Cognitive impairment: a challenge for community care.
A comparison of the domiciliary service receipt of cognitively impaired and equally dependent physically impaired elderly women

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Abstract

Objectives: to compare the domiciliary service receipt of cognitively impaired and equally dependent physically impaired elderly women prior to the passing of the UK Community Care Act.

Methods: secondary analysis of a population survey conducted in 1986 in the city of Cambridge. The analysis used data on 1585 women aged 75 and over living in the community. The effect of type of impairment on the receipt of domiciliary services (meals-on-wheels, home help and community nursing) is measured using a multivariate model which allows for adjustment for dependency level and other potential confounding factors.

Results: the odds of an elderly woman getting help from any of the domiciliary services whilst not being significantly affected by cognitive impairment (odds ratio 0.7, 95% CI 0.5-1.2) are increased by physical impairment (odds ratio 1.8, 95% CI 1.2-2.5). Similar results were found for the home help service. The differences were exaggerated in the case of the community nursing service, whilst receipt of meals-on-wheels was similar for women of with all types of impairment.

Conclusions: in the late 1980s, cognitively impaired elderly women received less help from the domiciliary services than equally dependent physically frail women who lived in similar household circumstances. The development of specialist services appropriate to the needs of cognitively impaired elderly people presents a challenge to community care policy, especially since this group are at high risk of institutionalization.

Keywords: cognitive impairment, community care, service receipt

Introduction

The central aim of the policy embodied in the UK National Health Service (NHS) and Community Care Act of 1990 is to develop community services to enable elderly people to live independently in the community for as long as possible [1]. The policy has particular implications for the care of the cognitively frail elderly since a high proportion of such people were in institutional care in the late 1980s, prior to the implementation of this policy. Recent analysis of the Office of Population Censuses and Surveys disability survey shows that one-third of those with severe cognitive disability, compatible with moderate or
severe dementia, aged 65 and over were in institutions in 1986. Whilst only 5.5% of the total population of the UK had this level of cognitive disability, almost half of all elderly people in institutional care were in this category [2]. If the policy of enabling elderly people to live in the community is to be effective, developments in community services must address the needs of cognitively frail people in particular.

There has been much speculation about the impact of the policy changes implemented in 1993 which are currently being investigated by the Evaluating Community Care for Elderly People project at the Personal Social Services Research Unit. The national provision of the community services home helps, meals-on-wheels, district nursing and day centre places is reported as having decreased in relation to the numbers of elderly people (aged 75+) in the population between 1985 and 1993 [1, 3], although the first objective of the Community Care Act is to "encourage the targeting of home-based services on those people whose need for them is greatest" [4]. To examine the effect of such targeting on the cognitively frail in particular we await the results of recent population-based epidemiological studies, in particular the Medical Research Council Longitudinal Study of Cognitive Function and Ageing. The impact of the policy changes can then be assessed by comparison with studies conducted prior to this period of change.

In the search for such a baseline measure of service receipt by cognitively frail elderly people, we examined the evidence provided by epidemiological studies conducted during the latter half of the 1980s [5-7]. Published studies, for example the Hughes Hall Project for Later Life, conducted in Cambridge in 1986, reported that demented elderly people received more service help than those who were cognitively normal [8], but a large proportion of the latter group were independent and therefore had no need for service help, whilst many of the demented group would also be physically impaired. The present study of the service receipt aims to overcome these problems by including physical as well as cognitive impairment factors, and a common measure of need for help—the dependency on others for help with basic activities of daily living (ADLs). In order to make adjustment for dependency level and other potential confounding factors affecting service receipt, multivariate confounding logistic regression was used.

Methods

Design

The study made use of the secondary analysis of a population survey conducted for the Hughes Hall Project for Later Life during 1986-87. A screening interview was given to 2609 residents of the city of Cambridge aged 75 and over, about one-third of the total population of the city [5]. The sample used for this analysis consisted of the 1585 women aged 75 and over living in the community. Men were excluded from this study because of the difficulty of ascertaining a level of disability for the majority whose domestic needs had always been attended to by women—their dependency was not a satisfactory measure of their disability.

Measures

Service receipt

The domiciliary services whose use was reported in the survey were home help, meals-on-wheels and community nursing. Subjects were said to have received service help if they or their informant reported that they had been visited in the previous week by either home help or meals-on-wheels, or in the previous month by a nurse. Different types of nurse were not distinguished.

Dependency score

Dependency is measured by the ADL scale [11], a widely used measure in studies of elderly people [6, 10, 20, 21]. Subjects were given a score from 0 (independent or needing occasional help only) to 2 (totally dependent on others) for each of seven activities: shopping, housework, laundry, cooking, bathing, taking medicines and dressing. The score was summed to give a dependency score between 0 and 14. Activities that did not ask about dependency on others (use of the telephone, getting to the toilet on time and walking) were not included, although walking was used in the physical impairment score.

Cognitive impairment

Cognitive impairment was measured by the Mini-Mental State Examination (MMSE) [13], a cognitive scale widely used in epidemiological studies. The number of correct answers was totalled to give a maximum of 30 using the same method of calculation as later studies of this cohort [14]. Individual items which were missing because the subject did not answer or did not know were counted as errors. Those subjects who scored 17 or less were classified as cognitively impaired. Seventeen is an established cut point on the MMSE scale with a high sensitivity and specificity for the detection of moderate or severe dementia [15-18], the level of dementia at which support in daily activities becomes necessary. Those whose MMSE had to be abandoned were also included in this category since only 8% of the 47 in this group who were subsequently given a diagnostic interview...
were found to have no psychiatric diagnosis, and 91% of those with a diagnosis were given a primary diagnosis of dementia [2].

**Physical impairment**

A physical impairment score was based on Comprehensive Assessment and Referral Evaluation items [19] constructed from scales of mobility, upper limb function and visual disability similar to those used by Kay et al. [20]. For mobility, subjects were given a score from 0 (completely mobile) to 4 ('takes no more than a few steps'). The rest of the score was based on interviewer ratings of 'poor eyesight that interfered with reading, writing or drawing' (in a good light, using aids) and 'weakness, tremor of hand that interfered with writing, drawing or folding paper', which were scored from 0 (no problem) to 2 (severe problem). The three scores were added to give a physical impairment score from 0 to 8. Those who scored 2 or more were classified as physically impaired—that is they had restricted mobility, walking no further than the gate or worse, a severe problem with eyesight or tremor or a combination of these problems.

The cut-off point on the physical impairment score was chosen so that people who were classified as physically impaired had, on average, a similar dependency score to those classified as cognitively impaired.

The average dependency score for those who were defined as cognitively impaired (MMSE ≤ 17) was 6.1. Those with a score of 2 or greater on the physical impairment score had an average dependency score of 5.9. This methodology ensured that the definition of 'cognitive impairment' and 'physical impairment' used here represented a similar level of dependency.

**Cognitive and physical impairment**

Some of the women were classified as both cognitively and physically impaired. This included those with independently co-existing impairments and those whose impairments were causally linked as in Parkinson's disease or the severely demented who no longer walk [8].

**Use of informant responses**

Many elderly people with cognitive impairment were confused and might give inaccurate information. However all those with low MMSE scores were eligible for the CAMDEX (Cambridge Examination for Mental Disorders of the Elderly) interview [21] in which a carer was asked the same questions about the dependency and service receipt of the subject. For the cases where informant ratings were available and differed from those of the subject, informant ratings were used. Information was available on the service receipt of 244 subjects, with 24 instances of disagreement between informant and subject, and on the dependency level of 238 subjects, with 46 instances of disagreement.

**Statistical methods**

In order to assess the influence of cognitive impairment and physical impairment on reported service receipt it was necessary to use a multivariate analysis in which we could control for other factors related to service receipt. A logistic regression analysis was used with the odds of receiving a service as the outcome variable. Firstly, the dependency score only was entered as a categorical explanatory variable. The dependency scores were then divided into three dependency levels based on the similarity of their coefficients in the model. These were minimal (score 0), moderate (score 1-4) and high (score 5-14). This dependency level was entered first into the model, then all other factors which were found to be associated univariately with service receipt were entered as potential explanatory categorical variables using forward selection based on the likelihood ratio test. Two-way interactions were similarly considered. Finally, the factors for severe cognitive impairment and physical impairment were entered into the model. Since the interaction between the factors for cognitive and physical impairment was not significant in the model, the effects of these factors on service receipt could be reported independently. A similar analysis was then carried out for each service individually.

**Results**

Of the 1585 women, 129 (8%) were classified as cognitively impaired and 353 (22%) as physically impaired, while 1166 (74%) had neither impairment. Half of the cognitively impaired subjects were also physically impaired, whilst only 18% of physically impaired people had cognitive impairment, resulting in the four categories shown in Table 1.

The proportion of women who received service help was significantly greater among those who were cognitively impaired than those with neither impairment, but was significantly greater for the physically impaired than the cognitively impaired. These differences were reflected in the dependency scores. Yet for physically impaired people, the presence of cognitive impairment appeared to make little difference to service receipt, whilst significantly increasing dependency. This illustrates the need to control for dependency when comparing the service receipt of cognitively and physically impaired individuals.

**Dependency**

In Table 2 dependency is controlled at three levels (categorized as described above). Service receipt increased with degree of dependency, both in the
Table 1. Characteristics of the sample by type of impairment

<table>
<thead>
<tr>
<th>Impairment</th>
<th>No. of cases</th>
<th>Service receipt</th>
<th>Age</th>
<th>Dependency score</th>
<th>Living alone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>%</td>
<td>95% CI</td>
<td>Mean</td>
<td>95% CI</td>
</tr>
<tr>
<td>Neither</td>
<td>1166</td>
<td>14</td>
<td>12.0, 16.0</td>
<td>80</td>
<td>79.7, 80.1</td>
</tr>
<tr>
<td>Cognitive</td>
<td>66</td>
<td>30</td>
<td>18.9, 41.1</td>
<td>82</td>
<td>80.5, 82.5</td>
</tr>
<tr>
<td>Physical</td>
<td>290</td>
<td>59</td>
<td>53.3, 64.7</td>
<td>83</td>
<td>82.8, 83.9</td>
</tr>
<tr>
<td>Both</td>
<td>63</td>
<td>63</td>
<td>51.1, 74.9</td>
<td>85</td>
<td>83.7, 86.4</td>
</tr>
<tr>
<td>All</td>
<td>1585</td>
<td>25</td>
<td>81</td>
<td>81</td>
<td>5.9</td>
</tr>
</tbody>
</table>

*a Subjects were said to have received service help if they or their informant reported that they had been visited in the previous week by either home help or meals-on-wheels, or in the previous month by a nurse. Different types of nurse were not distinguished.

*b Measured by the activities of daily living scale: subjects were given a score from 0 (independent or needing occasional help only) to 2 (totally dependent on others) for each of seven activities: shopping, housework, laundry, cooking, bathing, taking medicines and dressing. The score was summed to give a dependency score between 0 and 14. Activities that did not ask about dependency on others (use of the telephone, getting to the toilet on time and walking) were not included.

95% CI, 95% confidence interval.

Informal care

Another important consideration in the receipt of service help is the use of other sources of help. The data included information on who helped with each ADL for 727 (87%) of the women, 839 of whom were dependent above the minimal level. In this sample only one of the women who needed some help with an ADL said she had no help at all. Only 3.5% (26 cases) who needed help relied on sources other than informal help or the domiciliary services considered here (for example some employed private help and some of those who lived in sheltered accommodation were helped by the warden). Thus the help received by the women was essentially either from the domiciliary services available at that time—home help, meals-on-wheels or community nurse—or informal help from relatives, friends or neighbours. Those who had service help with an ADL had correspondingly less informal help, so factors related to the extent of informal care received would also be inversely associated with service receipt.

It is still possible, however, that cognitively impaired subjects who had no family available to provide any informal care were more likely to have been institutionalized than physically impaired people in a similar social situation; so that, for those living in the community, more cognitively impaired than physically impaired people would have an informal carer. This was, however, found not to be the case. The existence of an informal carer—defined as anyone giving informal help with any ADL—could be determined for 87% (727) of the 840 dependent elderly women. [For 13% (113/840) of the dependent women these data were not available for analysis for practical reasons. Taking the results based on those for whom the data were available is believed to be unbiased since whole sample and for women with each type of impairment. For both the physically impaired and unimpaired elderly women, those with cognitive impairment as defined in this study received less service help than the less severely impaired at each level of dependency. The only exception to this pattern was the category of minimally dependent physically fit women, but this exception was the result of only one isolated case. Since differences in service receipt were not accounted for by dependency, a multivariate analysis was required in which other potential confounding factors could be adjusted.

Table 2. Percentage of women receiving domiciliary service help by type of impairment and level of dependency

<table>
<thead>
<tr>
<th>Level of dependency</th>
<th>Impairment (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Neither</td>
</tr>
<tr>
<td>Minimal</td>
<td>2 (17/70)</td>
</tr>
<tr>
<td>Moderate</td>
<td>29 (118/404)</td>
</tr>
<tr>
<td>High</td>
<td>61 (26/43)</td>
</tr>
<tr>
<td>All^</td>
<td>14 (161/1154)</td>
</tr>
<tr>
<td>Missing</td>
<td>8 (1/12)</td>
</tr>
</tbody>
</table>

^Excluding missing cases.
the cases with missing data did not differ significantly from the others in age group (\(P = 0.7\)), dependency level (\(P = 0.8\)), cognitive impairment (\(P = 0.8\)) or physical impairment (\(P = 0.3\); probability values of Pearson's \(\chi^2\)).

It was found that 82% (596) of these women had an informal carer and that this proportion did not differ significantly between the categories of impairment (Pearson's \(\chi^2 P = 0.7\)).

### Living alone

The targeting of domiciliary services at those who live alone in the community has been widely reported [4, 7, 24]. This is confirmed in our study—29% of those who lived alone received service help compared with 18% of those who lived with others (Pearson's \(\chi^2 P < 0.00001\)). At the same time, cognitive impairment is significantly associated with living with others: 49% of the 129 cognitively impaired women lived with others compared with 40% of those who were less impaired (Pearson's \(\chi^2 P = 0.05\)).

Other factors found to be univariately associated with service receipt were residence in sheltered accommodation and age. Service receipt increased with age and 45% of those in sheltered accommodation had service help compared with 22% of those in private households.

The results of fitting the logistic regression models to the receipt of any service, and the models relating to the services individually are given in Table 3. The interaction between cognitive and physical impairment was not significant in any of the models—hence the effects of cognitive impairment and physical impairment on service receipt can be independently reported. When the factors of dependency, co-residence, age and residence in sheltered accommodation are adjusted for, physical impairment still has a significant effect on receipt of service help whereas cognitive impairment does not.

However, this pattern of service receipt did not prove to be the same for each of the domiciliary services. The receipt of meals-on-wheels was explained solely by level of dependency and co-residence. It was not significantly affected by type of impairment. The receipt of community nursing was also independent of age and residence but was significantly affected by cognitive as well as physical impairment. Cognitive impairment significantly reduced the odds of receiving a visit from a community nurse by a factor of 2, whilst the presence of physical impairment increased the odds by 3.2 (95% CI 1.9–5.1). The pattern for home help followed that of any service receipt.

The results for the community nurse service are of particular interest. This service provided assistance mainly with the self-care activities of bathing and dressing. In fact only 25% (two) of the cognitively impaired who needed help with bathing (and for whom we have information about the helper) and none of those who needed help with dressing received help from a nurse, the remainder being dependent on informal care. Of the physically impaired group, however, 53% (59) had a nurse to help with bathing and 21% (eight) to help with dressing, compared with 37% (13) and 7% (one) of those who were cognitively as well as physically impaired. Since continence had not been included in the measure of dependency, a particular check was made to see if this factor might explain the difference in visits by the community nurse. The results supported those given above: 51% of physically impaired but only 35% of cognitively impaired people with continence problems were visited by the community nurse.

In order to check whether our results may have been biased by the use of a low cut-off point for cognitive impairment, we compared the service receipt of less severely cognitively impaired subjects (MMSE 18–21) with our group who had MMSE \(\leq 17\). Of those with MMSE 18–21, 38% (77/200) received service help as opposed to 47% (59/127) of those with MMSE \(\leq 17\).

### Table 3. Logistic regression models: effect of cognitive and physical impairment on service receipt: odds ratios (ORs) and confidence intervals (CIs)

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Any domiciliary service(^a)</th>
<th>Community nurse(^a)</th>
<th>Home help(^a)</th>
<th>Meals-on-wheels(^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>OR 95% CI</td>
<td>OR 95% CI</td>
<td>OR 95% CI</td>
<td>OR 95% CI</td>
</tr>
<tr>
<td>Physical</td>
<td>1.8 1.2–2.5(^d)</td>
<td>3.2 1.9–5.1(^d)</td>
<td>1.6 1.1–2.3(^d)</td>
<td>1.0 0.6–1.6</td>
</tr>
<tr>
<td>Cognitive</td>
<td>0.7 0.5–1.2</td>
<td>0.5 0.3–0.9(^d)</td>
<td>0.7 0.4–1.2</td>
<td>1.3 0.7–2.2</td>
</tr>
</tbody>
</table>

\(^a\)Controlling for dependency, co-residence, age, the interaction of co-residence with dependency, and residence.

\(^b\)Controlling for dependency and co-residence.

\(^c\)In each case OR for not having that impairment is taken as 1. The interaction between physical impairment and cognitive impairment was not significant in any of the models.

\(^d\)Contributes significantly to the model at the 5% level.
Discussion

In this community-based study of elderly people aged 75 and over in the city of Cambridge in 1986–7, we found a bias in the delivery of domiciliary services against cognitively impaired women and in favour of physically impaired women, or their carers. In the case of the delivery of meals-on-wheels, this was explained by the lower reported dependency of cognitively impaired subjects and their tendency to live with others. However, these and other factors related to service receipt did not explain the differences in the delivery of the home help service or community nursing. Moreover, alternative sources of formal domiciliary help were negligible.

Since the proportions of women having no informal care were similar for all types of impairment, the burden of caring for the 82% of the dependent elderly women who had any informal care fell more onto those who cared for people who were cognitively impaired than those who were physically impaired.

Methodological issues

The Hughes Hall study used general practitioner registration as a sampling frame. In elderly subjects with high medical needs, non-registration was very unlikely in those living in the community. There was a high response rate of 95% and those interviewed constituted a sample of about one-third of the total population of the city, representative in age, sex and residence [5]. Since service provision in Cambridge in 1986 was very similar to that in the UK as a whole [21] the results are applicable to the country on average. They do, however, refer to women only and, given gender differences in service receipt [4, 23–25], will overestimate service provision if projected to the total population.

Since physical and cognitive function are continuous attributes, qualitative classifications based on them are inevitably comparative—that is, those not classified as impaired had a smaller degree of impairment than those described as 'impaired'. Hence, some of the women with neither type of impairment were dependent on others. Our results illustrate the large variation in dependency at given levels of impairment, in agreement with other studies [20]. In our analysis we were able to overcome this problem by controlling for dependency level.

There were several possible sources of bias in the study, but these would have tended to result in an overestimation of the service receipt of cognitively impaired people. Firstly, the MMSE score used to define cognitive impairment was low (≤17). Since this level indicated moderate or severe dementia, many of those with mild cognitive impairment will have been included in the groups described as having neither impairment or with physical impairment only. Since the mildly cognitively impaired received less service help than those more severely affected, increasing the cut-off point on the MMSE would have exaggerated our results.

Secondly, although the problem of the reliability of reporting by the cognitively impaired group was addressed by using informant answers where these differed from those given by the subject, it may be that carers tended to minimize the dependency of their cognitively impaired elderly relatives, as suggested by earlier studies of the survey [26].

Thirdly, the phrasing of the questions on dependence in ADL may not be as appropriate to cognitively frail as to physically frail people. For example, the question on dependence in dressing asked about abilities to do up buttons or laces, but not whether the respondent needed help with dressing appropriately. The effect of this and carer under-reporting would be to underestimate the dependency of the cognitively frail and overestimate their service receipt at a given level of dependency.

Finally, the assessment of service help included only those services which provided domiciliary help and did not include other services provided outside the home, such as day centre attendance, which may be particularly important in providing respite to carers of elderly cognitively frail people [8].

Implications

It may be argued that community nursing, which in the 1980s helped with self-care needs, is a 'medical' (NHS) service and therefore not appropriate to the needs of old people who are cognitively impaired. However, the alternative 'social' domiciliary service (home help) provision was also biased towards physically impaired subjects. The meals-on-wheels service proved an exception. Arber and colleagues conjecture that for this service, often provided by voluntary bodies, "the expressed need of the recipient may take on greater prominence" than the allocation criteria of the state services such as home helps [25]. Our results certainly confirm this conjecture, but lead us to conclude that the allocation criteria of the home help service was insensitive to the expressed needs of cognitively impaired people, or their carers. The carers of cognitively impaired subjects may have been more reluctant to ask for such help than those who cared for physically impaired people because they felt that those who were dependent would not meet the eligibility criteria which are perceived as physical.

We can also argue from the consumer's point of view that the services were not used because they did not meet the special needs of cognitively impaired people. Although they were dependent on the help of others with the same daily activities as were the physically impaired, the type of help needed was qualitatively different. The behavioural and communication...
problems of cognitively impaired people [25] can present difficulties in service delivery or can result in help being rejected. For example, the confused elderly woman may need to be encouraged to dress appropriately rather than to be dressed, or may not accept the intrusion of a home help in the household. It may that the meals-on-wheels service was more acceptable because it was less invasive than the other services.

In the light of community care policy, the implication of these arguments is that community services be developed which are appropriate to the needs of cognitively impaired older people, either through greater flexibility of existing services or by the development of specialist services, and by specialist training of those working with this population group [26]. Cognitively impaired people thus present a challenge for community care. This challenge is twofold: firstly to redress the bias found by this study and, secondly, to reduce the risk of institutionalization associated with cognitive impairment. The extent to which these challenges have been met by the recent changes in policy and organization can be measured by comparing the results of this study with those forthcoming from current research.

Acknowledgements

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Key points

- Cognitively impaired elderly women received less help from the domiciliary services than equally dependent physically frail women living in similar household circumstances.
- Cognitively impaired people present a challenge for community care, particularly since they are at high risk of institutionalization.
- Community services need to be developed which are appropriate to their needs of cognitively impaired people.

References


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