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Comparison of Caregiver Burden in First Episode Versus Chronic Psychosis

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A B S T R A C T

The aim of this study was to compare burden on caregivers of patients with first episode psychosis and caregivers of those with chronic psychosis. The study sample consisted of 39 caregivers of patients with first episode psychosis and 40 caregivers of patients with chronic psychosis. The Caregiver Burden Inventory (CBI) was used for data collection. The average caregiver burden in caregivers of patients with chronic psychosis was significantly higher than that in caregivers of patients with first episode psychosis. With regard to the subscales of CBI, there was a significantly higher level of burden in terms of time dependence, development, physical burden, and social burden in caregivers of patients with chronic psychosis than in caregivers of patients with first episode psychosis, while no such difference could be detected for the emotional burden. The absence of a difference in emotional burden suggests that caregivers of first episode psychosis may be going through an intense emotional experience, placing them in a high-risk status, despite an average caregiving experience duration of 11 months. Family interventions targeting the caregivers of patients with chronic psychosis or patients with first episode psychosis should be planned in accordance with the specific needs of these caregiver groups. It is also recommended to conduct programs involving the concurrent participation of the caregivers of patients with first episode psychosis and caregivers of patients with chronic psychosis and interventional programs such as "early psychosis support" for the caregivers of patients with first episode psychosis.

Shorter length of hospital stay in conjunction with a more pronounced focus on out-of-facility care for patients with psychiatric disorders has recently given the role of the "primary caregiver" to the families of these patients for their management (Atagün, Balaban, Atagün, Elagöz, & Özpolat, 2011; Awad & Voruganti, 2008; Caqueo-Urízar, Gutiérrez-Maldonado, & Miranda-Castillo, 2009; Gutierrez-Maldonado, Caqueo-Urízar, & Kavanagh, 2005). Approximately 50–90% of the patients with chronic mental conditions continue to live with their families following acute psychiatric treatment, leading to increased burden and responsibility on the side of families (Gümüş, 2006; Schulze & Rössler, 2006) that are evident even at the initial phase of psychotic disorders (Addington, Coldham, Jones, Ko, & Addington, 2003; Narendra, Bhattacharjee, Nishant, Sanjay, & Nizamie, 2011; Patel, Chawla, Krynicki, Rankin, & Upthegrove, 2014; Tennakoon et al., 2000). Despite this, there is a relative scarcity of data on the caregiving experience of the families at the early stages of the disease (Addington et al., 2003).

The burden is mostly the consequence of the addition of the caregiving role to the already existing roles of the family. The burden of care is described as "psychological state produced by the combination of physical work, emotional pressure, social restrictions, and economic demands arising from taking care for a patient" (Boydell et al., 2014; Gülseren et al., 2010; Gutierrez-Maldonado et al., 2005). The degree of the impact of severe emotional and behavioral disturbances in patients with psychosis on all family members is closely linked with the stage of the disease. While confusion and worry predominate in the family members of a patient with first episode psychosis, physical and emotional weariness may prevail with chronic patients. Family members may also experience anger, embarrassment, guilt, fear of being stigmatized, sorrow, or panic at the initial stage of psychosis (Boydell et al., 2014; McCann, Lubman, & Clark, 2011; Mótamedi et al., 2014; Teschinsky, 2000). It has also been stated that due to the absence of guidance or education, it is not a surprise to observe such feelings among family members, and that feelings such as despair or helplessness are common as a result of these emotions. Such feelings of despair may undermine the coping abilities, increase social isolation, and cause mild to moderate depression (Arslantaş & Adana, 2012; Askey, Gamble, & Gray, 2007). Furthermore, high levels of distress have been reported to represent an important factor in higher levels of perceived burden (McCleery, Addington, & Addington, 2007).

Long-standing disease may also result in a diminution in the level of care and attention provided by the family members, and the patient may be left in a relative state of isolation. The initial high level of care and attention early after the diagnosis may, in time, be replaced by the feelings of anger or loss, and chronic psychological distress may prevail in interfamilial relationships. Particularly, aggressive behavior associated

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with disease symptoms and the responsibilities of caregiving result in an intense emotional burden (Atagün et al., 2011; McCann et al., 2011). It has been found that negative emotions such as anger and fury are experienced more frequently during chronic caregiving process (Gülseren et al., 2010). On the other hand, more intense occurrence of emotions such as despair, anger, and inhibition is reported in certain families during the early stages of the disease, with a gradual decline in their intensity within 5–10 years. This stage has been referred to as the stage of "gaining awareness regarding the chronic nature of the condition." As family members become more aware of the chronicity of the condition, parents reevaluate their expectations and desires (McCann et al., 2011).

This multi-faceted problem experienced by the patient requires more active involvement of the family members in the therapeutic process as well as a multidimensional approach (Gümüş, 2006; Sın, Moone, & Newell, 2007). Although there are important studies conducted on the burden of caregivers of patients with the first episode schizophrenia in the world, in Turkey, there are a limited number of studies conducted on this issue (Atagün et al., 2011; Boydell et al., 2014; Corrigan, 2013; Gülseren et al., 2010; McCann et al., 2011; Mótamedi et al., 2014). The level of support provided to the family members of patients with psychosis has been reported to be inadequate, due to the insufficient number of rehabilitation facilities and the absence of sustainable programs in Turkey (Gümüş, 2006; Duman, Aştı, Üçok, & Kuşcu, 2007). Planning, implementing, and assessing the appropriate interventions by the nurses and determining the level of burden imposed upon the families in different stages of the disease bear great clinical significance, since ascertaining the level of burden among caregivers of patients with first episode psychosis or caregivers of those with chronic psychosis, who are likely to experience different levels of burden, will guide in planning the services to be provided.

The objective of the study was to compare the burden of care among caregivers of patients with first episode psychosis or chronic psychosis.

Research Questions:

- Q1. Is there a significant difference between time dependence burden subscale scores of CBI among caregivers of patients with first episode psychosis or chronic psychosis?
- Q2. Is there a significant difference between development burden subscale scores of CBI among caregivers of patients with first episode psychosis or chronic psychosis?
- Q3. Is there a significant difference between physical burden subscale scores of CBI among caregivers of patients with first episode psychosis or chronic psychosis?
- Q4. Is there a significant difference between social burden subscale scores of CBI among caregivers of patients with first episode psychosis or chronic psychosis?
- Q5. Is there a significant difference between emotional burden subscale scores of CBI among caregivers of patients with first episode psychosis or chronic psychosis?

1. MATERIALS AND METHODS

1.1. Study Design, Settings, and Participants

The present study is a descriptive study. The study sample consisted of the consenting caregivers of patients with first episode psychosis ($n = 39$) and chronic psychosis ($n = 40$) who were followed up at the psychiatric outpatient unit of a university hospital, psychiatric outpatient center of a training and research hospital, and the outpatient unit of a mental diseases hospital between April 2012 and September 2012. The study included the caregivers of outpatients assessed by a psychiatrist according to the DSM-IV diagnostic criteria. The tools used in the study were filled out by caregivers in the interview room of the outpatient unit by using the self-report technique. Inclusion criteria were as follows:

1. For patients with "first episode psychosis": being responsible for the care of a patient who already had his/her first episode, has a disease history of less than 2 years, and was diagnosed with schizophrenia or another psychotic disorder based on DSV-IV criteria (schizophreniform disorder, short psychotic disorder, delusional disorder, psychotic disorder not otherwise specified).
2. For patients with "chronic psychosis": being responsible for the care of a patient with a diagnosis of schizophrenia according to the DSM-IV criteria and a disease history of more than 2 years.
3. Age ≥18 and being primarily responsible for the care of the patient.
4. Residing in the same house or spending at least a 4-hour time period with the patient on a daily basis and having adequate literacy to read and complete the forms.

The reason why the inclusion criteria of the two groups in the study were different in terms of diagnosis is that it is difficult to establish a definitive diagnosis during the early and unclear phase of a psychotic disorder. Diagnosis of schizophrenia requires a process. The antecedent period of schizophrenia may vary from several days to several years. The initial diagnosis of 25% of patients is revised approximately within 6 months, and the diagnosis of some patients is still unclear even after 6 months (Türkbay, 2009). Therefore, the diagnosis of patients with first episode psychosis was largely diversified.

The patients were comparable in terms of gender, education, and marital status, and there were no significant differences between caregivers in terms of gender, education, degree of relationship to the patient, and employment status (Tables 1 and 2).

1.2. Instruments

The data form for descriptive characteristics of patients with psychosis or caregivers collected information on the age, gender, marital status, education level, employment status, duration of disease, and number of admissions for the patient group and on the age, gender, educational and employment status, relationship to the patient, socioeconomic level, duration of the provision of care, and daily hours of caregiving.

1.2.1. Caregiver Burden Inventory (CBI)

Caregiver Burden Inventory has been used to assess the level of burden imposed on the caregiver for study purposes. Caregiver Burden Inventory was originally developed by Novak and Guest from Canada to assess the burden experienced by the caregivers (Novak & Guest, 1989). Caregiver Burden Inventory assesses the five subscales for burden: time dependence burden measures caregiver burden due to restrictions on time; developmental burden measures the caregiver's perception of the impact of caregiving on his/her social life, family relationships, and time management; physical burden measures the negative health effects of tiredness and sleep difficulties on the caregiver; social burden measures the "role conflicts" that may be experienced in relationships with others (e.g., the spouse) or the restrictions in other roles (e.g., at workplace) as a result of the caregiving, the caregivers may feel themselves detached from other people or the efforts of caregiving may not be welcomed by the patient, and caregivers may experience conflicts with other individuals in other areas such as treatment plans etc.; and emotional burden reflects the negative feelings of the caregiver against the patient that are aroused by unusual or irritating behaviors of the patient (McCleery et al., 2007). For each subscale, a score between 0 and 20 is given and the total score for each individual may range between 0 and 100. Higher scores indicate higher levels of burden, with no cut-off points. The validity and reliability studies of CBI for Turkish populations have been carried out by Küçükgüçlü, Esen, and Yener (2009). The Cronbach alpha value obtained for the complete inventory is 0.94 (Küçükgüçlü et al., 2009). Caregiver Burden Inventory was used to assess the burden of care in caregivers of patients with first episode psychosis, and it was shown to be a reliable and valid tool for assessing the caregiver burden in this group of patients. Again, the Cronbach alpha value for the complete inventory is 0.94 (McCleery et al., 2007). In this study, the Cronbach alpha value for the overall CBI was 0.88.

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