Community care for demented and non-demented elderly people: a comparison study of financial burden, service use, and unmet needs in family supporters

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Abstract

Objective—To measure and compare perceived financial burden, use of services, and perceived unmet service needs of supporters of demented and non-demented elderly people.

Design—Comparison study of age and sex matched demented and non-demented elderly people and their supporters.

Setting—25 primary health care teams in Dundee.

Subjects—114 community resident elderly (age over 65) people with dementia, 114 age and sex matched comparators, and the main informal supporter of each elderly person.

Main outcome measures—Carers' perceptions of financial impact of looking after an old person, service use (from a list of locally available services), unmet service needs, and needs for three types of generic service (help with supervision, housework, or personal care).

Results—Financial impact was low, except for extra household expense in the dementia group. There was significantly greater use of mainstream domiciliary and day care services in the dementia group. Dementia was nevertheless associated with a high level of unmet need, mainly for more mainstream support and help with supervision of the elderly person.

Conclusion—Supervisory care for demented elderly people should be further developed within an expanded domiciliary service to meet supporters needs.

Introduction

For over a decade policy in the United Kingdom for the health and social care of older people has emphasised the importance of keeping people in their own homes for as long as possible while recognising the needs of family supporters and providing them with appropriate services.¹ Community care for demented elderly people is thought to pose special problems, with a high risk of breakdown leading to institutionalisation,^{2,3} increased burden for family supporters,^{4,6} and public preference for institutional care.⁷ It is also recognised that the economic impact of dementia on public services is high.^{8,9}

In the 1980s the Scottish Home and Health Department gave top priority to research and development in this subject.¹⁰ As a result several studies were funded, including our project, which examines the factors associated with the maintenance and breakdown in community care of elderly people with dementia in Dundee. In this paper we report the perceived financial impact on supporters of demented elderly people, their service use, and the perceptions of unmet service needs

and compare the findings with those in a group of supporters of age and sex matched elderly people without dementia.

Subjects and methods

We studied 114 community resident elderly (age over 65) people with dementia and 114 elderly people without dementia together with a family supporter in each case. Elderly people with suspected dementia were identified by primary health care teams in the city of Dundee. All primary health care teams were approached, and 25 (65.8%) agreed to participate. Once a list of names had been supplied by a primary health care team the elderly people were assessed for dementia by the project fieldworker. The fieldworker used a diagnostic schedule incorporating the Medical Research Council minimum dataset,¹¹ the 10 item mental status questionnaire,¹² the 12 item CAPE (Clifton assessment procedure for the elderly) information and orientation scale,¹³ and the 12 item organic disorders section of the survey psychiatric assessment schedule.¹⁴ As well as using the rating information, case notes, when available, for the people with suspected dementia were reviewed by a consultant in old age psychiatry (BRB) to exclude non-dementia causes of apparent dementia. A preliminary study showed acceptable validity and reliability with this approach.¹⁵

In addition to this standard procedure, 18 elderly people with dementia were identified through psychiatric referral and 16 through contact with a local day hospital. Comparators were identified for these people from the respective primary health care team's patient register and from among other attenders at the day hospital.

Forty five subjects with suspected dementia were excluded for lack of evidence of dementia, though 12 were borderline cases. A further 32 were excluded because they were in residential or hospital care, 15 because no supporter could be identified, and 17 because of refusal by the elderly person or his or her supporter. Eight other subjects were excluded for miscellaneous reasons.

Supporters were identified by the elderly person whenever possible and defined as someone with a minimum of once weekly contact who was resident in the surrounding area.

After inclusion of a demented elderly person and his or her supporter an age and sex matched elderly person without dementia was identified from the patient register of the same practice. These people were approached for their consent to the study. Those who consented were assessed by the project fieldworker, who used the same diagnostic schedule as for the

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dementia group to confirm the absence of dementia. Supporters were identified as in the dementia group. Any elderly person found to have dementia was (after a decision by the consultant psychiatrist) transferred to the dementia group and a new comparator elderly person and supporter identified and assessed. Ten demented elderly people were identified and included in the study by this route. Of 303 potential comparators, 23 were excluded because of suspected dementia, 23 because they were in residential or

hospital care, 43 because no supporter could be identified, 49 because of refusal, 40 because of inaccurate practice records, and 13 for miscellaneous reasons.

Both sets of supporters were interviewed by means of a structured questionnaire which covered many aspects of psychological, social, and financial status and sought views about services. This study was concerned only with financial impact, service use, and unmet service needs.

Financial impact was estimated by means of a questionnaire devised by the Health Economics Research Unit, based at the University of Aberdeen. Supporters were asked for their perceptions of the impact of care on their travel and household expenses and employment.

Service use and unmet service needs were estimated by asking supporters which of a list of locally available services they currently received (or had received within a specified period), how often they received them, and whether they would like more support from these services. For any service not received, the nature of the service was explained and the supporter asked whether he or she would like to receive it.

In addition, supporters were asked how many hours of support a week they would like from three types of generic service—namely, relief from occupying and supervising the elderly person, help with housework concerned with the elderly person, and help with personal care. Supporters who indicated a total need of more than nine hours a week were asked how many hours of support a week they would like from the three types of service if the total number of hours of support a week was restricted to nine. Cards, each representing one hour a week for the three services, were used to help supporters make their choices.

Results

Table I lists the characteristics of the two groups of elderly people. There were no significant differences in the prevalence of mobility, hearing, sight, or speech impairment. There were no significant differences between the two groups of supporters in age (dementia group: mean 59.2 years, range 23-87; non-dementia group: mean 58.3 years, range 24-85) or sex (dementia group: 73 women; non-dementia group: 75 women). The relationships between the elderly people and their supporters are shown in table II. Supporters of demented elderly people were significantly more often in contact, as judged by the number of days of contact per week ($z = -2.27$; $P < 0.05$). Furthermore, proportionally more supporters of demented elderly people provided or arranged care, while proportionally more comparators paid ordinary visits ($z = -3.88$; $P < 0.0001$).

Few non-resident supporters in either group (only five; 3.5% of non-resident supporters) reported that they had to face appreciable travel costs associated with the care of the elderly person. However, 28 (24.6%) supporters of demented elderly people compared with only five (4.4%) comparators reported that they faced substantial extra household expenditure associated with their caring role ($z = -4.39$; $P < 0.0001$). Few supporters in either group reported changes in employment as a result of caring. Three (2.6%) supporters in each group reported that they had retired early to provide care, while eight (7%) supporters of demented elderly people compared with three (2.6%) comparators reported other effects on employment. Forty one (36.0%) demented elderly people as compared with 18 (15.8%) non-demented elderly people received attendance allowance ($\chi^2 = 13.1$; $P < 0.0005$).

Use of all services except private domestic help was substantially greater in the dementia group (table III). Differences between the groups, however, were not

TABLE I—Characteristics of elderly subjects

Variable†	Dementia group	Comparators
Mean age (years) (range)	80.7 (66-97)	80.7 (66-97)
No (%) of women	98 (86.0)	98 (86.0)
No (%) with impairment of:		
Mobility (n=102)	40 (39.2)	53 (52.0)
Hearing (n=106)	43 (40.6)	30 (28.3)
Sight (n=104)	30 (28.8)	36 (34.6)
Speech (n=106)	9 (8.5)	5 (4.7)

†Numbers of matched pairs studied when fewer than 114 (because of missing data) are given in parentheses. Other values refer to all 114 pairs.

TABLE II—Relationships with supporter. Except where stated otherwise figures are numbers (percentages) of subjects

Variable†	Dementia group	Comparators
Co-resident (n=113)	48 (42.5)	38 (33.6)
Median No of days' contact per week (interquartile range)	7 (3-7)	4 (2-7)
Type of visit (n=113):		
Ordinary visit	17 (15.0)	62 (54.9)
Provided or arranged care	62 (54.9)	18 (15.9)
Provided and arranged care	34 (30.1)	33 (29.2)
Median No of months of care (interquartile range) (n=49)	36 (12-68)	48 (24-84)
Relation of supporter to elderly person:		
Spouse	26 (22.8)	18 (15.8)
Child‡	64 (56.1)	68 (59.6)
Sibling	16 (14.0)	12 (10.5)
Other	8 (7.0)	16 (14.0)

†Numbers of matched pairs studied when fewer than 114 (because of missing data) are given in parentheses. Other values refer to all 114 pairs.

‡"Child" includes children in law.

TABLE III—Service use. Except where stated otherwise figures are numbers (percentages) of subjects in all 114 matched pairs. Means also refer to whole sample

Variable	Dementia group	Comparators	Difference in total contact
General practitioner (any contact)	107 (93.6)	98 (86.0)	} NS
Mean contacts in past three months	2.6	2.3	
Home help (any contact)	65 (57.0)	41 (36.0)	} $\chi^2 = 8.82$; $P < 0.005$
Mean hours in past week	4.9	3.7	
District nurse (any contact)	66 (57.9)	39 (34.2)	} $\chi^2 = 12.3$; $P < 0.0005$
Mean contacts in past month	12.7	9.4	
Day hospital (any contact)	55 (48.2)	19 (16.7)	} $\chi^2 = 29.2$; $P < 0.0001$
Mean half days in past week	3.1	1.4	
Social worker (any contact)	65 (57.0)	28 (24.6)	} $\chi^2 = 20.6$; $P < 0.0001$
Mean contacts in past quarter	2.9	2.0	
Psychiatrist (any contact)	49 (43.0)	1 (0.9)	} $\chi^2 = 46.0$; $P < 0.0001$
Mean contacts in past year	1.9	0	
Geriatrician (any contact)	22 (19.3)	13 (11.4)	} NS
Mean contacts in past year	1.2	1.9	
Respite in residential home (any contact)	18 (15.8)	1 (0.9)	} Binomial†: $P = 0.0001$
Mean days in past year	24.2	0	
Sitter service (any contact)	15 (13.2)	2 (1.8)	} Binomial†: $P = 0.001$
Mean hours in past month	6.7	7.0	
Day centre (any contact)	20 (17.5)	8 (7.0)	} $\chi^2 = 4.32$; $P < 0.05$
Mean half days in past week	2.2	1.6	
Meals on wheels (any contact)	20 (17.5)	5 (4.4)	} Binomial†: $P = 0.0041$
Mean hours in past week	2.0	1.7	
Relatives' support group (any contact)	18 (15.8)	0	} Binomial†: $P = 0.0000$
Mean sessions in past three months	2.5	0	
Respite in hospital (any contact)	13 (11.4)	0	} Binomial†: $P = 0.213$
Mean days in hospital in past year	31.8	34.7	
Community psychiatric nurse (any contact)	14 (12.3)	0	} Binomial†: $P = 0.0001$
Mean contacts in past three months	1.8	0	
Health visitor (any contact)	16 (14.0)	11 (9.6)	} NS
Mean contacts in past three months	1.5	1.0	
Private domestic help (any contact)	3 (2.6)	2 (1.8)	} NS
Mean hours in past month	24.0	31.0	

NS=Not significant.

† χ^2 Distribution and binomial distribution calculated by McNemar's test.

TABLE IV—Unmet service needs. Figures are numbers (percentages) of subjects

Variable†	Dementia group	Comparators	Difference
Home help (n=114)	38 (33.3)	19 (16.7)	$\chi^2=7.20$; $P<0.01$
General practitioner (n=112)	30 (26.8)	16 (14.3)	$\chi^2=4.97$; $P<0.05$
Respite in rest home (n=112)	31 (27.7)	2 (1.8)	$\chi^2=23.8$; $P<0.0001$
Day care (n=114)	29 (25.4)	9 (7.9)	$\chi^2=10.0$; $P<0.005$
Day hospital (n=112)	29 (25.9)	5 (4.5)	$\chi^2=17.6$; $P<0.0001$
Meals on wheels (n=113)	28 (24.8)	5 (4.4)	$\chi^2=16.7$; $P<0.0001$
Sitter services (n=113)	27 (23.9)	3 (2.7)	$\chi^2=20.3$; $P<0.0001$
District nurse (n=114)	22 (19.3)	6 (5.3)	Binomial‡: $P=0.0015$
Private domestic help (n=112)	8 (7.1)	0	Binomial‡: $P=0.0078$
Health visitor (n=112)	15 (13.4)	5 (4.5)	Binomial‡: $P=0.0414$
Geriatrician (n=113)	20 (17.7)	1 (0.9)	Binomial‡: $P=0.0000$
Psychiatrist (n=113)	17 (15.0)	1 (0.9)	Binomial‡: $P=0.0000$
Community psychiatric nurse (n=112)	13 (11.6)	0	Binomial‡: $P=0.0002$
Social worker (n=113)	20 (17.7)	5 (4.4)	Binomial‡: $P=0.0026$
Relatives' group (n=112)	12 (10.7)	1 (0.9)	Binomial‡: $P=0.0034$
Respite hospital (n=112)	16 (14.3)	1 (0.9)	Binomial‡: $P=0.0003$
Sheltered housing (n=114)	23 (20.2)	16 (14.0)	NS

†Numbers of matched pairs are given in parentheses.

‡Distribution and binomial distribution calculated by McNemar's test.

TABLE V—Support preferences

Variable	Unlimited hours per week (median, interquartile range)†		Limited to nine hours per week (median, interquartile range)‡	
	Dementia group	Comparators	Dementia group	Comparators
Relief from occupying and supervising elder	3 (0-14)	0 (0-0)	5 (1.5-7.5)	4 (3-5)
Help with practical housework	3 (0-7)	0 (0-4)	2 (0-3.5)	4 (1-5)
Help with personal care	0 (0-3)	0 (0-0)	0 (0-3)	0 (0-3.5)

†108 Matched pairs.

‡Nine matched pairs.

significant for the use of a general practitioner, geriatrician, or health visitor.

Table IV shows the proportion of supporters indicating an unmet need for services. A high proportion of supporters of both groups had not heard of some services. Of the supporters of demented elderly people, 37.5% (42/112) had not heard about the community psychiatric nurse service, 30.4% (34/112) about private domestic help, 30.4% (34/112) about relatives' support groups, 28.6% (32/112) about health visitors, 27.4% (31/113) about geriatricians, and 25.0% (28/112) about respite care in hospitals.

When hours of support were unlimited the dementia group had significantly greater expressed need for support from all the generic services (supervision: $z=-6.10$, $P<0.0001$; housework: $z=-3.42$, $P<0.01$; personal care: $z=-5.07$, $P<0.0001$) (table V). There were too few matched pairs to test the differences between groups when provision was limited to nine hours. Within the group of dementia supporters 34.3% (37/108) expressed a need for one hour a day or more of help with supervision. In comparison, this same level of help was requested by 20.4% (22/108) of supporters with regard to housework and by 0.9% (only one of 108 supporters) with regard to personal care.

Discussion

The elderly people in this series were not a random sample. Nevertheless, we identified a population who in the main were known to their general practitioners but were not necessarily in contact with secondary care services.

It is probably impossible to make a clear distinction between normal family relationships and care. However, by comparing the experience of supporters of demented elderly people with that of supporters of non-demented elderly people we can get closer to identifying the impact of dementia over and above the normal experience of caring for an elderly relative. As might be expected, supporters of demented elderly

people were more engaged than were supporters of non-demented elderly people. This was shown by the increased frequency of contact and by the higher proportion concerned in providing or arranging care. Despite increased engagement supporters of demented elderly people did not report a high level of perceived financial impact except for household expenses. Low perceived financial impact on supporters of demented elderly people has been noted elsewhere in central Scotland¹⁶ but could reflect a lack of awareness rather than a lack of need for financial support.

Use of formal services was much higher in the dementia group. This was from mainstream services such as home help, sheltered housing, day care, and district nursing. High input from home help, district nursing, and day care to demented elderly people has been reported elsewhere in Britain.^{17,18} Financial impact on elderly people and their carers would be greater in parts of Britain where local authorities charge for day care and home help, though this was not normal practice in Dundee during this study for clients on low incomes.

In both groups there was a low level of perceived need for secondary care and private services, perhaps reflecting a lack of knowledge about these services. An earlier study of elderly service users in Dundee also found a low level of awareness of these types of services.¹⁹ Our findings relate to experience in a Scottish city with a high level of social and economic deprivation and little tradition of the use of private services. Experience elsewhere may be different.

The presence of dementia was associated with a high level of unmet need for mainstream medical services and domiciliary support. Perceived unmet need may be an indicator of psychological distress: perceived unmet need for services can be reduced without increasing service use,²⁰ and simply listening to supporters of demented elderly people may be therapeutic for the supporters.²¹⁻²³ The supporters' perspective is a useful component of needs assessment, which can inform the debate about the purchase of services. We did not try to obtain the views of the elderly people with dementia. Their views are important but are difficult to obtain. Our findings about supporters' views should encourage the further development and targeting of mainstream services for demented elderly people and their supporters. Our findings should also encourage innovation and development within mainstream services for occupying and supervising demented elderly people.

Priority should be given to the further development of supervisory care within an expanded domiciliary service. Impact would usefully be evaluated in controlled trials, with institutionalisation of the person

Key messages

- The needs of family carers of elderly people are increasingly being recognised
- Community care for demented elderly people is thought to pose special problems for carers but comparison studies with non-demented elderly people are rare
- The financial impact on family carers of demented elderly people in a Scottish city was not as high as expected
- The use of mainstream domiciliary and day care services was significantly higher for demented than non-demented elderly people
- Family carers of demented elderly people need more support in caring for these people

with dementia and wellbeing of the carer as appropriate end points.

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 - Adequately described and their condition defined?
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 - Credible?
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 - Interpretation and conclusions
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