

Psychological Well-Being in Families with a Member Suffering from Schizophrenia  
An Investigation into Long-Standing Problems

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**Levels of stress in carers of long-term schizophrenia sufferers attending a depot clinic were assessed. Nine out of 25 carers (36%) were identified as possible or definite cases on either the GHQ or the HAD. However, a substantial proportion of carers managed to cope with the difficulties without suffering psychologically. *British Journal of Psychiatry* (1992), 161, 249–251**

Few studies have looked at the effects on families of having to care for a relative with schizophrenia (Fadden *et al*, 1987) and, of these, some have not examined a discrete subgroup of patients, but have assessed a mixture of acute and chronic conditions. It seems reasonable to hypothesise that, because of the wide diversity of symptoms presented at different stages of the illness, the problems posed to relatives will also vary.

This study aimed to assess levels of stress in carers of schizophrenia sufferers with long-standing difficulties, who attended a depot clinic but otherwise received only limited regular professional support.

The hypotheses were:

- (a) family members who care for a person with schizophrenia show levels of psychological distress greater than those expected in the general population
- (b) in contrast to sufferers at an early stage of the illness, most stress to carers is caused by the negative symptoms of schizophrenia
- (c) the level of distress in carers is a function of objective and subjective burdens, as well as of patient symptoms.

**Method**

Subject families were drawn from an intramuscular injection (IMI) clinic based at a local day hospital. The family member who was defined as the primary caregiver was assessed using a combination of interview and self-report questionnaire. Where the patient lived with more than one family member, the 'primary caregiver' was defined as the person who spent most time in direct caregiving contact with the schizophrenic member.

Subjects were all carers of IMI clinic attenders who had a diagnosis of schizophrenia, at least one acute episode, and a date of onset of at least two years before the study.

Carers were all living with the person with schizophrenia, and were their parents, siblings or spouses/partners.

Subjects were excluded if the person with schizophrenia had recently been absent from home for over six months, was in an acute phase of his/her illness, or if the patient suffered from an additional disability such as mental handicap.

The IMI clinic provided around 40 potential subjects who were living with a schizophrenic relative (approximately one-third of the total clinic numbers).

The General Health Questionnaire (GHQ-28) (Goldberg & Hillier, 1979) was used to assess psychological well-being, with a threshold for discrimination between cases and non-cases of 5/6. The Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith, 1983) was also used to assess psychological well-being.

Burden was assessed using Section D (Adverse effects on others) of the Social Behaviour Assessment Schedule (SBAS) (Platt *et al*, 1983), which gives a measure of both objective and subjective burden on the carer, as well as assessing onset of difficulties and their 'patient relatedness', i.e. whether the difficulty occurred as a result of some aspects of the patient's behaviour.

An additional questionnaire was used to cover areas such as basic demographic details, contact with services, and perceptions of the future. The Modified MRC Social Behaviour Scale (Brewin & Wing, 1988) was used to measure behaviour in the patient which was likely to cause problems for relatives.

Psychotic symptoms were assessed using the Psychiatric Assessment Scale (PAS) (Krawiecka *et al*, 1977), a short rating scale designed for chronic psychiatric patients. This assessment was completed by the psychiatrist at a regular clinic appointment with the patient. Duration of illness was assessed both by asking the relative and by examining medical records.

The first author visited each principal carer at home, for an interview which lasted about an hour.

**Results**

A total of 25 carers was interviewed over a period of one month, being all those who had consented to take part in the study. A further six potential subjects were excluded under the exclusion criteria before seeking consent. In addition, the psychiatrist from the IMI clinic completed a PAS form on the 23 out of 25 patients who attended the clinic over the same period. The GHQ and HAD were completed by 24 subjects.

The majority of patients (14:11) were male. The mean age of the sample was 45.96 years (s.d. 14.9, range 19–75). The primary carers were predominantly female (15:10). There were nine mothers, four wives, two sisters, eight husbands, and two fathers. Nine respondents were housewives, seven were retired, and five were in full-time employment. Only one was unemployed. Two were in part-time employment, and one was on long-term sick leave.

Of the patients, only two were in full-time work, two had part-time jobs, one attended a work-training programme, and one a day hospital; of the rest, 14 were unemployed, two retired, and three housewives. Duration of illness ranged from two years to over 20 years.

The GHQ identified seven of the carers (29%) as cases. The HAD, in contrast, identified only four (16.6%) as definite cases, and three doubtful cases. A total of nine individuals were cases or doubtful cases on either the GHQ or the HAD.

There were some links between the two burden scores and distress. Objective burden (as measured by the SBAS) was significantly correlated with the GHQ anxiety and insomnia subscale score ( $r=0.59$ ,  $P<0.01$ , Pearson product-moment). Subjective burden was significantly correlated with the GHQ screening score ( $r=0.6$ ,  $P<0.01$ ), the GHQ anxiety and insomnia subscale score ( $r=0.56$ ,  $P<0.01$ ) and the HAD depression score ( $r=0.66$ ,  $P<0.01$ ).

The most common areas of objective burden were those of emotional or physical ill health in the informant. Of the problems, 66% were seen as at least possibly due to the patient, and 40% as definitely related, i.e. the patient was a causal factor in the development of the problem. All of those who judged that there was tension in the household attributed this to the subject (5/5). Of the carers with emotional ill health, 50% (7/14) definitely attributed these problems to the subject. Financial difficulties were also seen as being largely related (8/10) to the patient (40% (4/10)

definitely related). Difficulties in social life were seen as being somewhat related to the patient, regarded by 60% (3/5) as possibly related and by 20% (1/5) as definitely related. Other difficulties which were rarely related to the patient concerned leisure time, work and disruption to others. Time off work and disruption to the respondent were not reported.

Positive symptoms were rarer than negative symptoms. For example, on the PAS only three people were scored as suffering from delusions, and only one from hallucinations (see Table 1). In contrast, 15 suffered from flattened affect, and 11 from psychomotor retardation.

There was a significant relationship between whether the patients spent their time predominantly in a passive fashion (e.g. watching television, listening to music, sleeping), and the level of distress in the carer (HAD and GHQ) (e.g. GHQ,  $r=0.58$ ,  $P<0.01$ ), distress being higher in carers of passive patients. There were similar significant relationships between level of distress in the carer and certain of the negative symptoms in the patient reported on the MRC scale, such as slowness of movement (with GHQ screening score  $r=0.54$ ,  $P<0.01$ , and with the HAD anxiety score  $r=0.56$ ,  $P<0.01$ ), underactivity (correlations with HAD,  $r=0.57$ ,  $P<0.01$ ) and the three items relating to communication difficulties (e.g. conversation with GHQ depression scale,  $r=0.61$ ,  $P<0.001$ ).

#### Social and professional support and knowledge of diagnosis

Carers tended to have few sources of social or professional support. Six carers (24%) perceived nobody in their lives who would be a source of support if needed. By far the largest group of potential supporters were daughters. Over 50% of the sample (13) lived on their own with the subject.

Few people received any professional support other than the regular appointment at the IMI clinic. Twenty families had no contact with other facilities. Of the remainder, two patients attended a day hospital, two a day centre, and one a specialised club for individuals with long-standing mental health difficulties.

However, few relatives had considered either what additional help they might benefit from now or what help might be required in the future. Of course, it may be that they are ignorant of what is available rather than simply not wishing to seek help.

Relatively few carers knew what diagnosis had been given to their relative. Only 10 knew that their relative suffered from schizophrenia, nine did not know, and the other six produced a variety of alternative suggestions, e.g. 'drugs'.

#### Discussion

This study showed lower prevalence of psychological ill health than have some previous studies, e.g. the Scottish Schizophrenia Research Group's (1985) 75%, and Gibbons *et al*'s (1984) 72%. However, the present study's prevalence is still around twice that expected in the general population (Wing *et al*, 1981).

The data seem to reflect the difference between a sample, as in the present case, wholly made up of people with long-term schizophrenic difficulties, and

Table 1  
Patient symptoms as measured by the PAS

	Absent	Mild	Moderate	Marked	Severe
Depression	17	4	1	1	-
Anxiety	15	4	4	-	-
Delusions	20	2	-	-	1
Hallucinations	22	-	-	-	1
Incoherent speech	23	-	-	-	-
Poverty of speech	13	5	2	3	-
Flattened affect	8	9	5	1	-
Psychomotor retardation	12	7	3	1	-
<i>Side-effects</i>					
Tremor	12	7	3	1	-
Rigidity	22	-	-	1	-
Dystonia	23	-	-	-	-
Akathisia	19	1	-	-	-
Vision	23	-	-	-	-
Other (oral tardive dyskinesia)	21	1	-	-	-

a mixed sample including acute and recent-onset cases. Carers of recent-onset sufferers are often caused considerable stress by the sufferer's positive psychotic symptoms. Carers of long-term sufferers seem also under stress, but more from the less obvious, but equally pernicious, problems presented by the unrewarding nature of their relative's behaviour.

The present sample of reliable attenders at an IMI clinic may be a selected subgroup, and present their families lesser problems than do clients who have a less stable contact with services. For example, they may have their medication more closely monitored, or have better social networks.

It seemed, from interviewing the carers, that families fell into two categories, those who were coping well with relatively few difficulties, and those who were struggling with a wide range of problems which were both related and unrelated to the patient. It proved difficult to confirm this from the data, but it may have been reflected in the GHQ scores, which seemed to be split in this way, with subjects scoring either below the threshold, or considerably above (17 subjects scored 3 or under on the screening score, the other seven all scored over 9).

One should not dismiss the importance of the finding that, although some carers are finding it difficult to cope, a substantial proportion manage to cope with the difficulties posed by their relative without suffering from psychological ill-effects. This is a more positive outcome than is sometimes implied in discussions about caring for sufferers of long-term mental illness.

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## Neurosyphilis and Schizophrenia

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**Neurosyphilis continues to present in atypical forms, leading to erroneous diagnoses by physicians and psychiatrists. This patient, with a previous history of psychosis, presented in a catatonic state with rhabdomyolysis and renal failure. A subsequent breakdown was thought to be schizophrenic until unusual features led to a reassessment and discovery of neurosyphilis which was treated with penicillin and resulted in a remarkable clinical recovery.**

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The diagnosis of neurosyphilis is often overlooked, not

only because of its rarity but also because of its unusual and atypical patterns of presentation. In terms of disease manifestation, syphilis has always been a great masquerader. Lishman (1987) observes that "the psychiatrist must continue to bear it constantly in mind to check regularly with serological tests and look for cardinal signs in the pupillary reactions and tendon reflexes. The classical presentation of general paresis is nowadays rare and syphilis of the central nervous system can present with virtually any psychiatric complaint". We report a case diagnosed as schizophrenic until