

18 Carers

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*Extent of carer stress • Causes of carer stress • Effects of carer stress •
Ways of reducing carer stress • Elder abuse • Conclusion*

While it is recognised that caring for mentally and physically ill people can cause considerable stress, the precise nature of that stress, its causes and consequences remain unclear, despite a growing body of research.

Extent of carer stress

Early studies

Early studies on caring rarely included a comparison group of non-carers (reviewed by Baumgarten, 1989; Schulz *et al*, 1990). Without a control group it is difficult to determine whether care-giving is detrimental to health and well-being. Most carers are older people (average age around 60), who may experience problems of social isolation, poor health and unsatisfactory accommodation. These factors may contribute to impaired well-being, depression and difficulties in coping, quite independently from care-giving responsibilities. It was also unclear if caring for an older mentally ill person is more detrimental to health than caring for a younger mentally ill person, or an older person with physical illness.

Controlled studies

Controlled studies demonstrate that caring is stressful, as indicated by a wide variety of measures (see Box 18.1). Pruchno & Potashnik (1989)

Box 18.1 Measures of carer stress

Symptoms of psychological distress
Depressive symptoms
Psychotropic use
Medical care
Self-reported health
Immunological status
Stress scales
General Health Questionnaire scores

found that spouses looking after people with dementia were less likely to report good health; had higher rates of symptoms of psychological distress; higher rates of depressive symptoms; and were more likely to be taking psychotropic drugs, than age matched controls. Haley *et al* (1987) found that care-givers reported more depression; received more medication and health care; and reported poorer physical health.

Kiecolt-Glaser *et al* (1987) examined the immunological status of carers of Alzheimer patients and age- and gender-matched controls. They found several depressed immunological indicators in the carers, suggesting that prolonged strain had impacted on their physical health.

Importance of mental illness

Eagles and his colleagues (1987) found that the care-givers of elderly people with dementia scored higher on a strain scale than carers of elderly people without dementia. They did not differ on a measure of 'psychiatric morbidity'. This study is important because it involved carers recruited from a community survey, rather than from contact with services. The Hughes Hall Project for Later Life (O'Connor *et al*, 1990) provides some of the strongest evidence on the effects of care-giving for people with dementia. From a study group of over 2000 people, aged over 75, two groups of carers were identified: those caring for people with dementia and those caring for people without dementia. A measure of carer strain, but not scores on the General Health Questionnaire (GHQ; Goldberg, 1972) showed increasing strain with the severity of dementia. Gilleard (1984) found an overlap in the distress of carers of patients attending geriatric and psychogeriatric day hospitals in Scotland. In the psychogeriatric day hospitals, 63% of patients had dementia and 65% of carers scored 'psychiatric distress' on the GHQ. In the geriatric day hospitals only 8% of the patients had dementia while 46% of the carers scored distress. Carers in the two settings complained of similar behavioural problems.

Whittick (1988) compared the GHQ scores of middle-aged women caring for either a learning-disabled child or a parent with dementia. She found that the care-giving daughters reported significantly more distress than the care-giving mothers. Birkel (1987) found evidence of greater distress in the carers of mentally ill elderly people compared with the carers of physically ill, but mentally well elderly people. On the other hand, Liptzin *et al* (1988) found no difference in the reported burden between carers of depressed elderly clinic patients and carers of elderly clinic patients with dementia.

Although not always consistent, the evidence suggests that looking after people with dementia is a particularly stressful activity, which can impair health (Schulz *et al*, 1995). Psychiatric morbidity, especially depression, is more likely to occur in carers. There is less consistent evidence that caring affects the physical health of carers.

Causes of carer stress

Behavioural problems

A number of reviews (Morris *et al*, 1988; Baumgarten, 1989; Dunbar, 1995; Schulz *et al*, 1995) have concluded that behavioural problems contribute consistently and significantly to the level of stress experienced by carers. Several studies have reported positive correlations between the severity and frequency of problems and carer strain (Gilleard, 1984; Eagles *et al*, 1987; O'Connor *et al*, 1990).

It is difficult to establish which problems are most stressful for carers, as this may vary with the stage of dementia of the patient and the life course of the carer. O'Connor *et al* (1990) and Gilleard (1984) found strain to be most strongly associated with disturbed behaviour. Argyle *et al* (1985) found that behavioural disturbances (abuse, aggression, smearing and inappropriate micturition) and night-time disturbance were reported as being particularly difficult to cope with (see Chapter 6).

Poor communication

The importance of problems with communication has been reported in a number of studies (Greene *et al*, 1982; Gilleard *et al*, 1984; Argyle *et al*, 1985; O'Connor *et al*, 1990). This may explain why carer abuse is more common in patients with stroke and communication disorders (Homer & Gilleard, 1990).

Formal relationship

The significance of the formal relationship between carer and dependant has been examined in several studies of carer stress. Some studies have found that adult sons and daughters report more stress than wives or husbands (Gilleard *et al*, 1984; O'Connor *et al*, 1990) while others have found higher distress among spouses (Brodaty & Hadzi-Pavlovic, 1990; Baumgarten *et al*, 1992; Graftstrom *et al*, 1992).

A consistent finding is that husbands who care for a partner with dementia report lower stress and higher morale than wives (Zarit *et al*, 1986; Pruchno & Potashnik, 1989; O'Connor *et al*, 1990; Baumgarten *et al*, 1992; Mittelman *et al*, 1995). This may be explained by the coping strategies men use, and the assistance they receive (Gilhooly, 1987). Gilhooly found that male carers:

- (a) Adopted a more behavioural and practical approach to care-giving.
- (b) Were more able to distance themselves from their care-giving duties.
- (c) Found help with care-giving more socially acceptable.
- (d) Found help more readily available.

In addition, disinhibition associated with dementia may be more threatening to women than men. Personal violence from a husband with dementia, or excessive or inappropriate sexual demands, may be particularly stressful for wives who look after their husbands. Such experiences are largely absent in husbands caring for wives (Wright, 1991).

Home environment

The home environment may be an important factor in carer stress, especially in inner cities, where some couples find themselves isolated in multi-storey flats. Problems include poor support, endemic violence and cramped living conditions. While many clinicians automatically consider the adequacy of the home when making a domiciliary visit, it is remarkable that the contribution of housing conditions to care-giving stress has not been researched.

Premorbid closeness

Ratings of the quality and closeness of the premorbid relationship are negatively associated with carer stress (Gilleard *et al*, 1984; Morris *et al*, 1988). This may reflect the long-term effects of a positive emotional investment, or a retrospective view biased by present difficulties. One study favouring the former interpretation, found that premorbid relationship ratings did not change when carer stress was reduced by day hospital attendance (Gilleard *et al*, 1984).

Links have been established between a poor premorbid relationship, high expressed emotion in carers (Gilhooly & Whittick, 1989) and carer neglect (Homer & Gilleard, 1990). Clinically, the psychopathology of caring can often be traced to long-standing relationship disturbances, whether marital or parent-child. This is an area where family therapists can play an important therapeutic role (Richardson *et al*, 1994). A continuing sense of closeness between carer and dependant may sustain a sense of well-being in carers (Motenko, 1989).

One intriguing set of interactions are those between problem behaviours, premorbid relationships and distressed carers. While behaviour disorders are not simply the result of inter-personal and intra-personal pathology, it can be difficult for carers to separate problems caused by the 'mindlessness' of cortical decay from the 'wilfulness' resulting from expressed and unexpressed hostility in the relationship. The attributions made by carers are affected by the past, which continues to influence the manner in which difficulties express themselves in the home.

A number of factors, including the uncertainty surrounding dementia; the meanings to be attributed; the responsibilities to be taken on; and the extent to which the identity of the carer is challenged by the progress of mental decay, contribute to the stress of caring for someone with dementia.

Box 18.2 Factors associated with carer stress

Behavioural problems
 Poor communication
 Formal relationship
 Home environment
 Premorbid closeness

While research provides broad brush indicators (see Box 18.2), only good clinical practice can flesh out the complexities of meanings and misunderstandings that contribute to individual stress in care-giving.

Effects of carer stress

There are many potential effects of carer stress (Box 18.3). Importantly, carer stress can lead to the loss of supporting relationships. This is costly for society, dependants and carers.

Ways of reducing carer stress

There are several interventions that have been employed to reduce carer stress (Box 18.4), although few have been subject to careful controlled evaluation.

Respite care

Respite for carers tends to be provided as respite admissions or respite day care. However, a number of voluntary agencies offer 'sitting services', where a volunteer will stay at home with the dementing person while their relative has a break.

Despite some worrying findings (Rai *et al*, 1986) there is little evidence that respite hospital admissions lead to a deterioration in the health of

Box 18.3 Effects of carer stress

Increased use of expensive resources
 Elder abuse
 Withdrawal of carers from productive employment
 Poor relationships between carers and services
 Unhappy carers
 An uncaring society

Box 18.4 Factors which may reduce carer stress

Respite care
Home care support
Carer groups
Individual counselling
Family therapy
Institutionalisation

dependants (Seltzer *et al*, 1988; Selley & Campbell, 1989). Carers report significant benefits for themselves, such as better sleep, more free time and more socialising. Interestingly, over half of carers reported feeling sad or lonely while their relative is in hospital (Pearson, 1988). Although respite care is popular, controlled studies have failed to demonstrate clear-cut benefits for carers (Burdz *et al*, 1988; Lawton *et al*, 1989). The latter study was a comprehensive evaluation of respite care. Lawton *et al* concluded that the recipients of respite care resoundingly endorsed it, but neither their care-giving attitudes nor their physical and mental health varied according to the amount of respite they received (Lawton *et al*, 1989).

Studies of psychogeriatric day care also report high levels of consumer satisfaction (Panella *et al*, 1984; Diesfeldt, 1992). While no studies involving controlled comparisons have been conducted, there is evidence that some patients continue to live in the community as a result of reduced carer stress (Gilleard, 1987). The impact of in-home respite care has been less well examined, although some 'sitting services' are reported to have a favourable impact (Cloke, 1988; Turvey & Toner, 1991).

It seems that while respite receives high marks in terms of customer satisfaction, there is no direct evidence for its beneficial effects on the health of carers or patients (Knight *et al*, 1993).

Home care support services

Studies on the impact of augmented home care and case management have reported improvements in the well-being of carers (Challis *et al*, 1990). The problems of caring for someone with dementia are difficult to resolve through an enhanced 'package of care' model because of the psychological significance of the disease. However, the Lewisham intensive case management scheme showed that gains can be made. Less intensive interventions have failed to demonstrate this (Challis *et al*, 1996).

Not all studies are positive. Askham & Thompson (1990) found no evidence that the Guy's Age Concern Home Support Project led to greater carer well-being than 'services as normal'. Similarly, O'Connor *et al* (1991)

found that an early home intervention service had no measurable benefits beyond accelerating the process of institutionalisation of some elderly people with dementia living alone. Levin *et al* (1985) examined the effects of domiciliary services on carer stress and the rates of institutionalisation. They found that respite and home help services were associated with reduced carer stress. Other cross-sectional studies have not confirmed this finding (Gilhooly, 1987; Dunbar, 1995).

Carer groups

While home care support services offer input to patients and carers, carer support groups target the specific needs of carers. Groups have traditionally formed around statutory services such as day centres, day hospitals, nursing homes or hospital wards, and around voluntary organisations like the Alzheimer's Disease Society. A number of studies testify to the value of these groups, at least in the short term. These studies highlight the importance of: educational input (Chiverton & Caine, 1989); emotional support (Zarit & Zarit, 1982); and behavioural and problem-solving skills training (Gendron *et al*, 1986).

It has not been established which carers benefit most, and from what groups, but carers probably vote (if choices are available) with their feet. Carers whose relative is in some form of institutional care may obtain as much benefit as those involved in active caring. It is important not to overlook carers whose dependant has recently been admitted into 'care' (Rosenthal & Dawson, 1992).

There is evidence from Sydney that small carer groups which focus on enhancing coping skills lead to significant reductions in distress and institutionalisation (Brodaty & Gresham, 1989). One intriguing finding was that the 'waiting list' control group, who entered the programme six months after referral, failed to benefit psychologically. Brodaty & Gresham suggest that early interventions are effective in teaching preventative coping strategies. This is consistent with findings elsewhere (O'Connor *et al*, 1991).

Individual counselling

Individual counselling may achieve greater stress relief than group programmes (Collins, 1988; Knight *et al*, 1993). Family therapy has been reported as a useful intervention (Ratna & Davis, 1984; Benbow *et al*, 1990), although there are no systematic evaluations to date (Richardson *et al*, 1994). The results of one of the few randomised controlled trials of individual and family counselling did demonstrate a significant impact on reducing levels of spouse-care depression (Mittleman, 1995). Selecting carers for individual counselling remains a clinical and resource decision.

Elder abuse

The ill treatment of older people is not new, but was not reported until 1975. Alex Barker, a psychiatrist and the first director of the Hospital Advisory Service, reported “granny battering”. Elder abuse is now defined as “a repeated act against, or failure to act for, an elderly person, which causes distress or damage, and so prevents the living of a full life” (Fisk, 1997). Abuse takes many forms (Benbow & Haddam, 1993) (Box 18.5), and occurs in domestic and institutional settings.

In one study of older people admitted to respite care, 45% of carers admitted to carrying out some form of abuse. Important factors included alcohol, a poor previous relationship and reciprocal abuse (Homer & Gilleard, 1990). In the USA, Godkin *et al* (1989) found that 41% of abusing carers had mental health problems compared to 5% of non-abusers.

The USA has been quicker to recognise and act against elder abuse, and reporting elder abuse is mandatory in 80% of the USA. In the UK, reporting is not mandatory and social services have given it a lower priority than child abuse. However, most social services have guidelines, as have some NHS trusts. Age Concern and the British Geriatrics Society have fostered education, and there is an Elder Abuse Response helpline (0800 731 4141).

Fisk (1997) writes:

“Abuse appears in many forms and for many reasons. Close relatives, professional carers and society at large make victims of the elderly by reason of greed, revenge, desperation or ignorance. We urgently need better methods of identifying those who have been abused; of counselling or removing abusers; and of preventing abuse.”

Well-organised psychiatric services for old people should have high levels of suspicion and of compassion for abusive situations. Better services, which take full account of the strain on carers, may reduce abuse.

Conclusion

Caring for elderly mentally unwell people at home is difficult and often distressing. The distress is more commonly seen in carers who are already

Box 18.5 Forms of elder abuse

Physical violence
 Verbal abuse
 Neglect
 Financial exploitation
 Sexual abuse

in touch with services, which itself may be seen as a marker of potential breakdown of care. Children are at least as affected as partners, and daughters and wives more often than sons and husbands. Poor relationships usually get worse and the ill health of the carer or poor home conditions add to the difficulties. Behavioural (action oriented) coping strategies and reordering life's priorities (where possible) may improve the situation of carers. Practical assistance in the home via home helps improves carer well-being, although other domiciliary services have not been shown to have clear benefits. Similarly, respite care seems to help those who use it, although this is difficult to demonstrate in studies. Many carers of people with moderate or severe dementia only find relief when their relative goes into a home or hospital. Counselling may help carers who find this move a traumatic one. One must recognise that dementia remains for most carers a very personal tragedy.

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