The Perceived Burden of Care and its Correlates in Schizophrenia

Leyla GÜLSEREN1, Birmay ÇAM2, Berna KARAKOÇ2, Tamer YiĞİT2, Ayşen Esen DANACI3, Zeynep ÇUBUKÇUOĞLU4, Cumhur TAŞ4, Şeref GÜLSEREN1, Levent METE1

Abstract

Objective: The present study aimed to investigate the perceived level of burden of care and its correlates in family members of schizophrenia patients.

Method: The study included 239 schizophrenic patients that were followed-up at the psychiatric outpatient clinics of Izmir Ataturk Education and Research Hospital, and Celal Bayar University Medical School, and 239 of their primary caregivers. Patients were assessed using the Positive and Negative Syndrome Scale (PANNS), Global Assessment of Functioning Scale (GAF), Social Functioning Scale (SFS), Brief Cognitive State Examination (BCE), and UKU Side Effect Rating Scale. Their primary caregivers were assessed using the Perceived Family Burden Scale (PFBS), Beck Depression Inventory (BDI), and Beck Anxiety Inventory (BAI).

Results: Caregiver PFBS scores were correlated with male patients, female caregivers, inadequate social support, economic difficulty, the presence of chronic physical disorder in the caregivers, patient violence toward the caregivers, total duration of illness, the number of patient hospitalizations, PANNS total and subscale scores, and SFS, BDI, and BAI scores. Perceived burden of care was predicted by the severity of the patients’ positive symptoms, SFS independence/competence and interpersonal functioning subscale scores, and caregivers’ anxiety and depression levels.

Conclusion: In order to decrease the burden of care in schizophrenia we recommend effective management of patient symptoms, enhancement of patient social functioning, interventions that target caregivers with high-levels anxiety and depression, and social support provided by healthcare professionals.

Keywords: Schizophrenia, burden of care, Perceived Family Burden Scale

INTRODUCTION

According to psychological theory, family members are the major cause of schizophrenia. Frieda Fromm-Reichmann coined the term “schizophrenogenic mothers”. Bateson, Bowen, Lidz, Wynne, and Laing argued that specific family structures and communication patterns lead to schizophrenia within the family. These arguments were based on limited clinical observations and they negatively influenced the relationship between healthcare professionals and the families of schizophrenic patients and hence increased the burden of family members (Barrowclough and Tarrier, 1992; Awad and Voruganti, 2008).

The term “burden of care” emerged following the discovery of chlorpromazine in 1950 and the subsequent increase in use of antipsychotics for the treatment of schizophrenia. After the closure of mental hospitals, patients were followed-up outside of the hospital setting (Awad and Voruganti, 2008) and family members assumed responsibility for these patients, becoming the primary caregivers within the home environment. Researchers became interested in how the attitudes of caregivers toward schizophrenia patients influenced the disease’s prognosis. Brown et al. developed the “expressed emotion” concept in 1962 (Bebbington and Kuipers, 1994). These developments led researchers to study the
burden of care on family members responsible for schizophrenic patients. Caregivers became more involved in the treatment plan, and clinicians began to develop psychoeducational programs and psychotherapies to help these caregivers (Pitschel-Walz et al., 2001).

Burden of care refers to daily difficulties, problems that affect their lives, and negative life events that result from caring for or living with an ill family member (Platt, 1985; Winefield and Harvey, 1994). In 1966 Hoenig and Hamilton differentiated subjective and objective burden of care. Objective burden of care is the observable aspects of the burden, which involves disturbing patient behaviors, economic problems, and daily restrictions imposed on caregivers. It involves the negative impact of the illness on caregivers’ physical and mental functioning. Subjective burden of care refers to the level at which family members feel uncomfortable with these problems (Awad and Voruganti, 2008). It was reported that burden of care is a more significant predictor of early relapse than the expressed emotion of family members (Levene et al., 1996).

The burden of care in psychiatric illnesses was initially studied in caregivers of heterogeneous patient groups. Those that studied burden of care in schizophrenia used interviews or scales that were not specifically designed to assess the caregivers of schizophrenic patients. Later, researchers developed several scales to measure the burden of care in schizophrenia. They investigated the relationship between burden of care, and patient/illness-related variables (e.g., gender and symptom patterns) and caregiving variables (e.g., coping styles, psychological problems, presence of a supportive network, and beliefs about the etiology of schizophrenia) and made cross-cultural comparisons for the burden of care (Wijngaarden et al., 2003; Roick et al., 2007). Patient gender can affect the burden of care (Awad and Voruganti, 2008). The burden of care is also related to the severity of schizophrenic symptoms (Provencher and Mueser, 1997; Lowyck et al., 2004); however, findings concerning which symptom clusters increase the burden of care are inconsistent (Awad and Voruganti, 2008). Both positive symptoms (Gibbons et al., 1984) and negative symptoms (Raj et al., 1991; Gopinath and Chaturvedi, 1992) were observed to increase the burden of care. Some studies indicated that both symptom clusters affect the burden of care (Provencher and Mueser, 1997; Magliano et al., 2002; Roick et al., 2007). Although Gibbons et al. (1984) reported that the burden of care diminishes over time, Lowyck et al. (2001) observed that interventions for caregivers are needed in order to diminish the burden of care. A review of research on the quality of life of caregivers in schizophrenia (Caqueo-Urizar et al., 2009) showed that the burden of care increases and caregiver quality of life decreases with inadequate social support, family dysfunction, and a negative prognosis. In particular, economic burden can negatively affect the quality of life of caregivers in developing countries, in which there is a limited number of healthcare professionals and healthcare centers, and the cost of schizophrenia’s treatment is high. Additional research on the burden of care in such countries can be beneficial for the enhancement of healthcare services provided to patients and their caregivers.

There are few studies on the family members of schizophrenic patients in Turkey, and the existing ones included limited number of caregivers. Karancı (1995) studied Turkish caregivers’ beliefs about the etiology of schizophrenia, their expectations, and the burden of care. It was observed that the families of schizophrenic patients must contend with emotional problems, inter-family conflicts, and economic burden related to patient care and treatment. Gülseren et al. (1999a) compared family functioning of caregivers in bipolar disorder and schizophrenia, and reported that although family functioning deteriorated in both groups, the caregivers of schizophrenic patients had better family functioning. Doğan et al. (2002) provided a home-based education program for the families of patients diagnosed with schizophrenia. After 3 months of education they observed a decrease in the caregivers’ quality of life, psychological symptoms, perceived social support, and burden of care (which was measured with a form developed by the researchers). In another study researchers assessed caregivers using the Camberwell Family Interview and observed a relationship between high expressed emotion, and hopelessness and negative expectations of the future (Kuşçu et al., 2005). Another study reported a relationship between the level of social functioning of schizophrenic patients, and their families’ level of functioning (Danacı et al., 2005). Aydın et al. (2009) studied the relationship between the burden of care, and the sociodemographic and illness characteristics of schizophrenia. They reported that the burden of care increases as schizophrenia exacerbates, the number of hospitalizations increases, and the level of anxiety and depression in caregivers increases, whereas it decreases as the level of education of caregivers increases. Additionally, some researchers investigated family problems, and the emotions and needs of caregivers in schizophrenia, and conducted supportive and psychoeducational group studies (Sayil et al., 1984; Ünlüoğlu, 1994; Soygür et al., 1998; Gülseren et al., 1999b).
Burden of care in schizophrenia is a multidimensional concept. The families of schizophrenic patients in Turkey are faced with several difficulties in the absence of adequate practical support and education programming (Gülseren, 2002). The present study aimed to examine the level of burden of care in the caregivers of schizophrenic patients, the correlates of the burden of care, and the domains in which caregivers require support.

**METHODS AND MATERIALS**

**Participants**

The study included 239 schizophrenic patients that were followed-up at the psychiatric outpatient clinics of Izmir Ataturk Education and Research Hospital, and Celal Bayar University Medical School, and 239 of their primary caregivers. The member of each family that spent most of his or her time with the patient and was responsible for the patient’s care was selected as the primary caregiver. Different clinicians evaluated the patients and their caregivers.

**Exclusion/inclusion criteria**

Inclusion criteria for the patients were as follows: 1) diagnosis of schizophrenia according to DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2000); 2) age between 18 and 65 years; 3) the presence of symptoms for at least 1 year; 4) living with a family member for at least 1 year; 5) lack of any condition that would interfere with the interview process or administration of the scales, and 6) the provision of informed consent. Patients with a serious physical disability (e.g. paralysis, amputation) and those with mental retardation were excluded from the study.

Inclusion criteria for the caregivers were as follows: 1) living with the patient for at least 1 year, 2) spending more time with the patient than other family members, 3) responsible for the patient’s care, 4) age ≥18 years, and 5) the provision of informed consent. Caregivers with a physical disability (e.g. blind, deaf, and speech problems) or a mental disability (e.g. psychotic disorder, mental retardation, and dementia) were excluded from the study.

**Scales administered to patient**

Positive and Negative Syndrome Scale (PANNS): PANNS is a semi-structured interview containing 30 items that measure the severity of negative and positive symptoms of schizophrenia, and general psychopathology. It was developed by Kay et al. (1987) and was translated into Turkish by Kostakoğlu et al. (1999).

Global Assessment of Functioning Scale (GAF): GAF is a revised version of the Global Assessment Scale (Endicott et al., 1976) and was included in the DSM-III-R (American Psychiatric Association, 1987) for the assessment of global functioning in patients.

Social Functioning Scale (SFS): SFS was developed by Birchwood et al. (1990) and was translated into Turkish by Yaprak et al. (2002). It consists of 7 subscales that assess daily functioning, and current and altered social functioning in schizophrenic patients.

Brief Cognitive State Examination (BCE): BCE consists of 28 items that measure cognitive functioning in patients. Kayatekin et al. (1985) reported that the Turkish version of this scale is valid and reliable for use in the Turkish population.

UKU Side Effect Scale (UKU, Udvalg for Klinikse Undersegelser): UKU was developed by Lingjaerde et al. (1987) to assess the clinical side effects of psychotropic drugs used in therapeutic doses. It consists of 4 subscales that measure psychological, neurological, and autonomic and other side effects.

**Scales administered to the caregiver**

Perceived Family Burden Scale (PFBS): Levene et al. (1996) developed PFBS to assess the burden of care in families of schizophrenic patients. It is a self-report scale consisting of 24 items. It has 3 scores (subjective burden, objective burden, total score). The quantity of patient illness-related behavior (e.g. refusal of food, refusal of drugs, and meaningless speech) within the previous month encompasses the objective burden score. Caregiver evaluation and feelings about these behaviors encompasses the subjective burden score. Gülseren et al. (2007) translated the scale into Turkish.

Beck Depression Inventory (BDI): BDI assesses the level and severity of depression symptoms (Beck 1961) and was translated into Turkish by Hisli (1989).

Beck Anxiety Inventory (BAI): BAI assesses the frequency of anxiety symptoms of caregivers (Beck et al., 1988). Ulusoy et al. (1998) translated the BAI into Turkish.

Sociodemographic and Clinical Form: We developed a sociodemographic and clinical form to assess the sociodemographic characteristics of the patients and
their caregivers, and the potential risk factors for family burden (such as, social support, average amount of time spent with the patient per day, and stigmatization anxiety). Clinical characteristics of the patients, such as drugs used, regularity of drug taking behavior, whether or not the patient is monitored by a physician or hospital, were also assessed with this form.

**Statistical analysis**

Data were analyzed using SPSS v.11 for Windows. Chi-square and Student’s t tests were used to compare categorical variables and continuous variables, respectively. ANOVA was utilized for the comparison of more than 2 groups. Pearson’s correlation analysis was used for measuring correlations between variables. Linear regression analysis was used to analyze the predictors of the burden of care.

**RESULTS**

In all, 239 patients and 239 of their caregivers were recruited from the outpatient clinic of IAERH (150 patients, 150 caregivers) and CBUMS (89 patients, 89 caregivers). In total, 108 of the patients were female (45.2%) and 131 were male (54.8%). Mean patient age was 40.8 ± 12.2 years. Mean duration of illness was 12.6 ± 9.1 years. The level of education in 76 patients (28.1%) was primary school. Among the 239 patients, 206 (76.3%) were unemployed. Among the 239 caregivers, 145 (60.7%) were female and 94 (39.3%) were male. Most of the caregivers were the patients’ mothers (n = 84, 35.1%). Mean caregiver age was 50.7 ± 14.2 years. The level of education in 119 caregivers (% 44.1) was primary school, 184 caregivers (68.1%) were unemployed, and 127 of the female caregivers (87.6%) were unemployed. Scale scores for the patients and their caregivers are shown in Table 1.

PFBS total score was compared to the sociodemographic characteristics of the patients and caregivers. The results indicate that the burden of care was related to male patients, female caregivers, and the presence of a chronic physical disorder in the caregiver. Inadequate family social support from relatives and healthcare professionals, patient violent behaviors toward caregivers, family economic problems, and irregular monitoring of the patient by a physician or mental health center were also related to PFBS total score.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Student’s t score</th>
<th>Standard deviation</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient gender</td>
<td>t = 2.3*</td>
<td>236</td>
<td>0.025</td>
</tr>
<tr>
<td>Caregiver gender</td>
<td>t = 2.7*</td>
<td>236</td>
<td>0.006</td>
</tr>
<tr>
<td>Presence of violence (yes/no)</td>
<td>t = 3.3*</td>
<td>236</td>
<td>0.001</td>
</tr>
<tr>
<td>Caregiver physical illness (yes/no)</td>
<td>t = 3.2*</td>
<td>236</td>
<td>0.002</td>
</tr>
<tr>
<td>Economic status of the family</td>
<td>t = 2.3*</td>
<td>230</td>
<td>0.024</td>
</tr>
<tr>
<td>Support from healthcare professionals</td>
<td>F = 7.04**</td>
<td>2</td>
<td>0.001</td>
</tr>
<tr>
<td>Support from relatives</td>
<td>F = 3.9**</td>
<td>2</td>
<td>0.023</td>
</tr>
<tr>
<td>Regular monitoring</td>
<td>F = 21.7**</td>
<td>2</td>
<td>0.001</td>
</tr>
</tbody>
</table>

*Student’s t test. **ANOVA.
Table 3 shows the variables related to PFBS total score, subjective score, and objective score. There were positive correlations between PFBS total score and subscale scores, and PANSS total and subscales scores, total duration of illness, number of hospitalizations, BDI score, and BAI score. PFBS total score, subjective score, and objective score were negatively correlated with patient social functioning.

Table 4 shows the predictors of the burden of care variable. PFBS total score was predicted by caregiver anxiety and depression scores, patient PANSS positive symptom score, and the SFS independence-competence and interpersonal functioning subscale scores. PFBS objective score was predicted by caregiver anxiety score, and the SFS independence-competence and social withdrawal subscale scores. PFBS subjective score was predicted by caregiver anxiety score.
The present study examined the factors related to the burden of care in schizophrenia, and shows that the burden of care was related to sociodemographic and clinical characteristics of the patients and caregivers. We observed that caregivers of male schizophrenic patients reported higher-level burden of care, which is consistent with previous reports (Roick et al., 2007; Awad and Voruganti, 2008). Most of the male patients were unemployed and could not contribute to their family's finances, probably resulting in higher-level burden of care. Researchers have reported that schizophrenic patients are usually cared for by female family members (Awad and Voruganti, 2008; Nasr and Kausar, 2009). Similarly, we observed that most of the patients were cared for by female caregivers (mostly mothers). Female caregivers reported higher-level burden of care than the male caregivers, probably because of the fact that they were mostly housewives and had limited resources for functioning in different social contexts or assuming different social roles. One study reported caregivers felt as if they didn't belong to the external social world or to the world of the patient (Gülseren et al., 1999b), which indicates the role of caregiving and limited social resources in increasing the burden of care; however, a similar study conducted in Turkey did not report any relationship between the burden of care, and the genders of the patients and caregivers (Aydın et al., 2009).

A study conducted in Pakistan reported that caregivers experienced burden primarily in economic terms (Nasr and Kausar, 2009). Another study conducted in Turkey compared family functioning in the families of patients with bipolar disorder to those of patients with schizophrenia (Gülseren et al., 1999a), and reported that low-income level negatively affected family functioning. In the present study the burden of care scale did not provide any data on the burden clusters of caregivers, but the caregivers with economic problems reported higher levels of burden of care than those without economic problems. Moreover, we observed that the presence of physical illness in the caregivers was related to the burden of care. Families of schizophrenic patients had to contend with burdens related to economic problems (due to the unemployment of adult schizophrenic family members and the high cost of the treatment of schizophrenia) and caregiver health problems.

One study from India (Raj et al., 1991) reported that caregivers of patients with positive symptoms and those of patients with negative symptoms did not differ in terms of subjective or objective burden of care. After a 6-month-follow-up the researchers observed that the caregivers of patients with negative symptoms had higher-level subjective and objective burden of care. They posited that the caregivers of patients with negative symptoms experienced higher levels of burden of care because they initially perceived negative symptoms as more controllable by the patients. Gopinath and Chaturvedi (1992) similarly observed that negative symptoms (such as the lack of self-care or helping with household chores) led to a higher level of burden of care, as compared to positive symptoms. In contrast, Gibbons et al. (1984) reported that caregivers of patients with psychotic behaviors had higher-level of burden of care.

Provencher and Mueser (1997) suggested that subjective burden of care is related to both positive and negative symptoms, whereas objective burden of care is related only to negative symptoms, which indicates the negative effect of negative symptoms on caregiver functioning. Aydn et al. (2009) utilized the Zarit Caregiver Burden Scale to measure burden of care and did not observe a relationship between symptom clusters and the burden of care. We observed a positive relationship between positive and negative symptoms and general psychopathology, and all dimensions of burden of care. Positive symptom score was the only symptom cluster that predicted the burden of care. Moreover, caregivers that experienced the violent behavior of patients reported higher-level burden of care. These findings indicate that the management of schizophrenic symptoms and the rehabilitation of patients could decrease the burden of care associated with schizophrenia. In addition, psychoeducation programs for caregivers on the nature of positive and negative symptoms, and methods of coping with these symptoms could be utilized to diminish the burden of care.

Few studies have examined the correlates of the burden of care other than symptom clusters. No study has systematically evaluated the role of cognitive dysfunction or comorbidity in the burden of care (Awad and Voruganti, 2008). Perllick et al. (2006) investigated the burden of care in 623 caregivers recruited from the CATIE study. They reported that there weren't any relationships between the burden of care, and cognitive functioning in patients or side effects of the antipsychotic drugs. Similarly, we did not observe a relationship between the burden of care, and patient cognitive ability or side effects of the antipsychotic drugs, but this could have been related to the cross-sectional design of the study and the use of measures (BCE) not specific to cognitive ability in schizophrenic patients.

We observed that the burden of care was positively cor-
related with the total duration of illness and the number of hospitalizations. Similarly, Aydin et al. (2009) reported that the number of hospitalizations and the number of relapses were related to caregiver burden of care. Repeated hospitalization, in the context of schizophrenia, might have negative and positive effects on the functioning of family members (Gülseren et al., 1999a). As schizophrenia is a progressive disease, caregivers are faced with new deteriorations in the functioning of their patients. In Turkey interventions for schizophrenia usually target symptom reduction in the acute period and healthcare professionals cannot provide support to caregivers because of excessive medical workload. Thus, prolonged attacks and relapses, and stigmatization might increase caregiver burden of care. Furthermore, we observed that caregivers that did not receive adequate support from healthcare professionals and relatives reported higher levels of burden of care, which is in accordance with findings in other cultures (Magliano et al., 2000, 2002; Chien et al., 2004).

Ünlüoğlu et al. (1994) reported that caregivers are primarily anxious about society’s attitude towards the patient. They stressed the importance of cooperation between family members in dealing with the burden of care. Karancı (1995, 1997) posited that home-based professional care systems would be beneficial, both for patients and their caregivers. Our findings are consistent with the idea that cooperation between caregivers, psychological/psychoeducational interventions design for caregivers, self-help groups, interventions to reduce stigma, and enhancement of caregiver social network systems would decrease the burden of care in schizophrenia.

Living with a psychiatric patient can negatively affect the psychological and physical health of family members. Caregivers can experience psychological problems, such as anxiety and depression (Gibbons et al., 1984, Olridge and Hughes, 1992; Dyck et al., 1999; Pitschel-Walz et al., 2001). One study examined the psychological well being of caregivers using the General Health Scale and Hospital Anxiety-Depression Scale (Oldridge and Hughes, 1992). The researchers reported high scores in 36% of the caregivers. Although this rate was lower than the rate (72%) reported by Gibbons et al. (1984), it was higher than rate in the general population.

Aydin et al. (2009) reported that there was a relationship between the severity of anxiety and depression symptoms, and the quantity of daily care. We observed a positive relationship between burden score, and depression and anxiety scores in the caregivers. Depression predicted burden scale total score. Anxiety score predicted burden of care total score, and subjective and objective burden of care scores. Psychological problems experienced by caregivers might negatively affect their ability to cope with the patient’s illness. Long-term caring for a schizophrenic patient might also be a chronic stress factor, resulting in vulnerability to anxiety problems and depression. Caregivers might not be involved in the social activities they were before the onset of their family member’s illness, and can become socially isolated and depressed; the patient’s social isolation can exacerbate this situation. Interventions that target caregiver psychological problems would be helpful in diminishing the burden of care.

Danacı et al. (2005) examined 37 schizophrenic patients and their 37 caregivers using the Social Functioning Scale and Family Assessment Scale. They reported that patient social functioning was related to family functioning. Patient social functioning deteriorated as problems in communication between the family members increased. This study, however, did not examine the relationship between patient social functioning and the burden of care. Magliano et al. (2000) reported that increases in patient social functioning were related to decreases in the burden of care. We observed a negative correlation between all domains of patient social functioning and the burden of care. Social functioning independence/competence subscale score predicted both the Family Perceived burden scale total score and objective score. Interpersonal functioning subscale predicted the Family Perceived burden scale total score. Social withdrawal subscale predicted the objective burden of care score. Deterioration in patient social functioning might cause caregivers to assume more responsibility for the patients and to spend more time with them, which might increase the burden of care.

Patients with schizophrenia are increasingly treated at outpatient clinics and are cared for by family members. Hence, studies on the factors involved in the burden of care and interventions that reduce this burden are important. In order to diminish the burden of care patients symptoms should be managed and patient social functionality must be improved. Caregivers should be provided social support, especially by healthcare professionals. They should be provided psychoeducation concerning patient symptoms. Interventions for family members should not be restricted to the patient’s hospitalization period and must be available during each stage of the illness. The major limitations of the present study are its cross-sectional design and the inclusion of patients that were followed-up at outpatient clinics. We recommend additional longitudinal studies to investigate the role of the correlates of burden of care on the prognosis of schizophrenia.
REFERENCES


Disturbance. Arch Gen Psychiatry 33:766-771.


