
Burden of care in the home: issues for community management

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The number of beds available in the UK for the treatment of mental illness has fallen by over two-thirds since its peak in the mid-1950s. There is a worldwide trend of closure of large mental hospitals and integration of services for the mentally ill in their own local community. Community surveys have shown that an overwhelming majority of mentally ill people are treated in primary care or by specialists, but without being admitted to a hospital. This is now the preferred clinical practice (Shepherd *et al*, 1981).

Public acceptance of mental illness, use of depot neuroleptics, structured care and rehabilitation programmes, and in recent years the use of atypical antipsychotic drugs such as clozapine, crisis services and assertive outreach programmes have made the process of community-based treatment successful, at least in a proportion of people with severe mental illness (cf. Dean & Gadd, 1990; Holloway, 1991; Kerwin, 1995). However, as the number of hospital beds decreases, admissions have become shorter and patients are often discharged before they are fully recovered from an acute psychotic episode, with case management in the community (Powell *et al*, 1995). Families frequently complain of the abrupt 'dumping' back home of hospitalised and barely improved patients, often with considerable pressure and frequently without reasonable notification (Hyde & Goldman, 1993).

After discharge, up to 60% of first-admission patients return to live with their relatives (MacMillan *et al*, 1986), and when subsequent admissions are included, up to 50% of schizophrenic patients return to live with their supporter (Gibbons *et al*, 1984). In a survey conducted at the Maudsley Hospital, London, 40% of men and 46%

of women with long-standing mental illness lived with their families, and others lived in close proximity to relatives who provided a major supporting role (Mullen *et al*, 1992).

Minkoff (1978) estimated that 35–40% of discharged patients return to spouses and 35–40% to parents and other relatives. In Gibbons' study (Gibbons *et al*, 1984), 25% of the principal care-givers were aged 65 and over; and 11%, nearly all mothers, were over 75 years old. About 30% of care-givers were living alone with their ill relative. In a Camberwell survey over 50% of chronic schizophrenics were living with their parents or siblings; in many cases middle-aged single schizophrenics were living with their elderly parents (Stevens, 1972). In three studies from the USA, 80% or more of the known care-givers were parents in their late 50s or 60s (Lefley, 1987).

Care-giving burden

Studies have provided consistent evidence that the care-givers of persons with chronic mental illness suffer from a number of significant stresses and moderately high levels of burden (Grad & Sainsbury, 1963; Hoenig & Hamilton, 1966; Stevens, 1972; Fadden *et al*, 1987; Fisher *et al*, 1990). The care-giver is usually a relative of the ill person and the care given is invariably continuous. The care-giver often has additional responsibilities in the family and many of the ill recipients do not acknowledge or even recognise the assistance and help they are receiving. The care is given because of emotional bonding, duty, guilt and/or the lack of other available services in the community.

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The experiences of care-giving have been loosely linked together by the rather ill-defined concept of family burden. Burden has been seen as indicative of the breakdown of reciprocal arrangements that people maintain in their relationship, such that one person is doing more than their fair share. This may result in them taking on a greater proportion or number of shared tasks while restricting their other activities. This is accompanied by subjective dissatisfaction (Fadden *et al*, 1987).

Hoenig & Hamilton (1966) distinguished between subjective and objective burden. 'Subjective burden' is typically viewed as the emotional cost of the illness to family members (feelings of embarrassment, resentment and helplessness), whereas 'objective burden' is defined as the disruption to the everyday family life of the ill persons' relatives (e.g. financial burden, loss of free time, conflict with neighbours). However, investigators have not always been clear whether to include care-givers' personal distress as a component of subjective burden or as an outcome of burden

Although it is possible to distinguish between the individual stressors that relatives may experience and the resulting strain that these difficulties produce, the status of burden cannot be separated easily from either the stressors or the impact those stressors have on the individual. At the same time, most measures of burden relate specifically to the stressful effects of the relative's mental illness and are kept separate from those measures of more general strain and/or distress which can apply to individuals irrespective of their role as care-giver (Maurin & Boyd, 1990).

Measurement of burden

Agreement about what constitutes burden is limited and some have suggested abandoning the term altogether (Szmukler *et al*, 1996). When the term is used there are differences of opinion regarding how to sub-classify and measure it adequately. Different variables in subjective and objective burden (social stigma, dependency, marital disharmony, financial stress, physical abuse) might have different levels of impact on different care-givers, and the outcome of that stress might not be the same for all individuals.

Perhaps because of these disagreements there is a wide variety of burden instruments used in research. These have been reviewed by Platt (1985) and more recently by Schene *et al* (1994). These reviews make three broad points:

- (a) there is no agreement on the definition of the term burden;
- (b) there is more or less agreement on the dimensions that comprise burden; and
- (c) there is a need for further work to establish adequate psychometric properties of reliability and validity for the various scales used to measure burden.

It is possible to identify certain key dimensions of burden that have been assessed. These key dimensions are summarised in Box 1.

Dimensions of burden

Symptom-specific impact

There are several psychiatric symptoms, especially in people suffering from schizophrenia, that their care-givers find it difficult to deal with and which cause them to feel distressed and helpless. Behavioural disturbance, physical and verbal abuse, threatening and other dangerous irresponsible behaviour, are commonly found in schizophrenia and bipolar disorder.

Relatives show a surprising tolerance to disturbed behaviour (Waters & Northover, 1965). However, they reach a point of distress at which even they cannot continue coping with it. Supporters perceive that they are left to deal with substantial levels of difficult behaviour (MacCarthy *et al*, 1989). Creer & Wing (1974) reported that none of the relatives had received advice from professionals on the management of difficult behaviour,

Box 1. Dimensions of burden

Symptom-specific burden impact of the disability associated with the illness itself, both in terms of demands for assistance and supervision, and regarding the potential stigma associated with the illness

Social burden impact on family and other social relationships

Emotional burden impact on mental and emotional well-being

Financial burden impact on work and the general financial costs of care-giving

and some of them worked it out by trial and error. Relatives find aggressive behaviour, delusions, confusion, lack of self-care, apathy, anhedonia and extreme reclusiveness very burdensome (Hoening & Hamilton, 1966; Fadden *et al*, 1987; Lefley, 1987). At the same time, relatives often view negative symptoms as not being part of the illness but as 'laziness' and under full voluntary control. This can lead to over-critical comments by the relatives, which increase the uneasy atmosphere within the house. Likewise, the illness may lead to inactivity and a lack of shared responsibility. In Gibbons *et al*'s (1984) study, over 75% of schizophrenic patients had limited activity and gave little support, affection or (where appropriate) sexual love.

Social burden

Living with a relative who has a major mental illness has a severe impact on the care-giver's social and leisure activities. Social contacts can be reduced and care-givers can find themselves becoming increasingly isolated (MacCarthy *et al*, 1989). A relative may perceive psychiatric illness as a stigma and might not mix with others, or the ill relative's behavioural disturbance might make socialisation difficult. This is viewed by many relatives as a burden, as their own leisure activity sometimes cannot be undertaken. In other cases the patient ceases to go out, imposing further limitations on the social life of their partner (Fadden *et al*, 1987). The patient may contribute very little to household tasks and their contribution may not be welcome because their relative feels that any tasks performed simply add to their own work (Stevens, 1972). Quarrels and tension over domestic responsibilities may lead to an oppressive atmosphere within the home (Gubman *et al*, 1987). This in turn can lead to the gradual erosion of visits from friends, neighbours and other family members (Pai & Kapur, 1981).

Emotional burden

Relatives of mentally ill people make great sacrifices in their role as care-givers. They tend to tolerate disturbed behaviour and rarely complain. The feelings and conflicts produced by their care-giving responsibilities can have considerable impact. Studies have shown that about one-third of care-givers report three or four symptoms of emotional distress (MacCarthy *et al*, 1989). The level of care-giver distress has been related directly to the severity of the relative's psychosis and disturbed behaviour (Gibbons *et al*, 1984). Worry

about what will happen when they die or become too frail to help can affect older care-givers (Stevens, 1972; Cohler *et al*, 1991), and some family members can experience a sense of guilt or feel that they are to blame for their relative's illness (Sargeant, 1993).

Studies have shown that there is often a sense of sadness among family members of severely mentally ill persons, which has been likened to a delayed grief reaction reflecting the difficulties of coming to terms with the loss associated with the illness (Miller *et al*, 1990). There is also the distress arising from the care-giver's empathic response to the patient's own failed aspirations and impoverished life (Lefley, 1987).

Financial burden

Mental illness imposes an economic as well as a social cost to individuals, and to their families. Several studies have shown increased financial dependence and unemployment in people with psychiatric disorders (Rupp & Keith, 1993; Leon *et al*, 1995). Sometimes, a care-giver has to give up work to look after their ill relative. In the Camberwell Study only 38% of supporters were in the job market or looking for work (MacCarthy *et al*, 1989). When, in addition to mental illness, there is alcohol and substance misuse, as in almost half the patients suffering from schizophrenia, the economic burden is even greater (Clark, 1994). It is not uncommon for parents of an adult with schizophrenia to bail him or her out of debt. When parents as care-givers are elderly and on a pension, this can lead to poverty, social isolation, poor dietary habits, overcrowding (when a schizophrenic child returns home) and lack of leisure activities (Stevens, 1972).

Stigma, suicide and abuse

Mentally ill people are portrayed in the media as 'maniacs' who cannot be trusted, and such media coverage has considerable impact on how people view the mentally ill (Hyler *et al*, 1991). Families also carry this stigma and become socially isolated (Kuipers *et al*, 1989). This stigma has a negative impact on the rehabilitation of long-stay mentally ill people into the community, reducing social integration and increasing the isolation of both mentally ill people and their relatives (Wolff *et al*, 1996).

It is well known that mental illness can lead to suicide, and any attempt at suicide increases

vulnerability to future suicide (Hawton *et al.*, 1993). Unemployment, substance misuse, personality disorder and social class V are also factors associated with subsequent suicide (Morgan, 1993). Some of these factors could increase family burden through socio-economic deprivation and 'fear' of further suicide attempt by their relative. Previous suicide attempt of their relative or the threat of suicide can cause families to live under constant worry, significantly increasing further the burden on care-givers (Jones *et al.*, 1995).

The association between violence and mental illness is well known, but fortunately accounts for a minute proportion of society's total violence. In a recent review Monahan (1992) stated:

that even after taking into account social, demographic factors, patients in institutions or people chosen randomly from the open community, there appears to be a relationship between mental disorder and violent behaviour. Mental disorder is a risk factor for the occurrence of violence.

Several studies have shown that psychiatric in-patients and out-patients commit violence against staff (Link, 1992; Crichton, 1995). Link (1992) has found that psychiatric out-patients were engaged in significantly more violent behaviour than the community residents. About one-tenth of psychiatric in-patients commit violent assaults against hospital staff (Health Services Advisory Committee, 1987).

Among pre-trial prisoners, over 90% of psychotic men (and 50% of non-psychotic men) were well known to the psychiatric services before their offence, but only 25% of the psychotic men with active symptoms were receiving any specific treatment for their illness at the time of offence (Taylor & Monahan, 1996). In a study of people with schizophrenia who had killed, 90% had been discharged by psychiatric services about six months previously (Hafner & Baker, 1973).

In a British study (Humphreys *et al.*, 1992) conducted on 253 patients with a first episode of schizophrenia, 52 patients behaved in a potentially life-threatening manner. In 85% of cases the violence was deliberate, in that it was directed towards a particular person or persons. This study did not include patients who were verbally abusive or threatening. However constant threats and verbal abuse can be extremely distressing to the carer.

In a USA study of 1401 families, conducted by the National Alliance for the Mentally Ill, where a family member had a serious mental illness (mainly schizophrenia or mood disorder), it was reported that 10.6% of individuals with serious mental illness had physically harmed another person, and another 12.2% threatened to harm

another person. The study found a marked gender difference among those threatening to harm (24.9% males *v.* 12.5% females), but surprisingly little gender difference among those actually harming someone (11.9% males *v.* 9.5% females) (Steinwachs *et al.*, 1992).

Several other studies have reported aggressive behaviour and threats to others by their mentally ill relative (Grad & Sainsbury, 1963; Gibbons *et al.*, 1984). In Gibbons *et al.*'s study (1984), 49% of the schizophrenic patients exhibited harmful, threatening and noisy behaviour that caused distress to over 95% of their care-givers. There was evidence of hardship in 90% of the households. Supporters' subjective distress was directly related to the presence of psychosis and disturbed behaviour, and inversely related to the duration of illness.

Families often do not report physical abuse or verbal abuse by a mentally ill relative. Creer & Wing (1974) reported that the relatives of their schizophrenic group rarely complained about their difficulties for reasons of shame, guilt, denial of problems or unfavourable experiences when they had sought help. In their study, none of the relatives had received advice from professionals on the management of difficult behaviour at home.

Although several studies have reported violence and disruptive behaviour and their effect on family members, systematic studies looking at abuse and burden are lacking. Currently available scales measuring burden concentrate upon global categories of behaviour associated with burden and provide little detailed information about domestic abuse experienced by the care-givers, and its effect on their mental health.

In a study conducted on acute admissions to a Melbourne psychiatric unit we developed a semi-structured interview examining burden, carer abuse (e.g. losing temper, shouting, swearing, destroying household property, wounding, etc.) and the premorbid relationship between patients and their care-giving relatives (Vaddadi *et al.*, 1997, *in press*). Care-givers completed the General Health Questionnaire (GHQ; Goldberg & Williams, 1988). Three-quarters of the carers experienced verbal abuse and one in eight experienced physical abuse on several occasions, while 45% of the carers reported at least one episode of actual or threatened physical abuse. Eighty per cent of carers scored at a level of caseness for emotional and psychiatric disorder (GHQ >4). Patients with schizophrenia were more likely to lose their temper and strike the carer. Likelihood of abuse increased if the patient had schizophrenia, had a past or current history of drug misuse and a poor pre-episode relationship with their care-giving relative.

Burden of care and its management

People who care for a chronically mentally ill relative feel a severe burden, but often do not complain, and need practical and emotional support in the ongoing care of their ill relative.

The needs of the patient may be entirely different and unrelated to the care-giver's needs. Care-givers (parents especially) may have unexpectedly high goals set for their ill child, who might never achieve these. Such differences between the ill person and their care-giver produces considerable conflict and burden. For example, a schizophrenic son who just wants to stay at home, smoke cannabis and lead a life without goals may be living with his mother who would like him to move out of the house, socialise, complete his education, and marry. The different needs of these two individuals should be addressed separately and a carefully planned intervention programme discussed with them to lessen the conflict and reduce the burden of care.

Families become apprehensive and helpless when the same illness occurs repeatedly and with gradual functional deterioration. Therefore, the multi-disciplinary team needs to meet at regular intervals to discuss the clinical care programme, and both client and carer must be involved if therapeutic success is the goal. There are a number of strategies to reduce family burden and thereby enable both patient and carer to be helped.

Educational sessions

When families and clients are given adequate and clear information about their illness, the side-effects of drugs, advice about what signs to look for in case of relapse and illness-related employment issues, their therapeutic compliance increases and it helps to build a therapeutic relationship with the family. Staff should be prepared to admit that they do not know certain things about the illness and be prepared for repeated discussions and make constructive suggestions. This will not necessarily change the prognosis, but by making carers more aware of what to expect in ensuing years, they can make alternative arrangements to help reduce the burden and cope with the illness. The beneficial effects on care-giving burden of educational interventions have been shown in a number of studies (Kuipers *et al*, 1989; Birchwood *et al*, 1992).

Family therapy and relative group meetings

Environmental stress has been implicated as an important factor in the relapse of schizophrenia. Effective coping behaviour is crucial for households in which one or more person suffers from a chronic illness that is made worse by stress. Critical, hostile or rejecting attitudes, or emotionally over-involved and intrusive behaviour have been implicated as having a particularly deleterious effect on persons with schizophrenia. Research has shown that in neuroleptic-maintained schizophrenic patients, decrease in relatives' expressed emotion (EE) and/or less face-to-face contact with high-EE relatives appeared to be associated with a lower relapse rate (Leff *et al*, 1990).

While research in EE tends to identify the relative as a source of conflict and potential relapse and focuses upon changing the relatives' behaviour toward the patient, the use of relatives' groups, counselling and home support have been found effective in reducing care-giver burden (Pai & Kapur, 1983; Leff *et al*, 1990). These can be low-cost, effective techniques for families with severely mentally ill relatives (Kuipers *et al*, 1989).

Physical and verbal abuse and problem-solving

Physical and verbal abuse by a mentally ill relative could be multifactorial and needs proper evaluation. Underlying personality disorder, relapse of psychotic illness, use of illicit drugs and alcohol, and learned behaviour could all contribute to an aggressive outburst. Aggressive and threatening behaviour could be a means of achieving a goal. In high-EE households, over-criticism could be a cue to trigger aggressive behaviour towards the carer. Certain other behaviours, like excessive sleeping and refusing to do any housework, could create considerable tension in the household, leading again to criticism, verbal abuse and threats of violence.

Staff could help the family to understand the unacceptable or distress-producing behaviour and to focus on the dynamics and outcome of each behaviour, rather than on the individual. These problem behaviours could be broken down into smaller steps, and some behaviour modification strategies discussed with the involvement of all parties concerned. These need to be clearly written down, and outcomes and difficulties discussed at each session, with positive encouragement. It is also important to discuss relationship issues. A

poor interpersonal relationship can sometimes lead to impulsive behaviours.

Continuity of clinical care

Many families are dissatisfied with mental health services (Grella & Grusky, 1989). Frequently they complain of having to see a new doctor or nurse every six months and repeat histories. They also complain of medication being changed for no good reason (Hyde & Goldman, 1993), and of patients being given early discharge before symptoms are under control. Relatives prefer not to be held responsible for giving their ill relative oral tablets. Patients who do not like to take medication might see their relative as acting against them and this can be an enormous responsibility placed on relatives. Where possible, if compliance is an issue, depot neuroleptics should be considered.

Severely mentally ill people need consistency and continuity of care. Frequent staff changes are counter-productive therapeutically and generate undue anxiety in the care-giver. Involvement of a psychologically minded general practitioner, who could work with the community mental health team and the family is very useful, to maintain some consistency. An individual care programme should be discussed with the patient, the key-worker and whenever possible the care-giver should be included. The existence of a supportive and accessible relationship with the patient's keyworker or case manager plays a major part in reducing family burden and dissatisfaction (Grella & Grusky, 1989).

Psychological support for the carer

Families of mentally ill persons continue to be the major care-givers. They carry this burden for years without a break. It can take them years to accept the illness and they may search for new solutions because of the relapsing nature of the illness. They suffer from anxiety, depression, anger, guilt and insomnia, and feel sad and helpless as they witness the perceived loss of a once healthy relative. The stress associated with this burden of care, and the guilt feelings in both the ill relative and carer need to be addressed and treated. Discussing these issues in relatives group meetings or family sessions is a good beginning, as solutions could be found. Relatives' groups are helpful in offering psychological support with these problems (Kuipers & Westall, 1992).

Specific counselling has been proposed for relatives who experience severe difficulties in coming to terms with the patient's illness, and

several reports of effective counselling interventions have been reported (Pai & Kapur, 1983; Kuipers *et al*, 1989; Miller, 1996). Social support has been shown to buffer the effects of chronic life stresses and reduce the risk of depression (Cobb, 1976; Brown & Harris, 1978). Relatives should be encouraged to foster and/or maintain a positive social support network of their own.

Alternative accommodation, day centres and respite

As the care-givers get older, they themselves develop physical and/or psychological problems. It then might not be possible for them to continue the burden of looking after their long-term mentally ill relatives. Alternative supervised accommodation (e.g. hostel, group home) needs to be cautiously discussed with the family.

Alternatively, drop-in centres and day centres can give partial relief to the care-givers, as well as giving some structure to the patient's day, and helping them to socialise. Respite homes for patients with schizophrenia run by voluntary agencies give the carers a break from continuous duty.

Relatives themselves need to attend support groups and leisure activities to reduce the isolation that can arise from the care-giving role. Organisations such as the National Schizophrenia Fellowship and SANE (Schizophrenic: A National Emergency) have informal carers meetings, and these are often very useful.

Some of the principal management strategies to ameliorate the burden of care experienced by family members are summarised in Box 2.

Box 2. Management of burden: key points

- Use of the Care Programme Approach involving the care-giver
- Care-giver education about illness
- Developing strategies to address threats and aggression
- Family therapy and/or counselling
- Emotional and social support for the care-giver
- Relatives' support groups
- Respite care
- Day centre and/or drop-in services for the patient

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Multiple choice questions

- The following terminology has been used in burden research:
 - subjective burden
 - objective burden
 - family burden
 - community burden.
- The following statements are true:
 - burden among carers and families of schizophrenic patients is absent
 - the impact is financial rather than social
 - after discharge from hospital, most schizophrenics live in group homes or rented accommodation
 - families are generally satisfied with the contacts they have with mental health services.
- Studies have shown that:
 - substance misuse and mental illness increase family burden
 - carers of mentally ill people can develop a delayed grief reaction
 - one-third of carers of mentally ill people develop symptoms of stress
 - negative symptoms of schizophrenia do not burden relatives.

- It has been shown that:
 - mental disorder and violence are not significantly associated
 - one-tenth of psychiatric in-patients commit violent assaults against hospital staff
 - carers are rarely abused physically by mentally ill relatives
 - families do not always report abuse by their relative to staff.
- The following interventions are useful to reduce caregivers' burden:
 - family therapy
 - information about illness and drug side-effects
 - problem-solving techniques
 - relatives' support groups.

MCQ answers

1	2	3	4	5
a T	a F	a T	a F	a T
b T	b F	b T	b T	b T
c T	c F	c T	c F	c T
d T	d F	d F	d T	d T