

## The Burden of Care: The Impact of Functional Psychiatric Illness on the Patient's Family

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This paper reviews the literature on the effect of severe mental illness on other members of the patient's family. The burdens of caring for a patient at home are considerable. They often affect the caring relative's social and leisure activities, and financial problems arise frequently. Relatives have difficulties in understanding and coming to terms with illness-related behaviour. 'Negative' symptoms are often a particular problem. Despite their burden, relatives do not complain much, although they receive little support, advice or information from the professionals engaged in treating the patient; much is now known about the difficulties relatives face, but we still need to know how they can best be helped. Failure to do this will have bad effects on both relatives and patients.

Most studies of the families of psychiatric patients have been aetiological. Family processes have typically been examined because of an interest in the effect of the family on the patient's illness. The view that relatives may have a deleterious influence on the course of illness is reflected in the behaviour of many mental health professionals in the clinic, who may give an impression of blaming them or of regarding them only as exploitable sources of information.

Comparatively few workers have looked at the impact of a psychiatrically ill member on the rest of the family, or at how they cope with their situation, although the majority of patients now return to live in the community. Indeed, even after many years of illness, as many as 50% of patients remain in contact with relatives (Creer *et al.*, 1982). In our view, the existing studies of the effects of mental illness on the family have major implications in the fields both of psychiatric management and of social policy.

### The concept of burden

This concept shares characteristics with that of social performance, for one person's poor social performance is another person's burden. Both concepts are relative to social expectations which are likely to be very variable. Thus, as Platt (1981) has emphasised with regard to social performance, measurement can never be entirely satisfactory. Measures of burden likewise remain open to criticism (Platt, 1985).

The existence of a burden indicates the breakdown of the reciprocal arrangements that people maintain in their relationships, such that one person is doing 'more than their fair share'. This may merely result in them taking on greater proportion or number of

shared tasks, but it may also restrict their activities outside the relationship. This change in pattern can be assessed against approximate norms. In addition, it is often accompanied by subjective dissatisfaction. At a given level of objective burden, individual levels of distress show considerable variation (Platt, 1985). This further aspect of burden should not be ignored.

The dissection of the concept of burden through the effects on the performance of various roles carried out by the patient's relatives was an approach first used by Mills (1962). Grad & Sainsbury (1963*a, b*) advanced the measurement of burden by using a 3-point scale rather than the descriptive sketches given by their predecessors. Hoenig & Hamilton (1966, 1969) made the important distinction between 'objective' burden (e.g. effects on health, financial loss) and 'subjective' burden (the extent to which relatives felt they carried a burden). These techniques were applied by Creer & Wing (1974) in their study of the relatives of patients with schizophrenia. The methods used in the study of burden have now reached a reasonable level of sophistication despite the qualifications concerning measurement (Platt, 1985). A structured account of the behaviour of patients likely to give rise to problems is related to an equally structured assessment of the effects upon relatives and of the ways they have of coping.

### Early studies on families of psychiatric patients

The first studies of the demands on the families of those with mental illness were carried out by a group of social scientists in the United States in the mid-1950s (Clausen & Yarrow, 1955). They operated

within a theoretical framework developed from studies on deviance, social control and social perception (Schachter, 1951; Bruner & Tagiuri, 1954; Yarrow *et al*, 1955). The impetus for their research was clear:

Almost no systematically collected data exist to permit an analysis of what happens within the family group when a member develops a mental illness (Clausen *et al*, 1955).

They studied 33 families where the husband was a patient with a diagnosis of psychosis or psycho-neurosis. The investigators followed the wife's reaction from the time of her husband's first admission to 6 months after his return home, or to the end of his first year in hospital. This first study highlights a number of important themes which recur in subsequent research and which we will substantiate below.

#### The extent of burden

Because studies use different criteria for the severity of burden, only the most impressionistic sketch can be given of its extent among the relatives of patients with persistent disorders.

Mandelbrote & Folkard (1961*a,b*), in a study of schizophrenic patients, reported the degree to which families were restricted or disturbed by the patient's presence in the home, though it is not clear how they rated these factors. Fifty-five per cent of families were rated as disturbed in some way, though only 2% of relatives reported severe stress. The authors are vague about what they regard as stress on the family, describing typical stress situations as 'those in which the behaviour of the patient upset his family or prevented them from doing certain things'. Another shortcoming of the study is that at follow-up they did not interview the families of those patients (18% of sample) whom it had not been possible to maintain in the community, and who presumably had the most severe effects on their families. The authors found that there were more disturbed families in rural than in urban areas.

In Mills' (1962) study of unselected psychiatric patients, practically all were a source of anxiety to their relatives. More than 50% were described as 'difficult' at home and only 12% caused no practical difficulties. In Grad & Sainsbury's study (1963*a,b*) comparing a community-orientated and a traditional service, almost two-thirds of the families had been experiencing hardship because the patient was living at home, and in one-fifth the burden was severe.

Wing and his colleagues (1964) followed the course of 113 schizophrenic patients for a period of 1 year

after discharge. Where patients returned to live with their families, social relations were strained in 59% of cases, often to the limit of what would ordinarily be regarded as tolerable.

Waters & Northover (1965), in a 2 to 4-year follow-up of 42 schizophrenic men, similarly reported that many of the patients caused moderate to severe hardship to their relatives in terms of social embarrassment, inconvenience, and behaviour which frightened them or gave rise to tension in the family. Hoenig & Hamilton (1966, 1969) examined both 'objective' and 'subjective' burden. In their study, 76% of patients had some kind of adverse effect on the household.

The impression from these studies is therefore that burden exists and is extensive. This is reflected in the well established finding of high rates of divorce and separation in marriages where one patient is mentally ill. For example, in many cases observed by Brown and his colleagues (1966), the patient's illness had been instrumental in bringing about divorce or separation. The divorce and separation rates quoted in the study were three times the national average for female patients and four times the national average for males. However, in some ways, it is surprising that more marriages do not break up. In the study by Yarrow and his colleagues (1955*a*) several wives had contemplated separation or divorce, but all had decided to give the relationship another try. A similar adherence to the marriage, in the face of considerable difficulties and apparently meagre rewards, was noted by Fadden and her colleagues (1987).

#### Effects on social relationships

One of the most damaging consequences of living with a relative with a persistent mental illness is the detriment to social and leisure activities. This was noted in the first study of the problem (Yarrow *et al*, 1955*b*): wives consistently believed that mental illness was regarded by others as a stigma and expressed fears regarding social discrimination. In consequence, one-third adopted a pattern of 'aggressive concealment', making drastic changes in order to avoid or cut off former friends, with some going so far as to move to a different part of town. Another third had told only members of the family, or close friends who either understood the problem or had been in a similar situation themselves (Yarrow *et al*, 1955*b*).

A number of other studies have documented the restriction of social activity experienced by those who live with and care for patients with schizophrenia (e.g. Mandelbrote & Folkard, 1961*a,b*; Wing *et al*,

1964; Waters & Northover, 1965) and this may be especially marked when the relative is an elderly parent (Leff *et al*, 1982). However, such findings have also been reported for spouses of a group of patients with persistent depressive disorders (Fadden *et al*, 1987). These relatives spent over 60 hours a week in face-to-face contact with the patient and were correspondingly socially isolated. Grad & Sainsbury (1963*a,b*) add that the restrictions are not limited to those living with schizophrenic patients. It is not at all clear that the phenomenon of stigma contributes less to this social isolation than it did in 1955.

#### Financial difficulties

These have been emphasised in a number of studies (Yarrow *et al*, 1955*b*; Mandelbrote & Folkard, 1961*a,b*; Mills, 1962; Hoenig & Hamilton, 1966, 1969; Stevens, 1972). To some extent, difficulties may arise because caring for a patient with a persistent psychiatric disorder limits opportunities for an adequate income. The most severe problems, however, occur when the patient was formerly the breadwinner, particularly if circumstances prevent the relative from taking over this role. The extent to which the families of psychiatric patients are impoverished should not be underestimated.

#### Relatives' attitudes to the illness

Although mental health professionals, by their calling, readily accept that behaviour can be symptomatic of illness, this requires a major shift in attitude for relatives. Clausen and his colleagues (1955) pointed to the difficulties wives experienced in attributing meaning to their husbands' actions. Wives' attitudes about the normality of such unfamiliar behaviour continually altered, probably because of the overlap between the symptoms of mental illness and normal patterns of behaviour. Early interpretations tend to focus on physical difficulties, or character problems such as their husband being weak or lacking in willpower (Yarrow *et al*, 1955*a*). The authors note the psychological impact on the wife of having to consider her own possible role in the development of her husband's disorder, and of contemplating her future as the wife of a 'mental' patient. It is also clear from the study that the wives experienced anxiety, guilt and feelings of rejection towards their husbands as a consequence of the illness.

Most of the relatives described by Creer & Wing (1974) had at various times experienced anger at the way their lives had been spoiled and grief when they

recalled what the patient had been like before the onset of illness. In the study of Fadden and her colleagues (1987), many of the spouses of depressed patients expressed a sense of loss, as if they had been physically bereft of the person they had married. Anger and guilt were also prominent.

It is apparent from these accounts and others scattered throughout this literature, that the intrusion of mental illness into the family is a trauma which causes relatives considerable difficulties and with which they are given little help. Moreover, things may not become easier as time passes. Hoenig & Hamilton (1966, 1969) found that the likelihood of some objective burden increased the longer the patient remained ill. Mandelbrote & Folkard (1961*b*) similarly reported that progressively more families were rated as disturbed as time passed during their 4-year follow-up period.

#### Burdensome symptoms

There is a fairly clear-cut consensus from the available studies regarding the symptoms that relatives find most difficult. A common concern of the relatives in Mills' (1962) study was that patients might be a danger to themselves or others, and problems frequently arose with neighbours as a result of the patients' behaviour. Many relatives complained of disturbed nights, and reported that practical problems caused less difficulties than the patient's 'strange fancies' or 'dumb apathy'. Those patients who did not speak often created more distress than those whose speech was excessive, though the latter caused suffering too. In Grad & Sainsbury's (1963*a,b*) study, patients with psychosis presented more of a problem than those with neurotic disorders. The symptoms found to be associated with a rating of severe burden were aggression, delusions, hallucinations, confusion and an incapacity for self-care. However, the problems families complained of most often were not the clear-cut symptoms, such as violent or socially embarrassing behaviour, that are usually associated in the public mind with mental illness, but rather the frustrating, depressive and hypochondriacal preoccupations which the patients exhibited. Brown and his colleagues (1966) found the number of problems and the distress experienced by the relatives of schizophrenic patients were highly related to the degree of disturbed behaviour shown by the patient. Hoenig & Hamilton (1966, 1969) confirmed that relatives most frequently reported both aggressive behaviour and extreme seclusiveness or withdrawal as causing problems.

The symptoms which Creer & Wing (1974) reported as being most problematic for relatives of those with schizophrenia were the 'negative' ones, those associated with social withdrawal such as lack of conversation, underactivity, slowness and having few leisure interests. The other group of symptoms causing problems were socially embarrassing behaviours and the more obviously disturbed behaviours. The fact that relatives find the 'negative' symptoms of schizophrenia most difficult to cope with was again confirmed by Vaughn (1977) who did a content analysis of critical remarks made by relatives. Only one-third of the remarks concerned delusions, hallucinations or other florid symptoms while two-thirds referred to behaviour such as lack of communication, affection, interest and initiative. Relatives typically did not view these deficiencies as part of the illness but as personality attributes which were under the patient's voluntary control. They described the patients in such disparaging terms as 'lazy', 'selfish' and 'useless'.

In depressive illness, there are also symptoms which can in a broad sense be called negative, such as social withdrawal, quiet misery and so on. Fadden and her colleagues (1987) also reported that it was symptoms of this type that relatives found most difficult to deal with, although florid and embarrassing behaviour was also hard to tolerate.

A consistent picture emerges from these accounts. Whereas relatives are apprehensive of florid symptoms, it is the suppressive effects of mental illness on behaviour that cause the most problems, and this is partly due to the difficulty which relatives have in attributing such effects to mental illness.

#### **Relatives' burdens and the mental health services**

A prominent theme in this literature is the tolerance of relatives, and the relevance of this to the support they receive from the professionals caring for the patient. Mills (1962) noted that relatives accepted their burdens in spite of the great sacrifices involved and, in protecting the patient, endured really difficult behaviour. They sought re-admission only as a last resort. Wing and his colleagues (1964) emphasised that relatives did their best to put up with very disturbed behaviour, complained little and were willing to take on the role of nurse, frequently at the cost of considerable discomfort and distress.

Waters & Northover (1965) also remarked that relatives showed surprising tolerance of disturbed behaviour. Brown and his colleagues (1966) felt strongly that too much was sometimes being asked of relatives who, however, did not complain, either because they were too ashamed to talk about their

problems or because they had concluded that no effective help would be offered. It was evident that relatives needed expert aid, which they received only when their difficulties had reached a crisis. Brown and his colleagues (1966) warn against those involved in service provision assuming patients are better off at home because the majority of relatives do not complain: "The fact that there is this lack of complaint cannot be interpreted as a justification of community care".

Hoening & Hamilton (1966, 1969) found an interesting discrepancy between objective and subjective burden. Almost a quarter of the households carrying a good deal of objective burden made no complaints of subjective burden, reflecting once more the families' tolerance towards the mentally ill member. A more disturbing finding was that, among those people who felt that nothing more could be done for them, three-quarters suffered some objective burden, and almost a half complained of subjective burden. This shows the lack of expectation of help on the part of these relatives, and in fact only 7% of relatives in the study made any complaint about services.

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. Virtually none of the relatives had received advice from professionals on the management of difficult behaviour, and those who had worked out methods of dealing with problems did so by a painful process of trial and error. The authors concluded that there is no general recognition of the fact that relatives were functioning as 'primary care' agents, and suggested the introduction of a counselling scheme that would provide families with information and strategies for dealing with difficult situations.

In their further study of chronic patients of whom over 40% were cared for or supported by relatives, Creer and her colleagues (1982) also looked at how relatives felt about providing support—whether they were content, resigned or dissatisfied. It was clear that the situation reported by Creer & Wing (1974) was largely unchanged. These relatives were coping with very difficult behaviours, for the most part without complaint. The authors were particularly concerned about the failure of professionals to meet relatives' needs, including those for practical assistance and advice, for emotional support, and for providing them with occasional breaks from their demanding task. They pointed out that no professional group was concerned with the problems of relatives in their own right, and that services were almost exclusively patient-oriented.

Wing (1982) reiterated the problems faced by relatives who have no training in dealing with difficult behaviour, who unlike hospital staff are 'on duty' all the time, and whose emotional involvement with the patient makes it difficult for them to remain neutral in their interactions with patients. Once again he advocated that professionals should make themselves aware of the real problems that arise in families.

A number of other authors have drawn clear inferences from their findings for the way services are provided for the families of mental patients. Mandelbrot & Folkard (1961*a,b*) recommended that the burden on families should be lightened by arranging facilities to take the patient from the home for part of the day, and that more social workers were needed to deal with interpersonal problems within the families.

Mills (1962) was also of the opinion that relatives needed relief part of the day, at night or during crises, and that these patients remained in the community only at the cost of considerable hardship. She concluded:

If patients are more often to be treated from their own homes, then their families should not have to bear without help the severe practical problems and strains.

Waters & Northover (1965) regarded the lack of sustained support of patients' families as one of the important shortcomings of the community after-care provided for the patients. These papers were both written over 20 years ago, and there is no evidence that service provision has changed markedly. The implications are stark.

#### **The behaviour of professionals towards relatives**

It is clear that professionals do not provide much help for relatives. The early American study described above (Clausen & Yarrow, 1955) examined how this lack of provision was related to the communication between wives and their husbands' psychiatrists, and to the attitudes which each held towards the other (Deasy & Quinn, 1955). An analysis of the requests made of the psychiatrists by wives revealed that most (71%) were efforts to secure information regarding aetiology, diagnosis and prognosis, and advice on how to deal with the patient when he returned home. The remaining requests were either for help with personal problems (9%) or attempts to change the course of hospitalisation (20%). However, in almost two-thirds of cases, the wives expressed dissatisfaction because they were not provided with the information they required or

because the doctors were inaccessible. Most psychiatrists considered it reasonable that wives should expect information, and were aware that they did not always fulfil the needs of patients' families, either because of their heavy workload or because the nature of psychiatric illness made it difficult to answer many of the questions posed. Nevertheless the 23 psychiatrists interviewed focussed their attention almost exclusively on their patients, and contacted relatives only at the early stages of hospitalisation to secure information. Although they agreed that wives needed help from some source, they did not see this as their responsibility. When asked to describe the characteristics of a 'good' wife, they used terms such as "she has insight into her husband's condition, lets the doctors alone, co-operates with the hospital's plans for the patient". A 'bad' wife on the other hand was someone who "exhibits signs of emotional distress, tries to thwart the hospital, takes up a great deal of the doctor's time". Deasy & Quinn (1955) reported that the psychiatrists frequently felt they had to protect the patient from his wife as they believed that factors in the husband-wife relationship had contributed to the patient's illness.

It can be imagined that these attitudes, whatever their level of justification, do help to meet the relatives' needs. Although no subsequent study has looked specifically at professional attitudes, these themes continue to arise in reports of relatives' dealings with staff.

#### **Community care and the burdens of relatives**

The impetus for many of the studies described here was provided by the move towards community care. It is clear that if more patients are in the community, more relatives will have to care for them and will experience a consequential burden. A worrying finding, however, emerges from the first study specifically designed to examine the differential effects of a community-oriented service and a more traditional hospital-based service on the relatives of psychiatric patients (Grad & Sainsbury, 1963*a,b*). Not only were more people caring for relatives in the first scheme, but their degree of burden was actually greater. The authors speculated that this was because the burden on families in the traditional hospital approach was lightened by regular visits to the homes from the social work staff, while this was not the case in the community-based service.

#### **Sex differences**

Few investigators have reported on the differential effects of the sex of the relative on the degree of

burden. In many cases, this is because studies only looked at male patients.

Rogler & Hollingshead (1965) did examine gender difference in the degree of burden. They reported that schizophrenic illness in a wife had a more disruptive effect on the family than that in a husband. However, the study was carried out in the then rather traditional society of Puerto Rico and the findings have doubtful applicability to other cultures.

Few British studies have paid much attention to sex differences. Mandelbrote & Folkard (1961*a,b*) noted that, for male patients, there were more disturbed conjugal than parental families, this situation being reversed when the patient was female. In the study of depressed patients by Fadden and her colleagues (1987), wives were more isolated, possibly because they had fewer outlets to exploit when their spouse became mentally ill. It was also remarkable that wives often found it upsetting to have to take on traditionally male roles, even though they managed to do so competently. Such findings may have more general relevance and should perhaps be anticipated in the clinic.

#### Relatives' burdens in depressive disorder

The scant information about the specific effects of depression on the family of the patient has been recently reviewed elsewhere (Kuipers, 1987). It deals exclusively with the effects on spouses, although this may not be inappropriate as depressive patients are much more likely to be married and living with the marital partner than are people with schizophrenia. In these marriages there is frequently conflict (Hinchcliffe *et al*, 1978), particularly over role functions (Ovenstone, 1973*b*) and a high level of dependence (Birtchnell & Kennard, 1983). Fewer joint decisions are made with increasing pathology on the part of the husband (Collins *et al*, 1971), and the wives of depressive patients have significantly less independent social activity than controls (Nelson *et al*, 1970).

Fadden and her colleagues (1987) have recently conducted a pilot study of the spouses of persistently depressed patients of specified types, employing techniques of assessing burden developed in the more sophisticated studies of the effects of schizophrenia. Their findings show striking parallels with that work and emphasise the severity of the burden borne by spouses and the noticeably adverse effect upon their mental health.

Depression is not a minor problem for the community: the life-time expectancy of contacting a psychiatric hospital with depression may be as high

as 11.9% for men and 20.2% for women (Sturt *et al*, 1984). Nor is it a problem which leads only to short periods of disability. In many cases the problem becomes a chronic one: Mann & Cree (1975) in a study of 'new long-stay' patients aged between 18 and 65 in hospitals found that affective psychosis accounted for 15.8% of patients and formed the largest single group after schizophrenia.

It is clear that more extensive study is required to establish the extent and prevalence of the burdens borne by the relatives of depressed patients.

#### Implications for further research and the provision of services

Although this review shows that there is now a large body of literature based on the systematic study of relatives' difficulties, much less is known of the best strategies for relatives to use in coping with their problems and of how, even if professionals knew what to advise, they could ensure that their advice was adopted. There is only experiential or anecdotal knowledge in these areas. In their review of research on burden, Kreisman & Joy (1974) describe the 'scatter-shot' approach on the part of researchers who have failed to follow through on promising leads in their own data: "This lack of sustained interest has left us with fundamental pieces of information missing". It must be said that, 13 years later, the situation remains very similar.

The results of this ignorance are likely to be considerable. It is apparent from the earlier studies on 'Expressed Emotion' (Brown *et al*, 1962, 1972; Vaughn & Leff, 1976) that the behaviour of relatives has a significant influence on the patient's likelihood of relapse with schizophrenia. This finding probably applies equally to depression (Vaughn & Leff, 1976; Hooley *et al*, 1986). While not all relatives behave in the same way, it is the nature of the burden placed on them that leads some to resort to ineffective strategies of coping. The intervention studies that have been reported (Lieberman *et al*, 1981; Falloon *et al*, 1982; Leff *et al*, 1982; Barrowclough & Tarrier, 1984) and those now proceeding all adopt approaches that broadly aim to enhance the effectiveness of the relative's coping. The results confirm that improving the way relatives deal with the burdens of looking after a schizophrenic patient in the home has a beneficial effect on the course of the illness.

In addition to the indirect effects of burden on the patient's likelihood of relapse, there are direct effects upon the relatives' own mental health. This has been documented particularly for those married to depressed or neurotic partners (Kreitman, 1964;

Kreitman *et al*, 1970; Ovenstone, 1973a; Fadden *et al*, 1987) but has been noted for those living with schizophrenic patients (Brown *et al*, 1966; Hamilton & Hoenig, 1966, 1969; Stevens, 1972; Creer & Wing, 1974). The evidence inclines against an explanation in terms of assortative mating, at least in the groups studied.

### Conclusion

A number of points can be drawn from this literature on the effects of psychiatric illness upon the families who live with the patient. A more widespread interest was shown in the topic in the late 1950s and early 1960s when community care programmes were first introduced. The first attempts to refine the measurement of burden in families also date from this time. Schizophrenic patients constitute the only group in which interest in family burden has been sustained, although there is evidence that families of other patient groups are also seriously affected by the patient's illness.

It is clear that families typically tolerate a great deal of difficult behaviour and that they frequently find the less clear-cut symptoms the most difficult to bear. They often lack knowledge about the nature of the patient's illness but receive little help from professionals in the management of difficult behaviour except in times of crisis. In spite of all this they rarely make complaints. Coping with their relatives' problems frequently results in adverse effects on their own health, both physical and psychological. From the first studies to the most recent, the point has been made repeatedly by those working in the area that relatives must not be asked to bear these burdens unassisted, and that they should be provided with more help from professionals. Recent studies describing interventions with families have shown that such help can be effective and worthwhile.

The intervention studies that have already been carried out have resulted in reduced relapse rates for schizophrenic patients, and this might also be a realistic aim for other diagnostic groups. A prerequisite of such intervention is knowledge of what problems are in fact faced by relatives. The need for further research is therefore clear.

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