Families caring for people diagnosed as mentally ill : the literature re-examined / Christina Perring, Julia Twigg, and Karl Atkin.

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Families Caring for People Diagnosed as Mentally Ill:

THE LITERATURE RE-EXAMINED

Christina Perring, Julia Twigg and Karl Atkin

HMSO

What is it like to live with someone who has been diagnosed as mentally ill? This review looks at what is known from the literature about an often stressful situation and breaks new ground by relating that knowledge to existing work on informal care. It gives comprehensive coverage to otherwise scattered research findings and concentrates on three main areas: impact on the family; what makes life easier for some carers than for others; and formal services.

Providing a timely and thought-provoking critique of how families in this situation have often been seen, this is more than just a review. It will inform the current debates surrounding mental health policies.

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This review was prepared as part of the background to a larger research project concerned with evaluating support for informal carers. This, and its companion review, *Carers and Services: A Review of Research,* by J. Twigg, K. Atkin and C. Perring form the first publications of the research.

The project has been undertaken at the Social Policy Research Unit, University of York, and has been funded by the Department of Health. It forms part of a programme of work on informal care undertaken at the unit. Other publications in this field will appear as part of this HMSO/SPRU series. We would like to thank our many colleagues at SPRU for their helpful comments and suggestions. Particular thanks should go to Teresa Hagan, Gillian Parker and Patricia Thornton.

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The scope of the review

The policy objectives of community care imply a major increase in responsibility for families with a member who has been diagnosed as mentally ill. Most recently, this has been underlined in the Government White Paper *Caring for People* (1989), with its continuing commitment to developing community-based services and the eventual closure of long-stay hospitals.

But what is it like to live with someone who is diagnosed as mentally ill? There are two obvious yet distinct bodies of research that address this issue. One is work in the field of informal care. The other, which is the principal focus of this paper, is found in the psychiatric and psychological literature. For various reasons, neither body of work adequately answers the question. 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 non-recognition of informal carers inspired this review. As part of a wider study seeking to evaluate support to informal carers, it was necessary to understand what it means to be a carer of someone diagnosed as mentally ill. For the most part, current attitudes to, and service intervention for, carers are moulded by notions of what a carer is that have been derived from the existing informal care literature. Caring for someone who experiences mental distress, however, is rather different from caring for someone who needs physical care. There is less emphasis on performing tasks, and caring is likely to vary with fluctuations in the course of the mental illness. The nature of the relationship and of responsibility is also subtly different. The dominant concept of informal care therefore has to be re-examined.

The ultimate aims of this paper are to reach an understanding of what life is like for carers of people diagnosed as mentally ill and to begin to relate this to what is already known about informal care.

Limitations of the literature

This review covers the research reported in the psychiatric and psychological literature that has investigated the impact of mental illness on families. This is a small body of work when compared with that on informal care or on community mental health in general. It appears to be the only body of work that addresses, albeit indirectly, the informal care of people diagnosed as mentally ill.

The scope of this literature is limited in a number of ways. Before discussing these and their consequences for our understanding of the situation of carers, we should perhaps indicate some of the limitations imposed on this review by ourselves. We have not, for example, included any discussion of the situation where the cared-for person is a child, or where the problem is one of substance abuse. Neither does the review include research about black carers. Race and mental health is an area now recognised to be of great importance, though it is also a controversial field and one neglected in the U.K. until relatively recently. There is as yet comparatively little published work, and the few studies reviewed here that do address race are from within an older, ethnocentric tradition that is dominated by white perceptions of health and family life. We felt that these situations raised specific issues that were inappropriate for this review. The review also excludes the carers of elderly mentally infirm people. Research in this field had been more successfully integrated with other work relating to elderly people and their carers; and for this reason the subject has been dealt with in the companion publication to this: *Carers and Services: A Review of Research* by Twigg, Atkin and Perring (1990).

The research perspective that underlies this review is one that attempts to place the carer, rather than the identified patient, at the centre of inquiry. It is important, therefore, to stress how little of the research reported here has taken that approach and investigated the situation of the carer per se. As a result, the writing of the review has itself been a creative process. It was necessary to re-orientate the literature and this has revealed a number of barriers to understanding. These arise from the character of the literature and inhibit its integration with the main carer work.

Barriers to understanding

There has inevitably been a strong medical influence in the fields of psychiatry and psychology. This can be seen, for instance, in the choice of topics for research, the methods chosen to investigate these topics and the language used to describe the findings. This medical focus has had implications for definitions and theories of mental illness and for the degree to which a single aspect of the patient has been treated as the object of inquiry (Armstrong, 1983; Atkin, 1989; Pearson, 1983). This has often been accompanied by a neglect of the more general non-medical, societal and familial aspects of mental illness such as those that have been examined in feminist or race analyses (see Chesler, 1972; Ineichen, 1989; Pearson, 1983). Only those aspects of the situation assumed to be directly related to a medical outcome have been seen as relevant.

The medical influence has also led to a particular emphasis on schizophrenia. This has been described as the prototypical example of 'mental illness' (Mechanic, 1986) and has traditionally been the preserve of the medical profession. Most of the studies reported here focus on families of patients diagnosed as schizophrenic; some do not differentiate between diagnoses and only a few have focused on families of depressed people. As a result, our understanding of the situation is heavily biased towards the problems of schizophrenia. This imbalance of focus makes it hard to examine the differential impact on families of different psychiatric states. It is difficult, for example, to determine whether, and if so how, the situation of caring for someone who is clinically depressed differs from that of caring for someone who is diagnosed as schizophrenic.

The methodological approaches adopted in the fields of psychiatry and psychology have been largely influenced by those of the natural sciences. As a result, there has been an emphasis in this work on quantitative methodology, and it has been seen as appropriate to examine the situation in terms of variables and statistical relationships. Different aspects of family life are separated into variables, which are then measured or assessed. Researchers have, however, tended to use idiosyncratic measures and it is often difficult to draw direct comparisons across the research, since each study tends to conceptualise the situation somewhat differently. This is particularly so where 'global' measures of impact are generated by combining variables in ways that are particular to the research project. Little attention has been paid to the meaning of the situation for individual carers and to their interpretation of it. The situation is most frequently conceptualised within the rather limited framework of 'burden' and the complexity of the interactions and feelings have not been very intensively explored.

The language used to describe the findings both reflects and frames the orientations adopted. The language of informal care refers to disability, cared-for person, dependant, carer. The world of mental health refers to illness, patient, relative or supporter. The different assumptions that underlie this choice of language, as well as the language itself, have hampered the process of interpretation.

In addition to the barriers that arise in relating findings across different disciplines, there are perspectives within disciplines that pose barriers to understanding. Emphasis on the well-being of families in its own right is only a comparatively recent interest in the field. More usually, interest in the well-being of families has been only for its significance as a means to the greater end of helping the patient.

This general lack of attention to family well-being was highlighted as early as 1968 (Grad and Sainsbury, 1968). Some more recent reviews, such as that by Keisler (1982), include only a brief reference to families; the updated version (1984) of Talbott's influential book devotes only one of its 22 chapters to the families of chronic mental patients. This is despite the fact that 60 per cent of first-episode schizophrenic patients live with their families (MacCarthy, Kuipers, Hurry, Harper and LeSage, 1989a). Although Fadden, Bebbington and Kuipers (1987a) described this as a large body of literature, it remains unsatisfactory with regard to its coverage of, and relevance to, carers.

That the literature is unsatisfactory comes, in part, from the fact that there are distinct themes in the literature on families and mental health. Gubman and Tessler (1987) have described three of these, all of which show bias in their interest towards favourable outcome for the patient. These themes are the role of the family in both the origins of mental distress and rehabilitation, and what has become known as 'family burden'. Much of the research on the first two themes has been influenced by a perception of the family as having a potentially pathogenic influence on mental illness (e.g. Laing and Esterson, 1964/1982; Vaughn and Leff, 1976). Although the influence of this perspective has waned, there is a risk that aspects of it may inappropriately have been carried over into the third theme, that of family burden.

More recently, a change in orientation has taken place. This has occurred against the policy background of increased care in the community, as well as an increased interest in the carer generally. It is now more common to view the family as a source of support and care (Kreisman and Joy, 1974; Vaughn and Leff, 1981) and some attention has been paid to ways of enhancing this family role (Crotty and Kulys, 1986; Hawks, 1975). Some recent work has focused on families as coping with and adapting to the impact of mental illness (Hatfield and Lefley, 1987; Orford, 1987), though even this work is more concerned with developing a 'non-blaming stance' towards families, rather than with placing them at the centre of inquiry. Little work that maintains this latter focus has been reported.

It is difficult to abstract from the body of work under review any sense of what life is like for a carer of someone identified as having mental illness. This is seen, for instance, in major reviews of the literature where the principal focus has been on the effect of relatives on patients' well-being, rather than on the effect of the situation on families or carers themselves (Braun, Kochansky, Shapiro, Greenberg, Goudeman, Johnson and Shore, 1981; Fadden et al., 1987a; Kreisman and Joy, 1974). Most studies recognise that caring takes place within the context of family relationships but have tended to examine the effect of caring only in terms of disruption to different aspects of family life, known as 'family burden'. This provides a rather restricted view of the situation, and one that is in contrast to that presented in the main carer literature where more complex notions of the caring role have been developed.

Lastly, the mental health literature emphasises the impact on the family as a whole, rather than on individual carers. The carer literature suggests, however, that the caring responsibility is rarely shared and that a single individual tends to carry most of that responsibility (Parker, 1990). In the mental health literature, this sharper focus is blurred.

Conclusion

There are a number of characteristics of this literature that pose barriers to our understanding of this situation. These also act as obstacles to integrating this understanding with the literature on informal care. Emphasis has been on families, rather than on individuals, involved in a situation which is seen as one of 'burden' rather than as one of informal care. The medical interest that has influenced this work has tended to focus on the well-being of the patient, and on people diagnosed as schizophrenic. Methods of inquiry have neglected the meaning of the situation to those concerned. These differences of emphasis are rooted mainly in the different assumptions and perspectives that underlie the two distinct bodies of work. By examining these and reorientating the findings, we can begin to answer the question posed at the beginning of this chapter: 'What is it like to live with someone who is diagnosed as mentally ill?'.

The core of this review is devoted to three main areas of inquiry. Chapter Two examines the impact on the family; this includes a discussion of the research on what has become known as 'family burden'. Chapter Three considers why the impact of caring may be more difficult for some people than for others. A review of families and service provision follows in Chapter Four.

Impact on family life

In the psychiatric and psychological literature, the tasks performed by the family, the particular features of mental illness and the impact of both of these on family life have all become known as 'family burden'. Research evidence from different disciplines shows that the task of caring is likely to be burdensome. Conceptualisations of the situation that exclude more complex patterns of response are likely to provide only a partial representation of the situation. There have been only minor moves away from such narrow conceptualisations of the caring situation in the psychiatric and psychological literature. Creer, Sturt and Wykes (1982), for instance, have proposed that the term 'burden' be replaced by the more neutral term 'support'. In doing so, they implicitly recognise that the role of caring encompasses a slightly wider range of experience that may include the more positive aspects of a relationship. The dominant model, as in the rest of the carer literature, is that of 'family burden'. In this paper, we have sought to avoid some of the more negative and restrictive connotations of this by using the term 'impact'.

It is from this area of research that links can most readily be made to the main literature on carers, where the effect of caring for elderly people or those with disabilities, for instance, has been well documented (Parker 1990).

The caring tasks

Before turning to the different aspects of family life that are affected by caring, we describe the caring tasks themselves. These can be grouped into three main categories: practical tasks, coping with difficult behaviour and new responsibilities.

Practical tasks

Very few studies have provided good data on what carers of people diagnosed as mentally ill do. They have tended to emphasise the impact of caring on family life, rather than the detail of the caring task. This is in contrast to what is known about those caring for disabled people. One study that has detailed the range of tasks performed by carers was that of Creer et al. (1982). They divided their 18 items of what relatives do for dependants into the practical tasks that people are normally expected to do for themselves; the types of behaviour that might need supervision from the carer; and whether the dependent person can be left alone. As might be expected, relatively few of their 52 patients with mixed psychiatric diagnoses required help with washing and dressing. However, over half had some difficulty with household chores or needed help with financial arrangements. Medication was also an area where supervision was needed. In all, three quarters of relatives reported that at least some 'caring attention' was necessary with regard to socially difficult aspects of the patients' behaviour, which included serious attention-seeking behaviour, threats or violence, night disturbance, and carers being unable to leave the house unattended for longer than a few hours at a time.

Tasks were principally those of assuming responsibility for their dependant in various ways, rather than of giving practical help. In this respect, caring for someone diagnosed as mentally ill tends to be rather different from caring for someone with a physical disability where personal care or other practical help is usually an essential part of the care being provided. In some ways, it may be more like the care afforded to people with learning difficulties, who cannot assume full responsibility for their lives. However, with regard to mental illness, the need both to provide practical help and to assume responsibility fluctuates with the course of the illness. Another important difference is in the nature of the relationship between dependant and carer. The onset of mental illness typically occurs once the dependant has reached adolescence or adulthood, unlike the situation for a dependant with learning difficulties whose need for care is likely to have existed since birth.

Coping with difficult behaviour

Coping with the behaviour associated with mental illness is difficult for carers, just as it is for members of society as a whole. In many cases, it is this aspect of the situation that poses most problems for carers. Even so, few studies have described these behaviours in terms of what they mean to carers. What frequently happens is that a form of shorthand is used to identify clusters of behaviour. This refers to clinical terms like 'withdrawal' or 'florid symptoms', without explaining what the implications of these might be for carers.

Creer (1975) is unusual in providing a description of the sorts of behaviour with which carers have to contend, although she also tends to resort to this clinical shorthand. She reports how carers faced with a relapse of their relative diagnosed as schizophrenic see an increase of the behaviour typically associated with the syndrome. This might mean an increase both in social withdrawal and in behaviour that is described as 'more florid'. Social withdrawal is exemplified by people who shut themselves in their own rooms for hours or even days and, having lost the confidence to seek social life outside the home, became increasingly demanding of their family. This can act as a severe constraint on the carer's own life, especially when he or she feels unable to leave his or her relative. Neglect of appearance and cleanliness is common. Uncontrollable restlessness is one of the most disturbing examples of the more florid types of behaviour. Here, carers face behavioural difficulties similar to those shown by people with Alzheimer's Disease. These can include excessive activity such as pacing the room or, for younger adults, playing loud music at night. Such activity causes friction both in the family and with neighbours. The strong beliefs that dependent relatives may hold at such periods also cause difficulties for the carer. Creer gives examples of one patient who believed that 'he was being controlled by a hypnotist, and another that he and his family were being slowly poisoned' (p.3).

People who are depressed, whether or not this is associated with schizophrenia, show a range of behaviour that includes threatened, attempted or actual suicide, withdrawn behaviour with no inclination to speak, and frustrating hypochondriacal preoccupations (Grad and Sainsbury 1963). Social withdrawal and 'quiet misery' are common. Relatives have frequently reported these 'negative' symptoms as being more difficult to cope with than the more florid symptoms of schizophrenia (Creer and Wing, 1974; Vaughn, 1977, cited in Fadden et al, 1987a). There may be a tendency to ascribe attitudes like this to the identified patient's character, and see him or her as 'selfish' or 'lazy' (Vaughn, 1977 cited in Fadden et al, 1987a). This appears to make coping with a depressed relative especially difficult, as he or she, rather than depressive illness, is blamed:

> 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.
> (Fadden et al., 1987a, p.288)

These behaviours also left carers uncertain about how to respond. Creer reported that carers did not know whether to encourage sociability or to allow relatives to withdraw further. They did not want to be unsympathetic towards their relatives, but felt frustrated and baffled by bizarre behaviour. Embarrassment in public over their relatives' behaviour was common among carers. It appeared that carers found it easier to cope with stable rather than fluctuating, and with florid rather than withdrawn behaviour.

New responsibilities

The resurgence of symptoms often means that the relative is unable to cope with many practical details of everyday life, from personal care to household and financial responsibilities and personal relationships. The carer is at this point likely to have to assume a new role with regard to responsibilities. This may involve supervision of the dependant and the conduct of household roles. This new role is likely to be affected by the kin relationship between carer and dependant. A spouse confronted by the need to make financial decisions or to become the principal breadwinner is in a different position from the parent of an adult child who may be reverting to an earlier pattern of relationship. The change may be experienced differently by men and women, and by younger and older carers.

One study that recognised this shift with regard to spouse carers was that of Fadden, Bebbington and Kuipers (1987b). This small scale, though intensive, study examined the impact of caring for 24 spouses of depressed patients. The researchers related the impact of caring to what people expect from the reciprocal relationships that are seen as integral to family life. This aspect of family life may differ according to the particular kin relationship involved, although until recently the literature on informal care had tended to neglect the role of these differences (but see Parker, 1989, for a comprehensive study of spouse carers, and Finch, 1989, for an examination of family obligations).

Fadden et al.'s spouse carers had to take over many household responsibilities at a time when they were also experiencing the much felt loss of a confiding relationship. What Fadden and her colleagues were examining, however, was not so much the assumption of responsibility itself, but its presumed connection to role change within the family. Role changes and role conflict have been reported in other carer studies where high levels of role strain have been found, and relatives reported a need to increase their supervision of relatives because of difficult behaviour (Thompson and Doll, 1982).

These issues have also been examined in other literature concerned with carers. For instance, the loss of functioning that accompanies diseases such as Alzheimer's Disease, Huntington's Chorea (Korer and Fitzsimmons, 1985) or head injury also result in role changes. Related to this is the acute sense of loss and bereavement for the person whose changed behaviour is so extensive that the carer feels as though they are living with a completely different person. 'As one mother put it, "You just can't understand it. Here's someone you've known all these years and always got on well with, and suddenly he can't even stand being in the same room with you"' (Creer, 1975, p.4). Carers have to come to terms both with a shift in responsibility and with the loss of the person they knew.

It seems likely that when someone assumes the role of carer there will be permanent shifts in family roles and considerable unanticipated responsibility falling consistently to one carer. Studies appear to have neglected precise descriptions of such shifts in responsibility. This is likely to be related to, among other things, assumptions about relationships and to the neglect of possible differences between them.

Disruption to family life

Research on the impact on family life has looked at different areas such as marital and parental relationships, domestic routine, social life, leisure activity, employment, financial circumstances, and various aspects of health. Many studies have combined these aspects in different ways to produce a single 'global' measure of the situation. Platt (1985, Table 1) details criteria for evaluating burden scales. This is comprehensive and methodologically clear and provides a good illustration of the approach adopted in this body of research.

He identifies ten areas of family life that may be affected by caregiving and distinguishes these from the eleventh area of burden, impact directly attributable to the patient's behaviour. Sexual functioning is the only additional area that can be added from other studies reported here (Fadden et al., 1987a; Namyslowska, 1986). Platt's four dimensions of burden explicitly separate elements of the situation often confounded or overlooked in other studies, while his list of people to whom burden relates recognises the differential impact of experience for people within the household and outside it.

Most studies have reported considerable overall levels of disruption to family life where someone diagnosed as being mentally ill is being cared for. Thompson and Doll (1982) found that nearly three quarters of their 125 family caregivers were adversely affected by disruption to family life in at least one of five different areas. Johnstone, Owens, Gold, Crow and MacMillan (1984) used what they described as an arbitrary list of seven items to measure the overall impact on family life. Thirteen of their 42 informants reported no difficulties, while 18 'gave positive answers to at least three items' (p.587), indicating

Table 1 *Typology of burden* (drawn from Platt, 1985)

Eleven areas of burden

- Effect on
  - work/employment
  - social life, leisure
  - physical health
  - emotional/mental health
  - finances/income
  - family routine
  - family/household interaction
  - schooling/education
  - children
  - (interaction with) others outside the household/family
- Patient's behaviour as a burden

Four dimensions of burden

- Objective burden, which may be rated
  - if present, regardless of 'cause'
  - if present, and only if attributable to patient
- Subjective burden
  - arising directly out of patient's behaviour
  - arising as a consequence of (increased) objective burden

Five persons to whom burden relates

- Informant
- Specific others in household
- Informant's household as a totality
- Specific others outside the household
- Non-specific others outside the informant's household (e.g. community)

major difficulties. In a study with spouses of depressed patients, Fadden et al. (1987b) also found that relatives bear burdens that are far-reaching in many areas of their lives. They cite the high incidence of marital breakdown among families with a schizophrenic member as further evidence for this claim.

None of these studies included a comparison or control group. It is therefore difficult to be certain that the reported difficulties are associated with mental illness in the family and are not a feature of 'normal' family life. One study that did use a control group was that conducted in Poland by Namyslowska (1986). She found few differences in family functioning between research (those containing a schizophrenic member) and control families. One difference, however, was that research families spent their free time in more home-based pursuits; just over one third of research families saw this as due to the schizophrenic illness of the spouse. Another major difference was that fewer children from such homes participated in extra school activities. Other areas of family life, such as the economic, caretaking and educational, did not differ significantly between research and control families. The large number of families (1,832) used to establish normal levels of functioning in her study suggests it is unlikely that undetected psychiatric disturbance has contributed to the lack of difference between the two sets of families.

McCreadie, Wiles, Moore, Grant et al. (1987) compared scores for families with a member experiencing a first episode of schizophrenia (research families) with norms derived from a community sample. They found that research families scored significantly worse on global adjustment and social and leisure function, but better on parental functioning. These measures were scored on a 54-item questionnaire that provides an overall rating and a rating in each of seven role areas (the Social Adjustment Scale Self-Report, Weissman and Bothwell, 1976, cited in McCreadie et al., 1987).

Bromet, Ed and May (1984) found that, for families with a depressed adult, family functioning was affected only while the depressed adult was experiencing current symptoms. At that time, higher levels of marital conflict were reported in research than in control families, although this conflict did not extend to family relationships as a whole.

These studies show that, on an overall assessment of disruption to family life, many families experience considerable difficulty when they live with someone identified as mentally ill. Taken together, they are important in establishing the types of disturbance that may occur. Nevertheless, there has been a tradition in research on mental health, from Freud to the present day, of investigating only those families where disturbance is apparent. There is a need to set findings from this tradition in a context of evidence from 'normal' families, where the experience of possibly severe disturbance has also been reported.

There are aspects of the situation that remain unexamined in these studies. First, there is no clear description of what life is like for individual carers. This literature sets out to describe what the impact is like for the family as a whole, and rarely pays attention to the impact on individual family members. In particular, this means that the impact for the primary carer has not generally been addressed. Second, little attention is paid to the fact that the course of mental illness fluctuates, and periods of intensive caring may be broken by several months or years where the identified patient leads a symptom-free life. Fadden and her colleagues (1987b) hinted at this aspect of psychiatric distress when they commented that many of their interviews with the spouses of patients with manic depression were conducted when the patient was asymptomatic. This means that many reported findings cannot be taken to be representative of what life is like during periods of crisis. This is a major methodological difficulty in the literature.

Social and personal life

The most common finding among studies of families with a psychiatrically ill member was that social life was restricted or disrupted (Fadden et al. 1987b; Johnstone et al., 1984). This complements the findings of McCreadie et al. and Namyslowska who found a difference between control and research families with regard to leisure activities. Fadden et al.'s study is important because it concerned depressed people. She reported that particular distress for family members was associated with restricted social activity. This parallels the experience of restrictedness in the main carer literature. Further evidence for disruption to social life is found in studies that report problems with neighbours and role strain (Thompson and Doll, 1982), disruption of family relationship (Johnstone et al., 1984) and global adjustment (McCreadie et al. 1987). In addition, it is in recreational and cultural activities outside the home that research and control families show the most significant difference in functioning (Namyslowska, 1986).

One of the few studies that gives a sense of what happens to the social life of individual carers is by Fadden et al. (1987b). Spouses objected to the 'smothering' nature of the relationship that followed from a curtailment of social and recreational activity and isolation from friends. In addition, some studies have included brief descriptions that provide an impression of this and other aspects of the situation for individual carers (Creer, 1975). Again, there are parallels to be drawn with studies that have looked at the spouse carers of disabled adults where the loss of stimulating external social contact is widespread (Parker, 1989).

Most studies show that major sources of social support are severely restricted for carers, and loss of social life is frequently reported as one of the most distressing aspects of the situation. This clearly fits with Brown and Harris' (1978) view of the importance of close confiding relationships in protecting against depression. For many carers, close relationships are denied. In addition to the impact on their social life, they may be caring for a close relative who might normally be expected to be a source of emotional support. Spouse carers seem particularly likely to lose their major confiding relationship given that the nature of many forms of mental illness means that the identified patient is no longer able to offer such support to the carer.

Employment and financial circumstances

The impact of caring on employment is not uniform. Fadden and her colleagues (1987b) reported that few carers had had to make changes to their work routine, though work was reported as a strain by half of their interviewees and two women had taken up full time employment for financial reasons. Reduced performance at work was reported by 80 per cent of relatives interviewed by Gibbons, Horn, Powell and Gibbons (1984), while nearly half of the families in Johnstone et al.'s (1984) study had been affected either by giving up works or by taking time off to care. While it is clear from these studies that the proportions of people having to make changes to their employment pattern as a result of mental illness in the family is small, there are other effects, such as increased strain, which interviewees do relate to their employment role.

The nature of the tasks that characterise caring for someone with mental illness – responsibility as against physical tending, and fluctuating as against constant care – may lead to the supposition that carers in this situation will find it more feasible to combine caring and employment. The mainstream literature on informal care, however, has pointed to a complex relationship between gender, unpaid caregiving and paid employment. This relationship also encompasses other aspects of the situation such as household composition and marital status (Glendinning, 1989). We can draw no firm conclusions about the employment of this group of carers until adequate research has been conducted, but we can assume that any relationship between caring and employment is likely to be equally as complex as that reported in the carer literature.

The situation with regard to financial circumstances is clearer. The majority of studies that have investigated the financial situation have found difficulties which carers related directly to the presence of mental illness in the family. Thompson and Doll (1982) and Gibbons et al. (1984) both found very similar proportions of households were adversely affected (38 and 39 per cent respectively). Fadden et al. (1987b) found that for a large percentage of households, financial problems were reported as much worse since the spouse had become ill. Financial difficulties were often due to loss of income when the male breadwinner was unable to continue in paid employment (Johnstone et al., 1984). Again, Glendinning's work has shown complex patterns of financial consequences, which vary with, among other things, household composition.

Emotional impact

In addition to the tasks to be performed and their effect on family routine, researchers have also investigated how families respond emotionally to different aspects of the situation. Both this, and those aspects of the situation that are less amenable to quantitative measurement, have usually been referred to as 'subjective burden' in the literature. Most studies have sought to identify those aspects of the situation that are sources of the more negative emotional responses. Within a quantitative framework, this has been predominantly through correlational studies. While this approach may show that two aspects of a situation are associated, it does not necessarily establish either causality or the direction of any causal relationship that is established. It is therefore limited in its explanatory power. We describe the emotions that have been identified in different studies, before examining the correlates of these emotions.

A wide range of emotional responses to mental illness occurring in a family member has been identified in the literature. Kreisman and Joy (1974) showed that these have mostly been negative or upsetting, but occasionally they have included positive responses. Feelings of marginalisation, fear of the patient, anger and resentment and shame are common. On the other hand, more positive feelings of warmth and love for the dependant have also been reported (Gillis and Keet, 1965, cited in Kreisman and Joy; Namyslowska, 1986).

Thompson and Doll (1982) investigated some of the feelings that relatives might be expected to have. They used four main indicators – feelings of being overloaded, of being trapped, of resentment and of exclusion (or the need to withdraw from the patient). The most common feeling was of being overloaded. This they defined as being where there was 'a significant interference to the family and a noticeable emotional drain' (p.382). Nearly one half of their relatives reported feeling embarrassed and, in a separate measure, feeling trapped. Resentment and bitterness were expressed by 40 per cent of their sample; for 13 per cent of the sample, this bitterness was intense. Some need to withdraw from the patient was expressed by nearly one third of relatives, though very few (7 per cent) wished for greater social distance from the identified patient.

Creer, Sturt and Wykes (1982) used measures of satisfaction, resignation and dissatisfaction to assess the impact of supporting mentally ill relatives at home. The researchers first identified through detailed questioning specific responsibilities and tasks performed during the month prior to interview. They then assessed the emotional response to each task and made an overall rating. Nearly two thirds of relatives were content with their caring and household responsibilities, even when these were extensive. However, relatives frequently expressed a need for emotional support in coping with their own feelings and their reactions to the patient's behaviour and illness. Specific emotions reported were guilt, associated with the relatives blaming themselves for the patient's condition, and emotional exhaustion. 'With few exceptions, the research team concluded that relatives' complaints were not only justified but understated' (p.38).

This study recognises a slightly wider range of emotional response (from satisfaction to dissatisfaction) than many other studies. It thus includes the more positive responses to caring. By using the category 'resigned', these researchers have also recognised that relatives may have come to terms with a difficult situation. Conceptualisations of the caring role generally neglect or overlook the fact that the situation is too stressful to be seen as 'satisfactory', but that carers may nevertheless have come to accept the role as the best or only option available to them.

Many studies have shown a variety of unpleasant emotional experiences for relatives. Only a few have moved towards conceptualising caring as encompassing more pleasant emotional experiences. These experiences may be more prevalent than the literature suggests. However, it seems more likely that the dominant emotional responses are unpleasant.

In addition to providing details of the range of emotional experience, researchers have sought to identify specific aspects of the situation that are associated with these emotions. Kreisman and Joy (1974) concluded that shame and fear are as likely to be associated with unrestrained behaviour as with the formal labelling of the patient. Shame and perception of stigma have behavioural consequences too, such as a need for secrecy or concealment and withdrawal from friends. Practical considerations, such as the duration of the illness or number of hospital admissions, inevitably affect efforts to conceal what is felt to be a shameful family situation. Other clinical aspects of the situation that affect the family are considered in Chapter Three.

For a majority of relatives there is an association between emotional distress and the more measurable aspects of the situation. Gibbons et al. (1984) interviewed 143 schizophrenic patients and 166 people who supported them. In 90 per cent of households, these relatives or friends experienced distress caused by friction due to a variety of reasons. Financial hardship, reduced performance at work, physical ill health and disruption outside the household 'were distressing to 80 per cent of those affected' (p.75). Namyslowska (1986) found that 64 per cent of relatives believed schizophrenic illness in the family had affected their emotional life in some way. While some spouses reported that the illness had 'cemented their love', most people reported negative emotional responses in respect of changes in economic, educational and emotional functioning. The strongest negative emotional responses concerned change in the areas of recreational and sexual functioning and in feelings of security.

Studies have also sought links between distressing emotions and aspects of the situation that are less amenable to measurement. Creer (1975) found that emotional distress among relatives was related to fears for the future, frustration with the current unchanging situation, loss of the schizophrenic relative's 'former self' and a sense of failure as a parent. Some respondents reported a sense of guilt that could be exacerbated when professional workers attributed blame to the parenting. Creer concludes that, although such emotional responses are 'normal' reactions to a confusing situation, they can impair the ability of the carer to cope with the situation. Other studies, such as those by Creer, Sturt and Wykes (1982), Namyslowska (1986), and Seymour and Dawson (1986) confirm these findings that relatives identify the less easily measured aspects of the situation as being more closely associated with emotional distress than the more easily quantifiable features such as financial or educational disruption.

The dominant quantitative method of the literature under review often pays more attention to the more easily measured aspects of family life and less attention to issues of interpretation and meaning. However, the literature in general suggests that it is the more subtle and personal concerns (of losing a close relationship or anxieties for the individual's future) that are the aspects of the situation that cause greatest emotional distress to carers. Emphasis is not so much on tasks to perform as on difficulties to be managed or tolerated. Carers are thus placed in a position where they need to cope with long term difficulties. Despite this, the general literature on coping with stress has not been applied either to the family experience of mental illness specifically (Avison and Speechley, 1987) or to personal welfare at a more general level (Titterton, 1989). This is likely to be a fruitful area for future research, and is discussed more fully in Chapter Five.

Physical and psychiatric health

Another way of assessing families' response to the caring situation has been to use physical and psychiatric health as indicators. Again, studies have often used correlations to examine associations between health and different aspects of the caring situation.

One study that examined physical health was that of Creer (1975). She reported that less than 20 per cent of her sample of carers of schizophrenic relatives showed no impairment of physical health or well-being. One third showed a 'very severe' degree of impairment. Gibbons et al. (1984) found that nearly three quarters of relatives showed symptoms of physical or psychiatric ill health, as measured by the Social Behaviour Assessment Schedule (SBAS, Platt et al., 1980, cited in Gibbons et al.). This study, however, reports no further details about physical health.

The provisos raised by Parker (1990) are pertinent here when assessing the impact of caring on physical health. Problems of physical health increase with age, so that, 'as the General Household Survey shows around two thirds of people over the age of 45 report chronic health problems' (p. 53). Many people diagnosed as mentally ill are cared for by their parents, and it is likely that age is an important correlate with the carer's physical health. It is not always clear whether deterioration in health can be directly attributed to the caring role. Studies reported by Parker among elderly carers and mothers of handicapped children suggest that caring is not necessarily responsible, nor seen as responsible by carers, for a decline in health. Class, race and gender are other variables that affect health, though these have not been investigated rigorously in this body of literature. More detailed investigations are needed before firm conclusions can be made about links between physical health and caring for someone diagnosed as mentally ill. These will need to consider such aspects of the situation as age, socio-economic class, race and gender of the carer and also whether ill health can be properly attributed to the caring role.

It has been more common for researchers to investigate psychiatric distress than physical health among carers. As has been mentioned above, Gibbons et al. (1984) found that nearly three quarters of relatives showed symptoms of psychiatric or physical ill health, though their report does not differentiate between the two as measured by the SBAS. Relatives living with patients diagnosed for less than one year were more likely to show higher rates of psychiatric distress as measured by the General Health Questionnaire (GHQ). Nearly one half of these scored above the threshold that indicates a level of symptoms severe enough to suggest clinical disturbance. Overall, one third of relatives showed symptoms of this intensity. In addition, the Scottish First Episode Schizophrenia Study (McCreadie et al., 1987) found that relatives scored approximately three times higher than the community norm on the GHQ, showing a very high level of psychiatric distress. These studies, and other work such as that of Hirsch and Leff (1975), have shown that families with a mentally ill member experience levels of psychiatric distress that are more severe than those considered normal on the basis of community norms. Both of these studies also found that psychiatric distress among family members was associated with the patient's clinical status. A detailed analysis of the relevant aspects of clinical status is reported more fully in Chapter Three.

Other variables have also been shown to be associated with psychiatric distress in relatives. McCreadie et al. (1987) found that where symptoms were most severe, the relative was more likely to have poorer social adjustment, and poorer functioning both within the nuclear family and at work. Distress is generally greater where there is a shorter history of caring for someone with mental illness, as for someone with dementia (Gilhooly, 1984). Gibbons et al. (1984) have suggested that this reflects families' abilities to adapt to coping with the situation. There are other possible explanations. The early period of caring, before adjustment has taken place, has often been identified as particularly stressful. Relatives who have recently experienced the trauma of diagnosis may be showing the sort of distress known to follow life events (Brown and Harris, 1978). In addition, those families that do not cope do not remain intact. They are thus excluded from studies based on surviving families.

Studies such as these that use measures like the GHQ may underestimate symptom levels over prolonged periods of time. The measure assesses how respondents have been feeling during the previous two weeks compared with how they normally feel. If the caring situation has existed for several years, the baseline of what is normal may be different from situations where caring has been taking place only for weeks or months. This is a point emphasized by Parker (1990). She showed that as carers become used to the caring role, they may cease to regard the situation as unusually stressful and may overlook deterioration in health that has occurred over a long period of time. What is clear is that those families that do survive intact do so in part because they are able to accommodate to a distressing situation, but probably only at a cost of higher than normal levels of psychiatric distress.

Conclusion

Overall, despite conceptual difficulties and methodological diversity, there is among researchers some consensus both about the extent of impact and about the types of experience and behaviour that can be said to constitute and produce it. What is less clear is precisely whether and, if so, how this differs from the disturbance in 'normal' families. Platt's question of whether disturbance is attributable to the presence of a psychiatrically distressed person is highly relevant.

The question is not only whether other family members attribute disturbance to one individual, but also whether disturbance should be attributed to the presence of mental illness at all. 'Normal' family disturbance may risk being seen as pathological where a member has been labelled as psychiatrically ill and has become drawn into the service system. This may result in disturbance being mistakenly attributed to the mental illness of one individual. Studies that include control or comparison groups will help to clarify this issue. Finally, many gaps in basic knowledge remain about the impact of living with someone with psychiatric distress especially when it is remembered that most studies have focused on people with schizophrenia rather than other forms of mental illness.

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What makes caring more difficult for some than for others?

There are some characteristics of the caring situation that mean that difficulties are greater for some carers than for others. Personal characteristics that have been reported include socio-demographic variables, such as kin relationship, age and gender of the carer; clinical characteristics of the identified patient; and social support of both the family and the identified patient. In this body of work, however, characteristics such as age, gender and kin relationship have often been confounded. There is a need for studies that tease out such characteristics properly.

Kin relationship

There is growing interest in the main carer literature in how caring is constructed differently in different situations. One of the ways in which we increasingly refine the concept of carer is with regard to kin relationship. Important differences have been identified between, for instance, spouse and parental relationships (Parker, 1989).

Most studies that have investigated kin relationship between carer and dependant report no association between any particular kin relationship and increased strain for the carer (Gibbons et al., 1984; McCreadie et al. 1987; Seymour and Dawson, 1986; Thompson and Doll, 1982). These studies have examined a number of variables and related these to measures of distress and health. However, what they show is that, not surprisingly, relatives report different sorts of concern according to the kin relationship. Parents are concerned about the future care of their offspring, while spouses are distressed by changes in the marital role. This can be compared to findings in the main carer literature.

The range of kin relationships has not been systematically explored. Many studies (particularly the earlier ones such as those of Yarrow and Clausen and their co-workers, 1955) focused on wives caring for husbands and cannot be said adequately to have separated out the differences between issues of gender and issues of kin relationship.

Many people who develop mental illness do not marry (Cheadle, Freeman and Korer, 1978) while some relationships, such as those between siblings, are less likely to develop into caring ones. In addition, studies sometimes confound problems specific to kin relationships with those of co-residence (Gubman and Tessler, 1987).

The studies that show there is no differential impact with kin relationship may reflect the fact that measures of overall impact have been used. There is a need to use methods that are sensitive enough to assess those strains that are specific to particular kin relationships, and it is likely that only a specifically designed study will provide appropriate research material. So far as we are aware, this type of study has not been conducted. Those of Fadden et al. (1987b) and Rogler and Hollingshead (1965) were conducted with spouses only, and were not designed specifically to investigate gender differences even within this relationship. In addition, Rogler and Hollingshead's study was conducted among Puerto Ricans, and the possibility of differences with regard to racial and cultural characteristics has not been disentangled from differences with regard to gender or kin relationship. It is not possible to say definitively, for instance, whether spouses are more adversely affected than parents. This is an area where considerably more research is needed.

Age

The issue of age is particularly relevant given the common pattern of responsibility of parents caring for mentally ill offspring. The position of single dependent adults living with ageing parents has been highlighted as a particular problem (Braun et al., 1981; Creer and Wing, 1974; Seymour and Dawson 1986; Stevens, 1972). Stevens has also shown how this situation may benefit both carer and dependant, for the elderly parents may gain from the company of their adult offspring. This may be particularly so for an elderly widow. She points out that this type of caring relationship may offer an important source of social cohesion when the more usual family pattern is for adult offspring to move away from the family of origin and have little day to day contact with an ageing relative. However, there are also difficulties inherent in this situation. A frequent cause for anxiety among ageing relatives is the continuation of suitable care once they themselves are unable to offer daily support; and this type of symbiotic relationship may inhibit the dependant from living more independently in the community.

On the other hand, those investigations that have included age among a range of socio-demographic variables have shown no relationship between age and the impact of caring. These include the studies of Gibbons et al. (1984) and Thompson and Doll (1982). It is possible that where issues concerned with age are specifically investigated, then particular difficulties are identified – fears for the future or a symbiotic relationship that may inhibit independent living. However, such difficulties when measured within a quantitative framework may appear to present no greater difficulties for ageing parents than difficulties concerning the well-being of school age children present to younger carers. The findings on age may more usefully contribute towards an understanding of those aspects of the caring situation that are most salient at a particular stage of family history, rather than demonstrating that the role of caring is more stressful for older than for younger carers. It is clear that the diverse situations of carers present diverse difficulties. It seems likely that contradictory findings reported in the literature reflect this diversity.

Gender

A similarly mixed pattern of results is seen when gender of the carer is considered. Studies by Gibbons et al. (1984), McCreadie et al. (1987) and Thompson and Doll (1982) have shown that gender of the carer is not associated with differences in the impact of caring. Some studies of spousal relationships have shown that greater family disruption is found where wives are the carers (Fadden et al., 1987b; Namyslowska, 1986). Others have shown that disruption is greater where husbands are the carers (Rogler and Hollingshead, 1965). Mandlebrote and Folkard (1961) reported that where women were caring, disruption was greater in the conjugal rather than the parental role (cited in Fadden et al., 1987b).

Crotty and Kulys (1986) found a marked difference between the perceptions of male and female relatives. Nearly two thirds of the 39 women they interviewed did not see caring for a man as a burden. In contrast, nearly two thirds of their 17 male carers did see the situation as burdensome. The authors interpret this as being consistent with the way women are socialised in the United States, where the study took place. In Poland, Namyslowska (1986) found that men and women adopted different coping strategies. Men were 'inclined to denial' while women were 'looking for information even at the expense of security'. She was able to offer no explanation for this difference.

In many studies, gender and kin relationship have been confounded. Studies have not always distinguished between mothers and fathers, but have included both as parents. Rogler and Hollingshead's (1965) study showed a more destructive impact on family organisation where men were caring for their wives. The fact that husbands in this Puerto Rican society were less willing to adopt elements of the wife's role may be an issue more concerned with gender or with race than with kinship. Similarly, it is not clear whether the reason that wives of depressed husbands showed a higher level of social isolation than did male carers is because they were married or because they were women (Fadden et al., 1987b). That women often found it upsetting to have to adopt traditional male roles, such as employment, even when these were performed competently, suggests that it was the gender role change which was particularly difficult.

However, none of these studies was set up specifically to examine any differential impact associated with gender. In addition, Kreisman and Joy (1974) noted that the majority of studies in their review focused on women's perceptions and attitudes as they relate to male patients. This has resulted in 'meagre knowledge' about the perceptions and expectations of males, and about the differential impact on the family of illness in men or women. This is true also of the main carer literature, though Parker's (1989) study of non-elderly spouse carers has explored some of the complexities of gender and caring, a subject also addressed by Ungerson (1987).

Other socio-demographic characteristics

Other socio-demographic variables investigated in this body of literature have been examined in correlational studies, and these, like those reported above in regard to kin relationship, age and gender, show no difference in strain for carers. Variables studied in this way include social class (Gibbons et al.; Thompson and Doll) and race and education (Thompson and Doll). Gubman and Tessler pointed out that 'caregiving obligations and options vary by social class', with American middle class families being more likely to use money as a resource and working class families more likely to use time, goods and physical space (1987, p.236). This is compatible with the point made above in relation to age and differential impact: that the overall impact may not differ with particular variables, because each age or class have particular stresses that are difficult for families to bear. This may explain why these findings, that socio-demographic variables are not associated with differential strain for carers, bear little relation to the evidence in the general carer literature.

These findings can also be contrasted with recent qualitative studies in this country that illustrate important differences in caring roles with regard to race (Cameron, Badger, Evers and Atkin, 1989).

These differences are unlikely to be amenable to quantitative measurement and analysis, as they are bound up with the deep-rooted preconceptions that white researchers have of the caring as of other situations. These preconceptions have meant that ethnocentric measures of stress and conceptualisations of health or of the family situation have been treated as universally applicable. More recently, discourse analysis has been used to demonstrate the ethnocentric assumptions that underlie disability (Atkin, 1989).

Some researchers, for instance Cheadle et al. (1978), have looked at the household composition of patients, though they do not always relate this to impact on the carer. Gibbons et al. (1984) reported that whether the carer lived alone with the patient, or together with other family members, there was no increased strain for the carer. In contrast, Crotty and Kulys (1986) found that strain was greatest for carers in larger, rather than smaller, households. It seems likely that from the point of view of the carer, both living alone with the dependant and with other family members offers advantages and disadvantages. Carers living in a smaller household may have fewer social contacts and a more restricted lifestyle, but may also have fewer sources of conflict and less responsibility for other family members. The evidence so far is inconclusive.

As with the kin relationship findings, it seems likely that the impact of caring differs for different sectors of society, but that this diversity is not always revealed by the overall assessments used in quantitative approaches. This, in conjunction with the fact that studies are based on only those families that have survived intact, may mean that we know about socio-demographic variables only for a particular sub-group of families. We can generalise to those families that cope with caring for someone with mental illness, but not to all families where mental illness occurs, to families from different social, racial and economic backgrounds, or to individual family members.

The previous four sections have been concerned with various socio-demographic characteristics of carers. Several issues can be drawn together at this point. The situation of spouse carers of people with mental illness is one which has received special attention, in contrast to the rest of the carer literature. However, many studies appear to confound gender issues with those of the spousal relationship. Moreover, the focus of these studies has generally been the patient rather than the carer. This means that the spouse carer is perceived as an adjunct to the patient's well-being rather than as of concern in his or her own right. Further, it is generally male patients who have been the focus, and women the spouse carers. This emphasis on the female carer/male patient may serve to mask the differential impact of caring on men and women. It underlines the point made by Finch (1987), Dalley (1987) and Ungerson (1987) that caring is often seen as an extension of women's roles. It also shows how there is a transferring of gendered notions into the process of research, constraining the definition of what is an appropriate area for investigation.

One further consideration concerns the measures used to assess strain in the carer. Briscoe (1982) and others have examined gender bias in measures of psychiatric distress. Many instruments which are in wide use include indicators which appear to produce a higher score for women than for men. In addition, cultural expectations may inhibit men from reporting emotional distress. There may be a consistent distortion of the outcome measure which results in women being assessed as showing more strain. A more appropriate approach to the issue of differential impact may be to assume a diversity of experience. It seems likely that, as research on race and informal care continues, more precise accounts of differential impact will be developed, as they have for gender.

Characteristics of the identified patient

Some studies have shown that personal characteristics of the dependent person do not affect the carer's experience (Seymour and Dawson, 1986; Thompson and Doll, 1982). Others have shown that there is a differential impact for families, but that this operates in a complex way:

> The high-risk indicators for being seen as a burden are lack of a confidant when present in combination with some of the following characteristics: being a woman, being young, being well educated, and living in a large household. (Crotty and Kulys, 1986, p.186)

One way of explaining this finding is to use gender as the basis for analysis. Certain types of behaviour (the more florid symptoms of schizophrenia, for instance) may be more easily tolerated in men than in women because society holds different expectations of men and women. A different set of expectations may be placed on young women who are well educated and still living in the parental home, as against young men in this situation. Findings need to be interpreted within the context of cultural expectations.

Associations between characteristics of the dependant and differential impact on the family are not straightforward and this may help to explain why evidence is sometimes contradictory. The notion that the caring situation is likely to be complex supports the inference made above that there are limitations to the usefulness of correlational studies as a means to understanding what life is like for carers. It may be more appropriate to adopt approaches that use more complex statistical techniques (Noh, 1985) or qualitative methods.

There is more agreement about the impact of the clinical status of the identified patient on the caring situation. Disturbed behaviour, current clinical characteristics and a more recent onset of psychiatric symptoms were particularly distressing to relatives interviewed by Gibbons et al. (1984). McCreadie et al. (1987) found that both social function and GHQ scores in relatives were associated with patients' clinical status as measured by the Present State Examination (PSE) though not as measured by four other clinical assessment measures. The neurotic symptoms of the patient mainly accounted for this correlation. The authors interpret this as demonstrating that while carers respond to anxiety in the dependant by themselves showing symptoms of anxiety, this is not the case for people caring for those with psychotic symptoms. Here, carers adapt to the situation, in that they show fewer psychiatric symptoms. Presumably, this adaptation implies either separation from or adjustment to the situation, although McCreadie implies adjustment only.

The relationship between clinical status of the identified patient and family well-being, though well established (Hirsch and Leff, 1975), is again complex. Platt and Hirsch (1981) reported that disturbed behaviour in patients caused greater distress for the family than either their social performance or disruption to household routine. Thompson and Doll (1982) found that carers were consistently and significantly upset while the dependant was exhibiting psychiatric symptoms. However, lack of current symptoms did not necessarily mean that carers were not distressed by the situation. The past, present and anticipated clinical status of former patients all aroused feelings of being trapped, overloaded and resentful, while recent admission to hospital was more likely to be associated with feelings of embarrassment. Fadden and her colleagues (1987b) found differences in the ways that different psychiatric symptoms among former patients affected carers. Florid symptoms of depressed spouses produced fewer emotional difficulties for carers than the negative and more persistent symptoms such as withdrawal or apathy. The authors point out that this may be tempered by bias in reporting, as few spouses were experiencing florid symptoms at time of interview and add that 'there is no doubt that relatives were upset at times of acute disturbance' (p.667).

Several studies have examined hospital admission and its impact on the carer. Crotty and Kulys (1986) found that there was no association between how recently the patient had been in hospital and its impact on the household member who offered most support. Seymour and Dawson (1986) monitored change before and after the discharge of a schizophrenic relative from hospital, and found deterioration in the quality of life for carers, particularly when carers were elderly and the patient had been ill for greater lengths of time. However, their exceptionally low response rate of 14 per cent raises questions about the generalisability of their findings.

There is no doubt that, over a long period of time, studies have shown that relatives caring for someone diagnosed as mentally ill have a higher level of psychiatric symptoms than the population as a whole. There is also strong evidence to show that, of all the aspects of the caring situation so far reported, it is the psychiatric status of the former patient which is most frequently associated with this family distress.

Social support

Just as there are aspects of the caring situation that exacerbate the impact on families, so are there aspects that may moderate it. Among these is the well-established role of effective social support in moderating the detrimental effects of life events (Brown and Harris, 1978) such as bereavement (Walker, MacBride and Vachon, 1977). Social support appears to be important in the caring situation also, for both carer and dependant. Crotty and Kulys (1986) found that when a schizophrenic patient had a confiding relationship and when relatives perceived this to be the case, there was decreased family burden. They linked this latter factor with an earlier study (citing Lowenthal, 1964) which reported lower hospital admission rates for elderly psychiatric patients with confidants.

This work is particularly important in the context of the widespread experience of disruption to social life of families reported above, and of investigations of the social life of schizophrenic patients. Sommer and Osmond (1984) noted that the presence of a schizophrenic member 'tends to isolate the family from the community', and in support of this cited Creer and Wing (1974), Doll (1976), and Pasamanick, Scarpetti and Dinitz (1967). They observed that the social isolation of patients that is apparent in hospital continues once the patient is discharged into the community. This is, they argued, a particular feature of schizophrenic illness, as ex-prisoners do not show this social isolation and therefore institutionalisation cannot be held responsible for this feature. Questions can be raised, however, about the validity of their choice of comparison group and about the fact that they explored neither causality nor possible links between stigma and concealment reported by Kreisman and Joy.

Despite such criticisms, it does appear that social isolation is both a feature of schizophrenia and a particularly distressing experience for relatives. If, as Crotty and Kulys have shown, better levels of social support serve to modify the burden carried by families, then interventions which reduce social isolation of either the former patient or their families may be particularly helpful.

Conclusion

There is mixed evidence about the differential impact of caring from studies of socio-demographic variables such as age, gender, class and race. It is clear that more basic research is needed with regard to these issues, but it is also apparent that, particularly with regard to race, there are fundamental preconceptions (that amount to misperceptions) that need adjusting. It seems likely that the diversity of the caring situation has produced a diversity of findings. Two issues do seem to be clear from the evidence so far available, however. The psychiatric status of the former patient, and effective social support for the carer and the person being cared for, both have definite effects on the families' reporting of the situation as more or less burdensome.

CHAPTER FOUR

Families and service provision

It is clear that carers of relatives with mental illness face considerable difficulties. It may therefore be surprising that a number of studies have shown that carers prefer their mentally ill relative to be living in the community where possible. They are generally willing to support their relative in order for them to do this. For instance, Johnstone et al. (1984) found in their study of the long-term impact of caring for schizophrenic patients that 27 of their 42 informants were satisfied with the patient's presence at home, and only six felt the patient should live elsewhere. Sixteen relatives reported the patient's clinical condition was satisfactory while five felt the clinical problems were so severe that they should be dealt with elsewhere. Johnstone and her co-workers concluded that care 'was provided by relatives who were in many cases frail, ageing, and coping only with great difficulty' (p.589). Despite the many problems arising from the patients' illness, these relatives rarely expressed a wish for the patient to return to hospital. Further, relatives find the task is manageable when support is available from services, and that it is facilitated when families and patients form part of the service planning (Hoult, 1986).

These findings can be compared with West et al.'s survey (1983, 1984 cited in Parker, 1985) of popular views of where services should be provided for different dependency groups. Just over 85 per cent of their respondents drawn from a general population thought that some form of community care was the most appropriate form of provision for non-elderly adults with a psychiatric disorder, although community care does not necessarily equate with family care. This has been seen in studies which traced former psychiatric patients now living in the community (Jones, Robinson and Golightly, 1986; Perring, Hunt, Parry and O'Connor, 1987).

Research on the effect of service provision on families with a mentally ill member has focused, as has much research on mental illness in the community, on the course of the illness in the community, on the individual diagnosed as mentally ill and, in particular, on how the course of the illness is affected by different ways of providing service. Only occasionally have studies recognised and sought to assess the impact of different treatment programmes in terms of family well-being. For mental illness, as for other forms of provision, it is even more rare for families to be asked for their own response to service provision.

All of this limits the relevance of the studies with regard to an understanding of the impact of service provision on carers. However, there are three broad areas that are relevant: the differential impact on families of traditional and community-based services; forms of service that aim to provide information to families on specific aspects of mental illness; and those few studies that have had as their primary focus families' attitudes to and experience of service provision.

The impact of formal support

Braun et al. (1981) reviewed 38 outcome studies of different programmes of care for psychiatric patients and recognised the importance of measuring the impact of these programmes on family members. Although several of the researchers mentioned in their review also noted this, few have pursued it. Evidence from studies that compare hospital- and community-based treatment is cited in only limited detail by Braun et al., and is contradictory with regard to impact on families. Two studies demonstrated that family burden was greater when service was provided only in the community. These were the studies conducted in Britain in the 1960s (Brown et al., 1966; Grad and Sainsbury, 1968). In contrast, a study by Washburn et al. (1976) showed that day treatment produced less distress and family burden than a traditional hospital stay. Hertz, Endicott and Spitzer and their co-workers (1976–1979); Pasamanick and colleagues (1967, 1974); Stein, Test and Marx (1975) and Test and Stein (1978) reported that different forms of, or alternatives to, hospital care produced no significant differences in the impact on families.

There are many possible reasons for these contradictory findings. Follow-up periods for the different studies vary from six months to five years, with the exception of that by Washburn et al. where no follow-up period is mentioned. Studies evaluate a variety of programmes that include day care, modified hospital care (day care and short-term care) and alternatives to hospital care. The studies are of differing designs – non-experimental (Brown et al.), controlled trial (Grad and Sainsbury) and randomised trial (the remaining four studies). They define 'families' in different ways, and it is not always specified whether these are co-resident with the former patient. Two studies were conducted in Britain (those of Brown and Grad and their colleagues) and the remainder in the United States. The interventions took place from the early 1960s to the late 1970s. The only study that reported that a non-traditional approach was better for families was that of Washburn et al. The findings of this study are limited because there appears to be no follow-up period, and the study was based on a highly selected sample, which reduces its generalisability.

Studies conducted after Braun et al.'s review include those of Test and Stein (1980), Hoult's (1986) replication of this in Australia, and Platt and Hirsch (1981). While attending to family well-being, these continue to emphasise outcome for the patient. The studies of Test and Hoult and their associates showed how intervention programmes could improve prognosis for patients for the lifetime of the programme, without detriment to the family. Test and Stein allocated families to either an experimental group or to a control group. Treatment for the experimental group was conducted entirely in the community. Treatment for the control group consisted of short-term hospitalisation plus after-care — in other words, a traditional approach. Families in the experimental group were not adversely affected in terms of disruption to the family when compared to the control group. The authors pointed to certain limitations of their study. They emphasised the difficulties of obtaining an adequate response rate for the follow-up interviews with families. Of 50 eligible families in each of the two groups, fewer than half responded at the two follow-up interviews. They also pointed to the absence of any measure for personal experience of distress.

Hoult and his colleagues replicated the intervention study in Australia (1984, 1986). They assigned 120 psychiatric patients to either an experimental or a control group. Intensive support from an interdisciplinary team was available at short notice (30 minutes) on a 24 hour, everyday basis. Relatives in general regarded the community-based treatment positively; this included about half of the relatives who were resident with a patient. One respondent reported appreciation at being able to share the load so that the patient, with the fear of hospital admission removed, was able to seek help more promptly and thus avoid more severe relapse. The experience of community treatment was particularly valuable for a group of 11 first-episode patients, only four of whom were admitted to hospital in the 12-month study period. This was in contrast to 11 of 12 first-episode patients in the control group who needed hospital admission. Clinical status of the experimental group was significantly better than that of the control group at 12 months. Hoult argues that for staff, who preferred the mode of working, for relatives and for patients, the intensive community programme was preferable.

These studies are important because they demonstrate that treatment programmes based entirely in the community, but in two different countries, can offer improved well-being to family members. Taken together, they show benefit both for families and their mentally ill relative. However, both studies reported that once the experimental intervention ceased, there was no carry-over benefit. Further, the level of intervention was much higher than that of treatment normally offered in the community.

Platt and Hirsch (1981) reported that in the short term there were no overall differences for families where patients had been randomly allocated to either brief or standard hospital care. This reproduced the findings of Hertz and co-workers in the 1970s. Measures were taken at points in time one month before, and two weeks and 14 weeks after hospital admission. These covered distress and various aspects of family life. Individual correlations showed more distress for families with patients allocated 'Brief Care' at two weeks with regard to the patient's 'slowness', but less distress with regard to impact on 'family performance in employment' compared to 'Standard Care' families. At 14 weeks, standard care families showed more distress with respect to their own social and leisure activities and the patient's personal neglect, but less distress than brief care families over the patient's over-dependence.

Intensive and long-term intervention from services in the community can ensure that families' quality of life is not impoverished beyond an unbearable level and can also provide a better quality of life for the former patient than life in hospital. Generalisations from this conclusion must be made with utmost caution. These studies are evaluations of service provision that has been constructed for research purposes. They were not situations with normal levels of service provision. Research sampling methods have often overestimated the level of service, and intervention studies have deliberately increased service provision. It is likely that the levels of formal support normally available to families are considerably lower than those evaluated in research projects, and certainly unlikely to be of the same order as the provision evaluated in intervention studies such as Hoult's. In addition, studies with a range of follow-up periods demonstrate that any benefits are unlikely to continue once the intensive programme of care has ended. It is inappropriate to extrapolate directly from findings that show that community-based care is superior without examining the level and long term effects of that care.

Families' knowledge about the situation

The need for knowledge and information about the situation in which carers find themselves has been widely reported and emphasised, both in the literature under review here (Hatfield, 1979) and in the carer literature (Glendinning, 1983; Levin, Sinclair and Gorbach, 1983). Atkinson (1986), however, found that relatives provided and wide range of responses to questions about their situation, and concluded that the need for information was less salient than needs likely to be met by other service provision:

> The two problems which the greatest number of relatives mentioned were 'the future' and 'getting help when it's needed'. These were followed by the social problems of the patient, family friction and supervision. The three areas of help which relatives reported wanting most were: day care of some kind; changes in 'the professional approach'; direct help for relatives.
> (Atkinson, 1986, p.175)

As these problems are potentially affected through appropriate information-giving, Atkinson's conclusions are not necessarily incompatible with other work on providing information to families.

Most of the studies that have been reported have assessed the impact of knowledge about schizophrenia on families' ability to cope with mental illness. One important way in which information has been conveyed to families is through psychoeducation. This is a systematic and formalised way of providing families with information about the origins, course and experience of mental illness. This may take place in a variety of ways including family support groups, the provision of written material and family therapy. A significant amount of psychoeducation is now based on the influential theory of 'expressed emotion'. Here, a number of studies have shown prognosis is unfavourable in families where high levels of hostile or critical comment occur (the studies of Brown and Falloon and their colleagues, 1962, 1972 and 1982; see Kuipers, 1979, for a review of research on expressed emotion). Two recent studies have examined the role of expressed emotion in a setting that emphasises relatives' groups and counselling (Leff, Berkowitz, Shavit, Strachan, Glass and Vaughn, 1989; MacCarthy, Kuipers, Hurry, Harper and LeSage, 1989a). Both studies recommend relatives' groups as effective, but while Leff and colleagues stress the role of expressed emotion, MacCarthy et al. see the opportunity for relatives of being able to share some of their 'pent-up' feelings as an appropriate focus for intervention.

Barrowclough and Tarrier and their colleagues (1987, 1989) evaluated the role of psychoeducation in outcome for patients. They found that a substantial number of relatives were unlikely to modify their lay model of schizophrenia, particularly where the patient had a relatively long history of illness. Barrowclough and his colleagues developed the Knowledge about Schizophrenia Interview (KASI) together with an information booklet designed to be incorporated into an education programme based on theories of expressed emotion. KASI can be used to identify relatives whose attitudes may prove detrimental to the future course of the illness and who may therefore need extra advice and support. The researchers concluded that it is possible to run brief educational programmes with families which would lead to actions that will assist in the patients' recovery both in the short and in the longer term. Their study is within the tradition of focusing on patient, rather than on family well-being and it provides no indication of whether families themselves benefit from increased information.

There have also been studies concerned with psychoeducation outside this tradition. For instance, Ferris and Marshall (1987) described an educational project for families of chronically ill people within the 'nonblaming-stance' (citing Jung, Spaniol and Anthony, 1983). Here, an attitude is adopted by professional workers which explicitly avoids attributing blame to the family for either the origins or lack of improvement of mental illness. Ferris and Marshall proposed that education about the nature and management of schizophrenia, about effective communication, and about problem-solving skills was particularly helpful to families. While stressing that this is not an evaluation, they pointed out a number of activities that can help families. These include educational workshops and seminars attended by families, clients and professionals, establishing a thrift shop which offers sheltered employment for clients, and developing an advocacy role to improve state facilities. They note that there is also an enhancement of families' lifestyle from the improved and increased social contact associated with these activities. The question must be posed, then, as to whether the improved family situation was associated with increased information or with increased social contact. It seems likely that improved contact with service providers is an integral aspect of educational programmes: only an appropriately designed study would disentangle the relative contributions of improved information, improved social support and closer and more harmonious contact with professional workers.

There has been a trend towards the publication of books such as those by Anderson, Reiss and Hogarty (1986) or Atkinson (1986) which offer advice to practitioners and families on the management of schizophrenia in a family setting. Anderson et al. offer a model treatment programme and illustrate its application. They emphasis the need for professional workers and families to work as allies in reducing the stress experienced when mentally ill people live with families, and their programme of psychoeducation provides a planned and gradual way of achieving this. This programme is reviewed, together with other forms of aftercare for schizophrenics living at home, by Iodice and Wodarski (1987).

One finding that is unexpected in the context of this body of work on the beneficial role of information for families was reported by Namyslowska (1986). She found that people who were 'better informed about the illness are coping with its stress much less efficiently' (p.403). She proposed that use of a defence mechanism such as denial may be the most adaptive way of with chronic stress. She pointed out that this is in conflict with one view in systems theory which states that additional information is vital for a system under threat (such as a family) to be able to retain its structure.

This finding is atypical, and psychoeducation appears to be an increasingly important element in service provision. However, it was originally introduced in order to improve the situation for the dependent person, and this continues to be its primary focus. It should be seen as only one element in a package of provision. A service that aims to promote family well-being needs to emphasis other aspects of service provision that remain important to families, as well as psychoeducation.

Evaluating provision from the perspective of carers

It is important to remember that services have been primarily designed to meet the needs of the identified patient, although they will often benefit carers either directly or indirectly. This off-centre relationship is evident across the field of carer support (Twigg, Atkin and Perring, 1990). Comments from carers reflect this orientation in service provision. Several studies have canvassed carers for their views about their experience of existing services. Carers have also been asked about services which they might wish to receive, and some studies have asked carers for their opinions about what might be an 'ideal provision' (Perring, Hunt, Parry and O'Connor, 1987).

Studies have pointed to the generally low quality and quantity of carers' contact with services, both where respondents are drawn from relatives already in contact with some form of service provision (Creer 1975) and from a more general sample (Johnstone et al. 1984; Perring et al., 1987). Most of Creer's and Perring et al.'s respondents reported instances of contact with one especially helpful worker, though many voiced specific criticisms of the level of involvement by services. Johnstone and her co-workers (1984) found in their follow-up study that 51 of 66 families had no contact with a social worker, and that the greatest levels of distress were found among patients and their families receiving no social or medical attention.

Relatives have voiced a number of concerns about the quality of provision. Poor long-term involvement with professional workers is a particularly common criticism (Creer, 1975; Johnstone et al., 1984). This takes several forms such as frequent staff changes and the lack of opportunity for long-term contact with a constant figure who knows the patient's case (Johnstone et al.), ignoring parents' concerns until a crisis point is reached and compulsory hospital admission occurs (Creer; Creer, Sturt and Wykes, 1982), and lack of advice on the patient's return home from hospital (Creer). A second major theme is the attitude displayed by professional workers who were seen as unsympathetic to carers' difficulties (Creer). They failed to recognize family burden (Johnstone et al.), and poor communication between relatives and workers was experienced in the 'politely cool reception' accorded to relatives (Creer, Sturt and Wykes, p.37). Support from service providers also came from unanticipated sources, such as the police; for instance, when the dependant's behaviour was so disturbed that compulsory hospital admission became necessary (Perring et al., 1987). In this study, relatives did not report any one single form of service provision as being particularly helpful; they were more likely to name one individual from among the range of workers with whom they were in contact.

Other studies, such as those by McCreadie and his co-workers (1987) and MacCarthy et al. (1989a), have pointed out the importance of the timing of service involvement with families. This should begin as soon as the patient first enters hospital or early in the 'patient's career', and is for the well-being of both patient and family. The importance of the duration of service involvement has been demonstrated by the intervention studies reported earlier in this paper (Hoult, 1986; Test and Stein, 1980) which report that any benefits are lost once the intervention period ends. Permanent and appropriately-timed community support is therefore essential.

Overall, Creer reported that although one quarter of her respondents were satisfied with services, nearly one third were very dissatisfied.

It will be remembered that her respondents included a high proportion of relatives in contact with services, and may therefore be a special sample. While her study provides a clear commentary on those services which are received, it is likely to under-report the general experience of service receipt. In particular, her study does not represent the views of those who have withdrawn from service provision, possibly because of dissatisfaction with the service.

One important aspect of service that has been singled out for comment is co-operation between relatives and professional workers. There is a consensus among studies reviewed here that close co-operation is essential for the well-being of patient and relative alike (Hatfield, 1979; Iodice and Wodarski, 1987; Thompson and Doll, 1982). Studies that have assessed the nature of the relationship between relatives and professional workers have rarely shown that this co-operation is satisfactory from the relatives' point of view.

Other gaps in service provision have also been identified by asking respondents directly. Creer pointed to problems of access to suitable service at the onset of a first episode of schizophrenia. Creer's relatives also wanted day care, respite breaks and greater communication with professional staff. Northouse (1980) has commented on the absence of routine pathways to link families to sources of relief. Johnstone found that relatives believed that service providers lost interest in patients over time when they did not become well. Additional support at times of crisis was mentioned by relatives in the study by Perring et al. Fadden (1987b) and her co-workers, who asked similar questions of relatives of depressed patients, reported that relatives wanted information, consultation over treatment and earlier admission to hospital. All of these appear to be requesting closer contact with existing services. At different stages in the course of mental illness, then, inadequate services have been identified by carers themselves. Onset, times of crisis, periods of respite between crises and the need for long-term support, especially for those who show no improvement, are all situations which require different types of support for carers.

We must also devote some attention to the concept of unreported need. This is a problematic and contested concept, and Creer and Wing (1974) have succinctly pointed to processes that may contribute to low expectations, low demands and unmet needs:

> So certain characteristics of relatives can result in their needs being left unmet. They do not always see that they have a need. If they do perceive this, they may feel they have no right to ask for help or may not know that there are services intended to meet their needs. (Creer and Wing, 1974).

In addition, some of the reasons why relatives hold low expectations about formal support concern service provision itself. It is the nature of many services to be demand-led and non-intrusive, and to assume that those in need will ask for services. However, services which respond to crisis, rather than to prevention or maintenance, may not be the most appropriate form of service for carers with responsibilities for long-term care. Creer and Wing found that even 'articulate and knowledgeable' relatives did not always have their needs met by such a service.

Low expectation can be detected by discrepancies in statistics. Fadden et al. (1987a) citing Hoenig and Hamilton (1966, 1969), commented that of relatives who felt that no more could be done for them, three quarters experienced objective burden and half reported subjective burden. However, fewer than one tenth complained about services. An empirical investigation of the perspectives held by former psychiatric patients, their relatives and professional workers has revealed a number of differences in the perception of need:

> Thus, when relatives perceive budgeting as an area of need not recognised by former patients, or when professional workers point to inadequacies in a social network with which former patients express satisfaction, sites of possible unreported need can be identified. (Perring, forthcoming).

Other research teams have attempted to assess levels of unmet need with regard to service provision (Creer et al., 1982; MacCarthy, LeSage, Brewin, Brugha, Mangen and Wing, 1989b). Creer and her colleagues reported that two thirds of their 52 interviewees wanted some change to their present service, and that one third of relatives had at least one unmet need. The most common request was for practical help such as financial advice. Involvement in planning a treatment programme, information about managing difficult behaviour, breaks from caring and emotional support were other needs frequently unmet by current services MacCarthy and her colleagues used Brewin and Wing's *Needs for Care Assessment* to identify unmet needs among relatives. They found that relatives expressed little dissatisfaction with services and were mostly resigned to their situation, despite a large number of unmet needs. The highest rate of under-provision was with regard to emotional burden, which was widespread among the relatives. MacCarthy et al. recommend that the assessment of unmet need be included as part of routine clinical practice 'in order to ensure that they [the relatives] are adequately supported in the key role they play in the provision of community care'. In some studies, high levels of unmet need have been identified. Holden and Lewine (1982) suggest that these levels may under-report unmet need, given the characteristics of the people who participated in their study.

Several reasons for such widespread unmet need have been suggested. These include under-reporting of need (Creer and Wing, 1974), low expectation among respondents (Fadden et al., 1987a), inadequate assessment (Creer, Sturt and Wykes, 1982), professional workers assuming that tolerance among families implies no need for enhanced services (Fadden et al., 1987a), and the difficulties of providing a service to ease emotional burden (MacCarthy et al., 1989b).

The difficulties facing families of people who are mentally ill are diverse and numerous and it may be difficult to construct a package of services to match their needs. Creer and Wing (1974) have pointed out that professionals target their services at the patient, and that no professional group exists to offer support to relatives in their own right. Even studies aimed at improving services to relatives use well-being of the patient as an argument for doing so (Katschnig and Konieczna, 1989). Researchers, too, have often focused on patient, rather than family, well-being. Despite this lack of attention, a number of service-related factors have been shown to reduce the emotional distress of carers and the family disturbance which may be experienced as a result of caring at home for someone with mental illness. These include close contact with service providers (Birchwood and Smith, 1987; Hoult, 1986; Test and Stein, 1980); the provision of information and advice to relatives (Barrowclough et al., 1987); and day care provision (McCreadie et al., 1987). MacCarthy et al. (1989b) proposed that such services should be provided in flexible ways, and saw this as particularly important because of the long-term nature of family burden. Although these studies have often focused on the effect of provision of service for the dependent person, it can be concluded that those families which are intact cope with their caring tasks with comparatively few complaints, despite an absence of services.

One particular point to note is that no study so far reported has included information from families after care has ended. The purpose of service provision in relation to the ending of care is controversial, since the ending of care is likely to raise the issue of conflicting interests between carer and dependant. Some services may have the prevention of care breakdown as an explicit aim, while others may promote independent living as an appropriate goal for carer and dependant. This is likely to be related to service providers' views of carers as resources, co-workers or co-clients (Twigg, 1989).

Conclusion

There is an inevitable tension between meeting the needs of the carer and the needs of the dependant, and this poses difficulties for providing a balanced service. Appropriate service provision is less likely to be available when the issue of unreported need is neglected, as in this situation it will be particularly difficult to ensure a balance in provision. It is difficult to maintain a focus on the needs of relatives and carers when the needs of patients are so clearly visible. This tendency is compounded when services are structured to focus on an identified patient or client and to regard families as a backdrop which may be contributing to the psychiatric ill-health of that patient.

The ability of families to cope against a background of inadequate formal support does not mean that services to families need no improvement. The issues of unreported need, the continuing evidence that care by the family is associated with various indicators of stress, and criticisms that families make of their experience with professional workers all underline the fact that some effective intervention for families with a mentally ill member is essential, for the benefit of family and identified patient alike.

Where we are now

The purpose of this discussion paper has been twofold: to review such literature as is relevant to an understanding of the informal care of people diagnosed as mentally ill; and to begin to explore possible relationships between findings from the psychological and psychiatric literature on the one hand, and those from the work on informal care on the other. We are now in a position to develop our understanding of informal care in the light of the two bodies of research. We can begin by considering a few examples of different caring situations. These are drawn from four main areas: physical tasks and responsibility, restrictedness in family and social life, emotional distress and other less easily measured aspects of the situation, and service provision. We then move on to identify some of the gaps in understanding that may be addressed by future research.

Comparison with other carers

Much work on informal care has been concerned with the tasks of personal care and physical disability. This has had a profound influence on notions of what constitutes informal care. There are also caring situations, one of which is caring for someone diagnosed as mentally ill, where tasks of personal care are not the major feature of the situation. Responsibility and supervision can be prominent features of many caring situations, although the precise nature of this responsibility and supervision varies. Carers of people with learning difficulties are likely to have exercised considerable responsibility since the dependant's birth. This contrasts with the situation of carers of people with Alzheimer's Disease, who have taken on such responsibility at a later stage in the life of the dependent person. The responsibility exercised on behalf of someone who suffers from a degenerative disease is different from the responsibility necessary as a result of a mental impairment. With regard to mental illness, the responsibility is less clearly defined and sometimes only assumed periodically. This periodic quality is experienced by other categories of carer, for example, those caring for someone with multiple sclerosis or rheumatoid arthritis, but here responsibility is combined with physical care. In the case of mental illness, this defining feature tends to be absent and this may in the past have contributed to the exclusion of this category from the main carer literature.

Restriction of social life and leisure activities and disruption to family life are commonly reported in both sets of literature. Social life for all categories of carers has been shown to be severely restricted, and demonstrated throughout the literature to be highly distressing to those concerned. The reasons for restrictedness, however, vary with the impairment of the dependant and with characteristics (such as age, gender, race, health) of the carer. Thus, while carers of people who have been diagnosed as mentally ill may feel ashamed or embarrassed by the public behaviour of their dependant, carers of physically disabled people may face problems relating to the absence of appropriate physical access to public facilities. Both situations will limit carers' participation in 'normal' public life.

Social support, from both inside and outside the immediate family, has been shown to be difficult to obtain in a caring situation. In addition, the dependant may no longer be able to offer the same support as formerly. The notion of reciprocity appears to be central to an understanding of why carers find it difficult to make demands of family, neighbours or acquaintances. This appears to apply in both bodies of research. Disruption to other aspects of family life, such as employment and financial circumstances, have not been studied comprehensively enough to permit comparison with the situation of other carers. From Glendinning's (1989) work, it seems likely that the situation with regard to these aspects is complex, and this is an area where more basic research is needed.

Research reviewed here shows that carers commonly report the less easily measured aspects that relate to meaning and interpretation as more distressing than those that are clearer cut and therefore more easily measured. Some of these aspects, such as concerns that relate to bizarre behaviour or to loss of the person, are seen in several other caring situations. Coping with difficult behaviour, one of the aspects reported as particularly demanding by this group of carers, is also experienced by those caring for elderly people with senile dementia and for people with challenging behaviour. In particular, this may involve coping with suicide attempts and with violence. It is possible that in any of these caring situations, the family will have police or probation contact as a result of their relative's criminal or semi-criminal activity.

Abrupt change in the needs of a dependent person may arise because of a stroke, an accident, the onset of an incapacitating physical disease or the onset of mental illness. This change is likely to lead to extreme distress about the loss of the person, and about changes in responsibility and supervision of financial, medical and behavioural aspects of the dependant's life. Other aspects that are associated with particular emotional distress for carers, such as concern for the future, are also reported by carers of many different dependency groups. The particular aspect of the future that presents most emotional distress is, however, likely to vary with the particular situation. Most elderly carers, for instance, are likely to voice anxieties about the future well-being of their dependent offspring. Carers of people with mental illness are distressed by feeling stigmatised and ashamed by their situation. This distress is also reported by carers of other groups of people, such as those with learning difficulties or with HIV or AIDS (Miller, 1987).

In addition to the caring situation in the home, the review has also included the experience of carers with service providers. It might appear that this is one aspect of the situation that is unique to carers of people diagnosed as mentally ill, given possible links between dominant theories about mental illness and a stance among many professional workers that either explicitly or implicitly blames the carer for contributing to the origins or course of the diagnosed illness. This could be used to account for the exclusion of the carer from discussions about appropriate forms of care, or in comments from staff which cause distress to carers. This interpretation is likely to be an over-simplification of the situation, for difficulties are experienced by many carers with regard to their contact with services, even when the disease or disability is one that is not traditionally associated with theories that adopt a 'blaming' stance towards carers.

Remaining questions

This review has pointed to several sets of issues concerning informal care that warrant research attention. We have outlined one such issue above: namely, the need for a detailed comparison of the situation of those caring for mentally ill people with that of other carers. In addition, there are empirical and conceptual issues to be addressed.

Some possible refinements to the use of quantitative methods have been identified in the course of this review. Platt (1985) pointed to the need to identify the precise onset of any family disturbance, and to distinguish between the occurrence of any disturbance and the degree to which carers may attribute this to their dependant. He stressed that emotional responses can be reliably ascertained only from the informant concerned and not on behalf of another household member, and that in commenting on family or household disruption it is essential to identify the source of such information. Platt's typology is very comprehensive in identifying the various elements of the caring situation, and could be used to provide the basis of comparable, rather than idiosyncratic, measures of the caring situation. The technique of Creer and Wing and their colleagues, who sought information on actual events occurring within the month prior to interview, has the advantage of providing material that can be accurately recalled and that can offer instances of 'objective burden'. These instances can then be used as bases for an assessment of emotional response.

Other methodological improvements can be suggested. It is important to be certain that such distress as does occur in this situation is related to the presence of mental illness and is not merely a normal feature of family life. This requires either more studies that include control or comparison groups together with the research group, or more comparative work with the literature on family life. Many families do not survive intact when mental illness occurs and the experience of such families appears to be unresearched. Their experience may be particularly valuable in understanding the circumstances surrounding the ending of care. Similarly, attention to the start of the caring role and shifts in responsibility, and hence of family role, may elucidate differences in the task of caring for someone with mental illness as compared with other forms of caring. Comparatively few studies have investigated situations where mental illness other than schizophrenia has been diagnosed, and no study so far has addressed the periodic and fluctuating nature of many forms of mental distress and the impact this has on the carer or the family. The tendency of this body of literature to investigate the family as a whole fails to address the issue of considerable unanticipated responsibility falling consistently to one particular carer. Further, the family situation is assumed to be homogeneous, when in reality it may encompass spousal, sibling, or parental, as well as non-kin, relationships. Within these relationships, gender and age also have to be considered. This links with a second major area where more research is needed – the further theoretical development of informal care.

Addressing some of these issues will meet some of the substantive inadequacies that exist, such as those that concern the situation of people diagnosed as depressed, and the tendency to focus on the dependant, as a patient, rather than on the carer. Empirical research about other aspects of the caring situation is also needed. The relationship between the impact of caring on family disruption and the emotional distress experienced by carers is far from clear. It is possible that one carer may tolerate or cope with a situation which a second carer finds intolerable. It may be useful to include general models of coping with stress, as Avison and Speechley (1987) and Titterton (1989) propose, to address this aspect of informal care and personal welfare. This may provide an answer to the question of why it is that one carer is able to shrug off complaints from neighbours about loud noise, while another may feel profoundly disturbed. This will add depth at the psychological level to an understanding of the caring situation, and would introduce new approaches to meet some of the other points already raised. At the same time, such an approach would complement the understanding to be gained from, for instance, an analysis that is based on constraints at the structural level.

Although disruption to family life has been extensively documented, there is a less clear understanding of what makes caring easier for some people than for others. It seems unlikely that quantitative methods, such as those used in most of the studies reported here, will contribute to this understanding. For instance, race is one aspect of the situation that is increasingly recognised as contributing to a differential impact for carers (Atkin, Cameron, Evers and Badger, 1989). The integration of this work, together with research on race and mental illness, with the mainstream work on informal care will highlight some of the underlying assumptions in the field, such as the ethnocentrism of much of the work that is by white researchers and about white people. The differential impact of care is an additional area where more detailed work is required.

It is important to recognise that the above refinements relate principally to research that is conducted within a quantitative tradition, and that there are other ways in which informal care can be investigated. There is a need for a greater emphasis on process, understanding and meaning rather than simply on outcome. Work is needed at the conceptual level since, until now, the informal care of those diagnosed as mentally ill has mainly been seen as burden for families. There is little recognition of the possibility that carers may perceive the role in different terms, of the need to move away from the concept of burden as it is used in the body of work reviewed here, or of the need to refer to individual carers, rather than to families. The term burden is misleading in certain ways. Many relatives wish to care for their dependants, and it is not clear whether they see this task as a burden. Creer and Wing have suggested the use of 'support' as a more appropriate word, and the word 'supporter' is now more widely used than formerly. The term implies, however, a continuing focus on the patient, as someone who is being 'supported', and the relegation of the carer to a secondary role.

Secondly, the significance of the relationship between carer and cared-for person has not been fully considered. As Twigg (1989) has pointed out, carers are in an ambiguous and ill-defined position. While we are arguing that carers should be seen in their own right and that future work should address the previous imbalance of focus, it is also important to realise that carers are often significant to service providers and policy makers only because of their relationship with the cared-for person. This relationship may give rise to a potential conflict of interest between carer and cared-for person over compulsory outpatient treatment, for instance (Mulvey, Geller and Roth, 1987). This has only rarely been addressed empirically (Perring, forthcoming), but can also be examined at a conceptual level where responsibility, shifts in responsibility and how these relate to individual rights can be explored. The issue of rights tends to be clearer for people with learning difficulties, where responsibility appears to be constant, than for people diagnosed as mentally ill, where a sense of responsibility is more likely to fluctuate with episodes of distress. Both of these examples are in sharp contrast with the success of advocacy movements among those with physical impairment (e.g. war veterans in the US) that have campaigned for access to public facilities.

Conclusion

We have reviewed studies from the psychological and psychiatric literature and provided a detailed description of what life is like for those caring for someone diagnosed as mentally ill. We have also begun to integrate this work with the carer literature and, in doing so, have highlighted some areas where additional research is needed. Many aspects of the caring situation are common to both sets of circumstances. Despite some differences, we would argue that it is entirely appropriate to apply the concept of informal care to the situation of people diagnosed as mentally ill. We would further argue that doing so will clarify and enrich our understanding of informal care.

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