



# Burden experienced by caregivers of schizophrenia patients and its related factors

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## Abstract

**Background:** Deinstitutionalization of patients with schizophrenia shifted the primary locus of care from psychiatric hospitals to family and informal caregivers. Family members often play a vital role as caregivers in the lives of individuals with schizophrenia and other serious mental illnesses. This study aimed to assess the burden experienced by the caregivers of patients with schizophrenia and to evaluate its correlation with some demographic characteristics of patients, their caregivers, and the level of expressed emotion in the family.

**Methods:** This descriptive-analytic study was conducted on 172 schizophrenic patients and their primary caregivers, selected from the outpatient department of a psychiatric hospital in Tehran, Iran, using convenience sampling. Caregivers were evaluated with Zarit Burden Interview and Family Questionnaire to assess the burden experienced by the caregivers and the level of expressed emotion in the family, respectively. Data were analyzed using Spearman correlation coefficient and linear regression method. Data were analyzed using SPSS software (Version 21) and significance level was set at  $p < 0.05$ .

**Results:** The level of burden experienced by most of primary caregivers was higher than moderate. The scores obtained in the subscales of emotional over involvement and critical comments were higher than the cutoff point in 51.7% and 64.5% of caregivers, respectively, and the scores had a significant direct correlation with the burden experienced by the caregivers. The findings of multiple linear regression showed that lower family income ( $\beta = -0.33$ ,  $p < 0.001$ ), higher duration of disorder ( $\beta = 0.19$ ,  $p = 0.006$ ), and younger age at onset of the disorder ( $\beta = -0.26$ ,  $p = 0.001$ ) were predictive of higher burden of disease on caregivers.

**Conclusion:** Based on the results, some demographic factors of the primary caregivers, patients, and their family significantly affected the burden experienced by the primary caregivers. Most of the caregivers had high expressed emotions and a significant direct association existed between the expressed emotions and the burden experienced.

**Keywords:** Schizophrenia, Burden, Caregiver, Expressed emotion, Demographic characteristics

**Conflicts of Interest:** None declared

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## Introduction

During the past 20 years, deinstitutionalization activity has changed the primary location of care from mental hospitals to community-based outpatient clinics (1). Nonethe-

less, the financial resources for community-based interventions have been limited, and families of the patients with severe mental disorders have been requested to increase their responsibility to support the patients (2).

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### ↑What is “already known” in this topic:

- Burden of the caregivers of schizophrenic patients is considerable.
- Emotional expression in most of the caregivers is higher than the cutoff point.
- The spouses of male patients with schizophrenia experienced higher burden compared to female patients.

### →What this article adds:

- Family income, duration of illness, and the age of onset were predictive factors of primary caregiver burden.
- In contrast with previous studies in developing countries, longer time spent with the patient was a predictor of greater burden experienced by the caregivers.

This process has been particularly rapid in Iran. It has been estimated that more than 50% of patients with schizophrenia who had been discharged from psychiatric hospitals return to live with family members (3).

Family members often play a vital role as caregivers in the lives of individuals with schizophrenia and other serious mental illnesses (4). The burden of people caring for a family member with mental illness is considerable. The families must sometimes cope with the stress of the patient's disruptive symptoms, strained social relations within the family, loss of social support, diminishing opportunities for leisure, and deteriorating finances (5-7). Furthermore, family members often have mixed feelings, such as sorrow, anger, guilt, and shame. All these burdens severely tax the family members coping and adjustment abilities and the strain frequently results in anxiety, guilt, and depression (8). There is considerable research evidence on the high levels of financial burden, strain, and distress related to caring for an ill family member (9-10).

Expressed emotion (EE), is a measure of the family environment, which is based on how the relatives of a psychiatric patient spontaneously talk about the patient (11). Theoretically, a high level of EE at home can worsen the prognosis in patients with mental illness or act as a potential risk factor for family burden (12). Families of patients with schizophrenia are rated as 'High EE' if they are critical, hostile, or emotionally overinvolved (13).

Mottaghypour et al (2001) showed that about 60% of the families of patients with schizophrenia are in high EE range (14). This finding was similar to other studies in developed countries (high EE range 40% to 74%) and different from a study in India, with the high EE rate of 23% (15). Hence, normative data on EE is an important factor which should be considered before researchers can assess the high EE in the caregivers of patients with severe mental disorders (16).

The relationships of burden and sociodemographic variables have also been studied. Martin-Yellowe (1992) found that rural families of schizophrenic patients experienced significantly more financial burden than urban families (17). Also, stress level was higher among the family members of male patients (18). The relatives of patients with schizophrenia reported more social deficits in male patients compared to females (19). In a study by Trivedi et al (2003), it was found that parents and siblings of schizophrenic patients experienced more burdens in comparison to spouses. They also stated that young relatives and those aged 45 and older experienced more burden than the middle age group relatives (20). There is a positive correlation of family burden and duration of illness (21). Jenkins and Schumacher (1999) found that not only the patients' gender but also the gender of the caregivers must be considered (19).

The present study was conducted to determine the burden experienced by the families of patients with schizophrenia. This study also examined the relationship among the burden of the families (main caregivers), expressed emotion, some of the demographic characteristics of the patient and main caregivers, and duration of the disorder.

## Methods

### Participants

This was a descriptive-analytic study conducted in out-patient department of a university-affiliated psychiatric hospital in Tehran, Iran. The sample was composed of 172 patients with schizophrenia and their caregivers who were selected from October 2013 to March 2014. Participation rate was 87.3% and 25 patients were excluded; most of who were excluded because they were not willing to participate or to a lesser extent had severe physical or neurological disabilities. Participants were enrolled using convenience sampling. This study was conducted in accordance with the Declaration of Helsinki and all procedures were approved by the ethics committee of the Undersecretary of Research at Iran University of Medical Sciences.

### Measures

The Zarit Burden Interview (ZBI) is a 22-item assessment tool that measures caregiver's burden. It asks family caregivers about areas that may cause stress and strain, such as physical, psychological, economic, and relational problems. Items are answered on a 5-point scale ranging from (0) never to (4) always (22). The range of scores is from 0 to 88, with higher scores implying greater perceived caregiver burden. The Interpretation of scores is as follows: 0-20 (little or no burden), 21-40 (mild to moderate burden), 41-60 (moderate to severe burden), and 61-88 (severe burden). The psychometric properties of the ZBI include an acceptable interitem reliability and convergent validity, indicated by a Cronbach's alpha of 0.79 and a correlation coefficient of 0.71 between caregiver's global evaluation and ZBI scores. Test-retest reliability (0.71) and internal consistency (Cronbach's alpha= 0.91) have also been reported (22-24). Navidian et al translated and modified Zarit Burden Interview based on Iranian culture standards (3). Its reliability was calculated by test-retest method ( $r= 0.94$ ).

The Family Questionnaire (FQ) is a self-rating questionnaire (25) with 20 items, which was designed by Wiedemann et al in Germany (2002). It measures 2 subscales of EE, critical comment (CC), and emotional overinvolvement (EOI). The results of a study in Iran demonstrated that its internal consistency was 0.80 for the total score of the scale, 0.88 for the criticism subscale, and 0.83 for the EOI subscale (26). The cutoff point for the critical comment and emotional overinvolvement of the subscale was 23 and 27, respectively. In this study, the FQ was used to assess the EE level of the families. In accordance with other EE studies, the household was considered as high EE if one of the family members was rated as high EE (14).

Demographic questionnaire included some of the demographic characteristics of the patient and main caregiver, such as age, gender, educational level, marital status, occupational status, and duration of the disorder.

### Procedure

Patients suffering from schizophrenia who were living with at least 1 key member of the family were candidates for this study. It was ensured that the participants were not suffering from severe physical or neurologic conditions or intellectual disability at the same time. The patients were

recruited from an outpatient department of a psychiatric hospital. A caregiver was one who was a member of the family and had the most frequent contact with the patient; helped to support the patient financially, had most contribution in the patients' treatment, and aged at least 15 years.

Families of all patients were invited to a group briefing session (20 families in each session) and the objectives of the research were explained to them. Then, an informed consent was obtained from both patients and their families. Families who agreed to participate in the research were enrolled. After obtaining informed consent, the patients and their families were assessed by demographic questionnaire (for demographic characteristics and duration of the disorder). Next, the families were assessed using Zarit Burden Interview for burden of caregivers, and Family Questionnaire for expressed emotion. Group briefing sessions were managed by the main researcher. In addition, a psychologist with enough experience and familiar with these types of questionnaires worked as an assistant researcher and filled in the questionnaires and obtained informed consent. Moreover, for more orientation, she participated in a 4-hour training workshop concerning the questionnaires.

### Planned analysis

Descriptive summaries of sociodemographic characteristics of the patients and caregivers were provided for all participants. The mean scores for ZBI and FQ were calculated. The frequencies of high expressed emotion for subscales of FQ (based on the cut-off points) were presented. The correlation of ZBI score with FQ subscales and also correlation of caregivers' burden with some of the characteristics of patients, caregivers, and families were calculated by Spearman correlation coefficient. Moreover, multiple linear regression method was used to determine the predictive factors of caregivers' burden. Data were analyzed using SPSS software (Version 21) and p value less than 0.05 was considered significant.

### Results

This study was conducted at a university-affiliated outpatient psychiatric clinic in Tehran, Iran. The sample population consisted of 172 patients diagnosed with schizophrenia and 172 family members as primary caregivers for each patient. Demographic variables, such as age, gender, marital status, educational level, and employment status, were obtained (Table 1).

Of the patients, 57.6% had 1 to 3 and 42.4% had more than 3 family members living with them. A total of 50 patients (29.1%) lived with their spouse and children, 111 (64.5%) with their parents, and 11 (6.4%) lived with other family members. According to the data obtained from caregivers, 86 patients (50%) spent less than 6 hours daily with the caregiver involved in the study. A total of 64 patients (37.2%) spent 6-12 hours with their caregiver. More than 40% of the patients had been diagnosed when they were 18 to 27 years old. Also, about 80% of the patients' duration of illness was less than 9 years and their mean duration of illness was  $7.6 \pm 6.9$  years. This study showed that 105 households (61%) had an income of 7 500 000 to 10 000

Table 1. Descriptive analyses of patients and caregivers

	Patient N (%)	Caregiver N (%)
Age (M $\pm$ SD)	36.8 $\pm$ 10.5	46.3 $\pm$ 11.3
Gender		
Female	72 (41.9%)	129(75%)
Male	100 (58.1%)	43 (25%)
Education level		
Illiterate	0 (0%)	21(12.2%)
Elementary	73(42.4%)	24(14%)
High school	82 (42.7%)	99(57.6%)
University	17(14.9)	28(16.3%)
Employment status		
Employed	48(27.9%)	56(32.6%)
Unemployed	84(48.9%)	8(4.7%)
Retired	2(1.2%)	15(8.7%)
Housewife	29(16.8%)	85(49.4%)
Student	9(5.2%)	8(4.7%)
Marital status		
Single	95(55.2%)	18(11.4%)
Married	46(26.7%)	141(82%)
Divorced/Widowed	31(18%)	13(7.6%)

000 IR Rials (231- 308 US\$) a month, 45 households (26.2%) 5 000 000 to 7 500 000 IR Rials (154- 231 US\$) a month, 17 households (9.9%) 2 500 000 to 5 000 000 IR Rials (77-154 US\$) a month, and 5 households (2.9%) less than 2 500 000 IR Rials (77US\$) a month. None of the households had an income of more than 10 000 000 IR Rials (308 US\$) a month.

### The results of Zarit Burden Interview

The mean score of burden experienced by the primary caregivers in this study was  $49.7 \pm 13.8$ . Based on the interpretation of scoring of the questionnaire, the results showed that the level of burden experienced by more than 70% of the caregivers was higher than moderate.

### The results of family questionnaire

The mean total score of family questionnaire was  $51.3 \pm 9.9$ . The mean score was  $24.5 \pm 5.5$  for the subscale of critical comments and  $26.7 \pm 4.8$  for the emotional overinvolvement subscale. The frequency percentage of caregivers with a mean score equal or above the cutoff point, based on a cutoff point of 23 for the critical comments and a cutoff point of 27 for emotional overinvolvement, was 64.5% and 51.7%, respectively.

### The correlation of level of burden experienced by the primary caregiver and the family questionnaire score

The level of burden experienced by the primary caregiver was found to be associated with the subscales score of critical comments and emotional overinvolvement in the family questionnaire and these correlations were direct, indicating that the higher the critical comments and emotional overinvolvement expressed by the family, the greater the level of burden experienced by the primary caregiver ( $p < 0.001$ , Spearman's rho:  $r = 0.46$ ,  $p < 0.001$ , Spearman's rho:  $r = 0.38$ , respectively).

### The correlation of caregivers' burden with some of the characteristics of patients, primary caregivers, and families

There was a significant correlation between perceived family member caregiver burden and family income

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( $r=0.42$ ,  $p<0.001$ ), gender of the patient ( $r=0.16$ ,  $p=0.005$ ), number of family members ( $r=0.17$ ,  $p=0.001$ ), duration of illness ( $r=0.38$ ,  $p<0.01$ ), age at disease onset ( $r=0.36$ ,  $p<0.001$ ), and age of the caregiver ( $r=0.25$ ,  $p=0.03$ ) (Table 2).

The results of post hoc tests showed that those caregivers who were widowed or divorced ( $p=0.020$ ), female patients ( $p=0.020$ ), single patients ( $p=0.040$ ), unemployed patients ( $p=0.003$ ), families with lower income ( $p=0.003$ ), and those families who were tenants (did not own their place of residence) ( $p=0.04$ ), experienced more burden.

The results of Mann-Whitney tests showed that families with male patients ( $p=0.020$ ) families that did not own their place of residence ( $p=0.040$ ), caregivers experienced more

burden. In this study, the mean score of caregivers' burden was compared based on some demographic characteristics (Table 3).

The results of Kruskal-Wallis test showed that the experienced burden in caregivers was significantly different between groups of patients with different marital ( $p=0.042$ ) and occupational status ( $p=0.003$ ) as well as groups of caregivers with different marital status ( $p=0.024$ ) (Table 3).

Post hoc test results showed that widowed and divorced caregivers, compared to married caregivers (post hoc Dunn test adjusted by Bonferroni multiple test,  $p=0.020$ ) and unmarried patients and caregivers (post hoc Dunn test adjusted by Bonferroni multiple test,  $p=0.045$ ), experienced more burden.

Table 2. Correlation coefficients of caregivers' burden with some characteristics of patients, caregivers, and families

	r	p**
Age	0.250	0.030
The time that caregivers spend for patients /day	0.041	0.001
Age	0.080	0.520
Duration of illness	0.382	0.010
Age of onset	0.362	0.001
Family income/month	0.426	0.001
Number of family members	0.178	0.001

\*Continuous variables\*\*Spearman Correlation Coefficient test

Table 3. Relationship of caregivers' burden with other characteristics of patients, caregivers, and families

Variable	Burden (Mean ± SD)	p
Sex of caregiver		
Male	49.6±13.2	0.840*
Female	51.04±14.2	
Educational level of caregiver		0.502**
illiterate	51.8±15.5	
Elementary school	50.7±10.5	
High school	48.8±13.7	
College	47.2±15.6	
Marital status of caregiver		0.024***
Single	48.5±18.6	
married	49.2±12.9	
Widowed & divorced	56.8±15.1	
Employment status of caregiver		0.110***
Employed	48.9±13.8	
Housewife	50.4±12.5	
student	47.2±15.5	
retired	45.8±15.1	
unemployed	58.8±21.6	
Sex of patients		0.008**
Male	51.4±13	
Female	44.6± 14.8	
Educational level of patients		0.120**
Elementary school	51.8±13.9	
High school	48.6±13.1	
College	46.7±16.5	
Marital status of patients		0.042**
Single	48.5±20.1	
married	46.7±13.7	
Widowed & divorced	52.4±13.5	
Employment status of patients		0.003***
Employed	46.6±7.9	
Housewife	44.8±16.4	
student	48.6±7.6	
retired	50.5±14.8	
unemployed	54.1±11.3	
Ownership status of residential place		0.042**
owner	47.3±7.5	
tenant	54.3±9.3	
Patient lives with		0.503***
Spouse & children	47.7±14.0	
parents	50.9±12.9	
Other relatives	48.6±17.6	

\*Categorical variables

**Table 4.** Multiple Linear regressions on burden of caregivers

Variables	B	Std. Error	$\beta$	p
Family income/month	- 3.1	0.065	- 0.33	<0.001
Duration of illness	0.022	0.008	0.19	0.006
Age of onset	- 0.02	0.005	- 0.26	0.001

The overall model attained an adjusted  $R^2=0.31$ ;  $P=.007$

Post hoc test results revealed that unemployed patients (post hoc Dunn test adjusted by Bonferroni multiple test:  $p=0.003$ ) and caregivers experienced more burden.

### Predictive factors of caregivers' burden

The factors in significant correlation with caregivers' burden were entered in a multiple linear regression model, and the results showed that family income, duration of illness, and the age of onset were predictive factors of primary caregivers' burden (Table 4); this model explained 31% of the variance in the burden experienced by the families.

### Discussion

This study showed that the level of burden experienced by the majority of primary caregivers of patients with schizophrenia was moderate to severe (27). These results are also in accordance with those of Navidian et al (2008). They reported that the burden experienced by 73% of caregivers was above the average and as the patients aged, the burden experienced by the caregivers increased (3).

The findings revealed that the scores obtained in the 2 subscales of critical comments and emotional overinvolvement were higher than the cutoff points and had a significant direct correlation with the burden experienced by caregivers. Evidence shows that patients with schizophrenia coming from families with high expressed emotions have higher risk of relapse after discharge from the hospital (11, 28). One reason for high burden of disease in such families may be the higher number of relapses and the need for frequent hospitalizations. Studies indicate that stressors of patients can significantly affect the burden of disease experienced by the family (29). Miklowitz et al (2003) reported that educating patients with severe mental disorders and their families can significantly decrease the severity of symptoms, the relapse rate, and consequently the burden of disease (30).

Evaluation of burden experienced by the caregivers based on their demographic characteristics demonstrated that the burden was significantly higher in females, widowed, and divorced caregivers. These results are in line with those of Navidian and Bahari (2008). In their study, the burden experienced by the caregivers was higher in female, older, and divorced caregivers (3). One possible explanation for higher burden experienced by female caregivers may be the several responsibilities that a female has in most families, including house chores, taking care of children, being the primary caregiver of patients or the elderly in the family, and sometimes employment. All these factors can increase the responsibility and consequently the tension and distress in women and increase the burden experienced by them (31). The results also showed that the burden experienced by the divorced or widowed caregivers was

higher which may be attributed to the decreased social support, particularly perceived social support, in the divorced or widowed participants. Studies have demonstrated that divorced participants often have a lower perception of the social support in the community; and this issue can increase the burden experienced by these caregivers (32, 33).

In this study, the burden experienced by caregivers of male, unemployed, divorced, or widowed patients was higher than other patients. Mishra et al (1992) and Morse et al (2005) stated that the level of stress was higher among the family members of male patients (18, 34). The relatives of male schizophrenic patients reported that the existing social supports for male patients were more deficient than for female patients (19). The wives of men with schizophrenia experience greater anxiety, burnout, frustration, isolation from the society, and workload. Husbands' disease imposes greater financial and social responsibilities on these women, resulting in higher caregiver burden. Experience shows that unemployed, divorced, or widowed patients are among the groups with increased dependence due to their impaired social support network; thus, the burden experienced by their caregivers increases (3).

The results of the present study showed lower level of burden experienced by the caregiver in the following situations: higher income families, families who own their own home, families with  $\leq 3$  members, and caregivers spending less time with patients (less than 6 hours/day). The results also demonstrated that low income had a more significant impact on the caregivers' burden. Based on the report of national Statistic Center of Iran, the average income of each family in urban areas in 2013 was 17 030 000 Rials (523 US\$) (35). It seems that most of the families in this study were among the low-income families of the country. Also, this study revealed that the caregiver burden was lower in families owning their living place compared to those who were renting. Some previous studies have reported that in developing countries, longer hours spent by the caregiver with the patient, especially in crowded families, does not increase the caregiver burden (36, 37); this finding is in contrast with the findings of studies in Western countries. In this study, in contrast with previous studies (36, 37), the longer time the caregiver spends with the patient was found to be a predictor of greater burden experienced by the caregivers, and more crowded families experienced higher burden. Thus, findings of the present study were not in agreement with the patterns reported in non-Western countries. There is lower caregiver burden in developing countries, especially in crowded families, due to dividing tension and burden to all the family members. However, this is not the case in Iran and Western countries, especially in nuclear families, and increased caregiver burden is common.

Results of this study also showed that by increased duration of disease, the primary caregiver experienced greater burden. Such positive correlation has been confirmed in

many previous studies (21, 38) because burnout syndrome develops in family members, particularly in primary caregivers. The findings also showed that the variables that were significantly associated with caregiver burden (family income, duration of illness, and age of onset of disorder) have the ability to predict the severity of the burden in caregivers.

### Limitations

One main limitation of this study was its small sample size. Thus, larger sample size can definitely increase the power of the study and accuracy of results, particularly in subgroup analyses. Another limitation of this study was performing the study in a university-affiliated psychiatric hospital in Tehran (capital of Iran). Thus, generalization of results to other patients at the national level should be done with caution.

### Conclusion

Most caregivers of patients with schizophrenia experience significantly high level of burnout and burden. Most families of these patients have high expressed emotions. Also, there is a significant direct association between expressed emotions and the burden experienced. Some demographic factors of the patient and the caregiver, such as the socioeconomic status of the family, can significantly affect the burden experienced by the caregiver and increase it. Moreover, establishing social support networks and family education can also help these patients and their families. Furthermore, family education can help these patients and their families.

### Conflict of Interests

The authors declare that they have no competing interests.

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