

## Caring for the elderly mentally infirm at home: a survey of the supporters

C J GILLEARD, E GILLEARD, K GLEDHILL, AND J WHITTICK

*From the Department of Psychiatry, University of Edinburgh, Royal Edinburgh Hospital, Edinburgh, UK*

**SUMMARY** A sample of 129 supporters caring for an elderly mentally infirm relative consecutively referred to psychogeriatric daycare services was interviewed. Information was obtained on the problems encountered by their dependant, the extent of their involvement, the amount of formal and informal support received, the subjective strain and burden reported, and their expectations of their ability to continue in the caring role. An attempt has been made to use this information to describe the extent of strain and some of the determinants of strain involved in caring. The results suggest that the sex of the dependant and the age of the supporter together with the number of problems faced all influence the reported level of strain. The amount of existing community support, whether formal or informal, does not seem to mitigate significantly the strain placed on the principal carers.

Despite the early studies of the prevalence of dementia among elderly people living in the community<sup>1,2</sup> and the demonstration that such conditions are frequently unrecognised by community health services,<sup>3</sup> it is only recently that much attention has been focused on the problems faced by family and friends who provide the principal care for elderly mentally infirm people. One significant exception is the work of Sainsbury and Grad who carried out a detailed investigation of the impact of a community versus hospital based treatment programme on families of elderly psychiatric patients.<sup>4,5</sup> Whereas these studies have been widely extolled as showing the superiority of community care,<sup>6</sup> the two year follow up data provide little real reason for optimism as the families in the community service area reported a much greater burden (65% reporting some or severe burden during the two years) compared with families in the hospital based service area (only 21% reporting some or severe burden during the two years).<sup>4</sup> Moreover, for the dementing patients, the average number of weeks spent in hospital during the two years was actually higher in the community service group (44 weeks) than in the hospital service group (39 weeks). Other community service evaluations have yielded little positive evidence in their favour (see Kahn and Tobin for a more extensive review<sup>6</sup>). Certainly the work of Sainsbury and Grad served to highlight the important demands and problems faced by families of elderly

psychiatrically ill patients and was one of the first to detail the types of problems found to be worrying by the family.<sup>5</sup>

Further research has examined in more detail the problems of giving care to elderly mentally infirm relatives at home,<sup>7–9</sup> the strain associated with the role of caregiver,<sup>10–12</sup> and the adjustment and coping strategies used<sup>13,14</sup> (E Machin, unpublished data). Such studies have not yielded any coherent pattern, however, though certain features and associations have been consistent. Thus there is good reason to believe that it is the social and psychological problems which families face that create more stress than the physical/nursing needs of their dependant (J Zarit, paper presented at Western Psychological Association meeting, Sacramento, California, 1982). Grad and Sainsbury found that problems associated with odd, dangerous or disruptive behaviour were the most worrying<sup>5</sup>; Koopman-Boyden and Wells thought that the problems in the relationship between supporter and dependant were most upsetting<sup>7</sup>; Gilleard *et al* reported that problems of demandingness and need for attention/supervision were most predictive of strain<sup>8</sup>; and Greene *et al* reported the greatest association between supporter strain and apathetic inactivity on the part of the dependant.<sup>9</sup>

In coping with this strain strategies have been described which suggest that ignoring or distancing from the dependant serve to reduce the strain

experienced.<sup>13 14</sup> Some workers have suggested that men may more easily achieve this distancing from their dependant, whereas women may be more enmeshed in the relationship and less able to separate relationship needs and practical needs, hence experiencing greater strain as supporters compared with men (J Zarit, Sacramento, 1982).

Factors such as the quality of the past relationship and the extent of informal social support for the supporters have also been found to be important in determining the extent of the perceived burden or strain,<sup>10 11</sup> but there is a lack of coherence and definition in many of these findings.

The present research investigates the situation of carers looking after an elderly mentally infirm person, whose disability was sufficient to warrant the offer of a psychogeriatric day hospital place. The decision to offer day hospital care is often dependent on the recognition by the health services of (a) the presence of mental infirmity, and (b) the absence of acute illness sufficient to warrant admission as an inpatient. The extent to which the needs of the supporter are explicitly taken into account independently of the patient's level of impairment and disability is not known. Experience suggests that an operational judgment is made of "sufficient need" that emphasises the observed problem presented and reported to the clinician by his contact with the general practitioner, relatives, and patient, together with the evident distress reported by the supporter. By careful description of the sample of supporters and their dependants, it is hoped that some generalisations at least may be made. In particular, we wished to identify the nature of the problems presented, the extent of strain perceived, and the influence of formal and informal support, degree of contact with the patient, and the relationship between dependant and supporter on their level of reported strain.

## Method

### SUBJECTS

We interviewed 129 supporters of patients referred and accepted for daycare in their own homes. Each interview lasted for one to four hours. There were further interviews three and six months later, though the present study concentrates on information obtained before day hospital intervention. During the course of the interview, supporters completed questionnaires designed to measure strain, burden, psychiatric symptoms, past and present relationship with their dependant, and problems experienced. We sought to identify the course of illness (in most cases, dementia), the help sought and received, and the supporters' expectations of their future caring task.

Patients completed the CAPE information orientation test and the supporters the physical disability rating scale (CAPE survey version<sup>15</sup>). The patients were a consecutive series between July 1981 and July 1982 of admissions for daycare at the four psychogeriatric day hospitals serving the Lothian area. To be selected, the supporters had to live with their dependant or visit them at least three times a week. The patients had to be referrals from the community with a clearly identifiable supporter, and the supporter had to agree to being interviewed. The patients represented 40–50% of the intake of all new admissions to daycare for the index period.

### MEASURES

*Strain scale*—This is a 13 item scale derived from Machin's strain scale (unpublished data). Each item has three response alternatives; the items cover fear of accidents, sleep disturbance, worry, depression, frustration, health, disruption to household routine, embarrassment, demand for attention, and lack of pleasure in caring.

*Burden scale*—This is a five item, five point self rating of degree of burden, covering emotional, social, physical, financial, and general strain/burden reported by the carer, response points varying from "no strain/burden" (1) to "a great strain/burden" (5).

*General health questionnaire*—The 30 item GHQ<sup>16</sup> was used as a measure of emotional symptomatology. Results are being reported separately.

*Problem checklist*—A 28 item questionnaire derived from an earlier 25 item checklist<sup>8</sup> using a three point response format (never, occasionally, often) to 28 problem behaviours that could be exhibited by the patients, relating to disabilities, dependency, disturbance, demandingness, and wandering.

*Social interaction scale (present and premorbid versions)*—A six item, three point rating scale describing the quality of the relationship between supporter and dependant, derived from a similar scale by Machin (unpublished data).

Information from the interview included information on onset of illness; initial symptoms; first contact with general practitioner; symptoms on presentation; whether supporter has changed/stopped work; any change in living arrangements; whether help is received from other family members or other professional health and social services agencies (district nurse, health visitor, general practitioner, social worker, home help, meals on wheels, chiropodist, hairdresser, volunteer, other); whether more help (informal and formal) is required; benefits and allowances received; health rating of supporter; whether or not supporter wished to change the amount of time spent with that

dependant; supporters' expectations of cure/improvement; whether they would consider long term institutional care; and the supporters' understanding of their dependants' illness. Finally, the interviewer took the supporter through the previous week to obtain a retrospective diary of the amount of contact with the supporter, frequency of visits out by the supporter, frequency of visits to the supporter, and frequency of night time disturbance.

**Results**

Table 1 shows the mean ages of the supporters and their relationship to their dependant.

Table 1 *Supporters' ages, relationship to their dependants, and their dependants' ages*

	No	Supporters' age		Dependants' age	
		Mean	SD	Mean	SD
Husband	19	72.7	6.6	73.5	6.2
Wife	30	70.2	10.0	76.8	6.0
Daughter	49	50.6	8.2	80.8	7.2
Son	7	55.6	14.8	78.7	13.5
Daughter in law	6	47.0	7.9	78.0	6.3
Sister	9	75.0	6.8	74.2	6.4
Brother	1	68.0	—	85.0	—
Niece	3	59.0	7.0	80.7	0.6
Other	5	66.0	7.2	75.6	4.4
Overall	129	61.0	13.3		

As may be seen, supporters are mostly daughters and wives. Only 27 of the 129 supporters were men. In general, the dependants of same generation supporters (spouses, siblings) were younger than the dependants of second generation supporters (daughters, sons, etc).

It was decided to examine the differences between young and old—that is, above and below 65—supporters in their receipt of services and allowances, number of visitors, and the time they spent with their dependants.

Table 2 indicates that younger supporters are more likely to have changed their living arrangements, usually having their dependants move in with them, and are more likely to have given up work or changed to part time working as a result of their relative's infirmity. The older supporter has probably cared longer for their relative before contacting their general practitioner, spent more time with their dependant, and received less help from, and fewer visits from, other members of the family. There is, surprisingly, no difference in the services received or

in the main benefits claimed between older and younger supporters—though some benefits and concessions on energy and transport costs are obviously more taken up by the older supporters. As a whole the supporters are not receiving much help—less than a quarter of their dependants receive regular (weekly or monthly) visits from district nurses, one third home helps, less than 10% meals on wheels, and less than 10% receive attendance allowance (despite the fact that 40% of the supporters reported that, for most of the time, their dependant could not be left alone for even one hour).

Given the lack of help, especially to the elderly supporters who might be most in need, from both formal and informal support systems, our next concern has been to identify what problems are presented to the supporters by their elderly mentally infirm relative. Two measures of problems have been used—the 28 item problem checklist and the CAPE physical disability subscale.<sup>15</sup> Table 3 shows the frequency of each of the problem behaviours and their severity ratings (percentage of those supporters reporting each behaviour who rated it as “a great problem”).

In a sample of supporters mostly caring for dementing relatives forgetfulness is inevitably the most frequent problem, though not the problem most often considered “a great problem.” The problems causing most concern are the supporter being “tied” to their relative (cannot be left alone, not safe outside alone), followed by problems relating to hygiene and bladder and bowel functions. Disability and mobility problems (needing help at mealtimes, in getting in and out of a chair, bed, unable to manage stairs) were rarely considered great problems, nor were instances of behaviour disturbance (shouting, rude to visitors, temper outbursts, and use of bad language).

The next area we studied was the quantification of strain or burden. It is difficult to separate distress as a reaction to the situation from distress which, while perhaps caused by the situation, takes on an autonomous quality to produce physical and psychological symptoms indistinguishable in other ways from clinically important syndromes such as depression or hypertension. The present study focuses on two of our three measures which are most relevant—the strain and burden scales.

Difference in the level of strain and burden were examined according to whether the supporter lived with the patient (n = 88) or not (n = 39); whether the supporter was elderly (n = 58) or not (n = 70); and whether the dependant was male (n = 46) or female (n = 83). A three way analysis of variance was performed on the total strain and burden scales, treating sex of patient, age of supporter, and living group as the independent variables. Within cell

Table 2 Difference between old and young supporters in their receipt of help, services, allowances, visits, and contact with their dependants

Problem	Old (n = 58)		Young (n = 71)		Significance of difference
	No	%	No	%	
Change in living arrangements	4	7%	14	20%	p<0.05
Change in work	1	2%	15	21%	p<0.001
Time since onset of infirmity (y):					
≤1	10	17.6%	16	22.2%	
≤4	24	42.1%	28	40.5%	
>4	23	40.3%	25	36.2%	NS
Time since first contacting GP:					
≤3 months	11	19%	23	33%	
≤1 year	15	26%	25	36%	
>1 year	32	55%	22	31%	p<0.05
Reasons for contacting GP:					
Physical symptoms	26	45%	34	49%	NS
Cognitive symptoms	40	69%	39	56%	NS
Social behaviour changes	23	38%	25	36%	NS
Psychopathology	14	24%	30	43%	p<0.05
Adequacy of housing:					
Good	28	48%	38	55%	
Fair	25	43%	21	30%	
Poor	5	9%	10	14%	NS
Help from other family members	29	55%	49	71%	p<0.05
GP contacts in last month:					
≥3	12	22%	14	20%	
1 or 2	32	59%	37	52%	
None	10	19%	20	28%	NS
Visits:					
District nurse:					
Rarely	47	81%	52	74%	
Monthly	11	19%	18	26%	NS
GP:					
Rarely	42	72%	58	82%	
Monthly	16	28%	13	18%	NS
Social worker:					
Rarely	54	93%	67	96%	
Monthly	4	7%	3	4%	NS
Home help:					
None	38	65%	53	75%	
Weekly	20	35%	18	25%	NS
Meals on wheels:					
None	53	91%	66	93%	
Weekly	5	9%	5	7%	NS
Benefits:					
Attendance allowance:					
Yes	6	10%	6	9%	
No	51	90%	64	91%	NS
Supplementary benefits:					
Yes	5	9%	14	20%	
No	53	91%	57	80%	NS
Other allowances:					
Yes	13	22%	7	10%	
No	45	78%	64	90%	p<0.05
Visits by other family members:					
None	11	21%	10	15%	
Occasional	22	42%	13	19%	
Frequent	19	36%	44	66%	p<0.01

Numbers vary slightly in those answering the various questions.

variances did not differ significantly. The results indicated a main effect of supporter's age ( $F = 19.5$ ,  $df 1, 100$ ,  $p < 0.001$ ;  $F = 7.4$ ,  $df 1, 100$ ,  $p < 0.01$ ) and a two way interaction of the effects of living group and patient's sex on both the strain and burden scores ( $F = 8.36$ ,  $df 1, 100$ ,  $p < 0.01$   $F = 7.86$ ,  $df 1, 100$ ,  $p < 0.01$ ). Supporters living with a male dependant

had significantly higher scores than those living with a female dependant or living apart from a male dependant. Table 4 presents the mean scores.

The greatest strain and burden results from caring for an elderly mentally infirm man, who lives in the household, while supporters of male dependants not living with their dependant report the lowest level of

Table 3 Frequency and severity of problems faced by the supporters (n = 127)

Problem	Occurrence			No reply	Rating as "great problem" %
	Never	Occasional	Frequent		
Unable to dress without help	53	39	31	4	35
Demands attention	42	39	41	5	42
Needs help getting in and out of a chair	78	31	15	3	27
Uses bad language	92	23	7	5	23
Needs help getting in and out of bed	84	28	11	4	27
Interferes with personal social life	41	43	40	3	42
Cannot wash without help	51	38	33	5	29
Physically aggressive	87	33	7	—	33
Needs help at meal times	91	22	14	—	16
Vulgar habits	98	17	12	—	29
Soiling	82	27	18	—	49
Creates personality clashes	62	47	18	—	28
Forgets things that happened	6	26	95	—	38
Temper outbursts	54	56	17	—	25
Likely to fall	61	56	9	1	40
Rude to visitors	97	26	4	—	13
Cannot manage stairs	65	40	21	1	19
Not safe outside, alone	26	29	70	2	55
Cannot be left alone for 1h or more	62	13	51	1	71
Wanders at night	57	43	25	2	42
Careless about own appearance	49	32	46	—	29
Unable to walk outside, unaided	78	26	22	1	35
Cannot hold a sensible conversation	32	43	52	—	37
Noisy, shouts	88	32	7	—	24
Wets him/herself	82	24	20	1	49
No concern for personal hygiene	59	29	38	1	48
Unsteady on feet	28	59	40	—	28
Asking continual questions	54	36	36	1	26

Number varies as some supporters failed to respond to items in the checklist and were missed by interviewers.

strain. Examination of sex differences in the 28 item problem checklist failed to show any pronounced differences in the occurrence of the various problems, though items 1, 8, and 10 (dressing, physical aggression, and vulgar habits) were all reported to occur significantly less often in women. It may be that problems of aggression and vulgarity are extremely distressing at close quarters but either do not occur or impinge less when the supporter is essentially a visitor to the house. Finally, it should be recognised that the older supporters generally report their caring as less burdensome and less stressful, presumably because of the lack of alternative demands on their time and attention from others. Using an index composed of the need for additional help from professionals and from family and desire to reduce

the time spent with the elderly dependant, there was a greater expressed "need for relief" from younger ( $\bar{x} = 2.41$ , SD 1.8) compared with older supporters ( $\bar{x} = 1.73$ , SD 1.5)—Mann-Whitney U test,  $Z = 2.04$ ,  $p < 0.05$ .

The final section of this paper examines the relation of reported strain to the problems faced by supporters, their duration of time caring, the extent of formal or informal support received, and the quality of the premorbid relationship.

For the elderly supporters (n = 45 with complete data), the rank order correlation between the number of problems reported and both strain and burden were positive and significant,  $r = +0.56$  and  $+0.59$  respectively. Neither the duration of time spent caring nor the level of informal support

Table 4 Differences in level of strain and burden

Type of supporter	Strain score			Burden score		
	No	Mean	(SD)	No	Mean	(SD)
Old supporter	58	11.4	4.88	45	13.0	4.64
Young supporter	70	14.0	5.22	65	15.0	5.17
Supporter lives with male dependant	36	14.8	4.34	28	16.5	4.33
Supporter lives apart from male dependant	9	8.7	4.79	9	12.0	4.21
Supporter lives with female dependant	53	12.8	5.33	48	13.6	5.27
Supporter lives apart from female dependant	30	12.1	5.02	25	14.5	4.86

received were significantly associated with either strain ( $r = +0.02$ ,  $-0.08$ ) or burden ( $r = -0.08$ ,  $-0.08$ ). The degree of professional support received correlated weakly, but significantly, with strain ( $r = -0.23$ ,  $df\ 45$ ,  $p < 0.05$ ), but the correlation did not reach significance for burden score ( $r = -0.20$ ,  $df\ 45$ , NS). Social relationship in the past correlated  $+0.34$  and  $+0.32$  with strain and burden scores respectively, suggesting that a poorer premorbid relationship was associated with greater strain in caring.

For the younger supporters ( $n = 65$  with complete data) the results were similar. The total number of problems reported correlated highly with experienced strain ( $r = +0.57$ ) and burden ( $r = +0.53$ ). For burden, but not for strain, there was a significant rank order correlation with duration of time spent caring ( $r = +0.29$ ). Social relationship in the past also correlated with present strain ( $r = +0.33$ ) and burden ( $r = +0.33$ ). Correlations between strain and informal and formal care were not significant ( $r = +0.01$  and  $-0.02$ ), nor were the correlations between burden and levels of informal and formal care ( $r = +0.03$  and  $-0.02$ ).

Thus it appears that the principal determinant of the strain and burden of caring for the elderly infirm is, for both younger and older supporters, the number of problems presented to them by their dependant. The range of formal and informal support available to the supporters plays no significant part in the variations in the degree of stress reported.

For both groups of supporters a poorer premorbid relationship was also associated with higher levels of strain and burden. Nevertheless, premorbid relationship score correlated with the number of problems reported ( $r = +0.29$ , older supporters;  $+0.31$ , younger supporters). Possibly a poorer premorbid relationship creates more problems for the supporters, or indeed supporters faced with more numerous problems come to view the premorbid relationship in a more negative light, and hence the quality of the relationship may not independently contribute to the level of strain.

### Discussion and conclusions

The results of this survey indicate that a complex relation exists between the experience of caring for an elderly mentally infirm relative and the problems and strain experienced by their relatives. One of the more important mediating factors is the age of the supporting relative. Although spending more time and receiving less help and support from other family members, older supporters (spouses and siblings) report less strain from the experience of caring than do younger ones. Informal and formal support seems

to play little part in influencing the degree of strain, and for all supporters the single most important determinant of the stressfulness of the experience is the number of problems presented by their dependant. Being tied to their dependant, and feeling that they cannot be left alone, together with impaired hygiene and associated incontinence, seem to present the greatest problems. Finally, male dependants are perceived as being more stressful to live with than female dependants, which may explain the apparently greater probability of such patients being admitted to hospital (cf, Gaspar<sup>17</sup>).

The lack of influence of formal and informal community support in mitigating the degree of stress may simply reflect the basis of the strain, namely, hygiene, toilet problems, and the constant need for attention. No matter how often the district nurse or home help visits, nor how many times other relatives call round to help, the constant demand is unlikely to be perceived as having been lifted, and when the visitor leaves the supporters are still left with the same demands on them. For this reason one may speculate that only by partial or total institutionalisation (in day hospitals, or in geriatric/psychogeriatric longstay care wards) is enough relief likely to be afforded to such groups of supporters. The fact that the present sample was drawn from a consecutive series of referrals to psychogeriatric daycare may mean that they were a particularly vulnerable group, or even a group of people who easily complain. In an area where an effective and well recognised daycare service exists, however, it seems equally plausible that finding an equivalent number of supporters caring for an equivalent length of time, for dependants with similar disabilities who had not been offered daycare, would also produce an unrepresentative sample of particularly stoical or reclusive supporters. It seems unwise to dismiss the present sample as a group of unrepresentative complainers. More likely, they are more prepared than many to continue to care, provided that they receive help: thus, in response to one of the interview questions, "With day hospital support, do you feel able to continue caring for your relative at home?"—only 10 (8%) thought that they could not, while 98 (76%) thought they could, and 20 (16%) were uncertain. Despite the strains of looking after their dependant, the vast majority of these supporters had not given up caring.

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