

# Health-Related Quality of Life and Attitudes to Long-Term Care among Carers of Older People Using Social Services

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## Abstract

*Family carers provide more care than the combined efforts of the NHS and social services departments, and their value to the economy is estimated to be around £34 billion a year (Hirst, 1999). However, many carers have health problems of their own. Using three standardised measures to screen for activity limitation (ADLs), depression (GHQ-28) and health related quality of life (HRQoL) (SF36), a study of carers of people aged 75 and over referred consecutively to social services departments in adjacent inner city areas showed a high prevalence of limitations in activities of daily living (ADLs), that a substantial proportion (42 per cent) had GHQ-28 scores high enough to suggest depression and their scores on the SF-36 showed that many carers were low in vitality and tired. Co-resident carers had poorer psychological health and more difficulties with social functioning than non-resident carers, and were older, but were not significantly different in self-reported physical health. Whether carers wanted the cared-for person to remain at home for as long as possible depended on their relationship (spouse or not) and whether the older person was depressed. The carer's own psychological health was not related to their attitude to institutional care. The study suggests that targeting social care resources on carers showing psychological distress may not reduce downstream expenditure on long-term care.*

## Keywords

Carers, older people, social services, mental health problems, stress, cost effectiveness, interviews, screening

## Introduction

Informal carers provide more care than the combined efforts of the NHS and social services departments, and their value to the economy is estimated to be around £34 billion a year (Hirst, 1999). Supporting carers makes policy sense, and in part explains the introduction of legislation such as the *Carers (Recognition & Services) Act* (1995), *Carers and Disabled Children Act* (2000) and the *Carers (Equal Opportunities) Act* (2004). However, social service departments have to meet needs within their

limited resources, and there is some evidence that carers' needs are not fully assessed because of resource scarcity (Arksey, 2002). Separate carers assessments are not necessarily an established feature of care management practice and care managers lack an explicit framework to direct the assessment of carers needs (Seddon and Robinson, 2001). Since rationing of resources is likely to remain a task for social services for the foreseeable future, a selective method of rationing that identifies those with most to gain seems appropriate. Social workers could benefit from being able

to identify tractable health needs associated with the caring role, and targeting resources at those with greatest meetable needs (Arksey, 2002).

There is an assumption that the stresses and strains of long-term caring are deleterious for health but the evidence to support this is limited. Studies of carers' health have tended to be descriptive, based on selected samples and variable in their conceptualisation and measurement of carers' health (Moriarty, 2002). Co-resident carers (those who live in the same household as the person for whom they care) are thought to provide assistance at a greater level of intensity than non-resident carers, as do carers for individuals with mental health problems (Parker and Lawton, 1994), and amongst older carers with their own health problems this is assumed to have an impact (Milne *et al.*, 2001).

However, it is difficult to demonstrate direct causal relationships between caring and health, except for higher rates of depression associated with lack of control (Schulz *et al.*, 1990) and experiences of guilt and worry about the caring role (Nolan *et al.*, 1990). Although there is some evidence that carers of individuals with Parkinson's disease are significantly more likely to experience chronic illness (O'Reilly *et al.*, 1996), physical health may be no worse amongst most carers than amongst other people of the same age who do not have a caring role (Taylor *et al.*, 1995; Kersten *et al.*, 2001).

Poor psychological health among carers may be mediated by a lack of confiding relationships (Livingston *et al.*, 1996), and is associated with an increased probability that the cared for person will enter long-term care (Levin *et al.*, 1994; Moriarty and Webb, 2000). This association could be causal, whereby psychologically distressed carers seek to reduce their distress by favouring long term care for the cared-for individual, or a consequence of problems that are both distressing to the carer and severely

disabling to the older person. If the former explanation is correct, reducing psychological distress amongst carers could postpone the transfer of some older people to long-term care.

In this exploratory study we:

- mapped self-reported health amongst co-resident and non-resident carers using a health-related quality of life instrument;
- assessed the relationship between psychological ill-health and intensity of caring (using co-residence as a surrogate marker for intensity); and
- measured the association between carers' psychological wellbeing and their attitudes towards long-term care.

Our hypotheses were:

1. Carers would have higher levels of psychological distress than their peers who do not have caring roles, but similar levels of physical ill-health;
2. Co-resident carers would have worse self-reported health across physical and psychological domains; and
3. Psychological distress in the carer would be associated with a more positive attitude to long-term institutional care for the older person.

## Methods

The project, a study of different forms of joint working (Levin *et al.*, 2002), was carried out with the co-operation of social and health care staff and service users and their carers in two London boroughs covered by one health authority, one NHS Community Health Services Trust, and four Primary Care Groups (now two Primary Care Trusts). Older people aged 75 and over consecutively referred to the locality teams and undergoing complex assessments of their

needs were invited to participate in the study, as were their carers (if any). Older people whose assessment resulted in immediate entry to residential or nursing home care were excluded from the study. Interviews with consenting older people and their main carers were carried out as soon as possible after referral to establish their social circumstances, mental and physical health, their perceived needs and preference and the health and social services received or used. The interview schedules included closed and open-ended questions and standardised measures for the assessment of mental and physical state and satisfaction with services, including the Mini-Mental State Examination (MMSE) (Folstein *et al.*, 1975) and Geriatric Depression Scale (GDS) (Yesavage *et al.*, 1982/1983) for older people, and validated scales for carers (Levin *et al.*, 2002). This paper focuses on the findings for carers.

Carers were asked about their: demographic details including self-reported ethnicity; relationship to the older person; work commitments; duration of the caring role; and self-perceived physical and psychological health. The latter was asked with a question derived from the General Household Survey: *'Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do?'* The impact of their own health problems on carers' daily lives was assessed using two self-completion questionnaires, the General Health Questionnaire (GHQ-28) (Goldberg and Williams, 1988) and the Short Form-36 (SF-36) (Stewart and Ware, 1992; Ware, 1993).

The 28-item General Health Questionnaire (GHQ-28) is a well-validated screening instrument used to identify individuals who are likely to have a psychiatric illness. Goldberg (1985) advises that in general practice the cut-point 5/6 discriminates best between those in whom the probability of psychological disturbance is low and those in whom it is high. The higher that the GHQ

score is above the threshold, the higher the probability of symptoms of psychiatric illnesses such as depression or anxiety. The range of possible scores is 0-28.

The SF-36 from the Rand Medical Outcomes Study (MOS) is widely used in research and clinical practice to measure non-disease-specific general health status and its outcomes (Stewart and Ware, 1992; Ware *et al.*, 1993). The 36 items cover eight dimensions and reported health transition. These are: physical functioning, role limitations due to physical health problems, bodily pain, social functioning affected by physical or emotional health, general mental health covering psychological distress and well-being, role limitations due to emotional problems, vitality relating to energy or fatigue, and general health perception. The eight scales on the SF-36 have been constructed according to the recommended scoring system, with each score ranging from 0-100, where the higher the score the better functioning or health (Ware *et al.*, 1993). Because of the non-normal distribution of values, nonparametric analysis was performed using Mann-Whitney *U* tests in SPSS software.

## Results

We identified carers for 57 (72 per cent) of the 79 older people referred consecutively to the two social service departments, and who received comprehensive assessments. We obtained agreement for interviews from 47 carers looking after 48 older people, a response rate of 82 per cent.

### *Basic characteristics*

The majority of the carers interviewed were very close relatives. Fifty five per cent (n=26) of carers were adult children and 21 per cent (n=10) were spouses. Eighteen of the adult children were daughters and seven of the spouses were wives. A further 23 per cent (n=11) were friends or neighbours and the rest were a daughter-in-law, a sister, a nephew's wife, and a nephew. In terms of

self-reported ethnic group, three carers were Indian or from another minority ethnic group and the others (94 per cent) were White UK, Irish or Other. Two-thirds of the carers were women. The age range was 37 to 93 but few carers were aged less than 45 and only one in seven were aged 75 or over. The mean age of the carers was 62 (SD±13), varying from 64 (SD± 13.) for the men, to 61 (SD±13) for the women. Twenty-seven carers were co-resident (57 per cent) and 20 (43 per cent) were not. Co-resident carers were a significantly older group, having a mean age of 66 (SD±11) as against a mean of 57 (SD±13) for the others (Mann Whitney  $U$  131.5,  $Z=-2.851$ ,  $p=0.04$ ). Just over half the carers were married ( $n=25$ ) and two-thirds had children ( $n=30$ ). Thirty per cent of the carers were in paid employment ( $n=14$ ) and most of this group worked full-time ( $n=10$ ).

One quarter of the carers had been looking after their relative or friend for 18 months or less ( $n=11$ ); at the other end of the range, one quarter had been caring for over five and a half years ( $n=12$ ). The median number of months of caregiving was 36 and the mean was 50 (SD±45).

#### *Self-rated health*

Two-thirds of the carers ( $n=32$ , 68 per cent) said they had a long term illness, health problem or disability that limited their daily activities. Over three-quarters of the co-resident carers ( $n=21$ , 78 per cent) and just over half of the others had an activity limiting condition ( $n=11$ , 55 per cent).

#### *Psychological health*

At interview, 42 per cent ( $n=20$ ) of the carers had GHQ scores of six or higher. This proportion included 21 per cent of carers with scores of 10-24 ( $n=10$ ), suggesting that they were highly likely to be in need of

psychological help. The mean GHQ score was 5.8 (SD±6).

Women were more likely than men to have GHQ scores of six and over. Carers who rated their health as fair or poor were more likely to score over the threshold than others. Nor were they associated with the older people's MMSE scores, with the amount of help that the carers gave them with household and personal care, or with attitude to residential care.

#### *General health status*

Table 1 shows the mean scores and standard deviations for each of the dimensions of the SF36. Overall, the vitality sub-scale, a measure of energy or fatigue, scored the lowest of the eight dimensions. The score for all carers was low with a mean of 52; with co-resident carers scoring even lower at 47. In part, differences between co-resident and other carers can be explained by age. The older age of co-resident carers may explain some of the differences in the physical functioning scores.

There was a significant difference between co-resident carers and others in their mental health and well being, whereby co-resident carers scored only 65 compared with 73 for the others. These differences in vitality and mental health could explain the differences in social functioning. Although, overall, the social functioning scale had the highest score, the difference between co-resident and non-resident carers was the greatest (65 compared with 82).

**Table 1: Mean scores on dimensions of SF-36 by carer co-resident or not**

SF36-Dimension	Co-resident Carer	Non co-resident Carer	All carers	Significance
	Mean (SD)	Mean (SD)	Mean (SD)	
Physical functioning	61 (28)	73 (28)	66 (27)	M-W <i>U</i> 193.5, <i>Z</i> =-1.651, <i>p</i> =0.09
Social functioning	65 (30)	82 (24)	72 (29)	M-W <i>U</i> 171.5, <i>Z</i> =-2.020, <i>p</i> =0.04
Role limitation (physical)	60 (43)	80 (29)	67 (39)	NS
Role limitation (emotional)	57 (43)	77 (36)	65 (41)	NS
Bodily pain	64 (32)	71 (27)	67 (30)	NS
Mental health	65 (17)	73 (20)	69 (19)	M-W <i>U</i> 177.5, <i>Z</i> =-1.998 <i>p</i> =0.046
Vitality	47 (18)	59 (22)	52 (21)	
General health perception	58 (19)	67 (26)	62 (23)	M-W <i>U</i> 177.0, <i>Z</i> =-1.843, <i>p</i> =0.065
<i>n</i>	27	20	47	

Mental health and vitality scores had the strongest correlation (Pearson's  $r=-0.73$ ,  $p<=0.001$ ). There was also a strong correlation between carers' GHQ-28 scores and mental health scores, (Pearson's  $r=-0.67$ ,  $p<=0.001$ ), where greater levels of psychological stress related to poorer mental health scores. Higher GHQ scores were also associated with more bodily pain ( $r=-0.55$ ,  $p<=0.001$ ), poorer perceived general health, ( $r=-0.51$ ,  $p<=0.001$ ), and poorer vitality scores ( $r=-0.55$ ,  $p<=0.001$ ). There was also a moderate association between GHQ scores and role limitation for emotional reasons ( $r=-0.41$ ,  $p<=0.01$ ), and to a lesser extent to poorer physical functioning, ( $r=-0.29$ ,  $p<=0.05$ .)

Looking at some of the individual items in the SF-36, on rating their health in general, the proportions of carers reporting that their health was excellent or very good, good, and fair or poor were 45 per cent ( $n=21$ ), 32 per cent ( $n=15$ ) and 23 per cent ( $n=11$ ) respectively. In terms of physical functioning, over two-fifths of the carers

were limited by their health in moderate activities, and over half were limited to some extent in bending or kneeling. Almost half the carers reported that bodily pain had interfered with their normal work such as housework in the past month.

Turning to mental health, 52 per cent of carers ( $n=24$ ) had felt downhearted and low 'more than a little of the time' in the past month. Responding to another question, 54 per cent of carers ( $n=25$ ) had been a happy person 'all or most of the time'. However, 30 per cent of the carers ( $n=14$ ) had felt so 'down in the dumps' that nothing could cheer them up 'more than a little of the time'. Finally, in the past month physical health or emotional problems had interfered to some extent with the normal social activities of half of the carers.

#### *Attitudes to long term care*

One fifth of the carers said that someone had tried to arrange for the older person to enter a home permanently and, likewise, one fifth of

the carers had been offered long term care for the older person. Most carers wanted to look after the older person at home for as long as possible. Of the carers, only 15 per cent (n=7) thought that a move into long-term care was the best way to help the older person in the future. The majority wanted to maintain the present situation, if necessary with increased help from a service already received or from a new type of service.

This preference was confirmed when the carers were asked whether they would accept residential care for the older person if it were offered now. Overall, 57 per cent of carers (n=26) said that they would definitely or probably not accept residential care, 39 per cent (n=18) said that they would definitely or probably accept it, and 4 per cent (n=2) could not decide. These proportions include the 29 per cent of carers (n=13) that would definitely not have accepted residential care and the 17 per cent (n=8) who definitely would have accepted it.

Sixty three per cent of the carers of older people living alone (n=10) compared with 27 per cent of the others (n=8) would have accepted residential care. However, none of the 10 spouses wanted residential care. We found no significant differences in the mean GHQ scores of the carers who felt positive about residential care and those who did not (mean 5.4 (n=18) and 6.3 (n=28) respectively).

The level of cognitive functioning of the older person did not influence the carers' reactions to residential care. Carers were less likely to want residential care for older people who were depressed than for those who were not depressed (39 per cent, n=7 compared with 80 per cent, n=12) This finding relates only to the older people who completed the Geriatric Depression Scale and also had carers, and caution must be exercised in interpreting these findings because of the small numbers.

## Discussion

### *Limitations of the study*

The study localities are in inner city areas, and the experience of caring in such areas may not be the same in other environments. The study sample was derived from those in contact with social services and so does not necessarily reflect the experience of all carers of frail older people. Those who did not participate in the study may have different experiences of caring, and different states of health, than those who took part. Although this sample of carers is small, nevertheless it shows important characteristics that are relevant to the provision of health and social care services to older people.

### *Mapping the health of carers*

The majority of carers are themselves limited in daily activities by physical health problems, and almost half reported chronic pain that impeded everyday activities. Low vitality and fatigue are commonplace, especially amongst co-resident carers. On the SF36 the vitality sub-scale, a measure of energy or fatigue, scored the lowest of the eight dimensions, in line with other studies (Brazier *et al.*, 1992). Two in five carers have GHQ scores in the 'case' range, and one in five have scores high enough to suggest significant depression. The distribution and correlates of GHQ scores are similar to those found in other studies of carers. (Levin *et al.*, 1994; Moriarty and Webb, 2000) The proportion of carers with GHQ scores above the cut-point is higher than that reported for adults in community surveys (13-28 per cent) and similar that found in people visiting their general practitioners (Bowling *et al.*, 1992; Boardman *et al.*, 1997). These findings justify focussed attention on the health of carers by both social care staff and primary medical care services, because of the high levels of potentially modifiable morbidity. This high level of morbidity may make it difficult to distinguish between ill health

attributable directly to the stress and strain of caring and ill health due to age-related pathological processes.

*Hypothesis 1: Carers have worse psychological health than non-carers, but similar physical health*

Our findings support the views that there is no association between the caring role and physical ill health, but that the psychological health of carers is worse than would be expected given their age.

*Hypothesis 2: Co-resident carers have worse self-reported health*

Our findings suggest that this is clearly true only of social functioning and mental health, but there were trends towards worse self-reported physical functioning and general health perception. These findings may reflect the older age of the co-resident carers, rather than any effect of caring at a higher intensity.

*Hypothesis 3 Carer's psychological distress is not associated with positive attitudes to long-term care*

Previous work suggests that a carer's attitude to residential care strongly predicts whether an older person subsequently enters it. Other studies report strikingly similar proportions of carers known to services that were definitely positive and definitely negative about residential care (Levin *et al.*, 1989; Sinclair *et al.*, 1990; Levin *et al.*, 1994). We have found that carers' attitudes to long-term care for the older person were not related to their own level of psychological distress, contrary to other findings (Moriarty and Webb, 2000).

Our findings also suggest that two factors that did affect attitudes to residential care were the relationship of the carer to the older person (spouse or not), and whether the older person was depressed. We understand the relationship effect but cannot explain the effect of depression with certainty. It may be a chance finding related to the small sample

size, but it is also possible that older people who were depressed may have been less likely to manifest challenging behaviours and, hence, easier to be with than the others.

### Conclusion

Social workers working with older people need to consider the physical and mental health of carers and to work with health professionals to alleviate physical symptoms (like chronic pain) and psychological distress, because the burden of morbidity is so high amongst carers. To the extent that psychological distress may be related to caring tasks in some individuals (if not in most) this will have implications for meeting carers' needs. Most responsibility, however, will lie with health rather than social services. Co-resident carers cope with a heavier burden of psychological ill health (as measured by the SF36) than non-resident carers, and arguably deserve particular attention. Social workers wanting to prioritise the assessment of carers' needs by selecting carers showing psychological distress would be justified in doing so in terms of reducing their problems, but this would not necessarily lead to reduced downstream expenditure, if our findings are correct.

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