability score (range 0–13)	4531	0.89	2.46	0	13
Continence disability score (range 0–11.5)	4531	0.98	2.47	0	11.5
First reported condition underlying disability occurred within previous 2 years (1, yes; 0, no)	4383	0.23	0.42	0	1
Summary mental disability score (cognitive, behavioural, communication)	4531	1.75	3.70	0	21.0
Summary physical disability score (locomotion, reaching and stretching, holding)	4531	5.71	4.75	0	18.6

Although robust regression performs better than ordinary least squares (OLS) regression when the distribution of the disturbances is non-normal (Kmenta, 1986: pp. 264–265), we conducted some additional analyses. We first employed bootstrap analyses (Efron & Tibshirani, 1993) using bias-corrected methods and 1000 replications to calculate an alternative set of standard errors. As a second check on our analyses we also reran robust regressions taking the natural logarithm of costs as our dependent variable to check the significance of association between the explanatory and dependent variables.

Analyses using models with the natural logarithm of cost as the dependent variable found that coefficients statistically significant ($P<0.05$) in our initial models were almost always also significant in the models that employed the natural logarithm of costs. Furthermore, the standard errors calculated using the bootstrap did not differ from those estimated using the robust regression, and so we report here only the confidence intervals estimated using initial robust regressions.

Multi-collinearity between the disability variables encouraged us to compute two summary scores combining domains that were highly correlated and covered similar areas of functioning. These derived variables were similar to the factors derived by OPCS in their own analyses (Martin *et al*, 1988). Both scores can run from 0 to 20:

(i) A composite 'mental' disability score was calculated by taking a combination of the severity scores for intellectual functioning, behaviour and communication. The score was calculated using the $A+0.4B+0.3C$, where A is the worst score, B the second worst and C the third worst.

(ii) A composite 'physical' disability variable was calculated by taking a combination of the severity scores for locomotion, reaching and stretching, and dexterity. The score was derived using the same formula as above.

RESULTS

Sample characteristics: disability and costs

A detailed description of sample members, their service use patterns and the associated costs is given elsewhere (Kavanagh & Knapp, 1999). Here we briefly note only the cost differences between the three cognitive disability levels distinguished in that earlier paper, and describe the variables used in the regression analyses. Mean service costs were £35 per week for people with no cognitive disability, £57 for people with mild or moderate cognitive disability and £75 for people with severe cognitive disability. These were significantly different, although the tests did not control for possible covariates. We therefore do not know the extent to which these cost differences are due to cognitive disability and how much they reflect service responses to comorbid conditions or other aspects of disability.

As well as these differences, at each level of disability there was marked cost variation around the mean, which is an immediate prompt for the kind of multivariate analysis conducted here.

Regression analyses

The multiple regression analyses first retained individual disability domain scores as independent variables, alongside age, gender, living alone, and time elapsed since the primary disabling condition first occurred. Table 1 summarises the main features of these variables. Just over a third of the sample (37%) were male, mean age at the time of interview was 76 years, and two out of five people lived alone. Mean disability scores were low: the mean cognitive disability (intellectual functioning) score was 0.89 in a range extending from 0 to 13, and the mean behaviour rating was 0.68 in a range extending from 0 to 10.5.

The analyses found a number of factors to be associated with cost ($P<0.05$ unless indicated otherwise) in the analyses (Table 2): gender; living alone; severity of disability in the domains of locomotion, holding (dexterity), hearing ($P=0.099$), cognitive disability ($P=0.065$), behaviour and continence; and time since first reported condition underlying disability occurred. The bootstrap regression analyses largely confirm this pattern of association (final three columns of Table 2). In particular, the cognitive disability variable is not significant at the 5% level.

The link between cognitive disability and cost was clearly sensitive to the inclusion or exclusion of behavioural disability in the regression equations, since the two domains are closely correlated. In two further regression analyses (not reported) we excluded one of either behavioural disability or cognitive disability, and

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Table 2 Regression analyses using individual disability domains as independent variables

Variable	Coefficient	s.e.	*P*	95% CI
Gender (1, male; 0, female)	6.481	2.550	0.011	1.473 to 11.490
Age (years)	0.160	0.172	0.365	−0.182 to 0.494
Gender × living alone (1, yes; 0, no)	16.715	2.193	<0.001	12.406 to 21.025
Locomotive disability	4.311	0.350	<0.001	3.624 to 4.998
Holding (dexterity) disability	0.877	0.332	0.008	0.225 to 1.529
Hearing morbidity (1, yes; 0, no)	−2.985	1.807	0.099	−6.535 to 0.565
Cognitive disability	1.438	0.776	0.065	−0.087 to 2.964
Behavioural disability	2.095	1.000	0.036	0.133 to 4.058
Continence disability	1.253	0.535	0.020	0.202 to 2.304
Recent underlying condition (1, yes; 0, no)	17.986	2.842	<0.001	12.402 to 23.571
Constant term	−10.079	12.716	0.428	−35.065 to 14.906
n=4342 R^2=0.136				

Table 3 Regression analyses using summary disability measures as independent variables

Variable	Coefficient	s.e.	*P*	95% CI
Gender (1, male; 0, female)	3.631	2.625	0.167	−1.527 to 8.789
Age (years)	0.269	0.171	0.116	−0.067 to 0.605
Gender × living alone (1, yes; 0, no)	8.519	4.951	0.086	−1.210 to 18.248
Continence disability	1.517	0.518	0.004	0.499 to 2.535
Hearing morbidity (1, yes; 0, no)	−5.803	1.853	0.002	−9.444 to −2.163
Summary mental disability	1.681	0.416	<0.001	0.864 to 2.499
Summary mental disability × living alone	1.120	0.716	0.119	−0.287 to 2.527
Summary physical disability	2.507	0.273	<0.001	1.971 to 3.044
Summary physical disability × living alone	2.081	0.390	<0.001	1.316 to 2.847
Recent underlying condition (1, yes; 0, no)	18.059	2.833	<0.001	12.492 to 23.626
Constant term	−10.522	12.845	0.413	−35.761 to 14.716
n=4342 R^2=0.136				

Table 4 Regression analyses with only cognitive and non-disability independent variables

Variable	Coefficient	s.e.	*P*	95% CI (BC)
Gender (1, male; 0, female)	−0.838	2.760	0.761	−6.262 to 4.585
Age (years)	0.656	0.167	<0.001	0.328 to 0.984
Living alone (1, yes; 0, no)	10.655	2.265	<0.001	6.206 to 15.105
Gender × living alone (1, yes; 0, no)	5.777	5.606	0.303	−5.238 to 16.792
Cognitive disability	4.286	0.588	<0.001	3.130 to 5.442
Recent underlying condition (1, yes; 0, no)	16.590	2.899	<0.001	10.894 to 22.286
Constant term	−24.441	12.844	0.058	−49.679 to 0.796
n=4342 R^2=0.062				

retained the other. In each case the retained variable was strongly related to cost (significance $P<0.001$). We therefore explored whether the summary measures of mental and physical disability improved the predictions of total service costs (Table 3). In fact, the explanatory power of the regression was unchanged (R^2=0.136). Mental disability (a combined rating of cognitive disability, behaviour and communication) was significantly associated with cost ($P<0.001$). Other significant effects were similar to the earlier regression (see Table 2), and again the bootstrap and OLS results were consistent.

Our final set of regression analyses examined the association between cost and cognitive disability without controlling for comorbid disabilities. The results are summarised in Table 4. It can be seen that the overall goodness of fit is worse (R^2 is 0.062 compared with 0.136 in Tables 2 and 3), the cognitive disability variable is strongly significant, and its coefficient is three times larger than in the equation reported in Table 2. Whereas the marginal impact of a unit change in the cognitive disability measure is £4.29 ($P<0.001$) in this simple regression analysis, with all other disability measures excluded, the impact when taking into account the other disability effects was £1.44 (cognitive disability in Table 2) or £1.68 (summary mental disability in Table 3).

DISCUSSION

The ageing of the world population has been a major achievement for medical science and for the economic and social policies of the 20th century. However, these successes have brought their own challenges. The combined effects of a number of trends – in demography, labour force participation, geographical mobility and family patterns – have increased the need and demand for long-term care services. These increases have been well-known for a long time, and different countries have responded to them in different ways.

Pharmacotherapy for Alzheimer's disease

There are new challenges. New treatments and care arrangements have the potential to improve patient and carer health and quality of life, and the introduction of the cholinesterase inhibitor class of drugs raises some new issues. The new drugs may be effective for people with mild or moderate Alzheimer's disease, slowing down cognitive decline, raising competence in the activities of daily living and improving quality of life (Burns *et al*, 1999). If the clinical effects of these drugs are indeed achieved – Burns and colleagues refer to their effects as 'probably best described as modest' (Burns *et al*, 1999: p. 478) – what are the likely cost consequences?

Certainly there will be noticeable increases in drug expenditures. However, delayed progression to more severe cognitive disability, and with it reduced needs for care support in the community and

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possibly delayed admission to a care home or hospital, could reduce some other costs. There have been a number of economic studies. Stewart *et al* (1998), Neumann *et al* (1999), O'Brien *et al* (1999), Fenn & Gray (1999) and Hauber *et al* (2000) all conducted modelling exercises, built to varying degrees on observational data, with varying breadths of cost measurement, and predicting over various lengths of time. These studies suggest that the overall economic impact could be cost-neutral or cost-reducing, although any savings are likely to be modest.

The effects of comorbidity

The trials on which these economic models were based 'were carried out on a carefully selected sub-group of patients with mild-to-moderate [Alzheimer's disease] excluding those with coexisting illness or concurrent treatment' (Manca & Davies, 1999: p. 170). The economic investigation of this new class of drugs has not explored the links between cognitive disability, behavioural problems and other comorbid conditions and costs.

Although our earlier work found that a greater proportion of people with higher levels of cognitive disability were resident in institutional settings (Kavanagh & Knapp, 1999), here we have not examined the cost-raising impact of long-term admission to a care home or hospital bed. Among older people in households, the cost–cognitive disability gradient is not independent of the effects of other disabilities. Consequently, any cost reduction that follows from a slowing of the rate of cognitive decline in patients with Alzheimer's disease living at home may be modest unless there is a concomitant change in other disabilities. For the cross-sectional sample of older people in the present study, we certainly found significant correlations between cognitive and all other disabilities: 0.214 with locomotion, 0.169 with reaching and stretching, 0.224 with dexterity, 0.208 with seeing, 0.193 with hearing, 0.317 with continence, 0.426 with communication, 0.730 with behaviour, 0.052 with consciousness, 0.128 with digestion and 0.067 with disfigurement. All but one correlation was significant at $P<0.0001$. The exception was consciousness ($P<0.0005$). However, disentangling the relationship between these disability domains is difficult, particularly with cross-sectional data. Economic analyses based on well-conducted prospective studies could address these issues.

CLINICAL IMPLICATIONS

- The costs of supporting older people living in households are significantly associated with the levels of disability in each of a number of domains.
- The specific cost-raising impact of cognitive disability needs to be understood in the context of other influences.
- Interventions that might slow the rate of cognitive decline, such as the cholinesterase inhibitors, have the potential to reduce the costs of health and social care support. However, without data on the effects of treatment on other disability domains there is a danger that these potential cost reductions will be inadequately estimated.

LIMITATIONS

- The data were collected in the 1980s by non-clinical interviewers. However, they come from what is still the UK's most recent large-scale, national, random population-based survey, and include comprehensive service use and disability measures.
- Costs measure only direct service utilisation, and in particular exclude informal carer costs; although short-term in-patient care and periods of respite in care homes are included, permanent admissions are not costed.
- Cross-sectional data are used to reflect on what might be seen as a longitudinal question: how service costs respond to individual disability levels.

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Mediated effects of cognitive disability

We are certainly not the first to show that cognitive disability and costs are related, although some of the earlier studies did not examine the possibility that the relationship might be influenced by other health dimensions and disabilities (Ernst *et al*, 1997; Jönsson *et al*, 1999; Souêtre *et al*, 1999). Nor are we the first to conduct multivariate examinations of the sources of cost variation in a way that makes clear that the effects of cognitive disability on costs are mediated through, or complicated by, the presence of comorbid conditions (Boersma *et al*, 1997; Leon & Moyer, 1999; McNamee *et al*, 1999). However, in this study we have been able to build our analyses on data on a large sample of household-dwelling older people collected in a national, random survey. In addition, we have been able to employ suitable statistical methods to interrogate the data, taking account of the skewed distribution of total service costs. Severity of cognitive disability is certainly associated with cost, but one should be aware of the associations between costs and other disabilities given the multi-dimensional effect of dementia on disability and comorbidity among elderly people more generally.

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