

# From family 'burden' to caregiving

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In a recent review, Perring *et al* (1990) note: "carers of people diagnosed as having a mental illness have been neglected in the main carer literature, which tends to concentrate on carers of people who require some physical tending. By contrast, literature in the psychiatric and psychological fields, which has developed quite separately, has tended to marginalise the position of carers, or 'relatives' in favour of concentrating on the well-being of the identified patient. Only rarely has this latter work looked at relatives in their own right". This despite the central, though easily hidden, role of carers in a mental health policy fostering 'care in the community', and the evidence that their distress and morbidity are substantial (Fadden *et al*, 1987).

Until recently, relatives seldom asked for help, believing the patient should be the beneficiary of care. At the same time dissatisfaction by families with treatment and mental health services has been common (Hatfield, 1987). Relatives have seldom been involved in care planning. The perception that families are to blame for a member's mental illness, although eschewed today, leads to misunderstanding. Even work on 'expressed emotion' (EE) is sometimes seen by carers as perpetuating the idea that relatives are in some way responsible for the illness or for a poor outcome (Lefley, 1992). The question of whether the needs of patient and carers may ever be in conflict has been rarely raised (Bloch *et al*, 1994).

Research into the responses of carers of a mentally ill relative has gradually increased. Their central role in community care has become acknowledged, and the idea that their needs should be met receives political support. Their involvement in care planning has even been enshrined in a piece of recent legislation, the Mental Health (Patients in the Community) Act 1995 in which 'supervised discharge' orders will require consultation with the patient's carer.

It is generally agreed that carers experience a wide range of problems and that caregiving is best seen as multidimensional. Schene *et al* (1994) have surveyed some 21 measures of family 'burden', most of them dating from the last decade. Commonly included dimensions are the

effects of the illness on: family interaction, family routine, leisure opportunities, work/employment, mental health of the carer, physical health of the carer, children, others outside the family, and family finances. Also commonly covered are demands on the carer to help with a variety of daily living skills. Then there is a range of carer experiences – distress, stigma, worry, shame, and guilt. Most measures include at least ten dimensions. The authors conclude that there is more or less agreement about the dimensions that comprise the 'family burden' concept. There is less agreement with regard to the definition of the term burden.

## 'Burden'

Carers' problems are now usually framed in terms of 'burden', a term which I believe hinders our thinking about the processes involved. Two components of burden are usually discerned – 'objective' and 'subjective'. At first sight it seems reasonable to suppose that an objective dimension of burden can be defined along the lines of a disruption to family/household life *due to the patient's illness* "which is potentially verifiable and observable" (Platt, 1985). The problem here is a dependence on 'what might have been'. How can we know what the carer might have been doing or what activities the family might have pursued had they not had an ill relative? Often the illness has been present for some time and it is impossible to assess the degree to which family activities and relationships might have changed due to evolution of the family life cycle or the personalities of family members. Even if there appear to be restrictions in the carer's life in connection with a family member, how many of them can confidently be attributed to that person's illness?

'Subjective burden' has generally been thought about in two ways. In the first, it is tied to the previously assessed 'objective burden'; each difficult behaviour or disruption is assessed for its burdensomeness. In the second approach, general ratings are made of how distressed by the patient's illness the carer feels. The former rests

on the flimsy notion of 'objective burden'. It also excludes distress arising from 'non-objective' aspects of caregiving, for example, grief over the loss of the person the patient once was. The second approach usually fails to explicate how the distress might be connected with caregiving and tends to confuse 'subjective burden' with psychological morbidity as measured, for example, by the General Health Questionnaire (Goldberg, 1972).

### Models of caregiving

To date 'burden' has largely existed in a theoretical vacuum; few have attempted to locate the notion within a comprehensive account of caregiving. Few consistent relationships have been found between 'burden' and carer or patient characteristics apart from a trend for greater 'burden' with greater severity of the patient's symptoms and behavioural disturbances (usually rated by the carer) (Perring *et al.*, 1990).

A less restrictive concept of 'caregiving' can find a place in established models of psycho-social processes. An example is the 'stress-appraisal-coping' paradigm since it deals directly with the responses of normal people, such as carers, to stressful circumstances. As applied to caregiving, the demands (or stressors) are the patient's illness with its associated behaviours, and disabilities, and it is the way in which these are *appraised* by the carer that constitutes the experience of caregiving. The carer's coping strategies, linked to this appraisal, determine the likelihood of the carer suffering psychological morbidity such as depression. Other factors, such as social support or treatment services can modify the carer's appraisal and thus outcome (see Szmukler *et al.*, 1996a, for an example of this approach with results supporting the model).

A second major framework in which caregiving might find a place is carers' expressed emotion (EE). Clinical observation suggests that high EE may be in part related to coping and may be associated with greater caregiver distress. There is evidence that high EE relatives suffer more distress and have more unmet needs than those with low EE (Smith *et al.*, 1993).

A third approach is to examine caregiving in the context of family functioning – in terms of patterns of relationships, roles, rules, systems maintenance, and so on (Bloch *et al.*, 1994). It might be predicted, for example, that carers' distress is exacerbated in the presence of poor family functioning, or particular types of family relationships, or at particular phases of the family life cycle. From this perspective the term 'carer' itself may become problematic since it implies an outsider-defined relationship of dependency and a power imbalance which may

be at odds with a family's established reciprocities and obligations. This approach has been almost completely neglected.

### From 'burden' to caregiving

More than being simply unhelpful, one could further suggest that the term 'burden' is damaging. It is pejorative, connoting a passive 'load' borne by carers, one easily seen as unchangeable. In an era when patients are encouraged to participate actively in their own care, the inertia implied by the term is offensive. Caregiving is surely a dynamic process to which the carer, patient, friends, community agencies, and the mental health services contribute. It is unhelpful in yet another way: it restricts carers' reactions to the negative. Rewarding aspects of caregiving and valued aspects of the relationship with the patient are excluded even though carers, if asked, commonly report them (Szmukler *et al.*, 1996a).

A more appropriate term for what is being described is 'caregiving'. It is neutral in tone, allows for both negative and positive aspects, and has no built-in preconceptions. Negative aspects of caregiving could be termed 'caregiver distress', and positive aspects, 'caregiver rewards'. No doubt abandoning the term 'burden' will be difficult; it is now in common use, it perhaps expresses negative stereotypes of mental disorder which are hard to relinquish, and it trips nicely off the tongue. But if we seek to further our understanding and to help both carers and patients, we need to examine the hidden assumptions underlying the words we use.

### Interventions to reduce caregiver distress

Few intervention studies have been directed primarily at helping carers. Some short-term, mainly educational interventions have had a modest effect in improving carers' understanding of the patient's illness and changing attitudes positively (Cozolino *et al.*, 1988; Abramowitz & Coursey, 1989; Szmukler *et al.*, 1996b). Significant changes in coping and caregiver distress have only been evident in long-term programmes involving broader and more intensive psychosocial interventions (Falloon & Pederson, 1985). There is a dearth of adequately controlled studies examining the effectiveness of interventions, at either individual or service levels, aimed at reducing caregiver distress and enhancing well-being. While a start has been made in developing new approaches which focus directly on the needs of carers, there is still much to be done. Interventions are also a key means of investigating determinants of caregiving; for example, it might be predicted that an intervention will not

have a significant effect on distress unless it changes coping ability.

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