Abstract

Objective: The aim of the present study was to determine the knowledge and opinions of schizophrenic patients’ relatives regarding the disorder, its causes, treatment methods, and treatment outcomes, as well as to determine the variables that affected their knowledge and opinions.

Method: Data were collected by contacting 332 family members living with schizophrenia outpatients that were treated in 2 different healthcare institutions. A questionnaire form was administered to collect data from the family members regarding demographic features, patients’ clinical features, and family members’ knowledge of the diagnostics of schizophrenia. The questionnaire also contained 22 statements regarding the etiology, treatment methods, and treatment outcomes of schizophrenia. The data were compared in relation to the demographic features of the relatives and the clinical features of the patients.

Results: Most of the family members (62%) referred to the disorder as schizophrenia or psychosis, and 17.5% did not know the name of the disorder. Family members thought schizophrenia was a brain disorder (87.7%), a psychological disorder (95.9%), or a personality disorder (67.5%). All participants agreed with the statement, “medical treatment must be followed”. Magical attributions were believed to be involved in the disorder’s onset and its treatment by 27.7% of the participants; this belief was correlated with level of education. Duration of the disorder, number of hospitalizations, existence of another psychotic patient in the family, level of education of the family members, and gender were significant predictors for their opinions.

Conclusion: Clinical features of the patients and demographic features of the family members have a significant effect on the family members’ knowledge and opinions. Outcomes of the present study could be used in the development of psychoeducational programs.

Key Words: Schizophrenia, relatives, family members, knowledge, opinions.

INTRODUCTION

Emotional, behavioral, social, and financial problems experienced by schizophrenic patients may have significant effects on the family members living with them. Families of schizophrenic patients may have to endure a lifetime of hardship, along with the patient (Magliona et al., 1998). Furthermore, it was suggested that the needs of schizophrenic patients and their families (regarding treatment, care, and support of the patient) are not adequately met (Drapalski et al., 2008). Moreover, most family members feel alone in dealing with the burden caused by the patient’s condition (Magliona et al., 2001).

Living with a schizophrenic patient over a long period of time may impact family members’ opinions and beliefs about the disorder and its outcome. It has been known that families obtain information regarding schizophrenia through their first-hand experiences, rather than
from healthcare personnel or institutions (Gasque-Carter and Mary, 1999). In particular, the schizophrenia-related opinions and beliefs held by the family members that take care of the patient are among the factors impacting their behaviors, and thus the course of the disorder (Ran et al., 2003). For example, family members may become frustrated with the patient’s lethargy and inactivity, attributing them to patient laziness; however, if they knew that these symptoms were not due to laziness, but were symptoms of the disorder, they would tolerate such behaviors (Cozolino et al., 1988), which could decrease the patient’s perception of stress. The burden experienced by families that mistakenly think that their behaviors are responsible for the condition of the patient could be minimized by learning the facts about the disorder (Barrowclough et al., 1996). As such, it is vital that schizophrenic patients’ family members know the causes, treatment methods, course, and results of the disorder, because they are among the factors that may affect their help-seeking patterns and their approach to the disorder, as well as to the patient. It is well known that family education and family therapy have significant impacts on increasing family members’ level of knowledge and help-seeking behavior, as well as improving the functional outcome of the disorder (Hogarty et al., 1991; Merinder et al., 1999; Phillips et al., 2000; Ran et al., 2003; Lincoln et al., 2007).

Knowledge and opinions held by schizophrenic patients’ family members or care-givers vary by country, even between regions within a country, because of the differences in cultural practices and/or differences in healthcare systems and services (Angermeyer and Matschinger, 1996; Magliona et al., 2001; Holzinger et al., 2003; Sağduyu et al., 2003). For example, West German family members believe in-family disputes are the main cause of schizophrenia, but in East Germany they believe the main cause is social factors (Holzinger et al., 2003). In a study carried out in Germany by Angermeyer and Matschinger (1996), family members were reported to think that biological factors are the main cause of schizophrenia, but the general public thinks that stress-related psychological problems are the main cause of the disorder. The authors attributed this difference in beliefs between family members and the general public to the fact that family members usually have the opportunity to obtain factual knowledge by conferring with experts. Furthermore, family members’ beliefs regarding biological factors as the cause of the disorder were interpreted as their way of coping with the burden of self-blame. Kulhara et al. (2000) observed that most schizophrenia patients in India used magical/religious treatment methods based on their beliefs. Esterberg (2006) observed that African-American family members believe that along with biological factors, personality, family, and social factors are the causes of the disorder.

Determination of patients’ and family members’ knowledge and beliefs regarding schizophrenia is critical to the creation of training materials designed for their benefit (Magliona et al., 2001). Similar studies conducted in Turkey have involved relatively fewer family members (Karanci, 1995; Sağduyu et al., 2003). The present study aimed to investigate a large number of family members’ or caregivers’ knowledge and opinions regarding schizophrenia and its outcome.

METHODS

Sampling

The study was conducted at the Bakirköy State Hospital of Mental and Neurologic Diseases, and the Psychiatry Clinic of Kocaeli University, Medical Faculty over the course of 11 months. Schizophrenic outpatients’ (diagnosed according to DSM-IV, 1994) caregivers or family members were included in the study, and were interviewed individually in a hospital room. Informed consent was obtained from each participant. Inclusion criteria were age ≥ 18 years, literacy, and absence of any language problem. The study included 251 family members of patients from the Bakirköy State Hospital of Mental and Neurologic Diseases, and 81 family members of patients from the Psychiatry Clinic of the Kocaeli University, Medical Faculty. One family member per patient was interviewed.

Data collection instruments

A survey form designed to collect family demographic data (sex, relationship to the patient, age, and level of education) and data regarding the history of the patient (duration of illness, number of hospitalizations, existence of a similar disorder in other family members) was used. Data regarding the existence of a similar disorder in other family members was gathered via such questions as, “in your family or among your relatives, is there a person with a similar disorder?; are any family members taking similar medications?; has any other family member been to a doctor or hospitalized due to similar reasons, and if so, do you know his/her diagnosis?” We also used an illness data sheet (22 true/false statements), which was created based on the related literature (Barrowclough et al., 1987; Angermeyer and Matschinger, 1996; Magliona et al., 1999; Yang et al., 1999) and our
clinical experience. Interviews were conducted by ÖÇ, RB, and RE in a private hospital room. The interviewers provided additional information regarding the questions when the participants needed clarification.

Analysis

The participants’ answers (true/false) to the items on the illness data sheet were calculated as percentages. The family members’ demographic data were investigated in relation to the duration of the disorder and the number of hospitalizations using correlation analysis. The Mann-Whitney U-test was used to analyze the participants’ responses to the items on the illness data sheet in order to compare the true/false answers with the numeric variables. Similarly, the chi-square test was used to compare the true/false groups with the categorical variables, such as gender of the participant or the existence of another family member with a similar history. In order to determine the predictors of the participants’ perspectives, the variables determined to be significant, based on paired comparisons, were further analyzed using multiple logistic regression analysis (the forward logistic regression technique). P values < 0.05 were considered statistically significant.

FINDINGS

Family members

All 332 volunteer participants completed all the study procedures. The participants’ demographic data are presented in Table 1.

<table>
<thead>
<tr>
<th>TABLE 1. Demographic characteristics of the participants.</th>
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<td>Child</td>
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<td>Relative/Caregiver</td>
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<td>Another psychotic patient in the family*</td>
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<tr>
<td>Age**</td>
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<td>Education**</td>
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</table>

*Existence of another psychotic patient (schizophrenia, schizophreniaform disorder, schizoaffective disorder, or delusional disorder) in the family.

**A moderately negative correlation was observed between age and education level of the family members (r = -0.353, P = 0.001).

Patient data

Mean duration of the disorder (from onset of the disorder to interview) was 11.5 ± 8.3 years (range: 1-40 years; median: 9 years) and the mean number of hospitalizations was 4.3 ± 6 (range: 0-40; median: 3). A moderately positive correlation between duration of the disorder and the number of hospitalizations was observed (r = 0.449, P = 0.001).

Knowledge regarding the name of the disorder

Most of the participants (62%) referred to the patients’ disorder as schizophrenia (51.2%) or psychosis (10.8%). The remainder referred to it as a neurological disorder (9.5%), psychological disorder (6.9%), mental disorder (2.1%), or depression (2.1%). The name of the disorder was not known by 17.5% of the participants (Table 2).

<table>
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<th>TABLE 2. Participants’ knowledge regarding the name of the disorder.</th>
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<td>Name of the disorder</td>
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<td>Mental disorder</td>
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<td>Depression</td>
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<td>Not known</td>
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Knowledge regarding the disorder

The participants’ responses to the items on the illness data sheet are presented in Table 3.

Some of the variables were significantly associated with their responses, as follows:

1. The belief that the disorder is a brain disorder was associated with younger age (z = -2.084, P = 0.037) and the existence of another psychotic patient in the family (χ² = 6.375, P = 0.012).

2. The belief that the disorder is a personality disorder was associated with older age (z = -3.033, P = 0.002), longer duration of the disorder (z = -2.270, P = 0.023), and the existence of another psychotic patient in the family (χ² = 12.548, P < 0.0005).

3. The opinion that schizophrenia is caused by demons and devils was associated with lower level of education (z = -6.478, P < 0.0005) and a higher number of hospitalizations (z = -2.951, P = 0.003).

4. The opinion that genetic inheritance plays a role
in the disease was associated with the existence of another psychotic patient in the family ($\chi^2 = 46.978, P < 0.0005$) and female gender ($\chi^2 = 13.828, P < 0.0005$). The rate of the existence of another patient in the family was higher among female participants (44.6%) than male participants (25.7%).

5. The belief that domestic disputes can cause the disorder was associated with female gender ($\chi^2 = 9.090, P = 0.003$).

6. The belief that the disorder is divine punishment was associated with older age ($z = –3.341, P = 0.001$), lower level of education ($z = –9.129, P < 0.0005$), and a higher number of hospitalizations ($z = –5.133, P < 0.0005$).

7. The belief that schizophrenic patients are more prone than other people to commit crime was associated with the existence of another psychotic patient in the family ($\chi^2 = 46.978, P < 0.0005$), older age ($z = –2.322, P = 0.020$), lower level of education ($z = –3.272, P = 0.001$), longer duration of disorder ($z = –2.866, P = 0.004$), and a higher number of hospitalizations ($z = –5.133, P < 0.0005$).

8. The belief that schizophrenia patients cannot make appropriate decisions on their own was associated with lower level of education ($z = –2.627, P = 0.009$) and a higher number of hospitalizations ($z = –2.355, P = 0.019$).

9. The belief that schizophrenia is an ongoing disorder with relapses and remissions was associated with lower level of education ($z = –2.406, P = 0.016$) and female gender ($\chi^2 = 5.839, P = 0.016$).

10. The belief that schizophrenia can be treated by visiting religious clerics and shrines was associated with lower level of education ($z = –6.297, P < 0.0005$) and a higher number of hospitalizations ($z = –5.133, P < 0.0005$).

11. The belief that the patient must remain on medication long after he/she has recovered was associated with longer duration of the disorder ($z = –4.220, P < 0.0005$) and a higher number of hospitalizations ($z = –3.881, P < 0.0005$).

12. The belief that medications used for schizophrenia can cause infertility was associated with older age ($z = –2.725, P = 0.006$), lower level of education ($z = –7.119, P < 0.0005$), shorter duration of disorder ($z = –1.957, P = 0.045$), a higher number of hospitalization ($z = –2.236, P = 0.025$), and the existence of another psychotic patient in the family ($\chi^2 = 46.978, P < 0.0005$).

13. The belief that medications used for schizophrenia are addictive was associated with older age ($z = –2.322, P = 0.020$), lower level of education ($z = –4.222,
P < 0.0005), and a higher number of hospitalizations (z = –3.129, P = 0.002).

14. The belief that it is acceptable for patients to marry was associated with shorter duration of disorder (z = –3.105, P = 0.002).

15. The belief that employment is beneficial to patients was associated with higher level of education (z = –3.344, P = 0.001), shorter duration of disorder (z = –2.722, P = 0.006), and a lower number of hospitalizations (z = –2.712, P = 0.007).

16. The belief that patients can recover completely and become a normal member of society was associated with higher level of education (z = –2.270, P = 0.023), shorter duration of disorder (z = –2.795, P = 0.005), and a lower number of hospitalizations (z = –3.447, P = 0.001).

The variables that were significantly associated were subjected to multiple comparisons. Results of logistic regression analysis are presented in Table 4.

DISCUSSION

Data regarding the knowledge, beliefs, and perspectives of schizophrenic patients’ family members play an important role in deciding the content of family education programs, which are an important part of schizophrenia treatment. Misinformation can mislead the families of schizophrenic patients, and can adversely affect the course of the disorder. It was previously reported that educational activities directed towards patients’ family members transformed their knowledge and beliefs, and thus their attitudes regarding the care they provided to patients (Ran et al., 2003). The present study investigated the level of knowledge of schizophrenic patients’ family members regarding the disorder and yielded some important results.

The name of the disorder

About 50% of the participants referred to the disorder as schizophrenia, but about 17% did not know its name. Normally, family members are supposed to receive schizophrenia-related information from healthcare providers. Individuals providing care to the patient are expected to have inquired about the condition. Based on our clinical experience, we know that patients’ family members usually inquire about the disorder in an effort to increase their understanding of it; therefore, the question arises—do family members that take care of the patient not know the name of the disorder, or are they in denial. Answers to these questions are not within the scope of the present study. After being diagnosed with schizophrenia, people usually seek a second opinion in the hope that they were misdiagnosed; therefore, the rea-
son why some of the participants did not know the name of the disorder is unclear; was it due to a lack of knowledge or denial? Further studies are needed to explore family members’ denial of the disorder and the internal mechanisms involved.

**Nature of the disorder and causes**

Even though some participants did not know the name of the disorder, most of the participants provided correct answers to the questions regarding its nature. Ninety percent of the participants thought that schizophrenia is both a biological and psychological disorder, which shows that they did not experience a dilemma (brain vs. psychological disorder). This idea is also supported by their belief that medicinal treatment must be provided. Sağduyu et al. (2003) interviewed 98 family members of schizophrenic patients and reported that they defined schizophrenia as a state of extreme sadness (48%) or a state of psychological weakness (81.6%), and 76.5% believed that schizophrenia is a mental disorder.

The belief that schizophrenia is a brain disorder was greatly affected by the existence of another psychotic patient in the family \[\text{Exp}(\beta) = 3.05\]. Based on this association, it may be inferred that the participants made a connection between the heritability of schizophrenia and that is a brain disorder. In all, 54% of the participants believed that it is a hereditary condition. All of the participants that had another psychotic patient in the family were in this group. We think that the existence of another psychotic patient in the family may have influenced their belief that it is a hereditary condition \[\text{Exp}(\beta) = 5.34\]. Similarly, a study conducted in India reported that all 254 participants who cited genetics among the causes of schizophrenia had a positive family history (Srinivasan and Thara, 2001).

Domestic disputes (64%) and environmental factors (76%), which may be cited among the psychosocial factors in the etiology of the disorder, were largely selected by the participants. These rates are similar to what were reported by Sağduyu et al. (70.4%) (2003). We observed a significant correlation between the belief that domestic disputes are the cause of schizophrenia and being female. Furthermore, the female study participants significantly agreed with the statement, “it is an ongoing disorder with relapses and remissions”. This result may be explained by the notion that female family members might spend more time with the patient, as compared to male family members; therefore, they witness relapses caused by domestic disputes. Additionally, they may be better observers than males. Nonetheless, these inferences require further investigation. In another study conducted in Turkey stress (50%) and intra-familial conflicts (40%) were cited among the causes of the disorder (Karanci, 1995). In a study carried out in Italy involving 709 family members, 70% of the participants thought that psychosocial factors, such as stress, psychological trauma, and failed romantic relationships, are the causes of the disorder (Magliona et al., 2001). A Chinese study involving 245 family members of schizophrenic patients with a mean duration of illness of 2.5 years reported that 84% of the participants thought psychosocial factors (stress, personality problems, and relationship problems) were responsible for the disorder (Phillips et al., 2000).

**Magical aspects**

Twenty-eight percent of the participants in the present study thought that paranormal powers, such as demons and devils, might cause the disorder. In all, 36% of the participants thought that the disorder is divine punishment. Moreover, 21% of the participants thought that traditional solutions (visiting religious clerics and/or shrines) might be used to treat the disorder. Not surprisingly, all of these results correlated with lower level of education. Similar correlations between lower level of education and thinking that supernatural powers are both the cause as well as the treatment of the disorder were reported from China (Phillips et al., 2000), India (Srinivasan and Thara, 2001), Nigeria (Ohaeri and Fido, 2001), and Bali (Kurihara et al., 2006). Supernatural powers were thought to be the primary cause of the disorder by 67% of the participants in Nigeria and 64% of the participants in Bali. In a study carried out in India 12% of the participants thought that supernatural powers were responsible for the disorder; however, in another study carried out in China only 12% attributed the cause of the disorder to supernatural powers, which was reported to be due to the low number of rural family members in the study group. The reason why most people in underdeveloped countries think supernatural powers cause schizophrenia (and the reason why they seek treatment methods accordingly) might also be attributed to insufficient social security systems (Ohaeri and Fido, 2001).

**Personality disorder**

In the present study 68% of the participants thought that schizophrenia is a personality disorder, which was predicted by the existence of another psychotic patient in the family \[\text{Exp}(\beta) = 2.54\]. The common experience
among family members regarding the hereditary nature of schizophrenia might have caused them to think that it is a personality disorder. Considering schizophrenia as a personality disorder has previously been reported. Regarding family members’ belief that schizophrenia is a personality disorder, Angermeyer and Matschinger (1996) and Sağduyu et al. (2003) reported rates (50% and 65.3%, respectively) very close to those observed in the present study.

As well as considering schizophrenia a personality disorder, it is also possible that some consider personality disorder as the cause of schizophrenia. In a study conducted in China it was reported that personality disorder were thought to be the cause of the disorder, which was correlated with higher level of education (Phillips et al., 2000). The authors explained this phenomenon based on the idea that individuals with a higher level of education attribute the disorder to internal mechanisms rather than to external ones. Srinivasan and Thara (2001) reported an association between considering personality disorder as the cause of schizophrenia and duration of the disorder of less than 5 years, which was explained by the authors as the family members’ perception of schizophrenia as an adaptation problem caused by personality. In the present study, the personality variable was not investigated as a causal attribution.

In the present study 69% the participants thought that laziness is an outcome of schizophrenia. Furthermore, 84% of the participants thought that schizophrenic patients can’t make appropriate decisions on their own, which was predicted by lower level of education [Exp(β) = 1.11]; however, factors affecting family members’ beliefs regarding this issue requires additional research.

Recovery

In the present study 62% of the participants thought that schizophrenia is a treatable disorder, but 84% of the participants thought it is an ongoing disorder with relapses and remissions. The belief that schizophrenic patients can fully recover and become a normal member of society was inversely predicted by the number of hospitalizations [Exp(β) = 0.92]; as the number of hospitalizations increased, the number of family members with this belief decreased, perhaps because as the number of hospitalizations increased family members lost hope for recovery. In a study conducted in Italy it was reported that 40% of family members thought that the patient could not improve further (Magliona et al., 2001). In this study participants that thought psychosocial factors were the cause of schizophrenia were more hopeful than those that thought biological factors were the cause. It may be concluded that the biological point of view causes despair. In a study by Sağduyu et al. (2003) 80% of the participants thought schizophrenia is a treatable disorder.

In the present study 81% of the participants thought that the patient must continue to take medication long after he/she has recovered. Living with a patient with a chronic and recurrent disorder may have conditioned the family members regarding the continuous use of medications.

Psychosocial treatment

All family members agreed that medication must be used in the treatment of schizophrenia; however, 97% also thought that psychosocial treatment methods must also be used. Sağduyu et al. (2003) reported that 87.4% of patients’ relatives thought that schizophrenia could be treated with medicine and 72.6% thought that psychotherapy could treat it. Based on these findings, it is reasonable to conclude that in Turkey psychosocial treatment of schizophrenia is an expectation of schizophrenic patients’ family members.

Marriage, employment, and becoming a normal member of society

In the present study 24% of the family members thought that it is acceptable for schizophrenic patients to marry and 76% thought that employment is beneficial to schizophrenic patients. Both marriage [Exp(β) = 0.95] and employment [Exp(β) = 0.96] were inversely predicted by the duration of illness; as duration of the disorder increased, the number of participants that thought marriage was acceptable and employment beneficial decreased. Based on this finding, it can be inferred that family members are more hopeful at the time of disease onset, before they spend a long time with the patient. The number of participants that thought employment was helpful was positively predicted by their level of education [Exp(β) = 1.16] (1/0.86 = 1.16, Table 4). This finding might reflect their higher level of education as well as their satisfaction with their own work life. In order to explore this assumption, further studies are needed.

Although most of the family members thought that patients couldn’t make appropriate decisions on their own (84%), they also thought that schizophrenic patients should work and be a part of the community (91%). This seemingly contradictory result may be a reflection of family members’ optimism towards the pa-
tient’s future. Sağduyu et al. (2003) reported that 69% of participants thought that schizophrenic patients must be a part of the community.

In the present study the number of participants that thought schizophrenic patients can recover and be a normal member of the society decreased as the number of hospitalizations increased \[\text{Exp}(\beta)=0.92\], which may be reflecting the degrading effect of increasing number of hospitalization on their hopeful expectations.

**Tendency to commit crime**

In all, 65% of the present study’s participants thought that schizophrenic patients are more prone than other people to commit crime. Similarly, Sağduyu et al. (2003) reported that 71% of participants thought that schizophrenic patients are aggressive. In the present study the number of participants that thought schizophrenic patients are more prone than other people to commit crime was predicted by the existence of another psychotic patient in the family \[\text{Exp}(\beta)=1.73\], a higher number of hospitalizations \[\text{Exp}(\beta)=1.08\], longer duration of the disorder \[\text{Exp}(\beta)=1.04\], and lower level of education \[\text{Exp}(\beta)=1.08\]. This belief was primarily affected by the belief that schizophrenia is a hereditary disorder, but was also affected by the duration of illness, number of hospitalizations, and lower level of education. In order to explore the issue further, schizophrenic patients and their family members must be evaluated in terms of the mechanisms involved in their aggressiveness and tendency to commit crime.

**Infertility and addiction to medications**

In total, 32% of the present study’s participants thought that schizophrenia medications cause infertility, which was probably due to the sexual side effects of the medications. In all, 58% of the participants thought that schizophrenia medications are addictive. In another study conducted in Turkey a similar finding (67%) was reported (Sağduyu et al. 2003). The fact that some medications (such as biperiden and diazepam) used for the treatment of side effects are addictive and that may have resulted in this idea. The need for long-term use of these medications and the higher risk of relapse in the event of the discontinuance of the medication may have also affected their opinions. The belief that schizophrenia medications cause infertility and are addictive were predicted by lower level of education, which may be indicative of the knowledge acquisition and use skills among the family members with a higher level of education. The belief that schizophrenia medications cause infertility was associated with the duration of illness; as the duration increased the number of participants that thought this decreased, which may mean that the family members learned the facts about the disorder and its treatment.

Issues that may have a direct impact on the treatment of schizophrenia must be addressed in individual sessions, as well as in all kinds of educational programs used in the treatment of schizophrenia.

**CONCLUSION**

The present study reported the beliefs of the family members of long-term (mean duration: 11.5 years) schizophrenic patients. Family members might have spent a long time with the patients and probably conferred with healthcare providers more than the patients did, which may have affected their opinions. In general, duration of illness, the number of hospitalizations, family members’ level of education, the existence of another psychotic patient in the family, and gender affected their opinions about schizophrenia.

The findings of the present study may be helpful to the development of psycho-education and public awareness programs. It should be noted that experts dealing with schizophrenia-related problems have an opportunity to overcome several problems by educating families and caregivers about schizophrenic patients.

**Limitations of the study**

The present study did not include some variables, such as family members’ profession, level of income, place of residence, sociocultural status, amount of time they spent with the patient, and whether or not they received any psychiatric treatment, nor recent level of severity of the condition and patients’ demographic data, which would have impacted the results. Moreover, the data regarding the existence of another psychotic patient in the family were based on self-reports and have very limited reliability. Results of the present study must be considered in light of these limitations.
References


