ABSTRACT

Background: Studies that differentiate among diagnoses have detected divergent results in the experience of family burden.

Aim: This study aimed to investigate differences in family burden and participation in care between relatives from subgroups of psychoses, affective disorders and ‘other diagnoses’, and between different subgroups of relatives.

Method: In a Swedish longitudinal study performed in 1986, 1991 and 1997, 455 close relatives of both committed and voluntarily admitted patients were interviewed concerning different aspects of their burden, need for support and participation in the actual care situation.

Results: Relatives showed burdens in several of the aspects measured. In only one aspect of the investigated burden items was a difference found between different diagnostic subgroups. The relatives of patients with affective disorder more often had to give up leisure time. However, spouses showed more burdens and more often experienced sufficient participation in the patient’s treatment than other subgroups while siblings more seldom experienced burdens and more seldom felt that their own needs for support had been met by the psychiatric services. Within each diagnostic subgroup there were differences between subgroups of relatives.

Conclusion: Being a close relative, and living together with a severely mentally ill person in an acute situation, is one factor of importance for experiencing burden and participation in care, contradicting the conventional wisdom which differentiates between diagnoses.

INTRODUCTION

Family burden and participation in care
Research on the relatives of people with severe mental illnesses has shown that relatives are affected in many different areas of life (Cornwall & Scott, 1996; Lefley, 1987; Maurin & Barmann Boyd, 1990; Östman & Hansson, 2000a). The consequences of being related to someone with severe mental illness can be roughly divided into the obligation to offer long-term extensive care and the emotional distress and worries related to the life situation of the patient (Schene, 1990). Most studies have focused on the mother of a schizophrenic
patient (Bulger et al., 1993) or the spouse of a depressed patient (Fadden et al., 1987; Noh & Avison, 1988). Other family members and family members of patients with other diagnoses have been understudied (Rose, 1996). There is also a dearth of information regarding possible differences between subgroups of relatives.

Studies that differentiated between diagnoses have detected divergent results in the experience of family burden and distress. Noh and Turner (1987) reported different correlates of distress depending on the patient’s diagnosis. A study by Gibbons et al. (1984) reported no significant differences in distress or subjective burden between subgroups to persons with a schizophrenic disease.

Fadden et al. (1987) found that spouses of unipolar, bipolar and neurotic depressed patients displayed different perceptions of burden. Family members who lived with a patient during an episode of depression experienced a greater burden. Mueser et al. (1996) compared the burden that patients with specific problem behaviours such as patients with schizophrenia or bipolar disorder placed on relatives. Their study found that a psychiatric diagnosis might be of limited value in understanding the burden relatives experience due to specific psychiatric symptoms. Instead they found that burden is associated with specific problem behaviours regardless of psychiatric diagnosis.

Friedman et al. (1997) found that regardless of specific diagnosis, having a family member in an acute phase of mental disorder was a risk factor for poor family functioning compared to the functioning of control families.

Different aspects of family burden and participation in care are important parts of a Swedish longitudinal study of the quality of the mental health services performed in 1986, 1991 and 1997. The aim of the present part of the study is to investigate differences in family burden and participation in care between relatives of three different broad patient diagnostic subgroups. Another aim is to investigate differences in family burden and participation in care in subgroups of relatives.

**METHODS AND MATERIAL**

**Design**

This study is part of a multicentre study with three periods of investigation, 1986, 1991 and 1997, focusing on voluntary and compulsorily psychiatric inpatient care. The sample of patients in the investigation was selected to represent inpatients admitted to acute psychiatric wards, excluding: people aged under 18 and over 70 years, alcohol abusers, severely mentally retarded people, mentally disordered offenders, people with severe dementia and individuals not speaking Swedish. The relatives included in the studies were close relatives to the participating patients and both the patients and the relatives were recruited by informed consent.

A research psychiatrist assessed the patients’ psychosocial functioning and psychopathology, and diagnosed the patient. The interviews with the relatives were performed about a month after the admission to hospital, by trained psychiatric social workers. None of the interviewers were involved in the treatment of the patient. Some information concerning the patients was collected from case sheets. The Research Ethics Committee of the Medical Faculty, University of Uppsala, Sweden (B 850619 and B 970217), has approved the study.
Settings
The main study in 1986 and in 1991 concerned inpatient psychiatric services with a comprehensive responsibility for two geographically defined catchment areas in two counties in the middle of Sweden, with both urban and rural areas, and a total population of about 500,000 inhabitants. In 1997 a multi-centre study was launched including one of the original centres, and a further three Swedish centres with catchment areas ranging from 90,000 to 275,000 inhabitants.

Sample
The 1986 investigation
In 1986 a consecutive sample of 118 committed patients and 114 sex and age matched voluntarily admitted patients were asked to take part in the study, of which 100 committed and 99 voluntarily admitted patients finally participated. Seventy-two relatives of the committed patients and 81 relatives of the voluntarily admitted patients were interviewed. No socio-demographic characteristics were known about the relatives in the 1986 study (except that they were all adults), only the relationship to the patient.

The 1991 investigation
In 1991 a consecutive sample of 116 committed patients and 120 voluntarily admitted patients randomly selected were asked to take part in the study, and 95 committed and 94 voluntarily admitted patients accepted participation. Sixty-four relatives of the committed and 69 of the voluntarily admitted patients were interviewed.

The 1997 investigation
In 1997 a consecutive sample of 196 committed patients and a random sample of 179 voluntarily admitted patients were asked to take part in the study. One hundred and eighteen and 117 patients participated. Of those, 73 relatives of the committed and 89 of the voluntarily admitted patients were interviewed.

Diagnostic classification
The diagnoses of the patients were, by consensus between the research psychiatrists, divided into three broad subgroups: psychoses, affective disorders and a third group of the remaining diagnoses, called ‘other diagnoses’. Schizophrenia, delusional disorders, schizoaffective and schizopreniform disorders, and atypical psychoses were classified as psychoses. Mania, major and minor depression and bipolar affective disorders were classified as affective disorders. The subgroup ‘other diagnoses’ contained mostly different personality disorders, including anorexia nervosa.

Subgroups of relatives
The following subgroups of relatives were used in the investigation: parents (mothers and fathers), spouses (male and female partners living as spouses), grown-up children (children more than 18 years of age) and siblings (brothers and sisters more than 18 years of age). The fifth subgroup consisted of non-relatives (friends and professionals).
Table 1 shows some characteristics of the patients and the participating relatives in the three samples of 1986, 1991 and 1997. The diagnoses were in 1986 set according to DSM III (APA, 1980), in 1991 according to DSM III R (APA, 1987) and in 1997 according to DSM IV (APA, 1994). The patients’ psychosocial function was in 1986 measured by GAS (Endicott et al., 1976) and 1991 and 1997 by GAF (APA, 1987). There were no differences between the three patient samples with regard to the patient’s sex or if the patient voluntarily entered or was committed to hospital. However, patients were older in 1997 as compared to 1986 ($F = 9.48; p = .000$), and psychosocial functioning between the three periods according to GAS/GAF decreased ($F = 6.74; p = .002$). There were fewer psychoses diagnoses and more other diagnoses in 1997 ($\chi^2 = 14.96; p = .005$). Comparisons between the samples of participating relatives in 1991 and 1997 showed no differences with regard to age, sex or whether the relative lived together with the patient. There were more siblings in the 1997 sample compared to 1986 and 1991 ($\chi^2 = 22.45; p = .004$).

<table>
<thead>
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<th>Table 1</th>
<th>Background characteristics of the patients and the participating relatives in 1986, 1991 and 1997 (percentages)</th>
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<td>GAS/GAF (mean, range)</td>
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<td>Participating relatives</td>
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$\chi^2$ test; one-way ANOVA: ** = $p < .01$; *** = $p < .001$
Dropout of relatives
Dropout of relatives occurred at two different stages in the investigation. At first, when the patient refused contact with a relative or stated that they lacked a relative to interview, 101 relatives, and at a second stage when the relative refused an interview or when contact failed, 67 relatives.

Total sample
This study is based on interviews with 455 close relatives to a total sample of 623 patients participating in one of the three periods of investigation. The samples in the three periods of investigation showed a sufficient homogeneity, as shown in Table 1, in order to permit analysis of subgroups of the total sample.

The relative interview
The instrument used was a semi-structured questionnaire, developed from clinical experiences and focused on the burden of relatives, their need for support, and participation in care. It contains 95 questions, measuring the relative’s own subjective feelings. The instrument takes 60 to 90 minutes to administer, and the time frame for the questions is in most cases the month before the patient’s admission to hospital. The interrater reliability has been calculated and found satisfactory, with Cohen’s $\kappa = 0.98$ and an absolute correspondence of ratings in 96% of the questions. The test–retest reliability concerning burden and participation in care have been found to be generally satisfactory, measured both as percentage of concordance and as Cohen’s $\kappa$ (Östman & Hansson, 2000b). The instrument is also available in an English version and has been further described by Schene et al. (1994).

In the present study, the following items describing family burden and participation in care were used, and the respondents’ answers were classified as yes/no.

**Items describing family burden**
- Did the patient’s mental illness force you to give up leisure time?
- Did the patient’s mental illness force you to give up your own occupation?
- Did the patient’s mental illness affect the possibilities for you to have company of your own?
- Was there any physical violence against you on the part of the patient?
- Did you have any concerns and worries about the patient attempting suicide or self-damage?
- Did the patient’s mental illness lead to any mental health problems of your own?
- Did the patient’s mental illness impair your relationship with him/her?

**Aspects of participation**
- Did you notice treatment against the patient’s own will?
- Did you yourself experience a sufficient participation in the patient’s treatment?
- Did you feel that you need help and support from the psychiatric staff in this situation?
- Did you get the help and support you felt you needed from the psychiatric services in this situation?
- Do you view the psychiatric services as of good quality?
In an additional analysis, to make it possible to compare a total measure of burden in subgroups of relatives, a summary score was constructed of the seven first burden items stated earlier. This score could thus range from 0 to 7, depending on how many dimensions of burden were identified by each relative.

Statistics
The $\chi^2$ test was used to test for differences in proportions. Comparisons of answers describing burden items between subgroups were carried out with non-parametric tests, the Kruskal–Wallis test and the Mann–Whitney $U$-test. In an additional test of differences in the summary burden score calculated of the seven burden items, Student’s $t$-test was used. One-way ANOVA was used for analysing means of age and GAF/GAS scores. A significance level of 0.05 was used. The statistical software used was SPSS for Windows version 10.0.

RESULTS

Differences in family burden and participation in care with regard to diagnostic subgroup of the patient
Table 2 shows differences with regard to diagnostic subgroup of the patient in family burden and participation in care. In total, the relatives showed burdens in several of the aspects measured. About one third or more of the relatives had been forced to give up leisure time, were concerned about the patient attempting suicide, were isolated and prevented from having company of his/her own and experienced mental health problems of their own as a consequence of the situation. However, in only one aspect of the burden items was there a difference found between relatives from different diagnostic subgroups. The relatives of patients with affective disorder more often had had to give up leisure time ($\chi^2 = 6.77; p = .034$). No difference was found in the summary measure of burden between the three subgroups of diagnoses (mean 2.01 vs. mean 2.20 vs. mean 1.70).

Concerning participation in care and need for support, there were significant differences between diagnostic subgroups in two aspects. Relatives of patients with ‘other diagnoses’ more seldom noticed treatment against the patient’s own will ($\chi^2 = 9.79; p = .007$) and the relatives of patients with affective disorders more often experienced a sufficient participation in the patient’s treatment ($\chi^2 = 7.79; p = .020$).

Relationship between summary measure of family burden and if the relative is living together with the patient
When the relatives were divided depending upon whether they were living in the same household as the patient ($n = 295$, due to no information in the 1986 sample) there were differences in the summary measure of burden. Relatives living together with the patient showed an increased burden assessed by the summary burden score (2.41 vs. 1.56; $t = 4.93; p = .000$).

Differences in family burden and participation in care in subgroups of relatives
Table 3 shows differences in family burden, participation in care and need for own support between subgroups of relatives when the participating non-relatives were excluded in the analysis.
Concerning burden items, spouses more often than the other subgroups of relatives had to give up their work ($\chi^2 = 14.76; \ p = .002$) and more often felt isolated and prevented from having company of their own ($\chi^2 = 25.54; \ p = .000$). Siblings more seldom had to give up leisure time ($\chi^2 = 18.20; \ p = .000$) and also more seldom experienced mental health problems of their own ($\chi^2 = 12.31; \ p = .006$). Spouses also more often experienced a sufficient participation in the patient’s treatment ($\chi^2 = 8.45; \ p = .038$) and more often had a positive view of the quality of the psychiatric services ($\chi^2 = 8.25; \ p = .041$) while siblings and grown-up children more seldom than the other subgroups felt that their own need for support had been met by the psychiatric services ($\chi^2 = 11.68; \ p = .009$).

Furthermore, when investigating differences in summary measure of burden in the subgroups of relatives, siblings showed a significantly lower summary measure ($F = 9.20; \ p = .000$).

### Differences in family burden and participation in care with regard to the diagnostic subgroup of the patient and to different subgroups of relatives within these diagnostic subgroups

Within the psychoses subgroup, spouses showed an increased burden in three aspects. The spouse subgroup more often than the other two subgroups had to give up leisure time,
55% vs 9% and 35% ($\chi^2 = 15.96; p = .001$), had had to give up work, 36% vs 11% and 19% ($\chi^2 = 10.47; p = .015$) and was isolated and prevented from company of his/her own, 55% vs 19% and 36% ($\chi^2 = 10.11; p = .018$). No other differences were found among the subgroups of relatives in the psychoses group.

Within the diagnostic subgroup of patients with affective disorders some differences occurred. Spouses more often had had to give up work, 30% vs 4% and 23% ($\chi^2 = 8.40; p = .038$) and more often felt isolated and prevented from having company of his/her own, 55% vs 23% and 24% ($\chi^2 = 17.28; p = .001$). Furthermore, sons/daughters more often experienced mental health problems of their own, 69% vs 28% and 45% ($\chi^2 = 10.53; p = .015$), more seldom had been met in their need for support, 7% vs 18% and 40% ($\chi^2 = 14.88; p = .002$) and also more seldom had a positive view of the quality of the psychiatric services, 21% vs 33% and 48% ($\chi^2 = 7.97; p = .047$).

When comparing subgroups of relatives in the diagnostic subgroup ‘other diagnoses’ only two significant differences were found. Parents more often experienced mental health problems of their own, 63% vs 16% and 46% ($\chi^2 = 12.78; p = .005$) while sons/daughters more often felt isolated and prevented from having company of their own, 50% vs 5% and 25% ($\chi^2 = 8.27; p = .041$).
DISCUSSION

Despite an encouraging number of studies investigating family burden and distress in relatives of persons with severe mental illness, a minority has compared differences between relatives of different illnesses and subgroups of these relatives. Our study consists of personal interviews with a large sample of relatives of patients with different mental illnesses investigated at different periods of investigation, being united in one analysis. This methodology may be put into question, especially with regard to the use of three different versions of diagnostic manuals for assessing mental illnesses during the period of investigations. However, the over-all homogeneity in characteristics of the patients and relatives investigated in the three periods, and the subgroupings of diagnosis in consensus of the participating research psychiatrists, speaks in favour of the chosen method.

The structured interview used in this study showed burdens in several of the aspects measured. However, these burdens were shown to be of equivalent extent independently of diagnostic subgroup of the patient in our relatively broad categorization of patient illnesses. In only one aspect of the measured burden items was there a significant difference between relatives of different diagnostic subgroups. These results are in accordance with earlier findings of Mueser et al. (1996) and Mors et al. (1992). Mors et al. found, when examining the level of distress in relatives of psychiatric patients admitted for the first time, no differences between non-organic psychotic disorders, mood disorders, anxiety disorders and psychoactive substance disorders. Furthermore, this study showed that relatives living together with the patient showed increased burdens compared to relatives not living with the patient.

Despite the increasing involvement of relatives in caregiving, there has been relatively little interest in their experiences of the need for support and participation in the care situation, their point of view concerning care given and their attendance in the care situation. This study showed that relatives of persons with affective disorders contrasted with the other two diagnostic subgroups of relatives and showed an increased level of participation in the psychiatric services.

Wittmund et al. (2002) has earlier shown that psychiatric patients’ partners, independently of psychiatric diagnosis, are at a high risk of developing a depressive disorder. One advantage in our study is the possibility to compare reported experienced mental problems of several subgroups of relatives. Spouses were characterized by an increased number of burdens compared to other subgroups of relatives but reported as many mental problems as parents and grown-up children. Siblings on the contrary reported fewer mental problems. Spouses more often experienced sufficient participation in the patient’s treatment and had more considerable appreciation of the psychiatric services than the other subgroups. These results may indicate that the psychiatric services in clinical settings are more comfortable and used to co-operating with spouses of persons with affective disorders.

Furthermore, within both the diagnostic subgroups of psychosis and of affective disorders, spouses showed an increased burden in several aspects compared to the other subgroups of relatives. One explanation of these results can be found in the spouse’s sometimes additional role of being a parent to under-aged children, which increases the experience of burden as earlier shown in a study by Östman and Hansson (2002).

Within the diagnostic subgroup affective disorders the grown-up children showed more mental health problems of their own than in the other subgroups. These results are in
accordance with another study elucidating that psychiatric symptoms in parents are strongly related to psychiatric disorders in their adult children (Bijl et al., 2002). The grown-up children also experienced more dissatisfaction both with support from the psychiatric services and the psychiatric services as a whole.

CONCLUSIONS

The findings may illustrate that the situation in itself of being a close relative, living together with a severely mentally ill person in an acute illness situation, is one factor of importance for experiencing burden and may contradict the conventional wisdom of burden differentiating between different diagnoses. This study showed more differences between subgroups of relatives, elucidating the increased burden of spouses, than differences between relatives of different diagnostic subgroups.

Further qualitative research methods may complement this study and illuminate aspects regarding the context of the relatives’ burden and participation in care not discerned in this investigation.

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Margareta Östman, Dr Med Sc, Health and Society, University of Malmö, Sweden.

Tuula Wallsten, MD, Center for Clinical Research, University of Uppsala, Central Hospital, Västerås, Sweden.

Lars Kjellin, Dr Med Sc, Psychiatric Research Centre, Örebro, Sweden.

Correspondence to Dr Margareta Östman, Health and Society, University of Malmö, SE – 205 06 Malmö, Sweden.

Email: margareta.ostman@hs.mah.se