Determinants of Psychological Distress in Relatives of People With Chronic Schizophrenia

by Helen R. Winefield and Eileen J. Harvey

Abstract

Research shows that the relatives of people with chronic schizophrenia suffer psychological distress and interference in daily life from the burdens of caregiving. In this study, members of a self-help group for the relatives of schizophrenia sufferers provided information through a mail survey, using standardized measures of psychological distress and burden, and severity of the sufferer's illness. Caregiver psychological distress was high compared with test norms, and the level of behavioral disturbance in the sufferer was found to contribute to caregiver distress after controlling for the caregiver's age, sex, and social supports. An unexpected finding was that those caring for female sufferers reported greater distress than those caring for males.

The effective management of schizophrenia outside the hospital requires clear specification of what task the community, particularly the family, is being asked to undertake and their capacities to do so effectively. Family members who provide nonhospital care to sufferers of chronic schizophrenia frequently find this responsibility to be distressing and burdensome (Fadden et al. 1987; Johnson 1990). Relatives of those with chronic schizophrenia would not necessarily be happier if sufferers were permanently hospitalized, but they may still experience psychological distress and disruptions to their daily lives in assuming the role of caregiver, and they frequently express the wish for more assistance from the formal mental health system.

Psychoeducational groups are now widely accepted as a means of teaching relatives about schizophrenia and encouraging them in adaptive patterns of communication within the family (Goldstein et al. 1978; Halford and Hayes 1991). Outcomes include reduced family stress and less patient relapse. However, many families either fail to participate or withdraw prematurely from such programs (Tarrier 1991), perhaps because they want changes such as improved accommodation and vocational training for their ill relatives rather than additional information for themselves (Sommer 1990). As a first step toward improving the specificity and perhaps acceptability of support services for families, the present study sought to clarify the determinants of stress in the caregiving task for the relatives of those suffering from schizophrenia. In particular, we aimed to distinguish the sources of caregiver distress that are due to characteristics of the sufferer from those that might be caused by attributes of the caregiver.

The conceptual assumptions underlying this study are as follows. (1) The measurement of caregiver adjustment should be multimodal, use standard instruments of known reliability and validity, and distinguish between the caregiver's individual personality traits and the specific effects of the caregiving role. (2) Measures of the "burden" for caregivers should distinguish between subjective and objective aspects, such as between caregiver psychological distress and burden.

Reprint requests should be sent to Dr. H.R. Winefield, Dept. of Psychiatry, University of Adelaide, GPO Box 498, Adelaide, Australia 5001.
and actual disruptions to daily life (Platt 1985). (3) Surveys of caregiver needs must take account of the range of manifestations and severity levels of schizophrenia and of the different accommodation and other services available in different places and to users with different resources.

What little information is available about community adults in late middle-age suggests that a significant proportion of them have caregiving responsibilities for other than the chronically mentally ill (e.g., for elderly or physically or mentally handicapped family members) and that many without caregiving responsibilities still experience significant psychological distress related to other problems such as unemployment, financial and health worries, and bereavement. However, in describing the burdens of family caregiving in schizophrenia, few studies include comparison data on control subjects matched for age, sex, and social class who do not participate in the care of a relative with schizophrenia. An alternative to using control groups is to use multivariate statistics to examine the influence of caregiving separately from that of the background variables such as caregiver age and sex.

The first aim of the present study was to gather descriptive information about the caregiver’s task and the psychological and physical well-being of the caregivers. Based on the literature and clinical experience, we expected to find significant levels of psychological distress in people caring for a family member with schizophrenia and greater distress when the sufferer lived at home than elsewhere. The second aim was to distinguish the contribution of caregiver and sufferer characteristics to their distress. Hierarchical multiple regressions were performed with indicators of caregiver distress as dependent variables and with caregiver characteristics entered before patient characteristics so that any additional impact of caregiving could be demonstrated. It was hypothesized that caregivers’ age, sex, and social supports would affect their psychological state, but that the sufferer’s characteristics, such as length and severity of illness, would explain additional variance in caregiver distress.

Method

Subjects. The Schizophrenia Fellowship is a self-help group for those affected by schizophrenia and is used mainly by the relatives rather than the sufferers, like its namesake in Britain and like the National Alliance for the Mentally Ill in the United States. The South Australian branch provided a list of names and addresses of members, excluding professional and institutional members, and the 201 persons on the list were mailed a questionnaire to be completed anonymously. One follow-up reminder was sent a week later. One recipient who could not read English and 19 who did not have a relative with schizophrenia were excluded, leaving a sample size of 181. Completed questionnaires were received from 134 respondents for a return rate of 74 percent.

Measures. Respondents provided information about their age, sex, and relationship to the sufferer. (The term “sufferer” is used rather than “patient” as many of the persons concerned were not receiving regular psychiatric services.) Respondents also gave the following information about the family member with schizophrenia: age, sex, how much time had been spent living at home and in the hospital in the last year, and functional deficits in behavior assessed through the 39-item Life Skills Profile (LSP; Rosen et al. 1989). This validated Australian scale to assess behavioral deficits in people with schizophrenia provides scores for self-care, nonturbulence, social contact, communication, and responsibility; coefficient alphas (Cronbach 1951) for this sample ranged from 0.72 to 0.86.

Caregiver psychological state was assessed using the General Health Questionnaire (GHQ, 12-item version; Goldberg 1972), a measure of psychological disturbance validated for Australian community populations (Tennant 1977) that had high internal reliability in this sample (alpha coefficient = 0.91). The 20-item Positive and Negative Affect Scale (PANAS; Watson et al. 1988) was also included, with instructions to complete it “as you have felt in the last week” (alphas = 0.90 for negative affect and 0.86 for positive affect). As a comprehensive measure of physical and emotional well-being, the 38-item Nottingham Health Profile (NHP; Hunt and McEwen 1980) was administered. This instrument has been validated on a large South Australian population (Baum and Cooke 1989); it provides a symptom total and six weighted subscores (low energy, pain, emotional upset, sleep problems, social isolation, and physical immobility); alphas ranged from 0.60 to 0.88.

As an indicator of the burden of care, respondents noted the areas of their life that were affected by...
the caring task. Areas included employment, housework, social relationships, family relationships, sexual relations, interests and hobbies, and holidays. The list was adapted from Part II of the NHP. They were also invited to add written comments to the questionnaire about "your caregiving role and its effects on your life, or anything extra that would help you to cope."

Information about caregiver social supports was gathered with the Multi-Dimensional Support Scale (Winfield et al. 1992), which provides ratings of both availability and adequacy of support, in this case from three sources: "family and closest friends," "other people you know who care for a chronically dependent relative," and "the doctor and/or the psychiatrist who takes care of your relative." Items refer to the frequency of supportive behaviors such as listening, trying to understand, offering practical assistance, and giving information and also to the respondents' satisfaction with that frequency. The latter two sources contributed little support (see discussion below), so only family support was usable in the multiple regressions. The internal consistency of these scales was high for this sample: alphas = 0.83 for availability and 0.84 for adequacy (six items each). In addition, caregivers provided information about the sources of the help they had received to care for their relative with schizophrenia in the last year by checking off a list of possibilities and giving details of any others used.

Results

Respondent and Sufferer Characteristics. Most respondents were women (75.0%), and 46.7 percent of respondents were ≥ 60 years of age; 83.6 percent were the parents of the person diagnosed as suffering from schizophrenia; 9.7 percent were spouses, 60.4 percent were siblings, and 0.7 percent were offspring.

Sufferers were mostly men (76.1%), and 87.0 percent were < 40 years of age; they had first received the diagnosis of schizophrenia an average of 8.3 years ago (standard deviation = 6.0). Their behavioral deficits as assessed on the LSP were very similar to those in the normative sample (Rosen et al. 1989).

Respondents showed high levels of psychological distress. Using the binary method of GHQ scoring, 60.3 percent of caregivers met the usual criterion for being a "case" of psychiatric disorder, and 42.9 percent met the stricter criterion for a "serious case" (Henderson et al. 1979). Thus, the prevalence of psychiatric "caseness" was twice as high as that reported in a representative Australian community sample by Henderson et al. (1979) using the same measure. Respondents also scored well above norms for their age group from a large South Australian sample (n = 328) of the same age (Baum and Cooke 1989) on the NHP scales that reflected psychological disturbance. Subjects who had spoken with the patient's doctor in the last month, only 15.4 percent of subjects reported not knowing any other people with a chronically dependent relative, suggesting that even these members of a self-help group for relatives were quite often inactive members of the group. Of those who had had contact with other caregivers in the last month, only 15.4 percent had often or always received support, but this amount was just right for 44.0 percent of them.

In the last month, 36.6 percent of respondents had not seen or spoken to the doctor or psychiatrist with clinical responsibility for their family member with schizophrenia. Of those who had, 34.9 percent found that doctor often or always supportive, but 35.4 percent would have liked more support. Subjects who had spoken with the patient's doctor in the last month had greater psychological disturbance (GHQ means = 27.9 and 25.1, respectively, t[119] = 2.48, p < 0.05), worse health (average number of NHP symptoms = 7.4 and 4.8, respectively, t[121] = 2.43, p < 0.05), and more negative affect (PANAS means = 18.8 and 15.5), an average of 2.4 of 7 possibilities on the burden scale, most frequently social and family relationships (44.8% and 44.0%, respectively).

Help Received. In response to the social support questions, 40.2 percent of respondents reported that family and closest friends "often" or "always" acted in a supportive manner toward them (as defined by the test items, see above), and 42.9 percent reported that the frequency of family support received was "just right" for all items (the adequacy measure). As noted above, the other two potential sources of support contributed little: 30.5 percent of subjects reported not knowing any other people with a chronically dependent relative, suggesting that even these members of a self-help group for relatives were quite often inactive members of the group. Of those who had had contact with other caregivers in the last month, only 15.4 percent had often or always received support, but this amount was just right for 44.0 percent of them.
During the preceding year, relatives had received help in the caregiving task from a wide variety of professional and nonprofessional sources, shown in table 1. Nearly one-fifth of subjects (18.3%) had had no contact with any medical professional (first three categories in table 1) about their relative with schizophrenia during the past year. Those who had received any form of medical help did not differ psychologically from those who had not, but their relatives scored higher on the LSP responsibility scale (means = 15.0 and 11.9, respectively, \( t[131] = 3.72, p < 0.001 \)). The items on this scale concern compliance with medication and not losing or stealing things.

To check the influence on caregivers of sufferers living at home, psychological adjustment was compared for caregivers in situations where the sufferer had spent all the nonhospital time for the last year at home (\( n = 64 \)) with those who did not (\( n = 66 \)). No significant differences were found in measures of caregiver distress. Sufferers who had spent all their nonhospital time at the caregiver's home during the past year did not differ in age, sex, or length of illness from those who had not. However, they were less likely to be a son or daughter of the respondent (\( \chi^2 [1] = 3.85, p < 0.05 \)). The behavior of those living at home was reported as less turbulent and more responsible (non-turbulence means = 39.32 and 36.15, \( t[127] = 2.67, p < 0.01 \); responsibility means = 15.17 and 13.54, \( t[127] = 2.32, p < 0.05 \)).

In response to the open-ended invitation at the end of the questionnaire, the majority of subjects volunteered extra comments, several writing two to three pages. In addition, 12 subjects added their name, address, and telephone number to the anonymous questionnaire and offered encouraging remarks about the research. Subjects' comments were categorized post hoc by content. The most frequent were as follows: how much easier the respondent's life was since the sufferer no longer lived at home (\( n = 34 \)); the fears, depression, and other negative emotions of the respondent (\( n = 22 \)); evaluative remarks about professional services (\( n = 37 \) negative, \( n = 9 \) positive); the importance of getting the sufferer's medication right (\( n = 13 \)); and the need for more supervised accommodation and rehabilitation programs (\( n = 11 \)).

### Table 1. Sources of help received with the caregiving task, during the preceding year, as reported by survey respondents (\( n = 134 \))

<table>
<thead>
<tr>
<th>Sources of help (categories)</th>
<th>Receiving help from one or more source in category (( n ))</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family doctor</td>
<td>51</td>
<td>38.1</td>
</tr>
<tr>
<td>Private psychiatrist</td>
<td>33</td>
<td>24.6</td>
</tr>
<tr>
<td>Hospital psychiatrist</td>
<td>75</td>
<td>56.0</td>
</tr>
<tr>
<td>Financial assistance</td>
<td>28</td>
<td>20.9</td>
</tr>
<tr>
<td>Housing assistance</td>
<td>12</td>
<td>9.0</td>
</tr>
<tr>
<td>Police</td>
<td>16</td>
<td>11.9</td>
</tr>
<tr>
<td>Domestic assistance</td>
<td>9</td>
<td>6.7</td>
</tr>
<tr>
<td>Self-help/support group</td>
<td>19</td>
<td>14.2</td>
</tr>
</tbody>
</table>

Prediction of Caregiver Distress.

As a certain level of psychological and psychosomatic distress is predictable in any largely middle-aged community sample, hierarchical multiple regressions were used to explore whether the length or severity of the sufferer's illness explained additional variance in caregiver distress measures. The predictor variables were caregiver age, sex, and family social support availability and adequacy, entered stepwise in the first block, and patient sex, duration of illness, and LSP scores entered stepwise in the second block. Results are shown in table 2 for the outcome measures when the multiple regression equation predicted more than 25 percent of the variance (psychological disturbance by GHQ, negative affect on the PANAS, emotional upset subscale of the NHP, and number of life areas affected by burden of care); this criterion was not met for two other dependent variables (positive affect on PANAS and NHP symptom total).

Adequacy of family support was associated with caregivers' lower psychological disturbance, negative affect, and emotional upset. Older caregivers reported less negative affect, and older and female caregivers reported less burden. In three outcome measures (psychological disturbance, emotional upset, and burden), taking sufferer
Table 2. Hierarchical multiple regressions to predict caregiver distress, with caregiver variables entered first \((n = 134)\) and sufferer variables entered second

<table>
<thead>
<tr>
<th>Caregiver outcomes</th>
<th>Block</th>
<th>Variable</th>
<th>Beta</th>
<th>Adjusted (R^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological disturbance (GHQ)</td>
<td>1</td>
<td>Adequate family support</td>
<td>-0.40</td>
<td>0.16</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Nonturbulence</td>
<td>-0.28</td>
<td>0.23</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Years ill</td>
<td>-0.18</td>
<td>0.26</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female</td>
<td>0.18</td>
<td>0.28</td>
</tr>
<tr>
<td>Negative affect (PANAS)</td>
<td>1</td>
<td>Adequate family support</td>
<td>-0.41</td>
<td>0.17</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Caregiver age</td>
<td>-0.26</td>
<td>0.23</td>
</tr>
<tr>
<td>Emotional upset (NHP subscale)</td>
<td>1</td>
<td>Adequate family support</td>
<td>-0.47</td>
<td>0.21</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Nonturbulence</td>
<td>-0.31</td>
<td>0.31</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female</td>
<td>0.18</td>
<td>0.33</td>
</tr>
<tr>
<td>Burden (number of areas of life affected by caregiving)</td>
<td>1</td>
<td>Female caregiver</td>
<td>-0.27</td>
<td>0.072</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Caregiver age</td>
<td>-0.23</td>
<td>0.11</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Nonturbulence</td>
<td>-0.51</td>
<td>0.37</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Female</td>
<td>0.15</td>
<td>0.38</td>
</tr>
</tbody>
</table>

Note — GHQ = General Health Questionnaire (Goldberg 1972); PANAS = Positive and Negative Affect Scale (Watson et al. 1988); NHP = Nottingham Health Profile (Hunt and McEwen 1980); \(R^2\) = explained variance.

<table>
<thead>
<tr>
<th>Block 1: caregiver age, sex, and availability and adequacy of family supports; block 2. sufferer sex, years ill, and the five Life Skills Profile scores (Rosen et al. 1989)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(p &lt; 0.01); for the remainder (p &lt; 0.001).</td>
</tr>
</tbody>
</table>

Discussion

This study aimed to describe the psychological state and experienced needs of family members caring for a person with schizophrenia. As "community care" rather than institutionalization becomes the norm of service delivery, professionals need to understand how the provision of nonhospital care can be facilitated. Families of a person with schizophrenia have sometimes been seen as part of the patient's problem and sometimes as part of the treatment process, but rarely have their own psychological needs been given primary consideration (Lefley and Johnson 1990).

The relatives who were the subjects of this study were typically the aging mothers of adult sons, as has been the case in other studies of self-help group members (Sommer 1990). However, the subjects were probably not representative of all relatives of schizophrenia sufferers. As members of a self-help group they may have been self-selected for distress and for middle-class socioeconomic status (Creer and Wing 1974). Caution should, therefore, be used in interpreting the results. Recruitment of representative samples of relatives is a problem for researchers. For example, using the records of psychiatric hospitals to locate families that have a member with schizophrenia means that patients' consent to involve their relatives is necessary, and some relatives who might participate if given an opportunity are excluded by that process. It would obviously also be desirable to collect parallel data from community residents with no schizophrenia sufferer in the family who were matched on all important variables.

As hypothesized, the caregivers reported higher levels of psychological disturbance and emotionally related health problems (low energy, emotional upset, and sleep problems) than have Australian normative samples. However, contrary to hypothesis and also contrary to the gist of the open-ended comments, caregivers for sufferers who spent all their nonhospital time at home did not report significantly higher levels of distress on standardized instruments than did caregivers for sufferers who lived away from home when not in the hospital. Differences in caregiver distress may have been apparent if caregivers were grouped according to where the sufferer was living at the moment, but that information was not available. It
may well be relevant that home-based sufferers were reported to be less turbulent and more responsible in their behavior. In this sample, the average length of time since diagnosis was more than 8 years; caregivers may, therefore, have achieved situations where stress due to living arrangements was minimized as far as possible. Thus, in a sample of more recently diagnosed sufferers, caregivers might show the difference (in psychological state according to the sufferer’s place of residence) that we hypothesized.

As expected, the caregivers experienced considerable burden from caring for their relative with schizophrenia, and their ideas about what services would assist them to cope with this responsibility deserve further exploration. It is noteworthy in this regard that caregivers with inadequate family support seemed to be at particular risk of psychological disturbance. The direction of causality is unknown, and one cannot necessarily conclude that disturbance could be reduced by arranging for more support. Rather, there may be a case for helping the distressed individual to become a more effective elictor of natural social supports or to reappraise the adequacy of the supports that are available.

About a third of respondents had not seen the sufferer’s doctor in the last month, and of those who had done so, a third would have liked more support from that person. There was an association between caregivers having recently seen the doctor caring for their relative with schizophrenia and their reporting greater distress and burden. It seems likely that, rather than the doctor causing caregiver distress, the fact of seeing the doctor may itself imply a crisis in the sufferer’s health, which increases caregiver distress. The implication for professionals of the fact that they see relatives mainly at moments of patient crisis is that they may then overestimate the degree of incapacity or rejection that usually characterizes the relatives concerned. It is relevant to recall here that almost one-fifth of caregivers had had no help for the sufferer from any medical professional during the past year.

Sufferer characteristics that independently added most clearly to caregiver distress and complaints of burden were female sex and turbulent behavior. The latter scale on the LSP includes items referring to aggressiveness, readiness to take offense, recklessness and destructiveness, trouble with the police, and substance abuse. It is perhaps not surprising that caregivers should be more upset by these very socially intrusive manifestations of the illness than by the sufferer’s difficulties in self-care, communication, and social contact. There may be implications for preferring or developing treatment methods that focus on the reduction of social disruptiveness. While these symptoms of the illness may not be the most distressing to the sufferer, they did predict distress and conceivably a heightened likelihood of rejection by family caregivers. In future research it would also be desirable to gather independent ratings of sufferer disturbance. In this study, the relative’s report was the only source of information.

The finding that female sufferers were associated with greater caregiver distress across the spectrum of measures is contrary to the expectations of clinicians, that women with schizophrenia display less overt acting out than men and are therefore less burdensome for their families. Indeed women sufferers were reported to have poorer communication skills than men (means = 17.3 and 19.0, respectively, t[126] = 2.47, p < 0.05), the only significant sex difference on the LSP. The female sufferers in the present study were not more likely than males to be living at home or in the hospital, but they were more likely to be cared for by people aged under 60 (x² [1] = 12.04, p < 0.01) and who were not their parents (x² [1] = 13.00, p < 0.01). Whereas 90.2 percent of male sufferers were cared for by parents, 18.8 percent of the females were cared for by siblings and 15.6 percent by spouses. Perhaps behavioral expectations differed for the two sexes, or perhaps the effect of ill women on their children caused greater anxiety. For example, women with schizophrenia might be perceived as more incapacitated in caring for their children than are men with schizophrenia.

We have assumed in this article that the subjects, all relatives of a person with schizophrenia and members of the Schizophrenia Fellowship, could be designated as caregivers. This focus may seem unfamiliar to some mental health professionals, who may view some relatives as an integral part of the patient’s psychological problem or even as hindrances to the patient’s recovery. Where conflicts exist between the patient and the family, mental health professionals may feel obliged to take the patient’s perspective, and, of course, it is vital that the sufferers be believed and supported by their attending professionals. Yet the results of this study show that members of the patient’s family also need at-
tention, information, and support. Caring for a family member with schizophrenia is a stressful task, frequently with little reward in terms of gratitude and social recognition. Socially disruptive and antisocial behavior by the sufferer adds significantly to the caregiver’s distress and burden, and those who care for female sufferers (who are more often not their parents) are a particularly distressed minority who deserve further investigation.

References


Acknowledgments

This research was supported by a grant from the Commonwealth Department of Health, Housing and Community Services. The authors are grateful to the South Australian Schizophrenia Fellowship and to the respondents for their cooperation.

The Authors

Helen R. Winefield, Ph.D., is Senior Lecturer, and Eileen J. Harvey, B.Sc., Dip. Ap. Psych., is Research Officer, Department of Psychiatry, University of Adelaide, South Australia.