British Journal of Psychiatry (1990), **156**, 835–841

Problems Reported by Relatives in a Community Study of Dementia

D. W. O'CONNOR, P. A. POLLITT, M. ROTH, C. P. B. BROOK and B. B. REISS

The supporters of 120 demented elderly people completed rating scales of the frequency and severity of the problems they faced, the amount of strain they experienced and their psychological well-being. Problems and strain increased with the degree of dementia. Problems relating to physical dependency, forgetfulness and inertia were relatively common, while disturbed behaviours were relatively uncommon. Physical dependency and disturbed behaviour were less well tolerated than forgetfulness and inertia, but all problem categories were positively associated with measures of strain. Wives reported more problems and strain than husbands, and co-resident children were under greater strain than children who lived independently.

Community services will succeed in helping demented elderly people remain in their own homes only if the assistance they offer genuinely meets the needs of the family members who support them (O'Connor *et al*, 1989*a*). There is good evidence that early, practical intervention reduces the numbers of frail elderly people admitted to residential homes (Challis & Davies, 1986) but we have little information about which aspects of dementia create the greatest difficulty for relatives, the vast majority of whom will never be referred to specialist centres (O'Connor *et al*, 1988).

In a recent community survey, Eagles *et al* (1987*a*,*b*) found that the stress reported by relatives escalated as dementia advanced and that relatives who lived with a demented spouse or parent reported greater stress than those who lived separately. In addition, measures of stress correlated positively with the degree of disturbed and dependent behaviour exhibited by demented subjects.

We report here on the problems faced by the supporters of demented people identified in a survey of the prevalence of dementia in Cambridge. In particular, we examine the frequency and severity of problems associated with dementia, and the relationship between the problems reported by relatives and the level of strain they experienced.

Method

Survey design

The methods employed in this study have been described in detail elsewhere (O'Connor *et al*, 1989*b*). In brief, the names of all patients aged 75 years and over were taken from the age-sex registers of six Cambridge general practices together with a one in three sample of names from a seventh practice to make up the numbers required for a later part of the project. Only patients who were living at home or in sheltered accommodation are considered here.

Patients were screened for cognitive impairment using the Mini-Mental State Examination (Folstein *et al*, 1975) and those who scored 23 or below out of a maximum score of 30, together with a one in three sample of those scoring 24 and 25, were selected for more intensive investigation using the Cambridge Mental Disorders of the Elderly Examination (CAMDEX) (Roth *et al*, 1986).

The CAMDEX is a structured diagnostic interview schedule designed for use in community studies of dementia. It comprises a mental-state examination, a medical and psychiatric history, detailed cognitive testing and an interview with an informant (in this case, the patient's supporter), to determine whether there has been any deterioration in subjects' intellect, personality, behaviour or mood. Operational criteria for diagnosing dementia, virtually identical to DSM–III criteria (American Psychiatric Association, 1980), and descriptive criteria for rating dementia severity are appended to the schedule.

Rating scales

Wherever possible, the informant was the family member most frequently in contact with the elderly subject. If no family member was available, a friend, neighbour or home help was interviewed instead, but only the reports provided by relatives are included in this paper. Supporters were asked to complete a rating scale of the frequency and severity of 34 abnormal behaviours commonly associated with dementia (Gilleard, 1984). Behaviours were rated as occurring 'never' (zero points), 'occasionally' (one point) or 'frequently' (two points). Scores were summed to produce a 'problem frequency score' with a maximum score of 68 points. If behaviours arose at least occasionally, they were rated by supporters as causing 'no problem' (zero points), a 'small problem' (one point) or 'a big problem' (two points). Scores were summed to produce a 'problem severity score' with a maximum score of 68 points again. For the purposes of this paper, items were grouped into three categories, namely physical dependency (13 items), disturbed behaviour (11 items) and forgetfulness-inertia (10 items) and problem frequency and severity subscores were computed for each category.

https://doi.org/10.1192/bjp.156.6.835 Published online by Cambridge University Press

Supporters also completed a rating scale of strain which inquired into feelings of frustration, anxiety and depression, disturbed sleep, lack of holidays and financial difficulties (Gilleard, 1984). Items were coded as arising 'never' (zero points), 'sometimes' (one point) or 'often' (two points) with a maximum score of 26 points. Finally, supporters completed the 28-item version of the General Health Questionnaire (GHQ-28) (Goldberg & Hillier, 1979) which measures symptoms of anxiety, depression, somatic disturbance and social dysfunction.

Study population

Problem and strain scales were obtained for 120 of the 145 demented elderly people who were living at home or in sheltered accommodation with the support of a family member. Two subjects would not allow us to interview their relatives and data are missing for 23 supporters who lived too far away to be interviewed in person.

Fifty-eight subjects were mildly demented, 50 were moderately demented and 12 were severely demented. The ages of the 42 men and 78 women ranged from 75 to 106 with a mean of 83.9 years. Twenty-four had been assessed previously by the psychogeriatric service (2 mild, 11 moderate, 11 severe); none attended the psychogeriatric day centre and only four had been admitted for assessment or family relief (one moderate, three severe). Their supporters included 43 spouses, 50 children (18 co-resident) and 27 other relatives including siblings, nieces, nephews and grandchildren (seven co-resident).

Community-resident elderly people who were found using the CAMDEX to be cognitively intact provided baseline measures of problem frequency, problem severity and supporter strain. Rating scales were available in 107 of 151 cases. Data are missing for another 44 supporters. The normal subjects' mean age was 82.0 with a range of 75 to 97 years. A proportion were frail and physically disabled; 26 could walk no further than the front gate, 39 needed help with shopping and 42 could manage only light housework.

Results

Table I lists the rating scale scores given by the supporters of normal, mildly, moderately and severely demented subjects. The supporters of demented subjects reported a larger number of problems, greater problem severity and greater strain, and their scores increased in line with the advance of dementia; only the GHQ-28 failed to detect statistically significant differences between the normal and demented groups. Demented subjects were frequently rated as being physically dependent, forgetful and inert. By contrast, disturbed behaviours arose much less commonly. Physical dependency items were rated as causing major problems more commonly than disturbed behaviours or forgetfulness and inertia but these findings make greater

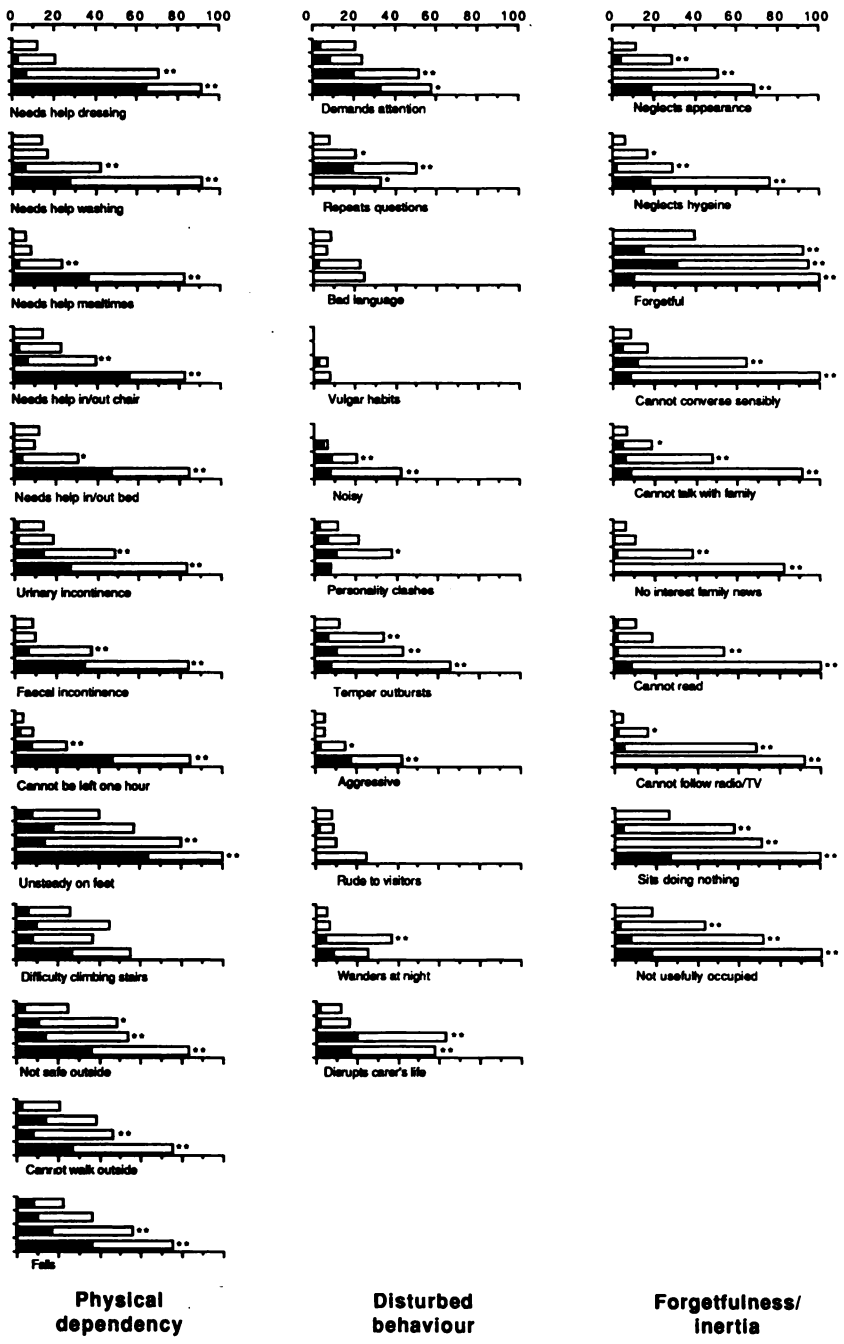
TABLE I

Mean scores (and standard deviations) on problem frequency, problem severity, strain and GHQ-28 rating scales

Rating scale	*Normal (n = 107)*	*Mild dementia (n = 58)*	*Moderate dementia (n = 50)*	*Severe dementia (n = 12)*	*Combined dementia (n = 120)*	*Maximum score*	*Paired t-tests (combined dementia cases)*
	Mean (s.d.)	*Mean (s.d.)*	*Mean (s.d.)*	*Mean (s.d.)*	*Mean (s.d.)*		
Problem frequency							
(A) physical dependency	3.2 (5.0)	5.2** (5.8)	9.2** (7.1)	18.7** (5.6)	10.5** (8.1)	26	A v. B, t = 11.94, $P<0.005$
							A v. C, t = 1.66, $P=0.099$
(B) disturbed behaviour	1.0 (2.1)	1.8** (2.3)	4.5** (4.0)	4.9** (4.0)	3.5** (3.9)	22	B v. C, t = 13.85, $P<0.005$
(C) inertia-forgetfulness	1.8 (2.8)	4.88* (3.5)	10.1** (5.2)	15.9** (3.1)	9.8** (6.1)	20	
Problem severity							
(A) physical dependency	2.4 (3.0)	3.3 (3.8)	5.0** (5.0)	13.3** (6.3)	5.1** (5.3)	26	A v. B, t = 3.97, $P<0.0005$
							A v. C, t = 4.97, $P<0.0005$
(B) disturbed behaviour	1.8 (2.0)	2.0* (2.4)	3.8* (3.8)	3.8 (4.2)	3.3* (3.6)	22	B v. C, t = 0.93, $P<0.357$
(C) inertia-forgetfulness	0.9 (1.8)	1.6 (2.3)	3.3** (3.0)	4.8** (3.8)	2.5** (2.9)	20	
Strain	4.3 (4.8)	7.0** (5.2)	10.3** (5.2)	11.4** (5.8)	9.1**	26	
GHQ-28	2.4 (3.9)	3.2 (4.8)	3.4 (4.3)	2.6 (5.3)	3.1	28	

*$P<0.05$, **$P<0.01$ (Mann-Whitney U-test, normal v. mild, moderate, severe and combined dementia).

https://doi.org/10.1192/bjp.156.6.835 Published online by Cambridge University Press



Problem frequency scores, demented v. normals, Pearson's X, (1 d.f.) $^{*}P<0.01$, $^{**}P<0.001$.

FIG. 1. Proportions of supporters who rated behaviours as occurring occasionally or frequently (white + black bars) and the proportions who rated behaviours as a severe problem (black bars). Scores for normal, mildly, moderately and severely demented subjects are shown in descending order.

https://doi.org/10.1192/bjp.156.6.835 Published online by Cambridge University Press

sense when problem severity is related to problem frequency (see below).

Figure 1 shows (a) the proportions of the supporters of normal and demented subjects who rated particular behaviours as occurring occasionally or frequently and (b) the proportions who rated behaviours as causing severe problems. The figure can be analysed in the following way. Taking 'needs help with dressing' as an example (column one, item one), 92% (black + white bar) of those with severely demented relatives (bottom bar) provided help with dressing at least occasionally and 64% (black bar only) rated dressing as a major problem. Put another way, 70% (64/92) of those who were required to provide help at least occasionally rated dressing as posing severe difficulties. This last figure adjusts for differences in the frequency of individual behaviours and gives a rough measure of supporters' level of tolerance. For this reason, the proportion of supporters reporting that a behaviour occurred at least occasionally who rated it as a severe problem will be called the 'tolerance ratio'.

Mildly demented elderly people achieved significantly higher problem frequency ratings than the normal controls on only a few items including repeating questions, temper outbursts, lack of concern for appearance and hygiene, forgetfulness and measures of apathy (e.g. sits doing nothing). By contrast, there were highly statistically significant differences between controls and moderately and severely demented subjects on virtually every item.

Although the supporters of severely demented elderly people rated many of the physical dependency items as posing frequent problems, most behaviours were remarkably well tolerated. For example, 82% of the severely demented subjects were incontinent of urine at least occasionally but only 23% of their supporters (or 28% of those affected) saw wetting as a major problem. The five least tolerated behaviours, taking all cases of dementia together, were demands for attention ('tolerance ratio' 41%), 'cannot be left one hour' (41%), noisiness (40%), falls (30%) and personality clashes (30%). The five best tolerated behaviours were lack of interest in family news (3%), 'sits doing nothing' (6%), 'cannot read' (7%), rudeness to visitors (9%) and 'not usefully

TABLE II

Mean rating-scale scores (and standard deviations) of spouses, co-resident and non-resident children caring for demented subjects

Severity of dementia	*Spouses (S) Mean (s.d.)*	*Co-resident children (CRC) Mean (s.d.)*	*Non-resident children (NRC) Mean (s.d.)*	*Mann–Whitney significance values**
Mild dementia	($n=18$)	(n = 7)	($n=19$)	
problem frequency	10.1	15.6	10.7	
	(7.2)	(10.1)	(8.0)	
problem severity	3.3	9.1	5.0	
	(4.8)	(8.3)	(6.2)	
strain	5.5	13.0	6.9	S v. CRC, $P=0.013$
	(4.9)	(5.5)	(4.4)	CRC v. NRC, $P=0.024$
GHQ-28	2.8	5.5	3.8	
	(4.1)	(5.5)	(6.2)	
Moderate dementia	($n=19$)	($n=9$)	($n=11$)	
problem frequency	24.1	31.2	17.6	CRC v. NRC, $P=0.013$
	(12.7)	(8.3)	(10.2)	
problem severity	11.0	14.7	7.9	
	(7.7)	(8.8)	(8.4)	
strain	9.9	14.2	9.9	CRC v. S, $P=0.057$
	(5.3)	(4.4)	(4.4)	CRC v. NRC, $P=0.084$
GHQ-28	4.9	3.4	2.9	
	(4.5)	(4.7)	(4.3)	
Severe dementia	($n=6$)	($n=2$)	($n=2$)	
problem frequency	38.5	47.5	39.5	not tested[1]
	(7.1)	(2.1)	(10.6)	
problem severity	19.5	27.0	33.5	
	(8.3)	(7.1)	(12.0)	not tested[1]
strain	10.8	11.5	16.5	
	(4.4)	(10.6)	(3.5)	not tested[1]
	(4.4)	(10.6)	(3.5)	
GHQ-28	1.2	2.0	9.0	
	(1.3)	(2.8)	(12.7)	

*Values listed only if $P<0.1$.

1. Not enough cases to permit statistical analysis.

https://doi.org/10.1192/bjp.156.6.835 Published online by Cambridge University Press

occupied' (10%). The mean 'tolerance ratios' for all cases of dementia were 25.5% for physical dependency items, 19.8% for disturbed behaviour items and 10.9% for forgetfulness-inertia items.

Strain scores, including those for cognitively intact subjects, correlated strongly with total problem frequency scores and total problem severity scores. Pearson correlation coefficients were +0.670 ($P<0.0005$) and +0.712 ($P<0.0005$) respectively. Correlation coefficients between strain scores and physical dependency, disturbed behaviour, and forgetfulness-inertia *frequency* subscores were +0.545, +0.580 and +0.318 respectively while the correlation coefficients between strain scores and physical dependency, disturbed behaviour and forgetfulness-inertia *severity* subscores were +0.539, +0.612 and +0.484 respectively. All of these coefficients were highly statistically significant ($P<0.0005$).

The rating-scale scores of spouses, co-resident and non-resident children are compared in Table II. Co-resident children cared for a smaller proportion of moderately and severely demented subjects than spouses and non-resident children but, even when dementia severity is held constant, they reported greater problem frequency and severity, and experienced more strain, than the latter two groups. Co-resident children caring for mildly demented relatives had significantly higher strain scores than either spouses or non-resident children while co-resident children caring for moderately demented relatives reported significantly more problems than spouses and appeared to experience more strain than both spouses and non-resident children. There were no significant differences on any of the scales between spouses, who were all co-resident, and children who lived in separate households. There were too few severely demented cases to permit statistical analysis.

The scores given by husbands and wives are compared in Table III. Husbands and wives caring for mildly demented spouses did not differ significantly on any of the scales used. However, wives caring for moderately demented husbands showed a tendency to report more problems, experience greater strain and have higher GHQ-28 scores than their male counterparts. We found no substantial evidence that wives were excessively burdened because of a greater reluctance to admit their spouses into care; 21% (15/55) of the demented men identified in the survey lived in institutions compared with 30% (49/116) of the demented women ($\chi^2=1.696$, 1 d.f., $P=0.193$). Certainly, we found more wives supporting demented husbands than husbands supporting dementing wives, but the reason for this discrepancy very probably lies in the greater longevity of women. Because women live longer than men, a higher proportion will have lost their spouses before the onset of their dementia.

Demented men, including those cared for by wives, children and other relatives, were rated as needing more help than demented women on several of the physical dependency items. For example, 60% of all demented men were said to need help with dressing compared with 32% of the women ($\chi^2=7.384$, 2 d.f. $P=0.007$); 48% needed help to wash compared with 27% of women ($\chi^2=4.319$, 2 d.f., $P=0.037$) and 38% needed help getting in or out of bed compared with 19% of women ($\chi^2=4.134$, 2 d.f., $P=0.042$). Women were rated as causing more problems than men on only a few items, namely demanding attention, creating personality clashes and asking questions repeatedly, but none of these differences were statistically significant.

TABLE III

Mean rating-scale scores (and standard deviations) of husbands and wives caring for demented spouses

Severity of dementia	*Husband caring for wife*	*Wife caring for husband*	*Mann–Whitney significance values**
	Mean (s.d.)	*Mean (s.d.)*	*Mean (s.d.)*
Mild dementia	($n=5$)	($n=13$)	
problem frequency	8.2 (10.2)	10.8 (6.1)	
problem severity	4.2 (7.8)	3.0 (3.3)	
strain	6.2 (8.4)	5.2 (3.0)	
GHQ-28	2.8 (5.7)	2.8 (3.4)	
Moderate dementia	($n=8$)	($n=11$)	
problem frequency	17.8 (11.7)	28.6 (11.8)	$P=0.065$
problem severity	10.2 (9.4)	11.5 (6.6)	
strain	7.0 (4.8)	12.3 (4.5)	$P=0.031$
GHQ-28	2.9 (2.9)	6.8 (5.0)	$P=0.067$
Severe dementia	($n=2$)	($n=4$)	
problem frequency	36.0 (12.7)	39.8 (4.9)	not tested[1]
problem severity	20.5 (13.4)	19.0 (7.3)	not tested[1]
strain	13.5 (3.5)	9.5 (4.7)	not tested[1]
GHQ-28	0.0 (0.0)	1.8 (1.3)	not tested[1]

*Values listed only if $P<0.1$.

1. Not enough data for statistical analysis.

The strain scale included the question, 'Do you get any satisfaction from caring for your relative?' Five (5%) of those supporting normal elderly relatives said that they derived no satisfaction from their role, compared with four (7%) and 10 (20%) of those supporting mildly and moderately demented relatives respectively ($\chi^2=12.53$, 6 d.f., $P=0.051$). Although five (42%) of those caring for severely demented elderly people said that they derived satisfaction only occasionally from their task, none said that they gained no satisfaction at all. Overall, there were no differences in the answers given by husbands and wives and none between those caring for male and female relatives. Co-resident children with demented parents gained least satisfaction: four (22%) gained no satisfaction at all, compared with six (13%) of the spouses and three (9%) of the non-resident children ($\chi^2=6.63$, 4 d.f., $P=0.157$).

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Discussion

The problems which supporters find most difficult to bear will vary from one survey to another because of differences in study locale and in the instruments used to measure problem frequency and severity. In hospital studies, the most onerous difficulties have been variously described as sleep disturbance, faecal incontinence and immobility (Sanford, 1975); passive, withdrawn behaviour and disturbed mood (Greene *et al*, 1982); demands for attention (Gilleard *et al*, 1982); and abusiveness, inappropriate micturition and faecal smearing (Argyle *et al*, 1985).

In this community population, physical dependence caused frequent problems of a relatively high degree of severity; disturbed behaviours occurred less frequently but were tolerated almost as poorly; and items relating to apathy and inertia were generally well tolerated despite being very common indeed. Even so, all three categories were significantly and positively associated with measures of strain, perhaps because behaviours rarely arise independently. Most confused, apathetic demented people will also require help with everyday activities and a proportion will also create disturbances from time to time. From a practical point of view, our findings underline the importance of the help and advice already provided by community nurses, occupational therapists and physiotherapists in the areas of bathing, dressing and mobility. Disturbed behaviours are much less easily remedied but publications like *The 36-Hour Day* (Mace & Rabins, 1985), which offer simple, clear advice about how to deal with wandering, repeated questioning and sleep disturbance, are much appreciated by family members and should be made readily available.

Although one-fifth of our moderately demented subjects had been assessed by psychiatrists, none attended the local psychogeriatric day unit. Consequently, we expected to find that they posed fewer problems than patients described in previous day hospital studies. This proved not to be the case. Gilleard *et al* (1984) administered an identical problem checklist and strain scale to the supporters of demented elderly people attending an Edinburgh psychogeriatric day hospital. We chose to compare these patients with our moderately demented group on the grounds that few of our mildly demented subjects warranted day hospital care, while all of our severely demented subjects were too profoundly disabled to be cared for in this sort of setting.

Similar proportions in the Edinburgh and Cambridge groups required help with physical care, were forgetful and lacked interest and drive. However, the proportions of supporters who rated problems as being severe were markedly different. For example, while 57% of the Edinburgh patients needed help to dress compared with 54% in our moderately demented group, dressing was rated as a major problem by 35% of the day hospital supporters compared with only 6% in Cambridge. Similarly, 61% of the day hospital patients were said to disrupt their supporters' lives compared with 63% in Cambridge. While 42% of the Edinburgh supporters rated this as a serious problem, only 20% of Cambridge supporters did so. The comparison is crude but our findings suggest that supporters' tolerance levels play a critical part in determining whether or not elderly people are referred for specialist assessment.

'Problem severity' and 'strain' are subjective measures and naturally some supporters will find the going harder than others. In our study, the wives of moderately demented men reported more problems and greater strain than husbands, even though demented men in Cambridge were no more likely than women to suffer from disorders such as strokes or Parkinson's disease which lead to greater than usual physical dependence (O'Connor *et al*, 1989*b*). One explanation is that women find the sheer physical effort involved in dressing, lifting and toileting more taxing than men. In addition, Gilhooly (1984) speculated that male supporters find it easier to go out, leaving their dependent spouses unattended. If this is the case, the break they get from caring might influence their perception of the difficulties they face.

We formed the strong impression that women take on the role of 'nurse' earlier than men, perhaps because their husbands expect them to do so. Many of the husbands in our study enjoyed being 'carers' and took great pride in their new-found accomplishments. For them, caring gave meaning and direction to their lives, in contrast to many of the wives who saw their role as burdensome. Admittedly, equal proportions of husbands and wives reported that they gained satisfaction from their work but the possibility remains that the latter find it easier to admit to 'problems' and 'strain' than to 'dissatisfaction' which might be interpreted as a sign of disloyalty. Our findings suggest that wives might benefit from being encouraged to allow their husbands to retain as much independence as possible, even if this leads to untidiness and inefficiency. Support groups, which many relatives find helpful, might be an ideal forum for this sort of discussion.

Gilleard *et al* (1984) found that children and children-in-law reported greater strain than spouses. In our study, the supporters under greatest strain were children living with a demented parent.

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Children who shared their home with a spouse, children of their own, and a demented mother or father faced a multitude of problems from which they had little or no escape, while many of the single or widowed children who lived alone with a demented parent led bleak and lonely lives. Since most of these sons and daughters were able-bodied, services like home helps and meals-on-wheels hardly applied. Instead, day care and relief admissions might be of particular benefit to this group.

Despite the burden imposed on supporters, the majority continued to derive satisfaction from their role and few achieved high scores on a rating scale of psychological ill-health. However, it is important to note that relatives who were completely unable to cope might have relinquished care and been lost to the study. Some supporters, by dint of temperament, ill-health or conflicting responsibilities, will find caring for a demented relative unusually difficult and withdraw at an early stage while others will choose to persist beyond the call of duty. The supporters of our severely demented subjects, all of whom had refused offers of institutional care, reported not much more strain that those caring for moderately demented subjects. This highly select group generally offer a much higher standard of care than insitutions and at a lower cost to the community. As a result, they clearly warrant the greatest possible efforts on the part of the social and psychiatric services to support them in their task for as long as possible.

Predicting which cases will benefit from intensive community care, and which cases would be better admitted into residential homes without further ado, will doubtless prove difficult because of the large number of variables which need to be taken into account, but the task is important if services are to be effectively and sensibly distributed (Opit, 1977). In one day hospital study, admission into care was associated with the number of problems faced by supporters and a persisting, high level of strain which was not alleviated by professional support (Gilleard, 1984). We are presently following-up surviving subjects and families to determine whether similar influences play a part in this community group.

Acknowledgements

The Hughes Hall Project for Later Life is funded by the Charles Wolfson Charitable Trust. We thank Drs J. Fellowes, J. Hyde and N. Miller for help with CAMDEX interviews, Mrs R. Coe for help with data entry and Dr B. M. Herbertson for support and advice.

References

AMERICAN PSYCHIATRIC ASSOCIATION (1980) *Diagnostic and Statistical Manual of Mental Disorders* (3rd edn) (DSM-III). Washington, DC: APA.

ARGYLE, N., JESTICE, S. & BROOK, C. P. B. (1985) Psychogeriatric patients: their supporters problems. *Age and Ageing*, **14**, 355–360.

CHALLIS, D. & DAVIES, B. (1986) *Case Management in Community Care: An Evaluated Experiment in the Home Care of the Elderly*. Aldershot: Gower Publishing Company.

EAGLES, J. M., CRAIG, A., RAWLINSON, F., *et al* (1987*a*) The psychological well-being of supporters of the demented elderly. *British Journal of Psychiatry*, **150**, 293–298.

——, BEATTIE, J. A. G., BLACKWOOD, G. W., *et al* (1987*b*) The mental health of elderly couples: the effects of a cognitively impaired spouse. *British Journal of Psychiatry*, **150**, 299–303.

FOLSTEIN, M. F., FOLSTEIN, S. E. & MCHUGH, P. R. (1975) "Mini-Mental State": a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, **12**, 189–198.

GILHOOLY, M. L. M. (1984) The impact of care-giving on care-givers: factors associated with the psychological well-being of people supporting a dementing relative in the community. *British Journal of Medical Psychology*, **57**, 35–44.

GILLEARD, C. J. (1984) *Living with Dementia: Community Care of the Elderly Mentally Infirm*. Beckenham. Croom Helm.

——, BOYD, W. D. & WATT, G. (1982) Problems in caring for the elderly mentally infirm at home. *Archives of Gerontology & Geriatrics*, **1**, 151–158.

——, GILLEARD, E., GLEDHILL, K., *et al* (1984) Caring for the elderly mentally infirm at home: a survey of the supporters. *Journal of Epidemiology and Community Health*, **38**, 319–325.

GOLDBERG, D. P. & HILLIER, V. F. (1979) A scaled version of the General Health Questionnaire. *Psychological Medicine*, **9**, 139–145.

GREENE, J. G., SMITH, R., GARDINER, M., *et al* (1982) Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. *Age and Ageing*, **11**, 121–126.

MACE, N. L. & RABINS, P. V. (1985) *The 36-Hour Day*. London: Hodder & Stoughton.

O'CONNOR, D. W., POLLITT, P. A., HYDE, J. B., *et al* (1988) Do general practitioners miss dementia in elderly patients? *British Medical Journal*, **297**, 1107–1110.

——, ——, BROOK, C. P. B., *et al* (1989*a*) The distribution of services to demented elderly people living in the community. *International Journal of Geriatric Psychiatry*, **4**, 339–344

——, ——, HYDE, J. B., *et al* (1989*b*) The prevalence of dementia as measured by the Cambridge Mental Disorders of the Elderly Examination. *Acta Psychiatrica Scandinavica*, **79**, 190–198.

OPIT, L. J. (1977) Domiciliary care for the elderly sick – economy or neglect? *British Medical Journal*, **1**, 30–33.

ROTH, M., TYM, E., MOUNTJOY, C. Q., *et al* (1986) CAMDEX: a standardised instrument for the diagnosis of mental disorder in the elderly with special reference to the early detection of dementia. *British Journal of Psychiatry*, **149**, 698–709.

SANFORD, J. R. A. (1975) Tolerance of debility in elderly dependants by supporters at home: its significance for hospital practice. *British Medical Journal*, **3**, 471–473.

*D. W. O'Connor, FRANZCP, *Research Fellow, Hughes Hall, Cambridge CB1 2EW*; P. A. Pollitt, PhD, *Research Fellow*; M. Roth, MD, FRCPsych, FRCP, *Professor Emeritus, University of Cambridge*; C. P. B. Brook, FRCPsych, *Consultant Psychiatrist, Fulbourn Hospital*; B. B. Reiss, FRCGP, *General Practitioner, Cambridge*

*Correspondence

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