

The Effect of Family-to-Family Support Programs Provided for Families of Schizophrenic Patients on Information about Illness, Family Burden and Self-Efficacy*



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SUMMARY

Objective: This study was conducted to determine the effects of family-to-family support programs provided for the families of schizophrenic patients on the need for information about the illness, family burden and self-efficacy

Method: The study was carried out with 34 relatives who have key roles in the lives of 34 outpatients who were diagnosed with schizophrenia under DSM-IV-TR. A volunteering family member was given training about the purpose, contents and planning of the program. The family member who had been trained then extended this training to other family members with the assistance of the psychiatric nurse. The training was done once a week, for a total of 12 sessions. The data were collected using a Disease Information Form (DIF), the Perceived Family Burden Scale (PFBS) and the Self-Efficacy Scale (SES).

Results: There was a significant decrease in the PFBS objective scores (from 11.76 ± 3.89 to 9.82 ± 4.03 , $p=0.000$), subjective scores (from 37.85 ± 14.57 to 32.74 ± 4.39 , $p=0.030$) and total scores (from 49.62 ± 18.25 to 42.56 ± 7.56 , $p=0.005$) and a significant increase in the SESS scores (from 82.65 ± 12.01 to 97.79 ± 7.17 , $p=0.000$). Before training, 58.8% of family members correctly answered that schizophrenia is a brain disease, while 94.1% correctly stated that it must be treated with medication; however, 55.9% of caregivers incorrectly believed in magical attributions relating to the disease. After training, all caregivers were able to answer correctly.

Conclusion: A family-to-family support program was found to be effective in reducing caregivers' need for information, reducing their burden, and increasing their self-efficacy in our country.

Key Words: Schizophrenia, family-to-family support program, families, knowledge of the disease, family burden, self-efficacy

INTRODUCTION

Schizophrenia is a disease that progresses with severe impairments in the individual's thoughts, emotions and behaviors, interpersonal relations, working life, and adaptation to society. The disease also causes heavy strains in the family; it may damage the harmony in the family and disturb the social environment in which the patient lives at various levels. It has become evident that the treatment of schizophrenia cannot be unidirectional; mental as well as social approaches should be taken into consideration (Öztürk and Uluşahin 2011).

Developments in mental health in the last 50 years have made it possible to provide care to individuals with serious mental diseases within their communities. This enables families to assume key roles in patients' lives and shifts the burden of care from hospitals to families and other community-based institutions (Macleod et al. 2011, Liberman 2011). Family members, who are not professionals, represent a significant portion of the health economics in many countries (Macleod et al. 2011), and families usually have to face the unpredictable and weird behaviors of their patients, as well as emotional distresses such as stigmatization, isolation, guilt and loneliness, and oppressing issues such as interfamily conflicts and

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exhaustion in the care process (Chien et al. 2004). Studies have reported that the majority of families had insufficient interaction with team members and insufficient knowledge of the disease. They did not know how to cope with the disease and they could be excessively critical and protective of their patients (Miura et al. 2004, Harrison et al. 1998). With the increasing importance of the role of the family in patient care, various family intervention programs have been developed, such as mental education and family education alongside mental social interventions (Chien et al. 2008). Although studies have reported positive effects of family mental training (Yildirim and Ekinçi 2010, Higgins et al. 2007, Cheng and Chan 2005), many families do not receive continuous service in qualified practice standards. As an alternative to mental training programs, family and peer-based training programs have emerged. The family-to-family training program is one such program that is most widely used as a family training model (Chien and Norman 2009, Dixon et al. 2001).

Due to the insufficiency of institutions dealing with mental health services in providing mental training to the families of patients with serious mental diseases, the National Alliance on Mental Illness (NAMI) introduced peer-managed family training courses (Liberman 2011). This program was developed in 1990 by Joyce Burland and supported by NAMI. In this program, which lasts 12 weeks with 2 to 3-hour sessions per week, a family member who received training provides training to other family members on mental diseases, medicinal therapies and other treatments, recovery, self-care, communication and problem solving skills, and community resources (Dixon et al. 2001).

Family support groups have been reported to be more effective than the traditional mental social interventions used in mental health services. Family interventions involving informative support from peers and practical help among participants are stated to be more effective for families in coping with stress and care problems (Chien et al. 2008). It was reported in a random, controlled study made by Chien and Chan (2004) that the families that participated in family-to-family support groups had improvements in patients' social functioning and use of mental health services and a decrease in the frequency of their hospitalization as compared to both families that received mental training and those in the control group. Another study revealed that there was an improvement in patient and family functioning and a decrease in caregiver burden and length of hospitalization in families that participated in family support groups as compared to those that were in mental training or in control groups (Chien et al. 2006).

Family members experience a perception of burden due to the loss of ability that occurs in their patients (Liberman, 2011). Burden is the negative effect of an individual with mental illness on the family. Objective burden refers to the negative outcomes in family routines and subjective burden refers to the emotional distress experienced by the caregiver (Grandon et al. 2008). It is reported that the burden perceived by caregivers could affect the level of well-being, conjugal relationships, satisfaction from care, relationships with other family

members, and perceived severity of illness (Weimand et al. 2010).

Self-efficacy is the individual's belief as to how successful he/she will be in overcoming the difficult situations that he/she may encounter in the future (Gözüm and Aksayan, 1999). Perception of burden and difficulties of giving care may cause impairment of physical and mental health in caregivers and also reduce the quality of care by negatively affecting the ability to cope (Navidian et al. 2012, Chien et al. 2008).

In effectively coping with the difficulties encountered by families when giving care, it is important that families' knowledge about the disease, family burden and self-efficacy are assessed and appropriate interventions are undertaken. For this reason, this study was carried out to determine the effect of the family-to-family support program administered to the families of schizophrenic patients on the knowledge about the disease, family burden and self-efficacy.

METHOD

This pretest-posttest semi-experimental study was conducted between February and July 2012 with 34 relatives who assumed a key caregiving role in the lives of 34 outpatients who were diagnosed with schizophrenia under the DSM-IV-TR (American Psychiatric Association, 2000) criteria at the Psychiatry Outpatient Clinic of Erzincan State Hospital.

Participants

Initially, 39 family members took part in the study, but the study was carried out with 34 (87.18% participation) family members, as 5 family members could not complete the sessions due to time constraints and lack of interest in the program. The family member who assumed the key caregiving role in the life of the patient was identified through conversations with the patients and their families. The individual who spent the most time with the patient and assumed the care of the patient was accepted as the person who assumed the key caregiver role.

Inclusion/exclusion criteria

Inclusion criteria were having lived for at least one year with their patient who had been diagnosed with schizophrenia under the DSM-IV-TR criteria, being between 18 and 65 years of age and volunteering to take part in the study. Exclusion criteria were having any physical (hearing, speech disorders) or mental (psychotic disorder, mental retardation, etc.) defect.

Collection of data

The pre- and post-tests of the study were collected by AY and RHA, with most of the family members (28 family members, 82.35%) filling them out by themselves in a room suitable for interviews in the outpatient clinic environment. Those who did not want to fill them out by themselves completed the tests during 15 to 20 minute face-to-face interviews; these family members were literate but needed explanations for the

questions they did not understand. During the pretest, 39 family members were administered a descriptive questionnaire, the Disease Information Questionnaire (DIQ), the Perceived Family Burden Scale (PFBS) and the Self-Efficacy Scale (SES). Onemonth after the twelve-session programended, the same DIQ, PFBS and SES that had been administered during the pretest were administered again to the 34 family members who completed the program.

Instruments

The Questionnaire: 8 questions that identified the descriptive characteristics of the family member and the disease-related characteristics of the patient (age, gender, education level, kinship with the patient, duration of the disease, number of hospitalizations, presence of the same or similar illness in the family and relatives, name of the disease).

The Disease Information Questionnaire: 22 questions with true/false choices to assess the knowledge and beliefs of family members about the disease, its causes and consequences (Yıldız et al. 2010).

The Perceived Family Burden Scale: The scale, which questions the burden of the family member in the last one month, was developed by Levene et al. (1996) and was tested for validity and reliability by Arslantaş et al. (2011). In a general evaluation, it assesses what behaviors the patient has at present (objective component) and to what extent such behaviors bother the relatives (subjective component). If a behavior inquired about in a particular question is not present in the patient, that item is given a zero (0). If the behavior questioned is present in the patient, the discomfort of that behavior to the family is rated on a four-point Likert-type scale as not at all (1), a little (2), considerably (3) and a great deal (4); each item is scored between 0 and 4. The total score is obtained by summing these scores (Arslantaş et al. 2011).

The Self-Efficacy Scale: This is a 23-item Likert-type self-assessment scale that was developed by Sherer and Maddux (1982) to assess behaviors and behavioral changes and tested by Gözüml and Aksayan (1999) for validity and reliability. In the scale, the subjects are asked to mark one of the following choices for each item 1-“it does not describe me at all”, 2-“it describes me a little”, 3-“I am indecisive”, 4-“it describes me well” and 5-“it describes me very well”. The score given to each item is taken into account. However, items 2, 4, 5, 6, 7, 10, 11, 12, 14, 16, 17, 18, 20 and 22 are scored reversely. Possible scores range from 23 to 115 (Gözüml and Aksayan, 1999).

Procedure

After completing the pretests, the first author, who is a psychiatric nurse, trained a volunteering family member (a 35-year-old female university graduate) about the purpose, contents and planning of the program, as well as group management, for two hours a day for 3 days. At the end of the training, the competence of the volunteer family member was assessed through a mutual question-answer method. With the assistance of the psychiatric nurse, the trained family member then

gave training to the other family members. Family members were divided into three groups of 11-12 individuals. They met once per week for a two-hour session for a total of 12 sessions over 3 months. The sessions started when the enrollment number of the first group was reached. The psychiatric nurse was more active during the first two sessions of the program.

The program contents included acquaintance and sharing of emotions, mental disorders (causes of mental disorders, general symptoms in mental disorders) and schizophrenia (what kind of disease schizophrenia is, insistent symptoms of the disease, coping with insistent symptoms and alerting signs), sharing of experiences and difficulties encountered, medicines (characteristics of antipsychotic drugs including their benefits and side effects, what needs to be done in case of a side effect, drugs that eliminate side effects), other treatments (Electro Convulsive Therapy), mental social interventions (training on mental social skill in patients, family training), communicational skills (importance and elements of effective communication), effect of the disease on family life, developing problem solving skills (steps for problem solving, points to be considered in communicating with patients and in problem solving), managing care at home, social resources (mental health centers, schizophrenia associations), stigmatization (negative effects of stigmatization on patients and their families, fighting stigma), and evaluation (Yıldız, 2011, Dixon et al. 2001). The topics were presented slowly and briefly in a to-the-point manner using simple and understandable language without a lot of detail; mutual interactions and continuous repetitions were carried out. Before each session, the family member leading the training and the psychiatric nurse exchanged information on the subject matter of the session for approximately two hours. The caregivers were also provided with a booklet covering the contents of the program.

The sessions were held on Fridays (10:00-12:00 and 15:00-17:00) and Saturdays (13:00-15:00) in the multi-purpose training room of Erzincan State Hospital. The caregivers were given reminders before the sessions; they were also given a phone number through which they could reach the psychiatric nurse at any time.

Ethical Considerations

An approval from Erzincan University of Health Sciences the ethics committee, a written permission from the Provincial Health Directorate of Erzincan and informed consents from the families were obtained before commencing the study.

Analyses

In the analysis of data, the descriptive characteristics and responses to DIQ questions are shown in numbers and percent distributions. The pre-training and post-training mean scores of PFBS and SES were compared by a t-test and the significance of the differences in DIQ questions by the McNemar chi-square test. Statistical analyses were carried out using the SPSS package program, version 15.0, and the level of significance was accepted as $p < 0.05$.

RESULTS

Characteristics of the families and patients

79.4% of the caregivers were female and 35.3% of them were siblings; the other characteristics are shown in Table 1. The mean duration of the disease was 11.59 ± 7.89 years and the number of hospitalizations was 3.44 ± 4.92 .

Information on the name of the disease

Before the training program, most of the families (55.9%) knew the name of the disease as schizophrenia, 17.6% of them as neurological disease, 11.8% as mental disease and 5.9% as psychosis, whereas 8.8% did not know the name of the disease.

The effects of the family-to-family support program

After the training, all of the families stated the name of the disease as schizophrenia. The pre-training and post-training responses of the families in DIQ are presented in Table 2. By McNemar analysis, the knowledge of the families about the disease had significantly increased in all questions (Table 2).

A significant decrease was found in the families' post-training PFBS objective (from 11.76 ± 3.89 to 9.82 ± 4.03 , $p=0.000$), subjective (from 37.85 ± 14.57 to 32.74 ± 4.39 , $p=0.030$) and total (from 49.62 ± 18.25 to 42.56 ± 7.56 , $p=0.005$) scores and a significant increase in their SES (from 82.65 ± 12.01 to 97.79 ± 7.17 , $p=0.000$) scores (Table 3).

In other words, there was an increase in the families' knowledge of the disease and their perception of self-efficacy and a decrease in their perception of burden.

DISCUSSION

The increase in the number of family support groups in recent years is a result of the self- and mutual help social movement against prevailing diseases and difficult living conditions and people have begun to be more interested in family health needs (Chien et al. 2008). Families of schizophrenic patients can experience interfamily communication problems, grief, deprivation, anger, shame and a sense of guilt due to reasons such as a lack of knowledge about the disease, difficulties in caregiving and a decrease in the ability to cope (Macleod et al. 2011). It has been reported that positive coping strategies cannot be used by families due to lack of knowledge (Lim and Ahn, 2003), and family needs cannot be met due to patient care; these situations lead to a perception of subjective burden (Chien et al. 2004). In one study, family burden was affected by factors such as inadequate social support, severity of symptoms in the patient and the patient's level of social functioning (Gülseren et al. 2010). Since families' incorrect knowledge about the disease will adversely affect the prognosis of the disease, it is important to determine the views and beliefs

of families about the disease and to provide information in training programs in line with their needs (Yıldız et al. 2010).

Family-based interventions aim at improving the family's competence and functioning, increasing compliance with the treatment and cooperation, and minimizing the dependence on professionals (Tüzer and Göka, 2002). Intercultural controlled family intervention studies support the effectiveness of family interventions based on evidence. It is reported that, as a result of family-to-family training programs, families become more knowledgeable about the causes and treatment of mental diseases, their relatives act more prudently and confidently in coping with the illness, and they become more considerate in their relationships with local mental health services (Liberman 2011). In a study by Lim and Ahn (2003), they found that increased knowledge about the disease in families reduced the caregivers' perception of burden and families also demonstrated help-seeking behaviors such as receiving information and training. They also reported that reduced family burden is associated with a positive attitude of family members towards their patients, increased social support, decreased rate of hospitalization of patients and increased social functioning (Hanzawa et al. 2010).

Psychiatric nurses make important contributions to patient and family outcomes by organizing mental social training and community-based structured family support programs. The results of this study demonstrated that a family-to-family support program was effective in increasing families' knowledge of the name, nature and causes of the disease and relevant medications, as well as their self-efficacy, and in decreasing their perception of burden. Although the fact that this illness can be relieved in the light of today's developments but it will not disappear completely caused a decline in the belief of families in a total recovery from the illness and mixing with the society, it was observed that they developed realistic expectations about the treatment.

In a review of 68 studies conducted by psychiatric nurses with families, it was found that interventions had been made directly by nurses in 18% of the studies and by nurses as members of a multidisciplinary team in 24%. These studies also revealed that there was an increase in knowledge in families that joined family-to-family support groups, as well as a decrease in family burden and an increase in coping ability (Macleod et al. 2011). The family-to-family support program administered by Bademli (2012) in our country had positive results on families' methods of coping with stress and their mental health. In a review of 25 family support programs administered by either families or health professionals to the families of patients with schizophrenia or other psychotic disorders, it was found that these programs had had significant effects on the well-being of both the families and their patients and had led to an increase in the families' knowledge of the disease, their ability to cope and the level of social support, as well as a decrease in their burden and stress (Chien and Norman, 2009). In a systematic meta-analysis of family-to-family support programs administered to the families of schizophrenic patients, there was a decrease in the burden of the family

members who took part in a family-to-family support program, an increase in their social support, family functioning and self-efficacy and a decrease in their need for information (Bademli and ÇetinkayaDuman, 2011).

Through effective strategies, family support groups encourage the “we are all in the same boat” attitude and being a role model in patient care. The program offers an opportunity for caregivers to share their emotions and experiences and to develop empathy and emotional support without any fear or stigmatization. During the program, families focus not only on the difficulties of giving care to their own patients, but also on the thoughts, experiences and lives of other families (Chien et al. 2008). Rather than conceptual information being presented by health professionals, they obtain information in a practical way directly from other families that have experienced the same or similar problems and solved them (Heller et al. 1997, Chien ve ark. 2007); in this way, they have the opportunity to review their lives from a different and new perspective (Chien et al. 2008). In other words, the program gives the possibility to increase self-efficacy by way of developing confidence in the ability to change behavior. In a study conducted by Dixon et al. (2001), the families that joined the family-to-family support group were found to gain significant power in the family, society and service system and their distress and anxiety with respect to their patients decreased when they were assessed upon completion of the program and 6 months after the program (Dixon et al. 2001). Other studies also revealed that there was a decrease in the perceived subjective burden and depression scores of the families that joined a family-to-family support program, a decrease in the frequency and duration of hospitalization of their patients, and an increase in strengthening and self-care, self-efficacy, knowledge of mental diseases and the level of comprehension of the mental health system, as well as in family functioning and the number of individuals in the family giving support (Chien 2008, Chien et al. 2008, Dixon et al. 2004, Solomon et al. 1994).

Since family is the most important natural source from which positive contributions can be obtained in coping with the disease, establishing cooperation between the family and treatment staff increases the effectiveness of the treatment (Yıldız, 2011). The modern roles of nursing include protecting, defending, healing, relieving and educating the patient, (Öz, 2010). Psychiatric nurses are a member of the multidisciplinary team that provide mental social services to individuals with mental illnesses (Donegan and Palmer-Erbs, 1998) and they assume a major role in attaining cooperation between the patient, family, social services and health institutions (Fortinash and Holoday-Worret, 1996). The topics of schizophrenia and its treatment, sharing of experiences and difficulties faced, communication skills, development of problem solving skills and management of care at home that are included in the program were seen to be effective in increasing the knowledge of the disease, in creating more efficiency in coping with the difficulties experienced and, through these, in decreasing the perception of burden.

In our study, the families stated after the training program that they could comfortably express their emotions and thoughts without any sense of guilt or shame; they became more sensitive towards the problems and could cope with the difficulties they faced in relation to patient care, the family and various other situations. It is not possible in our country to offer continuous and scheduled mental social training and support programs to the families of patients with schizophrenia. Proliferation of community-based mental health services in our country, including administration of family-to-family support programs, can contribute significantly to increasing quality of life in patients and their families.

Although lack of a control group and a limited sample size had restrictions on the study results, we think that this attempt will light the way for future studies.

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