

# Mental and physical frailty in older people: the costs and benefits of informal care

RIS MRC CFAS (Resource Implications Study of Medical Research Council Cognitive Function and Ageing Study)\*

## **ABSTRACT**

The financial, opportunity and social costs and benefits of providing informal support to frail older people are described within an economic framework. Mentally and/or physically frail older people were identified through screening interviews with random community samples of people aged 65 and over in four UK areas: 884 frail older people living in private households nominated key informal supporters and 650 of these supporters were interviewed. Around half the supporters reported financial costs (43 per cent) or lost social opportunities (45 per cent). A minority of supporters had reduced their working hours or withdrawn from employment because of caregiving. Nearly all supporters reported at least one social cost (92 per cent) and identified at least one positive aspect of caregiving (95 per cent). Co-resident supporters were more likely to report opportunity costs and loss of health and well-being. Daughters supporting a frail parent were generally most likely, and friends or neighbours least likely, to report each type of cost. Supporters of older people who were both mentally and physically frail reported significantly greater opportunity and social costs. The benefits of caregiving were not consistently related to co-residency, relationship of supporter or frailty type. Possible strategies for decreasing the costs and increasing the benefits of caregiving are discussed.

**KEY WORDS** – older people, informal caregiving, costs, benefits, health, disability, mental health.

## **Introduction**

For at least two decades it has been government policy in the UK to maintain frail older people at home as long as is viable (DHSS 1977; DHSS 1981; Secretaries of State for Health 1989). The majority of

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older people, when asked, report a preference for remaining at home even when increasing frailty requires support from families (Salvage *et al.* 1989). Families provide the majority of support to older people who are living at home (Parker 1990). Not all families, however, are able and willing to support their frail older relatives at home (Levin *et al.* 1989).

Studies of informal support for older people have burgeoned in the last decade (Twigg and Atkin 1994). The majority of British studies are cross-sectional, often based on single localities and unrepresentative of the general population. They tend to focus on the 'burden' or the social costs of providing support to older people (for example, Ungerson 1987; Morris *et al.* 1988; Levin *et al.* 1989; Nolan *et al.* 1990; O'Connor *et al.* 1990; Anderson 1992).

The full economic costs to informal supporters of providing support to older people have rarely been estimated because of the technical problems involved (Chetwynd 1983). Attempts to do so include Nissel (1984), Joshi (1992), Netten (1989), Caring Costs (1991), Nissel and Bonnerjea (1982), Phillips (1993), McLaughlin and Ritchie (1994), and Philp *et al.* (1995). The OPCS surveys of 1968 (Harris *et al.* 1971) and 1984 (Martin *et al.* 1988) collected limited cost data on the additional financial costs of disability among older people. Glendinning (1992) has estimated the effect on the earnings of people of working age who provide support. McLaughlin (1991) studied the additional expenditure incurred by recipients of the Invalid Care Allowance, while Horton and Berthoud (1990) have studied Attendance Allowance claimants. There is substantial evidence from these studies that informal supporters suffer financially from extra expenditure or reduced earnings. However, Challis and Davies (1986) estimated financial costs for earnings foregone and other expenses incurred and concluded 'most informal carers did not seem to bear substantial financial caring costs' (1986: 179).

Few studies have considered the benefits to families and friends of providing informal support (Aronson 1990; Clifford 1990; Hinrichsen *et al.* 1992; Grant and Nolan 1993). Benefits may arise from reciprocity or repaying for past care when the supporter needed help (Finch 1989; Qureshi and Walker 1989). Other potential benefits of caregiving include improved relationships between supporters and recipients, fulfilment of a social obligation, satisfaction from providing the best possible care, and an outlet for the caregiver's altruism (*e.g.* Nolan *et al.* 1996).

Relatively little is known about the relationship between the type of disability of the cared-for person and the costs and benefits of

caregiving. Studies have tended either to treat caregivers as a homogeneous group irrespective of the nature of the disability (*e.g.* Martin *et al.* 1988), or have focused on caregivers of people with a particular disability (*e.g.* Levin *et al.* 1989; Anderson 1992). Comparative studies have not consistently confirmed the commonly held view that supporting people with cognitive impairments is more stressful than supporting people who are physically frail (Gilleard 1984; Eagles *et al.* 1987; Draper *et al.* 1992; Yeatman *et al.* 1993; Wijerantne and Lovestone 1996). Since several of the studies (*e.g.* Gilleard 1984; Draper *et al.* 1992; Wijerantne and Lovestone 1996) focused on caregivers of users of day centres, the extent to which the findings are applicable to other caregivers is unclear.

Although a number of authors have suggested that men have a different approach to caregiving from women (*e.g.* Zarit *et al.* 1986; Twigg and Atkin 1994), studies of stress experienced by male and female caregivers of older people have produced mixed findings. While some have reported significantly greater stress amongst female caregivers (*e.g.* Cantor 1983; George and Gwyther 1986), others have found no difference in levels of stress according to gender (*e.g.* Zarit *et al.* 1980; Fitting *et al.* 1986; Carlson and Robertson 1993). There is evidence that caregiving has a greater impact on the paid employment of female caregivers, with women being more likely to withdraw from paid employment (*e.g.* Stone *et al.* 1987), and to report a range of difficulties at work (Martin *et al.* 1995). There has been little empirical work on the relationship between the benefits of caregiving and characteristics of caregivers, although links between gender and certain benefits have been proposed. For example, it has been suggested that the work of male caregivers is likely to be acknowledged and admired whereas similar efforts by female caregivers pass unnoticed (Twigg and Atkin 1994; Rose and Bruce 1995). Nolan *et al.* (1996) found only limited evidence of gender differences in sources of satisfaction.

Co-residency is known to be associated with the type of help provided (*e.g.* Parker and Lawton 1994). The relationship between social costs and co-residency appears, however, to be less straightforward and may vary according to other factors, for example, the amount of help provided (Sinclair *et al.* 1990) and the type of frailty of the cared-for person (Yeatman *et al.* 1993).

Many studies have focused on a single group of caregivers, most often spouses (*e.g.* Zarit *et al.* 1986; Pruchno and Potashnik 1989) or daughters (*e.g.* Lewis and Meredith 1988). There is clear evidence that the level of involvement and type of help provided is significantly associated with the relationship of the caregiver to the cared-for person,

with friends and neighbours having a more peripheral role than relatives (e.g. Green 1988; Sinclair *et al.* 1990; Wenger 1990a). Although Gilhooly (1984) suggested that stress is inversely related to distance in terms of kinship, with caregivers holding close kinship ties experiencing higher levels of stress, this has not been supported by other studies (e.g. Levin *et al.* 1983; Jones and Vetter 1984). In their study of the benefits of caregiving, Nolan *et al.* (1996) found that spouse caregivers were significantly more likely than daughters to identify eight (of thirty) items as sources of satisfaction. Since co-residency, relationship and gender of the caregiver are all interrelated, it is likely that some of the inconsistencies between studies are caused by the lack of multivariate analysis (Parker 1990).

This paper brings together all aspects of financial and social costs as well as the perceived benefits of informal support. It is based on an analysis of cross-sectional data at initial interview from a two-year longitudinal study of the resource implications of mental and physical frailty among older people. The aims of the paper are to assess the costs and benefits of providing informal support to mentally or physically frail older people living in private households in order to highlight the implications for social policy, and to clarify the relationship between costs and benefits and co-residency, gender and relationship of the informal supporter and the type of frailty of the older person.

The next section describes the methodological approaches used to assess costs and benefits. Using a societal perspective, measurement and valuation principles are set out in a standard cost-benefit framework. The design of the study and the characteristics of frail older people and their informal supporters are then described. The role of informal supporters in the present study is summarised in order to contextualise the detailed examination of costs and benefits of informal support which follows. The key findings are summarised in terms of three themes associated with the costs and benefits of caregiving: co-residency of supporters, the relationship between subject and supporter, and the type of frailty. The paper concludes by identifying policy implications.

### **An economic perspective on caregiving**

The key costs and benefits of informal support are schematically summarised in Table 1 from the different perspectives of caregivers, care receivers and society. A priori we would expect the different parties concerned in informal support to experience different costs and

TABLE 1. *The costs and benefits of informal caregiving*

	Costs	Benefits
Caregiver	<i>Financial</i> – extra expenditure on household items and for travelling <i>Time</i> – loss of work or leisure opportunities <i>Social</i> – psychological stress, strain on family relationships, increased ill-health of caregiver	<i>Financial</i> – saving of costs of residential or nursing home care <i>Social</i> – satisfaction of providing care, improved relationships
Subject receiving care	<i>Financial</i> – extra household expenditure <i>Social</i> – psychological fears of ‘burdening’ caregiver(s)	<i>Financial</i> – saving of costs of residential or nursing home care <i>Social</i> – psychological benefits of remaining at home
Society	<i>Social</i> – lost productivity from caregivers forced out of the labour market	<i>Financial</i> – reduced expenditure on formal service provision <i>Social</i> – general satisfactions that people are being cared for appropriately

benefits. The costs falling on informal supporters of older people at home are of three main types: financial, time and social.

#### *Financial costs*

It is clear that supporting a frail older person may have financial implications for supporters. For example, non-resident supporters may incur travelling expenses when visiting the older person. Additional household expenses may arise where the frail older person requires a special diet or where incontinence leads to increased laundry costs. In the present study, information on financial costs was collected by questioning supporters on their perceptions and estimates of increased household expenditures.

The data collected are subject to the usual difficulties when collecting financial information. Few people have a clear idea about the amount they spend on small to medium sized commodities, and they have difficulty in disaggregating expenditure arising from the disabilities of one person from general household expenditure (Parker 1990; Netten and Beecham 1993).

#### *Time costs*

The rationale for evaluating time costs is that time, like all resources, is scarce and has value in alternative uses or, in other words, has an opportunity cost. For informal supporters time spent providing support to others will have alternative uses either for work or leisure. The

concept of opportunity cost suggests that the measurement of caregiving time costs requires two major pieces of information – the quantification of time used and the identification of the alternative uses to which that time could be put. Neither of these tasks is easy.

*Measurement of caregiving time.* Quantification of time is difficult as supporters may not be able to report or record accurately the time spent providing support for the subject. There is also the problem of identifying whether an activity is undertaken solely because of the frailty of the subject. For example, activities such as personal care will be easy to classify, but others such as general household duties, social visiting and meal preparation are more difficult; all or part of the time used may be devoted to activities which would have occurred in the absence of frailty. Even if the frail older person were not in the household, the time taken over some activities would not decrease (*e.g.* general household cleaning) and, for other activities, there may be only small changes in the time taken (*e.g.* meal preparation). Similarly, it is often difficult to distinguish between time spent in the house to ensure the safety of the subject during which usual indoor interests can be followed, from time spent providing intense surveillance which precludes all other activity.

These difficulties in measuring time spent caregiving could have been overcome by using direct observation or by a detailed time budget technique (Robinson 1985). However, such methods were beyond the scope of the present study. Instead respondents were asked to complete a simple contact grid covering all times of the day and night of the previous seven days. Each day of the week was divided into eight time periods:

- Rising to breakfast (up to 9 a.m.);
- Morning (9 a.m.–12 noon);
- Lunch (12–2 p.m.);
- Afternoon (2–5 p.m.);
- Tea (5–7 p.m.);
- Evening (7–10 p.m.);
- Going to bed; and
- Night.

Respondents were asked to trace backwards from the previous day, indicating whether or not they had been in contact with the frail older person during each time period. The grid therefore provided information on the number of periods of contact and timing, and regularity of contact between caregivers and the frail older person they supported, though not on the duration of contact.

The limitations of this grid are fairly apparent. The researcher's definition of social time may not fit with respondents' actual time for providing meals or for subjects' times for rising and going to bed. Overlap between categories may be substantial so that some respondents may be recorded as having contact in two time periods, whereas another respondent who spent more time with the subject may only be recorded as having contact in a single time period.

A range of approaches to valuing time spent caregiving have been used, but so far it has not been possible to identify a single value that can be appropriately applied to informal caregiving (Netten and Beecham 1993). In view of the difficulties in obtaining accurate information on the time spent caregiving and in valuing such time, no attempt was made to place a value on time costs for individual supporters in the present study.

*Identification of alternative uses of caregiving time.* Although the main alternative uses of time may be work or recreation, difficulties occur in identifying opportunity costs for supporters who are unable to take up their preferred choice because of constraints other than those imposed by caregiving. For example, there may be people who are unemployed but who would otherwise work despite having to undertake caring activities. Empirically, it is also possible to find people who feel they have excess leisure time and who regard caregiving as a release from the boredom of inactivity (Wright 1987). In the present study, opportunities lost for working and non-working time were explored during interviews with supporters.

#### *Social costs*

Social costs of caregiving refer to the physical and psychological ill-effects of caregiving. Such effects may well lead to supporters experiencing higher levels of ill-health than their peer groups (Parker 1990). Social costs of caregiving were assessed by exploring supporters' feelings about, and experiences of, caregiving. Additional information on psychological well-being was collected through the 30-item General Health Questionnaire (Goldberg 1972).

#### *The benefits of caregiving*

Fulfilment of the routines of caregiving can bring a sense of satisfaction. Economic theory of diminishing marginal utility would predict that caregiving would be subject to the same rules as other activities: the

total amount of satisfaction (or utility) with the occupation increases but at a diminishing rate, so that within a given period of time each successive episode of providing care adds less to total satisfaction than the previous episode. Economic approaches subsume all the different types of benefit into one marginal valuation schedule (Smith and Wright 1994). Other approaches have sought to discuss more fully the different sources of satisfaction with caregiving. In the present study, the perceived benefits of caregiving were explored by open-ended questions during interviews with supporters.

In terms of the scheme laid out in Table 1, there are financial as well as psychological benefits of caregiving, such as reduced expenditure on residual, nursing or hospital care, or on formal community care services. Financial aspects are likely to increase in importance as charging for community- and residential-based social care increases in scope and amount.

Due to methodological problems, no attempt was made to place a monetary value on the social costs and benefits of caregiving. Instead, a descriptive account of the positive and negative effects of caregiving on the well-being of supporters is presented.

## **Methods of data collection**

### *Identification of frail older subjects*

The data for this paper were collected as part of the Resource Implications Study of frail older people (RIS). The sample of frail older people was identified through the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS 1998).

Stratified random samples were drawn from Family Health Service Authority lists of patients registered with general practitioners. The aim was to achieve at least 2500 interviews in each area, half with people aged between 65 and 74 years, and half with people aged 75 and over. Screening interviews with study subjects were undertaken in four geographically defined areas in England (Newcastle, Nottingham, part of the city of Oxford and a larger part of rural Cambridgeshire). People who were mentally and/or physically frail were identified and invited to participate in RIS. People were defined as mentally frail if they scored a level of confidence of three or more on the organic syndrome cluster of the AGE-CAT: Automated Geriatric Examination Computer Assisted Taxonomy (Copeland *et al.* 1986; Dewey and Copeland 1986). This level has been shown to correspond to a clinical case of



dementia. People scoring eleven or more on a modified version of the Townsend Disability Scale were defined as physically frail (Bond and Carstairs 1982; Wilkin and Thompson 1989). People who met both of the above criteria were defined as mentally and physically frail. There was a small number of subjects who responded only to priority questions within the screening interview either because they were extremely physically frail or ill, or because initial screening items indicated that the individual was so cognitively impaired that responses to other questions would have been inappropriate. They were included with subjects defined as both mentally and physically frail. The screening interviews identified 1664 frail older people.

#### *Identification of informal supporters*

This paper is concerned only with those frail older people resident in private households. Such individuals who agreed to participate in RIS were asked to nominate their informal supporters. Formal caregivers and paid supporters of subjects living in private households were not included in the study. For each subject one informal supporter was identified as the key supporter, providing most help. Nominated key supporters were approached three months after the screening interview with the subject and invited to participate in an interview themselves. Follow-up interviews with key supporters were conducted at six months, one year and two years after the initial interview. This paper reports only responses to initial interviews with key supporters.

#### *Representativeness and characteristics of subjects*

Of the 1444 frail older people who agreed to participate, 1127 (78 per cent) lived in private households and of these 884 (78 per cent) nominated an adult key supporter. Table 2 summarises the characteristics of subjects by the availability of informal support. Subjects with no informal supporter were more likely to be female, less likely to be married and more likely to be mentally and physically frail only. Comparison of the characteristics of subjects for whom a key supporter was or was not interviewed, suggests little non-response bias, although subjects whose key supporter was not interviewed tend to be younger.

#### *Representativeness and characteristics of informal supporters*

Of the 884 key supporters nominated, 650 (74 per cent) were interviewed. Fifteen per cent of key supporters refused to be interviewed, five per cent of supporters were not approached at the

TABLE 2. *Characteristics of subjects by availability of informal support*

	No informal supporter <sup>1</sup>	Informal supporter not interviewed <sup>2</sup>	Informal supporter interviewed	All
	%	%	%	%
Female	79**	64	70	70
Married	11***	45	44	37
Non manual occupation	33*	26	26	27
Type of frailty:				
Mentally frail only	26	21	15	18
Physically frail only	66	62	69	67
Mentally and physically frail	8***	17	16	15
n (= 100%) <sup>3</sup>	232	216	605	1053
Median age (years and interquartile range)	81 (76–86)	79* (74–85)	81 (76–85)	81 (74–85)

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ .

<sup>1</sup> Asterisks in this column indicate significant differences between subjects with no informal supporter and all subjects with informal supporters.

<sup>2</sup> Asterisks in this column indicate significant differences between subjects whose informal supporter was or was not interviewed.

<sup>3</sup> n indicates the minimum number of respondents

subject's request, three per cent of supporters were not approached owing to the death of the subject, and the remaining three per cent were not interviewed for some other reason. Analysis of the characteristics of supporters with whom an interview was or was not achieved indicates no significant differences in terms of their gender or relationship to the subject, suggesting little non-response bias.

The age of key supporters ranged from 18 to 88 years with a median age of 63 (interquartile range 52 to 74 years); 67 per cent were women and 55 per cent lived with the subject. The main categories of key supporters were spouses (38 per cent), daughters (30 per cent), sons (9 per cent), daughters-in-law (4 per cent), other relatives (11 per cent) and friends or neighbours (8 per cent).

#### *Data collected*

During the initial interview, data were collected about the informal supporter and their supporting role. These included relationship to subject, age, gender, living arrangements, type of help provided, the financial, time and social costs associated with caregiving, and the rewards of providing informal support. Data were also collected about the subject during interviews with informal supporters. These included

their functional abilities, level of confusion, frequency of challenging behaviours, living arrangements and health status.

#### *Methods of data analysis*

The aim of the analysis was to assess the costs and benefits of caregiving and to examine how these varied according to three key explanatory variables – whether the supporter lived with the subject, relationship of supporter to the subject, and type of frailty of the subject (mentally frail only, physically frail only, or mentally and physically frail). Since gender and relationship to supporter are interrelated, gender was also included as an explanatory variable. Stepwise logistic regression was conducted using SPSSx to identify which, if any, of these explanatory variables were the most important predictors of each of the costs and benefits assessed. Once regression had clarified the relative importance of the explanatory variables, appropriate cross-tabulations of the raw data were conducted. Where regression indicated similarities between subgroups, these were combined in the cross-tabulations (*e.g.* husbands and wives are grouped as spouses where appropriate). The results from these cross-tabulations are presented in the text and tables. In the case of continuous variables, such as the financial costs associated with caregiving, multiple regression was conducted. In view of the skewed distribution of the raw expenditure data, a log transformation of the data was used in the regression. Mann-Whitney tests were then used to test for differences between median values on the raw data, rather than conducting t-tests on the transformed data. Only associations significant at the one per cent level are described in the text, although weaker associations ( $p < 0.05$ ) are noted on the tables.

#### **Relationship between subject and key supporter characteristics**

Since the characteristics of subjects may influence the experience of caregiving, we examined the extent to which particular subgroups of supporters were providing support to subjects with more severe, functional, behavioural and cognitive difficulties (Table 3).

#### *Characteristics of subjects with co-resident and non-resident supporters*

Older subjects with co-resident supporters were more likely to be male, married and were younger than those with non-resident supporters (all  $p < 0.001$ , Table 3). These differences reflect the high proportion of spouse caregivers among co-resident supporters. When older subjects

TABLE 3. Characteristics of subjects by the relationship of the key supporter to the subject and place of residence

	In same household (%)			In separate household (%)			All key supporters <sup>3</sup> (%)
	Spouse	Daughter	Other	All <sup>1</sup>	Daughter	Other	
<b>Functional abilities:</b>							
with any functional incapacity	84	94	78	85	80	72	81**
difficulties with dressing	56	58	38	54*	28	16	40***
difficulties with bathing	79	90	75	80	68	59	73***
difficulties with feeding	31	40	20	31	14	15	24***
Ability to carry out individual activities of daily living:							
unable to prepare meal	67	79	65	68	44	39	57***
unable to reach overhead shelf	68	69	60	67	64	49	62***
unable to use telephone	24	44	35	29**	18	15	23***
unable to tie a knot	33	38	28	33	17	31	24**
unable to get to and use toilet	16	25	5	15*	4	5	11***
unable to take medicines	28	50	33	32**	17	18	26***
<b>Continence:</b>							
ever incontinent of urine	32	48	47	37*	40	30	36
ever incontinent of bowels	14	31	13	16**	20	12	16
<b>Challenging behaviour:</b>							
with one or more frequent problems	22	39	29	26*	37	24	28
ever wander or created disturbance at night	14	29	16	17*	10	9	14**
ever repeat questions or words	24	44	35	29*	44	33	33*
<b>Confusion:</b>							
problems with long term memory	13	8	7	11	9	3	9*
problems naming and recognising people	11	23	6	12*	6	4	0**
problems locating bed	2	8	4	3	1	1	2*
problems with orientation on outings	13	28	15	15*	17	13	15
problems holding a normal conversation	17	37	11	19**	21	12	17
in poor health	31	14	9	25***	23	23	24
<b>Demographic characteristics:</b>							
male	51	23	23	42***	15	16	30***
married	100	8	7	70***	15	7	44***
median age (years) and	77	83	83	79***	83	84	81***
interquartile range	(71-81)	(80-90)	(78.5-87)	(72-83)	(79-87)	(79-87)	(76-85)
n (= 100%)	232	47	51	334	125	128	587

Note: n indicates minimum number of respondents. \* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001.

<sup>1</sup> Asterisks in this column indicate significant differences between co-resident supporters according to their relationship to the subject.

<sup>2</sup> Asterisks in this column indicate significant differences between supporters living in a separate household according to their relationship to the subject.

<sup>3</sup> Asterisks in this column indicate significant differences between supporters according to their place of residence.

with a spouse supporter were excluded there were no significant differences in the demographic characteristics of subjects according to whether or not they lived with their supporter.

Co-resident supporters were more likely to report that the subject had some functional incapacity (measured using the Crichton Royal Behavioural Rating Scale; Wilkin and Thompson 1989). In particular they reported more difficulties with self-care tasks such as dressing, bathing and feeding. Furthermore, co-resident supporters were more likely to rate the subject as being unable to carry out a range of activities of daily living. Co-resident supporters were more likely to report that the subject wandered or created a disturbance at night, but were less likely to report problems with repetitive speech. Although there were no differences according to co-residency in the overall proportions of subjects reported to have any problems with confusion (using the Crichton Royal Behavioural Rating Scale), supporters who lived with the subject were more likely to report problems with long-term memory, recognising and naming people, and awareness of the location of their bed. It should be noted, however, that some of these difficulties may be explained by the closer contact between co-resident supporters and subjects.

#### *Characteristics of subjects with different types of co-resident supporters*

As already described, there were significant differences between the demographic characteristics of subjects supported by a spouse and those with other co-resident supporters. In addition, as Table 3 shows, spouse caregivers were more likely to rate the subject's health as poor and less likely to report incontinence of urine. Both spouses and daughters were more likely to report difficulties with dressing than were other supporters. Co-resident daughters were more likely to report that the subject was unable to do certain activities of daily living, had incontinence of bowels and at least one frequent challenging behaviour. Subjects living with daughters were also more likely to be reported as having problems with recognising and naming people, orientation on outings and hold a normal conversation.

#### *Characteristics of subjects with different types of non-resident supporters*

As can also be seen in Table 3, subjects supported by a daughter living in a separate household were more likely to be married than those supported by other relatives or friends and neighbours. While daughters were more likely to report that the subject was unable to reach an overhead shelf and had difficulties with dressing, they were less likely

to report difficulty with tasks requiring fine motor co-ordination. As with co-resident supporters, subjects supported by daughters were more likely to be reported as having at least one frequent challenging behaviour and difficulties holding a normal conversation.

These findings indicate that older subjects with co-resident supporters were more likely to be reported as having functional difficulties than those with non-resident supporters, but were relatively similar in terms of cognitive impairment. Although subjects supported by spouses differed significantly in demographic characteristics to those with other co-resident supporters, there were relatively few other differences in functional or cognitive abilities. There was some evidence that subjects supported by co-resident daughters were more likely to have difficulties with recognising and naming people, orientation and communication than those who lived with other supporters, although this was not reflected in overall measures of cognitive function such as the Mini Mental State Examination (Folstein *et al.* 1975) or the confusion subscale of the Crichton Royal Behavioural Rating Scale (Wilkin and Thompson 1989). Among non-resident supporters, daughters appeared to be supporting subjects who tended to have more difficulties than those supported by others, although the differences were not large and were not reflected in overall measures of physical or cognitive functioning. These differences in the characteristics of subjects supported by different types of caregivers, are important in interpreting the differences in the costs and benefits of caregiving to be presented. It is important to note, however, that many of the variables examined are based on subjective assessments made by supporters; these assessments are unlikely to be independent of the supporters' experience of and feelings about caregiving.

### **Nature of informal support**

#### *Frequency and type of help provided*

Nearly all co-resident supporters reported that they helped every day, compared with only 36 per cent of non-resident supporters ( $p < 0.001$ , Table 4).

Informal supporters were asked whether they helped with a range of activities of daily living (ADL) and instrumental activities of daily living (IADL). These activities were identified as being representative of a range of activities with which subjects might receive help. That subjects received help does not necessarily mean they were unable to do the activity themselves. Similarly, that key supporters did not help with

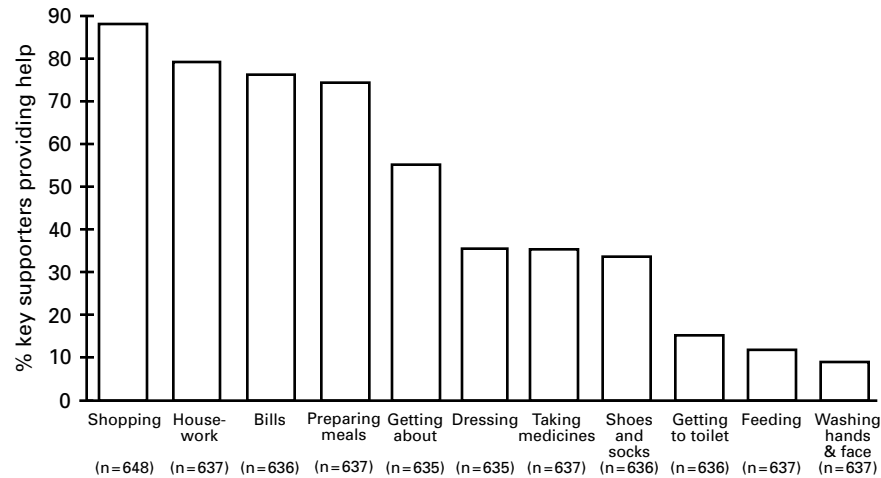


Figure 1. Help provided by key supporters with activities of daily living.

an activity does not necessarily mean that the subject received no help, since other supporters (either paid or informal) may have provided assistance. The help provided by key supporters is shown in Figure 1.

A caring typology, summarising the types of help provided with ADL and IADL, was devised by Parker and Lawton (1994) for their secondary analysis of the General Household Survey. Although data were not collected on an identical range of caring tasks in our study, it was nonetheless possible to construct approximately these categories from the available data. The typology includes six mutually exclusive categories: personal and physical care; personal not physical care; physical not personal care; practical and other help; practical help only; and other help only. Personal care includes help with activities such as dressing, washing, toileting and feeding. Physical care is concerned with the provision of help with getting about. The first three categories are based only on involvement in personal or physical care tasks, regardless of any other types of care the supporter provides. The remaining categories are used where neither personal nor physical care is given. Practical and other help includes a combination of help with domestic tasks (*e.g.* shopping, meals, housework) and help with finances or giving medicines or both of these. Practical help only is used where help is provided solely with domestic tasks. Other help is used to describe help with finances and/or giving medicines only (Parker and Lawton 1994). The final two categories were combined in the present analyses because of the small numbers of supporters providing these types of help (Table 4).

TABLE 4. *Frequency and type of help provided by place of residence of the key supporter*<sup>1</sup>

	In same household	In separate household	All key supporters
	%	%	%
Frequency of help provided			
Every day	96	36	69
Most days	3	31	16
Less often	1	33	15
Type of help provided			
Personal and physical	42	14	30
Personal not physical	21	8	15
Physical not personal	16	37	25
Practical and other help	15	25	20
Practical or other help only	6	16	10
n <sup>2</sup> (= 100%)	354	282	638

<sup>1</sup>Frequency and type of supporter were significantly associated with place of residence of key supporter at  $p < 0.001$ .

<sup>2</sup>n indicates minimum number of respondents.

The type of help provided by supporters varied significantly according to their place of residence ( $p < 0.001$ ). Co-resident supporters were more likely to provide personal care (either with or without physical care) than non-resident supporters. Once place of residence was taken into account there were few significant differences in the type of help provided according to the relationship between the supporter and the subject. Among co-resident supporters, wives were more likely to provide personal not physical care (31 per cent compared with 15 per cent of other supporters,  $p < 0.001$ ) and were less likely to provide physical not personal care (3 per cent compared with 23 per cent of other supporters,  $p < 0.001$ ). Among non-resident supporters, friends and neighbours were more likely to provide practical or other help only (30 per cent compared with 12 per cent of other supporters,  $p < 0.001$ ).

Type of frailty was also an important predictor of help provided. Supporters of mentally frail subjects were less likely to provide help with personal and physical care (9 per cent compared with 31 per cent of supporters of physically frail subjects and 43 per cent of supporters of mentally and physically frail subjects,  $p < 0.001$ ). Supporters of physically frail subjects were more likely to provide physical not personal care (31 per cent compared with 8 per cent of supporters of mentally frail subjects and 12 per cent of supporters of mentally and physically frail subjects,  $p < 0.001$ ). Supporters of mentally frail



subjects were more likely to provide practical and/or other help (68 per cent compared with 23 per cent of supporters of physically frail subjects and 23 per cent of mentally and physically frail subjects,  $p < 0.001$ ).

*Availability of other informal supporters*

Forty-two per cent of all key supporters reported that they were the only informal supporter who helped the subject with activities like collecting prescriptions, helping with the payment of bills, doing housework or giving help with dressing. The remaining supporters identified a total of 631 other informal supporters. The majority of these supporters (55 per cent) were assisted by only one other informal supporter, although in a small number of cases there were three or four other informal supporters (11 per cent and six per cent respectively). Co-resident supporters were less likely to identify other supporters (46 per cent compared with 73 per cent of non-resident supporters,  $p < 0.001$ ).

**Costs and benefits of caregiving**

*Financial costs of informal support*

Expenses incurred by supporters are shown in Table 5. Seventy-eight per cent of supporters reported no additional costs due to travelling, either because they lived with the older subject (56 per cent) or within walking distance (17 per cent) or did not have to pay for travel (4 per cent). Not surprisingly friends or neighbours were less likely to report travel costs than other non-resident supporters (19 per cent compared with 58 per cent of other supporters,  $p < 0.001$ ). Among those with travelling expenses, the median weekly expenditure was £3.00, with daughters reported as spending significantly more than other supporters ( $p < 0.01$ ).

The majority of supporters (79 per cent) reported that they personally did not have any other extra expenses due to caregiving; this was independent of co-residency, relationship and type of frailty. For those with additional expenses, the median weekly outlay was £6.00, with daughters reporting significantly greater weekly expenditure than other types of supporters ( $p < 0.001$ ).

Taking both travel costs and other expenses into account, 43 per cent of supporters had financial costs associated with caregiving. Overall, only eight per cent of supporters reported both travel and other expenses; 16 per cent had travel expenses only and 19 per cent had other expenses only. Co-resident supporters were less likely to report

TABLE 5. *Weekly expenses associated with caregiving by the relationship of the key supporter*

	Daughter	Other	All
Travelling expenses:			
Median	£3.75	£2.50	£3.00*
Interquartile range	£2.13–7.50	£1.29–3.75	£1.81–6.54
n	68	60	128
Other expenses:			
Median	£10.00	£5.00	£6.00**
Interquartile range	£5.00–18.00	£2.00–10.00	£3.00–10.00
n	37	71	108
Total expenses:			
Median	£7.00	£3.75	£5.00**
Interquartile range	£2.50–15.00	£2.09–9.00	£2.08–10.00
n	84	115	199

\* $p < 0.01$ , \*\* $p < 0.001$ .

any financial costs (29 per cent compared with 59 per cent of non-resident supporters,  $p < 0.001$ ). Among non-resident supporters, friends and neighbours were less likely to report any expenses associated with caregiving (33 per cent compared with 65 per cent of other supporters,  $p < 0.001$ ). Total weekly expenditure ranged from 25 pence to some £350, with a median weekly outlay of £5.00 (interquartile range of £2.08 to £10.00). Total expenses were significantly greater for daughters ( $p < 0.001$ ) and for co-resident supporters (median expenses of £6.00 compared with £3.75 per week for non-resident supporters,  $p < 0.001$ ).

#### *Time costs of informal support*

The frequency and regularity of contact between supporters and subjects was estimated using a contact grid covering the seven-day period preceding interview. Of 650 supporters interviewed, only 16 provided incomplete data for this grid and six supporters reported no contact in the previous seven days for appropriate reasons (*e.g.* the subject or supporter had been away from home). Excluding these supporters, Figure 2 shows the pattern of contact between supporters and older subjects during the different recording periods of the day. It indicates that, on the whole, supporters were either in contact every night or never in contact during the night, and that contacts were more likely to be variable during the morning, lunch-time and the evening.

Based on the information recorded on the contact grid, Table 6 shows that four distinct patterns of contact were identified: an irregular pattern of contact was characterised by at least one period of contact

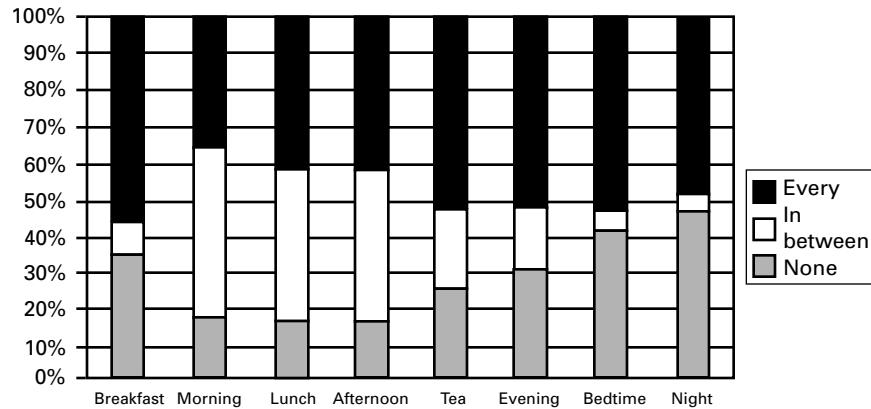


Figure 2. Patterns of contact in different time categories.

TABLE 6. Patterns of contact by the relationship of the key supporter to the subject and place of residence

	In same household			In separate household	All <sup>1</sup>
	Spouse	Other	All <sup>2</sup>	All	
	%	%	%	%	%
Irregular	1	4	2	43	20
Regular	4	25	10	52	29
Most of the time, most days	52	52	52	4	31
All of the time	43	19	36	1	20
n (= 100%)	245	103	348	280	628

<sup>1</sup> Pattern of contact varied significantly according to place of residence of the key supporter ( $p < 0.001$ ).

<sup>2</sup> For co-resident supporters pattern of contact varied significantly according to their relationship to the subject ( $p < 0.001$ ).

on up to four days, but the timing of contacts varied; supporters with a regular pattern of contact consistently called at the same time (usually a meal time) between three and seven days; supporters in contact most of the time on most days had some contact every day and spent several time periods with the subject on most days; the final group comprises supporters who had some contact at every time point every day. This does not necessarily imply that they were in continuous contact, since the supporter may only have been present for part of a time period. Co-resident supporters were, not surprisingly, more likely to be in contact most of the time on most days or all of the time. This was particularly likely to be the case for spouses (95 per cent), but also for other co-resident supporters (71 per cent). These data raise the

TABLE 7. *Impact of caregiving on employment by the relationship of the key supporter to the subject and place of residence*

	In same household		In separate household		
	Daughter	All	Other	All <sup>2</sup>	All <sup>1</sup>
Work causes difficulty with caregiving	27	31	20	28*	29
Caregiving causes difficulty with work	23	29	6	11	15**
Hours of work changed or reduced	36	26	3	12**	15*
n (= 100 %) <sup>3</sup>	22	42	65	142	184

\*  $p < 0.05$ , \*\*  $p < 0.01$ .

<sup>1</sup> Asterisks in this column indicate significant differences between supporters according to their place of residence.

<sup>2</sup> Asterisks in this column indicate significant differences between supporters living in a separate household according to their relationship to the subject.

<sup>3</sup> n indicates the minimum number of respondents.

conceptual and methodological problem of seeking to measure the opportunity cost of support through contact time; for example, where older people are not frail we would expect to see similar patterns of contact between household members.

Non-resident supporters who have frequent contacts are likely to incur the greatest opportunity costs. Five per cent of non-resident supporters were in contact at least most of the time on most days. This high level of contact is likely to have meant that such supporters have substantial opportunity costs.

*Impact of caregiving on employment.* Supporters who were currently in paid employment were asked whether caregiving caused any problems with their work and vice versa. Table 7 shows that over one-quarter of supporters reported that work caused problems with caregiving. Co-resident supporters were more likely to report that caregiving caused problems with work ( $p < 0.01$ ).

Supporters currently in employment were also asked whether they had changed or reduced their hours of work because of the demands of caregiving. Overall, 15 per cent had altered their working arrangements: more specifically, six per cent had changed their hours and nine per cent had reduced them. Overall, daughters were more likely to have changed or reduced their hours (23 per cent compared with six per cent of other supporters,  $p < 0.01$ ).

Amongst supporters of working age, those who had worked previously but were not currently in employment were asked their

TABLE 8. *Impact of caregiving on unwaged time by the relationship of the key supporter to the subject and place of residence*

	In same household		In separate household			
	Daughter	All	Other relative	Friend/ neighbour	All <sup>2</sup>	All <sup>1</sup>
Unable to visit others	6	44	20	0	23**	35***
Withdrawn from social activities	44	35	10	4	13**	25***
Unable to go on holiday	35	33	5	2	9**	22***
All of the above restrictions	16	13	1	0	3*	8***
n (= 100%) <sup>3</sup>	136	348	96	54	286	634

\* p < 0.05, \*\* p < 0.01, \*\*\* p < 0.001.

<sup>1</sup> Asterisks in this column indicate significant differences between supporters according to their place of residence.

<sup>2</sup> Asterisks in this column indicate significant differences between supporters living in a separate household according to their relationship to the subject.

<sup>3</sup> n indicates the minimum number of respondents.

reason for giving up work. Of 107 respondents, 20 per cent reported that they had given up work to support the subject. Type of frailty was the most important predictor of leaving work with supporters of mentally and physically frail subjects being most likely to withdraw from work because of caregiving (42 per cent compared with 15 per cent of supporters of mentally frail subjects and 13 per cent of supporters of physically frail subjects,  $p < 0.01$ ).

Of those supporters of working age who were not currently in employment but reported that they would like to have a paid job, 53 per cent gave supporting the subject as their reason for not working. Daughters were more likely to cite 'caring for the subject' as the reason for not being in paid employment (71 per cent compared with 34 per cent of other supporters,  $p < 0.01$ ).

*Impact of caregiving on unwaged time.* The impact of caregiving on unwaged time, as Table 8 shows, was more prevalent than on working time. Around one-third of supporters reported that caregiving prevented them from going out to meet other people, and about one-quarter reported being excluded from social activities or unable to go on holiday within the last year due to caregiving. Overall, 48 per cent of supporters reported at least one of these restrictions, but only a small minority (eight per cent) reported all three restrictions. Co-residency was the most important predictor of these restrictions, with co-resident supporters being more likely to report each of these restrictions and to

report all three restrictions (all  $p < 0.001$ ). The relationship of the supporter to the subject was also related to restrictions, particularly for non-resident supporters. Among such supporters daughters were generally most likely and friends and neighbours least likely to report each of these restrictions (all  $p < 0.01$ ), although sons and daughters were equally likely to report withdrawing from social activities due to caregiving (17 per cent compared with six per cent of other non-resident supporters,  $p < 0.01$ ). The gender of co-resident supporters was a significant predictor of restrictions in visiting other people (42 per cent of female compared with 31 per cent of male supporters,  $p < 0.01$ ).

The impact of caregiving on unwaged time was also significantly associated with type of frailty, with supporters of subjects who were mentally and physically frail being most likely to report restrictions. Over half of such supporters felt that caregiving prevented them from going out to meet other people (56 per cent compared with 27 per cent of supporters of mentally frail only subjects and 32 per cent of supporters of physically frail only subjects,  $p < 0.001$ ). Supporters of subjects who were mentally and physically frail were also more likely to have withdrawn from social activities (39 per cent compared with 13 per cent of supporters of mentally frail subjects and 25 per cent of supporters of physically frail subjects,  $p < 0.001$ ) and to have been unable to go on holiday due to caregiving (33 per cent compared with 17 per cent of supporters of mentally frail subjects and 21 per cent of supporters of physically frail subjects,  $p < 0.01$ ). The likelihood of reporting all three of these restrictions was also associated with frailty type (18 per cent of supporters of mentally and physically frail subjects compared with six per cent of supporters of mentally frail subjects and six per cent of supporters of physically frail subjects,  $p < 0.001$ ).

#### *Social costs of informal support*

The social costs of informal support were assessed by asking supporters about their feelings and experiences of caregiving, whether their health had been affected by caregiving and by using the 30-item General Health Questionnaire (GHQ) to measure general well-being (Goldberg 1972). As can be seen from Table 9, worrying about accidents (most often falling) was the most commonly expressed social cost. Around half of the supporters felt frustrated with the caregiving situation or felt angry with the frail older subject. Supporters were slightly less likely to report feeling depressed by the subject's condition or angry about the caregiving situation. Only a minority of supporters

TABLE 9. *Social costs of caregiving by the relationship of the key supporter to the subject*

	Spouse	Daughter	Other relative	Friend/ neighbour	All
	%	%	%	%	%
Worries about accidents	67	81	73	64	72**
Frustrated by caregiving situation	45	65	46	33	50***
Angry with subject	41	57	45	28	45***
Depressed by subject's condition	45	48	38	20	42***
Angry with caregiving situation	38	51	35	39	41*
Depressed by caregiving situation	19	42	20	8	25***
Embarrassed by subject's condition	16	23	13	2	16***
Health affected by caregiving	40	48	25	9	36***
GHQ score $\geq$ 5	46	43	29	13	38***
n (= 100%)	241	191	139	62	633

n indicates minimum number of respondents.

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ .

felt depressed by the caregiving situation or embarrassed by the subject's condition. Overall, around one-third of supporters felt that their health had been affected by caregiving and a slightly higher proportion scored five or more on the GHQ, indicating possible psychiatric morbidity. Nearly all supporters (92 per cent) identified at least one social cost of caregiving.

Logistic regression indicated the importance of both the relationship of the supporter to the subject and type of frailty in predicting the social costs of caregiving. Table 9 shows that daughters were generally most likely, and friends or neighbours generally least likely to express each of these social costs. The exceptions to this general pattern were that spouses were as likely as daughters to have a high GHQ score and friends and neighbours were as likely as spouses and other relatives to say that they felt angry about the caregiving situation.

The social costs of caregiving by type of frailty are shown in Table 10. Not surprisingly, these were generally greater for supporters of older people who were both mentally and physically frail, although for one variable (feeling angry about the situation) the difference according to frailty type was not statistically significant. Supporters of subjects who were mentally or physically frail only appeared to have broadly similar experiences of caregiving in terms of the social costs, although supporters of subjects who were mentally frail only were less likely to identify any social costs.

Co-residency was a significant predictor of only two of the social costs of caregiving: co-resident supporters were more likely to report that

TABLE 10. *Social costs of caregiving by type of frailty*

	Mentally frail only	Physically frail only	Mentally and physically frail	All
	%	%	%	%
Worries about accidents	62	73	76	72*
Frustrated by caregiving situation	51	46	66	50**
Angry with subject	45	40	66	45***
Depressed by subject's condition	37	40	57	42**
Angry with caregiving situation	35	40	51	41
Depressed by caregiving situation	27	22	38	25**
Embarrassed by subject's condition	20	11	31	16***
Health affected by caregiving	32	34	52	36**
GHQ score $\geq$ 5	31	35	57	38***
n (= 100%)	97	434	102	633

n indicates the minimum number of respondents.

\*  $p < 0.05$ , \*\*  $p < 0.01$ , \*\*\*  $p < 0.001$ .

their health had been affected (42 per cent compared with 30 per cent of non-resident supporters,  $p < 0.01$ ), and to have a high GHQ score (45 per cent compared with 29 per cent of non-resident supporters,  $p < 0.001$ ; see also Resource Implications Study Group 1997). Two other variables emerged as important predictors of individual social costs. The likelihood of worrying about accidents was significantly greater for all next generation supporters (79 per cent of sons and daughters compared with 67 per cent of other supporters,  $p < 0.001$ ). The proportion of supporters whose health had been affected by caregiving was significantly related to gender (27 per cent of male and 41 per cent of female supporters felt that their health had been affected,  $p < 0.001$ ). The relationship of the supporter remained a significant predictor even after taking these gender differences into account, with daughters being more likely than other female supporters to report that their health had been affected (48 per cent compared with 35 per cent of other female supporters,  $p < 0.01$ ).

#### *The benefits of informal support*

Of 644 respondents 95 per cent identified something good and/or rewarding about caregiving (Table 11). The most common themes (50 per cent of supporters) were that they were able to improve the subject's well-being, for example by helping to keep the subject healthy, or had a sense of satisfaction or achievement. Around a third



TABLE 11. *Benefits of caregiving and significant predictors*<sup>1</sup>

	All key supporters	Key predictors
	%	
Improves subject's well being	50	
Sense of satisfaction or achievement	50	
Feel appreciated	32	Friend/neighbour, other relative
Companionship	29	Type of frailty, co-residency
Enable to remain at home	14	Co-residency, next generation supporter
Reciprocating past help	14	Next generation supporter
Sense of fulfilling duty	9	
No benefits	5	Type of frailty
n (= 100%)	644	

<sup>1</sup>Significant predictors were identified through logistic regression including relationship of supporter (as a series of binary variables), co-residency, gender of supporter and type of frailty as explanatory variables. Only predictors significant at  $p < 0.01$  are shown.

felt that they were appreciated by the subject or mentioned companionship as a benefit. Other benefits identified by smaller proportions of supporters included enabling the subject to remain at home, a sense of reciprocating for past help and a feeling of fulfilling one's duty.

The positive aspects of caregiving were not consistently related to type of frailty, relationship of supporter or place of residence and three benefits were not significantly predicted by any of these variables. Supporters who were friends or neighbours or other relatives of the subject were more likely to identify feeling appreciated as a benefit of caregiving than other supporters (55 per cent of friends, 40 per cent of other relatives compared with 27 per cent of spouses and daughters,  $p < 0.001$ ). Companionship was less likely to be identified as a benefit of caregiving by supporters of subjects who were both mentally and physically frail (16 per cent compared with 29 per cent of supporters of mentally frail subjects and 32 per cent of supporters of physically frail subjects,  $p < 0.01$ ). Companionship was more likely to be mentioned as a benefit by co-resident supporters (33 per cent compared with 24 per cent of non-resident supporters,  $p < 0.01$ ). Co-resident supporters were also more likely to identify enabling the subject to remain at home as a benefit (18 per cent compared with nine per cent,  $p < 0.01$ ). Among co-resident supporters, sons and daughters were more likely to identify this as a benefit than other types of supporters (31 per cent compared with 15 per cent of other co-resident supporters,  $p < 0.01$ ). Next generation supporters were also more likely to feel that caregiving

provided an opportunity to repay the subject for past help (23 per cent compared with eight per cent of other supporters,  $p < 0.001$ ). Finally, supporters of subjects who were both mentally and physically frail were more likely to say that there were no benefits of caregiving (12 per cent compared with three per cent of supporters of mentally frail subjects and three per cent of supporters of physically frail subjects,  $p < 0.001$ ).

## **Discussion**

New data have been used to examine the costs and benefits of informal caregiving for older people who are mentally and/or physically frail. These cross-sectional data confirm many of the observations made about informal caregiving in small local cross-sectional or qualitative studies (*e.g.* O'Connor *et al.* 1990; Bowling 1984; Lewis and Meredith 1988; Ungerson 1987). Reflecting contemporary informal caregiving in the UK, the data highlight the different costs and benefits that informal supporters face according to whether they live with the older person, their relationship to the older person and type of frailty of the older person.

### *Costs and benefits associated with co-residency*

Consistent with previous studies (*e.g.* Arber and Ginn 1991; Parker and Lawton 1994), greater involvement in caregiving was evident for co-resident supporters in terms of the type and frequency of help provided (Table 4). Co-resident supporters were less likely to identify other informal supporters who assisted with caregiving. Co-resident supporters were more likely to provide help with a range of personal care tasks and this may explain some of the differences in the type and frequency of help provided. Gender differences may also account for some of the differences, male subjects may receive more assistance with domestic tasks due to traditional gender role assumptions and there was a significantly higher proportion of male subjects in the co-resident group (Table 3). Although co-resident supporters were less likely to identify additional financial costs, among supporters with expenses, co-resident supporters estimated significantly greater financial expenditure. There was also evidence of increased opportunity costs for this group of supporters. In terms of paid employment, co-resident supporters were more likely to report that caregiving presented problems with work (Table 7). However, there was no evidence that

overall this group of supporters were more likely to have limited their participation in the labour market due to caregiving. The impact of caregiving on unwaged time was significantly greater for co-resident supporters, both for routine activities such as getting out to visit other people or participating in social activities, and for infrequent activities such as going on holiday (Table 8).

Consistent with their greater involvement in caregiving and associated increase in opportunity costs, co-resident supporters were more likely to report that their health had been affected by caregiving and to score five or more on the GHQ, indicating increased likelihood of psychiatric illness (Table 9). Finally, there were some differences in the benefits associated with caregiving reported by co-resident and other supporters. Co-resident supporters were more likely to identify companionship and enabling the subject to remain at home as benefits (Table 11).

*Costs and benefits associated with relationship of the key supporter*

*Spouses as key supporters.* Previous studies have found that, despite poor health, older spouse caregivers do not report caregiving as particularly stressful (Johnson and Catalone 1981; Wenger 1990*b*). In the present study, wives were less likely than other co-resident supporters to provide physical but not personal care. This may reflect the greater age of wife supporters, many of whom were frail themselves and therefore less able to assist with physically supporting the subject. As would be expected, spouses had higher levels of contact than other types of co-resident supporters. With these exceptions, perhaps surprisingly in view of the significantly different characteristics of the subjects supported by spouses (Table 3), there were few differences in the costs and benefits of caregiving reported by spouses and other types of supporters, or between husbands and wives.

*Daughters as key supporters.* Small-scale studies of daughters as caregivers have documented the stress and 'burden' created by their caregiving status (Lewis and Meredith 1988; Ungerson 1987). Data presented here provide considerable evidence that daughters have a quantitatively different experience of caregiving from other types of supporters. These results need to be interpreted in the context of Table 3, which shows some differences in the characteristics of older subjects supported by daughters, but these do not appear to be pronounced enough to adequately explain all of the differences identified. More detailed multivariate analyses including additional potential explana-

tory variables would clarify whether other factors contribute to the differences between daughters and other supporters reported in this paper.

Although daughters were not more likely than other types of supporters to have travel expenses or other additional expenditure related to caregiving, among those with expenses, daughters reported spending significantly more than other types of supporters. It is probable that identifying financial costs specifically associated with caregiving is easier for some types of supporters than others. Supporters who are spouses or lifelong co-residents may be more likely to underestimate expenses than other supporters, since they may view the household as a single income unit. In contrast, where the supporter lives in a separate household or where co-residency is relatively recent, it may be easier to separate expenses due to caregiving from more general household expenditure. The greater expenses associated with caregiving reported by daughters, may be due partially to their increased ability to allocate expenditure, rather than to differences in expenditure. A more sophisticated methodology would be needed to explore issues of expenditure in more detail, and would need to be carried out as the sole focus of a study in order to avoid over-burdening respondents.

There was evidence also that daughters experienced greater opportunity costs. Daughters were more likely than other supporters to respond to the conflict between paid employment and caregiving by limiting their involvement in the labour market, either by reducing their hours or by not taking up paid employment. There is a strong chance that this would have affected their financial position. The impact of caregiving on unwaged time was also significantly greater for daughters. There may, however, be difficulties in disentangling cause and effect when assessing opportunity costs. For example, the high proportions of supporters reporting that caregiving had led to restrictions on their social activities and withdrawal from the labour market, may partially reflect the social acceptability of caregiving as a justification for not engaging in these activities. It is likely that an increase in caregiving activities and time spent caregiving would be associated with each of these events, although not necessarily the cause of them.

In view of these greater financial and opportunity costs, it is not surprising to find that daughters were more likely to express each of the social costs of caregiving. In contrast to the above findings, there were few significant differences in the benefits of caregiving reported by daughters and other supporters. All next-generation supporters were

more likely to identify enabling the subject to remain at home and repaying the subject for help given previously, as benefits of caregiving.

*Friends and neighbours as key supporters.* Political rhetoric often highlights the importance of friends and neighbours as potential caregivers. Although friends and neighbours have been shown to be involved in providing social support (Wenger 1990a), friendship is not a particularly suitable basis for care provision (Allan 1986). In the present study, this group of supporters, virtually all of whom lived in a separate household, were least heavily involved in caregiving. Although there were no differences in the frequency with which help was provided, the most common type of help provided by friends and neighbours was assistance with practical or other tasks only. Reflecting this generally low involvement in caregiving, there was little evidence of significant social costs being borne by friends or neighbours. Friends or neighbours were less likely than other types of supporters to identify each of the social costs of caregiving, with the exception of feeling angry about the situation. Compared with other supporters, friends or neighbours were more likely to identify feeling appreciated as a benefit of caregiving.

#### *Costs and benefits associated with type of frailty*

Supporters of older subjects who were both mentally and physically frail, in general identified greater costs and fewer benefits of caregiving than those who were supporting an older person who was either mentally or physically frail only. As would be expected the type of help provided was significantly associated with type of frailty, with supporters of mentally and physically frail subjects being most likely to provide personal and physical help.

Whether or not supporters incurred any travel or other expenses (and the amount of such expenses) was independent of frailty type. Although there were no differences in the impact of caregiving on current paid employment, supporters of mentally and physically frail subjects were more likely to have withdrawn from the labour market by giving up a paid job in order to provide support. This may have significant implications for the financial circumstances of such supporters, both short and long term. The findings are in contrast to those of Philp *et al.* (1995), who found that supporters of older people with dementia were more likely to have substantial additional household expenditure, but were no more likely to have taken early retirement than supporters of non-demented older people. These

discrepancies in results probably reflect the different sampling approaches used to identify people with dementia in the two studies. Furthermore, the comparator group used by Philp *et al.* (1995) is likely to have included older people who would not have been defined as physically frail in our study.

Although there were no differences in the amount of contact with the subject according to type of frailty, the impact of caregiving on unwaged time was significantly greater for supporters of mentally and physically frail subjects.

Each of the social costs associated with caregiving was most likely to be reported by supporters of subjects who were mentally and physically frail (Table 10). Of particular significance are the higher proportions of supporters of mentally and physically frail subjects reporting that caregiving had adversely affected their health and scoring five or more on the GHQ (Table 10).

The greater difficulties experienced by many of the supporters of mentally and physically frail subjects, were mirrored in the finding that such supporters were most likely to report that there were no benefits or positive aspects of caregiving. Companionship was also less likely to be identified as a benefit of caregiving. The differences in reported costs and benefits by supporters of subjects who were either mentally or physically frail were small and on the whole insignificant.

### **Implications for public policy**

There are a number of assumptions underpinning public policy on support for older people who are physically or mentally frail. Two are particularly relevant to the findings of this study. First, it is assumed that family and kin are available to provide high levels of support to their older relatives. Our data confirm other studies that this continues to be the case. However, trends such as changes in the structure and size of the family, increased geographical mobility in the working population, retirement migration and increased economic activity by women might challenge this assumption in the future (Bond and Buck 1994; McGlone and Cronin 1994; Allen and Perkins 1995).

A second assumption of public policy is that families, friends and neighbours are willing to provide the necessary support. Again our data suggest that this is generally the case, but with the caveat that friends and neighbours are not generally involved in providing intensive support and are therefore not exhibiting the same commitment or sense of obligation observed among family members, particularly daughters

and spouses. It is difficult to assess whether the current solidarity across the generations will survive the stresses of contemporary life, the changing nature of family life and the decreasing support of the State. A number of practical responses to the needs of informal supporters, however, are feasible within the continuing climate of cost containment. Interventions can be directed towards decreasing the costs and increasing the benefits of caregiving.

*Reducing the costs of caregiving*

*Reducing financial costs.* A significant minority of caregivers respond to conflicts between paid employment and caregiving by reducing their involvement in the labour market, either by withdrawing from paid employment, reducing their hours or not taking up paid work. In the long term, trends in pension provision will become a disincentive for people to give up work or reduce working hours in order to provide informal support. A major policy incentive would be for the State to pay full-time national insurance and pension contributions to caregivers.

Attendance allowances are essential to enable some caregivers to continue to support frail older people at home, but they have a poor take up (McLaughlin 1991). Methods to improve the targeting and take up of this benefit would help maintain frail older people at home. The allowance can be used to buy in social services and private help which could benefit older people and caregivers. Invalid Care Allowance is payable to caregivers who are of working age and providing at least 35 hours of care each week. These criteria are likely to exclude many of the younger caregivers in our sample who provide less intensive support but nonetheless report loss of employment opportunities or reduced earnings.

*Reducing opportunity costs.* While only a minority of supporters had reduced their involvement in paid employment, nearly half reported reduced leisure opportunities as a result of caregiving. Increased provision and improved targeting of respite care would be of benefit to many informal supporters and their older relatives. Respite care can take many forms (Levin *et al.* 1994) and could be used in a variety of ways. Regular respite could enable some supporters to continue in paid employment, sitting services could enable supporters to pursue some leisure activities, while holiday respite could enable those who want a longer break to 'recharge their batteries'. Informal supporters of mentally and physically frail people would particularly benefit from respite care since they reported greater disruption to their social lives

than supporters of other types of frailty. Respite care is not a panacea, however, and has to be a flexible service which matches the needs of both caregivers and those they care for.

Developing a broader network of informal supporters is an alternative strategy which would reduce the opportunity costs experienced by supporters. Previous studies have described the way in which caregiving tends to devolve on a single informal supporter and have commented on the rarity of genuinely shared care (Sinclair *et al.* 1990; Twigg and Atkin 1995). Further research is needed to identify the barriers to shared informal care and to develop interventions to address these. However, the likely difficulties in increasing the number of supporters actively involved in caregiving should not be underestimated (Sinclair *et al.* 1990).

*Reducing social costs.* A common theme throughout the psychological and medical literature is the evidence that caregiving is stressful to many informal caregivers, and that stress will lead to a breakdown in informal support (see, for example, Gilhooly 1986; Zarit *et al.* 1986, Gilleard 1987; Levin *et al.* 1989; Jerrom *et al.* 1993; Levin *et al.* 1994). Voluntary organisations have in general responded rather better to the challenge to develop innovative approaches to controlling stress than have the public health and personal social services. Strategies shown to be effective in reducing the social costs of caregiving include: providing emotional support, providing information and training in caregiving skills and providing mainstream services.

Individual psychosocial interventions have been more successful than support groups in helping people to cope with the stress of caregiving (Knight *et al.* 1993). Regular telephone contact with a nurse has been shown to benefit outpatients with chronic illness who live alone, in terms of psychosocial adjustment (Roberts *et al.* 1995), and may provide an appropriate model to adapt for vulnerable caregivers (Skipwith 1994).

Studies have highlighted caregivers' lack of knowledge and understanding of conditions such as stroke (Wellwood *et al.* 1994), and many support groups for caregivers have included an educational component (*e.g.* Toseland and Rossiter 1989). Training programmes addressing issues such as stress management and the management of challenging behaviour would benefit supporters of subjects with disruptive behaviour.

Finally, reviews have demonstrated the effectiveness of services such as home helps and respite care in reducing caregiver stress (*e.g.* Sinclair *et al.* 1990; Twigg *et al.* 1990; Melzer *et al.* 1992). Public services need



to recognise the greater needs of co-resident caregivers, particularly daughters and to target vulnerable groups.

*Increasing the benefits of caregiving*

Some of the benefits identified by informal supporters are difficult for policy makers and service providers to address (for example, feelings of reciprocity). One benefit which would be relatively cheap and straightforward to achieve is raising caregivers' self esteem, particularly since our data suggest that currently those supporters who are most involved are least likely to feel appreciated. Enhancing caregivers' sense of achievement and satisfaction by improving the well-being of the cared-for person would also help to maximise the perceived benefits of caregiving.

Financial incentives in a variety of forms may be necessary to maintain the level of informal support in the next century. Although friends and neighbours provided less intense support than family caregivers, nearly half of these supporters reported feeling angry about the caregiving situation, suggesting that a greater reliance on this group in the future may lead to alienation of potential supporters. Financial support might be necessary to maximise the potential support available from this group.

Maintaining the health and morale of informal supporters has been a major objective of the reorganisation of community care (Secretaries of State for Health *et al.* 1989). At a time of continuing cost-containment policies within public services, the targeting of services on vulnerable groups of caregivers is necessary. This study has identified these as being co-resident supporters, supporters of people who are both mentally and physically frail, and daughters. In targeting these groups it will be important that public services do not fail to monitor other less vulnerable groups. Finally, it is essential to respect supporters' own perceptions of the services they require, and to empower them to continue their support in the way which best suits their needs and the needs of the person they are supporting.

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## References

- Allan, G. 1986. Friendship and care for elderly people. *Ageing and Society*, **6**, 1–12.
- Allen, I. and Perkins, E. 1995. *The Future of Family Care for Older People*. HMSO, London.
- Anderson, R. 1992. *The Aftermath of Stroke. The Experience of Patients and their Families*. Cambridge University Press, Cambridge.
- Arber, S. and Ginn, J. 1991. *Gender and Later Life. A Sociological Analysis of Resources and Constraints*. Sage Publications, London.
- Aronson, J. 1990. Women's perspectives on informal care of the elderly: public ideology and personal experience of giving and receiving care. *Ageing and Society*, **10**, 61–84.
- Bond, J. and Buck, D. 1994. *Comparative Study of Social Protection for Dependency in Old Age in the United Kingdom. Report No. 63. Report prepared for the Commission of the European Communities Directorate General V: Employment, Social Affairs, Industrial Relations*. Centre for Health Services Research, University of Newcastle upon Tyne.
- Bond, J. and Carstairs, V. 1982. *Services for the Elderly: a Survey of the Characteristics and Needs of a Population of 5,000 Old People. Scottish Health Services Studies No. 42*. Scottish Home and Health Department, Edinburgh.
- Bowling, A. 1984. Caring for the elderly widowed – the burden on their supporters. *British Journal of Social Work*, **14**, 435–55.
- Cantor, M. H. 1983. Strain among caregivers: a study of experience in the United States. *The Gerontologist*, **23**, 597–604.
- Caring Costs 1991. *Taking Care, Making Do. The Costs of Caring for a Disabled Person at Home*. Caring Costs, London.
- Carlson, K. W. and Robertson, S. E. 1993. Husbands and wives of dementia patients: burden and social support. *Canadian Journal of Rehabilitation*, **3**, 163–73.
- Challis, D. and Davies, B. 1986. *Case Management in Community Care*. Gower, Aldershot.
- Chetwynd, S. J. 1983. Costing the role of the principal care-giver in the domiciliary care of the elderly. *Community Health Studies*, **VII**, 2, 146–9.
- Clifford, D. 1990. *The Social Costs and Rewards of Caring*. Avebury, Aldershot.
- Copeland, J. R. M., Dewey, M. E. and Griffiths-Jones, H. M. 1986. A computerized psychiatric diagnostic system and case nomenclature for elderly subjects: GMS and AGE-CAT. *Psychological Medicine*, **16**, 89–99.
- Department of Health and Social Security 1977. *Priorities in the Health and Social Services: the Way Forward*. HMSO, London.
- Department of Health and Social Security 1981. *Growing Older*. HMSO, London.
- Dewey, M. E. and Copeland, J. R. M. 1986. Computerised psychiatric diagnosis in the elderly: AGE-CAT. *Journal of Microcomputer Applications*, **9**, 135–40.
- Draper, B. M., Poulos, C. J., Cole, A. M. D., Poulos, R. G. and Ehrlich, F. 1992. A comparison of caregivers for elderly stroke and dementia victims. *Journal of the American Geriatrics Society*, **40**, 896–901.
- Eagles, J. M., Craig, A., Rawlinson, F., Restall, D. B., Beattie, J. A. G. and Besson, J. A. O. 1987. The psychological well-being of supporters of the demented elderly. *British Journal of Psychiatry*, **150**, 293–8.

- Finch, J. 1989. *Family Obligations and Social Change*. Polity Press, Cambridge.
- Fitting, M., Rabins, P., Lucas, M. J. and Eastham, J. 1986. Caregivers for dementia patients: a comparison of husbands and wives. *The Gerontologist*, **26**, 248–52.
- Folstein, M. F., Folstein, S. E. and 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**, 189–98.
- George, L. K. and Gwyther, L. P. 1986. Caregiver wellbeing: a multidimensional examination of family caregivers of demented adults. *The Gerontologist*, **26**, 253–9.
- 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.
- Gilhooly, M. L. M. 1986. Senile dementia: factors associated with caregivers' preference for institutional care. *British Journal of Medical Psychology*, **59**, 165–71.
- Gilleard, C. J. 1984. Problems posed for supporting relatives of geriatric and psychogeriatric day patients. *Acta Psychiatrica Scandinavica*, **70**, 196–208.
- Gilleard, C. J. 1987. Influence of emotional distress among supporters on the outcome of psychogeriatric day care. *British Journal of Psychiatry*, **150**, 219–23.
- Glendinning, C. 1992. *The Costs of Informal Care: Looking Inside the Household*. HMSO, London.
- Goldberg, D. P. 1972. *The Detection of Psychiatric Illness by Questionnaire: a Technique for the Identification and Assessment of Non-psychotic Psychiatric Illness*. Oxford University Press, London.
- Grant, G. and Nolan, M. 1993. Informal carers: sources and concomitants of satisfaction. *Health and Social Care*, **1**, 147–59.
- Green, H. 1988. *Informal Carers: General Household Survey*. OPCS Social Survey Division, London.
- Harris, I., Cox, E. and Smith, C. R. W. 1971. *Handicapped and Impaired in Great Britain Part 1*. HMSO, London.
- Hinrichsen, G. A., Hernandez, N. A. and Pollack, S. 1992. Difficulties and rewards in family care of the depressed older adult. *The Gerontologist*, **32**, 4, 486–92.
- Horton, C. and Berthoud, R. 1990. *The Attendance Allowance and the Costs of Caring*. Policy Studies Institute, London.
- Jerrom, B., Mian, I., Rukanyake, N. G. and Prothero, D. 1993. Stress on relative caregivers of dementia sufferers and predictors of the breakdown of community care. *International Journal of Geriatric Psychiatry*, **8**, 331–7.
- Johnson, L. C. and Catalone, D. J. 1981. Childless elderly and their family supports. *The Gerontologist*, **6**, 610–18.
- Jones, D. A. and Vetter, N. J. 1984. A survey of those who care for the elderly at home: their problems and their needs. *Social Science and Medicine*, **19**, 511–14.
- Joshi, H. 1992. The cost of caring. In Glendinning, C. and Millar, J. (eds). *Women and Poverty in Britain: the 1990s*. Harvester Wheatsheaf, London.
- Knight, B. G., Lutzky, S. M. and Macofsky-Urban, F. 1993. A meta-analytic review of interventions for caregiver distress: recommendations for future research. *The Gerontologist*, **33**, 240–8.
- Levin, E., Sinclair, I. and Gorbach, P. 1983. *The Supporters of Confused Elderly People at Home: extract from main report*. National Institute for Social Work Research Unit, London.
- Levin, E., Sinclair, I. and Gorbach, P. 1989. *Families, Services and Confusion in Old Age*. Avebury, Aldershot.
- Levin, E., Moriarty, J. and Gorbach, P. 1994. *Better for the Break*. HMSO, London.
- Lewis, J. and Meredith, B. 1988. *Daughters Who Care: Daughters Caring for Mothers at Home*. Routledge, London.

- Martin, J., Meltzer, H. and Elliot, D. 1988. *Office of Population Censuses and Surveys Disability Surveys, Report 1: The Prevalence of Disability among Adults*. HMSO, London.
- Martin Matthew, A. and Campbell, L. D. 1995. Gender roles, employment and informal care. In Arber, S. and Ginn, J. (eds). *Connecting Gender and Ageing*. Open University Press, Buckingham.
- McGlone, F. and Cronin, N. 1994. *A Crisis in Care? The Future of Family and State Care for Older People in the European Union*. Family Policy Studies Centre, London.
- McLaughlin, E. 1991. *Social Security and Community Care: the Case of the Invalid Care Allowance*. HMSO, London.
- McLaughlin, E. and Ritchie, J. 1994. Legacies of caring: the experiences and circumstances of ex-carers. *Health and Social Care*, **2**, 241–53.
- Melzer, D., Hopkins, S., Pencheon, C., Brayne, C. and Williams, R. 1992. *Epidemiologically Based Needs Assessment: Dementia*. 5. NHS Management Executive, London.
- Morris, R. G., Morris, L. W. and Britton, P. G. 1988. Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. *British Journal of Psychiatry*, **153**, 147–56.
- MRC CFAS 1998. Cognitive function and dementia in six areas of England and Wales: the distribution of MMSE and prevalence of GMS organicity level in the MRC CFA Study. *Psychological Medicine*, **28**, 319–35.
- Netten, A. 1989. *An Approach to Costing Informal Care: Discussion Paper 637*. University of Kent at Canterbury, Person Social Services Research Unit.
- Netten, A. and Beecham, J. 1993. *Costing Community Care. Theory and Practice*. Ashgate Publishing Ltd, Aldershot.
- Nissel, M. 1984. The family costs of looking after handicapped elderly relatives. *Ageing and Society*, **4**, 185–204.
- Nissel, M. and Bonnerjea, L. 1982. *Family Care of the Handicapped Elderly: Who Pays?* Policy Studies Institute, London.
- Nolan, M. R., Gant, G. and Ellis, N. C. 1990. Stress is in the eye of the beholder: reconceptualizing the measurement of carer burden. *Journal of Advanced Nursing*, **15**, 544–55.
- Nolan, M., Grant, G. and Keady, J. 1996. *Understanding Family Care*. Open University Press, Buckingham.
- O'Connor, D., Pollit, P., Roth, M., Brook, C. and Reiss, B. B. 1990. Problems reported by relatives in a community study of dementia. *British Journal of Psychiatry*, **156**, 835–41.
- Parker, G. 1990. *With Due Care and Attention: a Review of Research on Informal Care, Edition 2*. Family Policy Studies Centre, London.
- Parker, G. and Lawton, D. 1994. *Different Types of Care, Different Types of Carer. Evidence from The General Household Survey*. HMSO, London.
- Phillips, V. L. 1993. *Caring for Severely Disabled People. Care Providers and their Costs. A Report for the Independent Living Fund*. Centre for Socio-Legal Studies, Oxford.
- Philp, I., McKee, K. J., Meldrum, P., Ballinger, B. R., Gilhooly, M. L. M., Gordon, D. S., Mutch, W. J. and Whittick, J. E. 1995. Community care for demented and non-demented elderly people: a comparison study of financial burden service use and unmet needs in family supporters. *British Medical Journal*, **310**, 1503–6.
- Pruchno, R. A. and Potashnik, S. L. 1989. Caregiving spouses: physical and mental health in perspective. *Journal of the American Geriatrics Society*, **37**, 8, 697–705.
- Qureshi, H. and Walker, A. 1989. *The Caring Relationship. Elderly People and their Families*. MacMillan, London.
- Resource Implications Study Group of MRC CFA Study 1997. Psychological distress amongst informal supporters of frail older people at home in institutions. *International Journal of Geriatric Psychiatry*, **12**, 737–44.

- Roberts, J., Bohn Brown, G., Streiner, D., Gafni, A., Pallister, R., Hoxby, H., Drummond-Young, M., LeGris, J. and Meichenbaum, D. 1995. Problem-solving counselling or phone-call support for outpatients with chronic illness: effective for whom? *Canadian Journal of Nursing Research*, **27**, 3, 111–37.
- Robinson, J. P. 1985. The validity and reliability of diaries versus alternative time use measures. In Juster, F. T. and Stafford, F. P. (eds). *Time, Goods, and Well-Being*. University of Michigan, Michigan.
- Rose, H. and Bruce, E. 1995. Mutual care but differential esteem: caring between older couples. In Arber, S. and Ginn, J. (eds). *Connecting Gender and Ageing*. Open University Press, Buckingham.
- Salvage, A. V., Jones, D. A. and Vetter, N. J. 1989. Opinions of people aged over 75 years on private and local authority residential care. *Age and Ageing*, **18**, 380–6.
- Secretaries of State for Health, Social and Security, Wales and Scotland. 1989. *Caring for People. Community Care in the Next Decade and Beyond. CM849 (White Paper)*. HMSO, London.
- Sinclair, I., Parker, R., Leat, D. and Williams, J. 1990. *The Kaleidoscope of Care: A Review of Research on Welfare Provision for Elderly People*. HMSO, London.
- Skipwith, D. H. 1994. Telephone counseling interventions with caregivers of elders. *Journal of Psychosocial Nursing and Mental Health Services*, **32**, 3, 7–12.
- Smith, K. and Wright, K. 1994. Informal care and economic appraisal: a discussion of possible methodological approaches. *Health Economics*, **3**, 137–48.
- Stone, R., Cafferata, G. L. and Sangl, J. 1987. Caregivers of the frail elderly: a national profile. *The Gerontologist*, **27**, 616–26.
- Toseland, R. W. and Rossiter, C. M. 1989. Group interventions to support family caregivers: a review and analysis. *The Gerontologist*, **29**, 438–48.
- Twigg, J., Atkin, K. and Perring, C. 1990. *Carers and Services: a Review of Research*. HMSO, London.
- Twigg, J. and Atkin, K. 1994. *Carers Perceived. Policy and Practice in Informal Care*. Open University Press, Buckingham.
- Twigg, J. and Atkin, K. 1995. Carers and services: factors mediating service provision. *Journal of Social Policy*, **24**, 1, 5–30.
- Ungerson, C. 1987. *Policy is Personal: Sex, Gender and Informal Care*. Tavistock, London.
- Wellwood, I., Dennis, M. S. and Warlow, C. P. 1994. Perceptions and knowledge of stroke among surviving patients with stroke and their carers. *Age and Ageing*, **23**, 293–8.
- Wenger, G. C. 1990a. Elderly carers: the need for appropriate intervention. *Ageing and Society*, **10**, 197–219.
- Wenger, G. C. 1990b. The special role of friends and neighbours. *Journal of Aging Studies*, **4**, 2, 149–69.
- Wijerantne, C. and Lovestone, S. 1996. A pilot study comparing psychological and physical morbidity in carers of elderly people with dementia and those with depression. *International Journal of Geriatric Psychiatry*, **11**, 8, 741–4.
- Wilkin, D. and Thompson, C. 1989. *Users' Guide to Dependency Measures for Elderly People*. University of Sheffield, Joint Unit for Social Services Research, Sheffield.
- Wright, K. 1987. *The Economics of Informal Care. Discussion Paper 23*. Centre for Health Economics, University of York.
- Yeatman, R., Bennetts, K., Allen, N., Ames, D., Flicker, L. and Waltrowicz, W. 1993. Is caring for elderly relatives with depression as stressful as caring for those with dementia? A pilot study in Melbourne. *International Journal of Geriatric Psychiatry*, **8**, 339–42.
- Zarit, S. H., Reever, K. E. and Bach-Peterson, J. 1980. Relatives of the impaired elderly: correlates of feelings of burden, *The Gerontologist*, **20**, 649–55.

Zarit, S. H., Todd, P. A. and Zarit, J. M. 1986. Subjective burden of husbands and wives as caregivers: a longitudinal study. *The Gerontologist*, **26**, 3, 260–6.

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