Original Paper

The burden experienced by relatives of those with a severe mental illness – differences between those living with and those living apart from the patient

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Abstract

Background: There are few studies that describe differences in measures of burden and participation in care relating to whether the relatives live with or apart from the person with a mental illness.

Aim: To investigate different aspects of family burden, need for support and participation in care situations specifically considering whether the relative and the patient are living together or apart.

Method: 162 relatives (73 relatives of committed patients and 89 relatives of voluntarily admitted patients) answered a semi-structured questionnaire concerning their situation as a relative of a severely mentally ill person.

Results: There was increased experienced family burden in several aspects due to the relative and patient living together. However, relatives who lived with the patient were less likely to believe that the patient would be better off dead, experienced more participation in the patient's treatment and more often viewed the psychiatric services as being of good quality than those relatives who did not live with the patient.

Conclusion: Persons with a severe mental illness who are admitted to inpatient units are in need of different aspects of intensive psychiatric care. Some of these needs are supplied by relatives in everyday life, often without any support. In providing for the needs of relatives, in relieving their burden, the psychiatric services needs to implement different methods according to whether the relatives live with or apart from the patient.

Keywords

Family burden; compulsory care; needs of relatives; questionnaire

INTRODUCTION

Families who have a member with a severe mental illness often experience personal distress and burden. This burden is often the result of the addition of the caregiving role to already existing family roles (Schene, 1990).

It should not be assumed that only family members who live with the patient find their caregiving role stressful or have concerns about the patient's wellbeing. Relatives not residing in the same home as the patient also experience aspects of burden.

BACKGROUND

Family burden in general is distinguished into two types: objective and subjective burden.

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Objective burden involves disruption to the family due to the individual's illness and is usually observable (Szmukler et al., 1996). Subjective burden involves the psychological consequences of the individual's illness for the family (Schene et al., 1994).

There are few studies that describe differences in measures of burden and participation in care relating to whether the relatives live with or apart from the person in the family with a mental illness. When only the different aspects of family burden are considered, the results are inconsistent with each other. Some studies show similar levels of burden independently of joint household (Martens & Addington, 2001; Laidlaw et al., 2002; Scazufca, 2002). Other studies show an increased burden and stress level for the relative living with the patient (Jacob & Krahn, 1987; Jungbauer et al., 2003) and some studies point to even higher levels of stress for those not living with the patient (Scazufca, 2002).

The relatives' experience of their participation in the care situation and their need for support from the psychiatric services are seldom investigated in research concerning relatives of severely mentally ill people. The research available (Östman & Hansson, 1999) shows low levels of participation in care of the relatives and also low levels of support in managing their situation from the psychiatric services.

Different aspects of family burden and participation in care were important parts of a study of the quality of the mental health service in four Swedish counties performed in 1997–1999. In this study relatives of both compulsorily and voluntarily admitted patients were interviewed concerning different aspects of their burden, need for support and participation in the actual care situation. In the study aspects concerning both objective burden and the psychological effects of being a relative of a severely mentally ill person were stressed and assessed.

The aim of the present part of the study was to investigate different aspects of family burden, need for support and participation in the actual

care situation specifically considering whether the relative and the patient are living together or living apart.

METHODS AND MATERIAL

Design

The present study is a Swedish additional study within a Nordic study of the use of coercion in the mental health care system (Hoyer et al., 2002). It is a multicentre study, focusing on voluntary and compulsory psychiatric inpatient care.

A consecutive sample of committed patients and a random sample of voluntarily admitted patients to acute psychiatric wards were included in the study. People younger than 18 and older than 70 years of age, alcohol abusers, severely mentally disabled people, mentally disordered offenders, people with severe dementia and individuals not speaking Swedish were excluded. The patients included were contacted by a psychiatrist shortly after admission, within five days at the most. They were asked if they wanted to participate in the study and, if they gave permission for a close relative to be interviewed, whom to contact. The psychiatrist assessed the patients' psychosocial functioning and psychopathology, diagnosing them according to DSM-IV (American Psychiatric Association, 1994). Three weeks after admission to hospital a clinical psychologist or a psychiatrist interviewed the patients.

The relatives included in the study were close relatives of the patient. The interviews with the relatives were performed approximately 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 and an interview with the patient.

The study has been approved by the Research Ethics Committee of the Medical Faculty, University of Uppsala, Sweden (B 970217).

Setting

The study has as its base the inpatient psychiatric services of four different Swedish psychiatric centres, each with comprehensive responsibility for a geographically defined catchment area of both urban and rural areas, and a total population of between 90,000 and 260,000 inhabitants. The psychiatric departments in the counties have 3.13–5.13 beds per 10,000 inhabitants for short-term psychiatric care.

Sample

In the study a consecutive sample of 196 committed patients and 179 voluntarily admitted patients (who were randomly selected) were asked to take part in the study. At a first interview, 138 committed and 144 voluntarily admitted patients participated and at a follow-up around three weeks from admission, 118 and 117 patients respectively, took part. During the latter interview, the patients were asked for permission to contact a relative. Altogether 162 relatives, 73 relatives of the committed and 89 relatives of the voluntarily admitted patients were interviewed. Dropout of relatives occurred at two different stages in the investigation: when the patients refused contact with a relative or stated that they lacked a relative to interview, and when the relative refused an interview or when contact failed. The dropouts in this study occurred twice as often at the first stage. Of the relatives asked to participate, 13% refused or were not able to perform the interview.

The following was known about the participating patients whose close relatives were interviewed. Thirty-eight per cent of the patients were men. The mean age was 43 years (19–69). Thirty-one per cent of both the committed and the voluntarily admitted patients had a psychosis diagnosis according to DSM IV, including schizophrenia, delusional disorders, schizoaffective and schizophreniform disorders and atypical psychoses; 44% were diagnosed as affective mood disorders and 25% had other diagnoses. Their psychosocial function as measured by GAF (American Psychiatric Association, 1987) was 37 (10–71). Background characteristics of the participating relatives are shown in Table 1.

Table 1. Background characteristics of the relatives participating in the study

	Men n = 78 (%)	Women n = 84 (%)	Total n = 162 (%)
Age (years)			
19	5	0	3
20–39	32	23	27
40–59	43	51	48
60+	20	26	23
Relationship to the patient			
Spouse	47*** ^a	12	29
Parent	10	42*** ^b	27
Son/daughter	16	18	13
Other, sibling	21	33	27
Non-relative	6	2	4
Living in the same household	51*** ^c	25	38
Duration of relationship (years)			
0–19	27	14	20
20–39	62	69	66
40–59	11	17	14

p < 0.01, *p < 0.001

^achi² = 36.9; df = 4; p < 0.001

^bchi² = 34.7; df = 4; p < 0.001

^cchi² = 11.9; df = 1; p < 0.01

The interview with the relatives

A semi-structured questionnaire was used to interview relatives about their situation as the relative of a severely mentally ill person and their experience of either compulsory or voluntary psychiatric care. The questionnaire was developed through clinical experience and focuses on the burden of relatives, their need for support, and their participation in the care. It contains 95 questions, measuring the relative's own subjective feelings. Eight dimensions of burden and participation in care are covered, as well as measures of family attitudes towards mental health care in a general hospital. The questionnaire takes 60–90 min to complete, of which the burden items take about 45 min. The time frame for the questions in most cases is the month before the patient's admission to hospital. The questionnaire was developed for face-to-face interviews, but is also suitable for use in telephone interviews. The interrater reliability has been calculated and found to be 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 has been found to be generally satisfactory, measured both as percentage of concordance and as Cohen's kappa (Östman & Hansson, 2000). The questionnaire is also available in an English version and is further described in Schene et al. (1994) and in Östman (2000).

In the present study, the following questions relating to family burden and participating in care were investigated, and the respondents' answers were classified as yes/no.

Questions relating to family burden:

- Have there been contacts on a daily basis between you and the patient aiming to help the patient?
- Has the patient's mental illness forced you to give up your own leisure time?
- Has the patient's mental illness affected the possibilities of you having company of your own?
- Has there been any physical violence against you on the part of the patient?
- Have you had any concerns and worries about the patient attempting suicide or self-harm?
- Has the patient's mental illness impaired the relationship between you and him/her?
- Has the patient's mental illness led to any mental health problems of your own?
- Are there times when you wish that the patient had never been born, or that you and the person had never met?
- Are there times when you think that the patient would be better off dead?
- Is the burden of the situation of being a relative so heavy that you have your own thoughts of suicide?

Questions concerning participation in care:

- Did you or another close relative initiate the admission to hospital?
- Were you demanding inpatient treatment?
- Did you experience a sufficient participation in the patient's treatment?
- Has there been any contact between you and the staff of the psychiatric services during the past year?

- Do you feel supported by the psychiatric services in carrying the burden of having a relative with mental illness?
- Do you view the psychiatric services as being of good quality?

Statistics

The chi-square test was used to test for differences in proportions. Comparisons of answers to questions describing psychological factors between sub-groups were carried out with non-parametric tests; the Kruskal-Wallis test and the Mann Whitney U-test. A p level of 0.05 was considered significant.

RESULTS

Aspects of family burden in relatives of persons admitted to a psychiatric hospital

Of the relatives, 52% had contact on a daily basis with the patient the month before admission to hospital, with an aim of helping the patient, and in the experience of 24% the patient appraised the caregiving situation negatively. Nine percent of the relatives had been exposed to physical violence on the part of the patient and 31% had concerns and worries about the patient attempting suicide or self-harm.

According to the relatives, 28% had been forced to give up their own leisure time and 15% had been forced to give up their occupation. One third stated that the patient's mental illness had affected the relative's possibilities of having company of his/her own, either by isolating the relative from their own company or by influencing relations with others, and 25% of the relatives experienced that the patient's mental illness had impaired the relationship between the relative and the patient.

Twenty-one per cent of the relatives had experienced times when they wished that the patient had never been born or that they had never met the patient; 40% of the relatives had mental health problems of their own as a consequence of being a relative of a mentally ill person. Some relatives, 10%, had had suicidal thoughts of their own at least once. Eighteen

per cent of the relatives sometimes believed that the ill relative would be better off dead.

Factors of participation in care of relatives of persons admitted to a psychiatric hospital

One third of the relatives had initiated the admission to hospital and one fifth of the relatives stated that they had demanded inpatient treatment for the patient. Thirty-five percent were satisfied with their level of participation in the patient's treatment and 45% of the relatives recognized contact between themselves and the staff of the psychiatric services during the past year. One quarter of the relatives felt that they had been supported by staff of the psychiatric services in carrying the burden of being a relative of a person with mental illness and 65% of the relatives viewed the psychiatric services as being of good quality.

Differences in patient background characteristics between those patients living with and those apart from a relative

When controlling for background factors of the patient, there were some differences identified between those patients living with and those not living with a relative (Table 2). A greater proportion of the men were not living with a relative; 44% v 28% (chi-square = 3.99; df = 1; $p = 0.046$). Also, patients admitted compulsorily to the ward were less likely to be living with a relative; 52% v 34% (chi-square = 4.47; df = 1; $p = 0.034$). In contrast, patients with custody of their children more often lived together with a relative, 41% v 14% (chi-square = 16.44; df = 2; $p = 0.000$). No significant differences were found according to the diagnostic subgroup of the patient, the patient's age and psychosocial functioning or if the patient is a parent to under-aged children.

The relationship between assessed factors of family burden and whether or not the relative and patient live together

When the factors of family burden assessed in this study were considered against whether or not the relative was living with the patient, differences were found in a majority of measured

Table 2. Background characteristics of the patients comparing whether or not the patient and relative live together

	Patient living with the relative n = 61(%)	Patient not living with the relative n = 101(%)
Sex		
Men	28	44 ^{*,a}
Women	72	56
Diagnostic subgroup		
Psychosis	23	36
Affective disorders	54	38
Other diagnosis	23	27
Index admission		
Compulsory	34	52 ^{*,b}
Voluntary	66	49
Parenthood		
Patient is a parent to minor children	46	29
If parent, patient has custody of the minor children (n = 28 vs n = 29)	41 ^{***,c}	14
Psychosocial function	mean (SD)	mean (SD)
GAF	36 (15)	37 (12)
Age	43 (13)	43 (13)

* $p < 0.05$, *** $p < 0.001$

^achi² = 3.99; df = 1; $p = 0.046$

^bchi² = 4.47; df = 1; $p = 0.034$

^cchi² = 16.44; df = 2; $p = 0.000$

aspects (Table 3a). Those relatives who lived with the patient more often had contact on a daily basis with an aim of helping the patient (80% v 35%; chi-square = 312.78; $p = 0.000$) and more often found that the patient appraised the caregiving situation negatively (36% v 17%; chi-square = 7.70; $p = 0.006$). More relatives had been forced to give up an occupation (28% v 8%; chi-square = 11.60; $p = 0.001$) and their own leisure time (39% v 21%; chi-square = 6.53; $p = 0.011$).

Relatives living with the patient more often found that the patient's mental illness had affected the possibilities of their having company of their own than those living apart (51% v 24%; chi-square = 12.42; df = 1; $p = 0.000$) as well as leading to mental health problems for the relative (51% v 24%; chi-square = 12.42; $p = 0.000$). Relatives living with the patient also more often reported having times when they wished that the patient had never been born or that they had never met the patient,

Table 3a. Relationship between factors of family burden and whether or not the patient and the relative live together

Family Burden:	Patient living with the relative n = 61(%)	Patient not living with the relative n = 101(%)
There had been contacts on a daily basis between the relative and the patient aimed at helping the patient	80 ^a	35
The relative experienced that the patient appraised the caregiving situation negatively	36 ^b	17
The relative had been forced to give up their own leisure time	39 ^c	21
The relative had been forced to give up an occupation	28 ^d	8
The patient's mental illness had affected the relative's possibilities of having company of his/her own	51 ^e	24
There had been physical violence against the relative on the part of the patient	11	8
The relative had had concerns and worries about the patient attempting suicide or self-harm	26	34
The patient's mental illness had impaired the relationship between the relative and the patient	49	35
The patient's mental illness had led to mental health problems for the relative	51 ^f	24
There were times when the relative wished that the patient had never been born or that they had never met the patient	30 ^g	16
The relative sometimes believed that the patient would be better off dead	3	27 ^h
The burden on the relative was so heavy that the relative had had suicidal thoughts	15	7

^achi² = 31.78; p = 0.000^bchi² = 7.70; p = 0.006^cchi² = 6.53; p = 0.011^dchi² = 11.60; p = 0.001^echi² = 12.42; p = 0.000^fchi² = 12.42; p = 0.000^gchi² = 4.28; p = 0.038^hchi² = 14.24; p = 0.000

compared with those living apart (30% v 16%; chi-square = 4.28; p = 0.038). In contrast, relatives living together with the patient more seldom believed that the patient would be better off dead (3 % v 27%; chi-square = 14.24; p = 0.000).

The relationship between assessed factors of participation in care and whether or not the relative and patient live together

When factors of participation in care assessed in this study were considered against whether or not the relative was living with the patient, only two differences were found (Table 3b). More relatives living with the patient experienced sufficient participation in the patient's treatment (48% v 28%; chi-square = 6.55; p = 0.010) and also more often viewed the psychiatric services as being of good quality than those living apart (77% v 58%; chi-square = 4.45; p = 0.035).

DISCUSSION

This study confirms that being a relative of a severely mentally ill person gives rise to both an extensive objective as well as of a far-reaching subjective burden, including thoughts about life and death concerning both the patient and themselves. The study also confirms that contact exists between relatives and staff, sometimes in a very supportive way, and a majority of the relatives are of the opinion that the psychiatric services are of a good quality.

In most cases, research on family burden deals with a parent caring for a person with a schizophrenic disorder irrespective of possible differences in family burden resulting from living with or apart from the mentally ill person (Magliano et al., 2000; Martens & Addington, 2001; Shibire et al., 2003; Lowyck et al., 2004;

Table 3b. Relationship between factors of family burden and whether or not the patient and the relative live together

	Patient living with the relative n = 61(%)	Patient not living with the relative n = 101(%)
Participation in care:		
The relative initiated the admission to hospital	36	33
The relative demanded inpatient treatment	21	24
The relative experienced sufficient participation in the patient's treatment	48 ^a	28
There had been contact between the relative and the staff of the psychiatric services during the past year	44	46
The relative had support from the psychiatric services in carrying the burden of being a relative of a person with a mental illness	30	20
The relative viewed the psychiatric services as being of good quality	77 ^b	58

^achi² = 6.55; p = 0.010
^bchi² = 4.45; p = 0.035

Meijer et al., 2004; Madianos et al., 2004; Gutiérrez-Maldonado et al., 2005).

Studies like ours, investigating differences in family burden between caregivers living with or apart from the patient, do exist for patients with a diagnosis of schizophrenia (Winefield & Harvey, 1994; Jungbauer et al., 2003; Laidlaw et al., 2002) but are not found in other groups of diagnoses. The findings in our study of an increased experienced burden in most of the aspects measured when living with the patient is not an unexpected discovery. However, there are divergent results found in earlier research on populations of solely schizophrenic patient groups. Winefield and Harvey (1994) is one study supporting the result of this study. They reported that high levels of contact between the patient and the relative was associated with greater burden. The number of areas of the caregiver's life affected by 'caregiving' responsibilities was also significantly related to level of contact. They also found that only one quarter of the relatives enjoyed having the patient living with them. Many of the relatives accepted living with the patient only to avoid adverse outcomes for the patient. Results in concordance with the findings in this study show that relatives living together more often wished that the patient had never been born or that the relative had not met the patient than those living apart.

Contrary to our study, Martens & Addington (2001) and Laidlaw et al. (2002) found no

differences in stress levels, psychological well-being or burden of caregivers between primary caregivers living with and those living separately from patients with a chronic schizophrenic disorder.

Of specific interest is the finding in our study that relatives living with the patient more seldomly believe that the patient would be better off dead than those living apart. These relatives also have a more positive view of the psychiatric services and an increased participation in care. The link between the relative and the patient seems to be of a different pattern when the relative and the patient are living together than apart from each other. This finding is also in concordance with Winefield & Harvey (1994) who found that almost half of the caregiver group living with the patient, reported that the staff, when needed, were always helpful.

Relatives living with the patient found that the patient appraised the caregiving situation negatively. This is in spite of the fact that these relatives stated that they had had to give up their own occupation and their own leisure time to help the patient more often than those relatives who did not live with the patient. The consequences of this, for the relationship between the patient and the relatives, are not known.

Our study shows one gender difference in the study population of patients admitted to inpatient care. Male patients more often lived

alone than female patients. Other findings were that patients admitted involuntarily to the ward also more often lived apart from their relatives than voluntary patients and patients who had custody of their children more often lived with a relative than those without children. These findings may suggest that men, involuntarily admitted to ward, without custody of their children are in need of special attention from the psychiatric services since they are also left without a close social network of relatives.

CONCLUSION

Persons with a severe mental illness admitted to inpatient units are in need of different aspects of intensive psychiatric care. Some of these needs are supplied by relatives in everyday life, often without any support. In providing for the needs of relatives, in relieving their burden, the psychiatric services need to implement different methods according to whether the relative is living with or apart from the patient.

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