



Emotions, Ideas and Experiences of Caregivers of Patients With Schizophrenia About "Family to Family Support Program"



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ABSTRACT

"Family to Family Support Program" is a significant intervention program to assist families by informing them about treatment procedures and coping strategies, increasing their functionality, helping them to overcome the challenges of the disease. This study was particularly designed to investigate the emotions, thoughts, and experiences of caregivers of schizophrenia patients who participated in "Family to Family Support Program." The study was conducted with one of the qualitative research methods, phenomenological method. The study sample included caregivers who care for schizophrenia patients and participated in the "Family to Family Support Program". Twenty caregivers were included in the sample. The study was carried out in İzmir Schizophrenia Support Association. The study data were collected with four open ended questions. The average age of the participants was 56.77 ± 72.89 , 10 male caregivers and 10 female caregivers, 9 caregivers were fathers, 6 caregivers were mothers, and 5 of them were siblings. The thematic analysis indicated that the emotions, thoughts and experiences of caregivers can be categorized in four groups: "I learned to deal with my problems", "I am conscious in my interaction with the patient and I know and I am not alone", "I feel much better", and "Schizophrenia is not the end of the road, knowledge sorts things out." Caregivers who participated in "Family to Family Support Program" expressed their satisfaction that they were benefited from the program, their coping skills were improved, they experienced less challenges when providing care, they understood the disease better, and it felt comfortable.

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Chronic mental disorders adversely affect patients and their families alike and they can become a major cause of stress. Patients with schizophrenia often live with their families and therefore they have a significant part in the care and treatment of the patient (Addington, McCleery, & Addington, 2005; Chien, 2008; Li, Lambert, & Lambert, 2007; Saunders, 2003). With an attempt to cope with the challenges resulted from living with the patient, family members openly express their wish to cooperate with the health professionals and actively participate in the treatment procedures. It is recently maintained in relevant studies that family interventions are substantially important in the treatment of schizophrenia, and that these interventions contribute to the well-being of family members, assist them to cope with the disorder, influence their mental balance, and enable the patients' integration into the treatment procedures by improving the cooperation between family members and health professionals (Chien, 2008; Doğan, 2002; Maldonado & Urizar, 2007; Saunders, 1999).

"Family to Family Support Program" (FFSP) was implemented in several studies and it has been reported that caregivers have an increasing awareness toward the causes and the treatment of the disorder and

they are better able to cope with the difficulties. It has also been added that family members have less negative feelings and more social support as well as a reducing level of anxiety toward the condition of the patient (Chien, 2008; Dixon et al., 2004; Schenk, Lippincott, Bennett, & Steigman, 2008; Young, 2001).

FFSP was developed by Joyce Burland in 1990 and it is structured as a social program that provides peer information and support for the parents. FFSP is open to family members, spouses and friends of patients with a chronic mental disorder. When the program was first developed, it was implemented with groups of caregivers whose patients were diagnosed with schizophrenia, bipolar disorder and major depression. The target group was extended later on and more caregivers of the patients diagnosed with panic disorder and obsessive compulsive disorder were included in the program. The program was initially called "Journey of Hope" but it was revised as FFSP in 1997 when National Alliance on Mental Disorders began to promote the program (Baxter, 2001). A similar program to FFSP in the United States is Family to Family Mutual Support Program still in practice in China (Chien & Norman, 2003).

FFSP is a support program through which family members are informed about the mental disorders and encouraged to share their ideas and emotions. The primary objective of the program is to empower the caregiver in self-help and provide emotional support. The second purpose of the program is to prevent the traumatic influence of the chronic mental disorder on the caregiver. The third purpose is to ensure self therapy for the caregiver through self education (Baxter, 2001).

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¹ Interest in families of schizophrenia patients.

FFSP is basically practiced with the caregivers of patients with schizophrenia and it can be considered as an intervention program that informs the family members about the disorder, treatment and coping strategies, increasing the functionality of the family. It also assists family members to cope with the disorder and mitigates the problems that family members have to go through (Dixon et al., 2001). It was also confirmed with the results obtained in these studies in which FFSP was implemented that caregivers attained a better understanding of the causes and the treatment of the mental disorder and they were better able to cope with the challenges they had. It was also concluded that caregivers of the patient with schizophrenia had lower levels of negative feelings and higher levels of social support whereas they reportedly had lower levels of anxiety about the patient's condition (Chien, 2008; Dixon et al., 2004; Schenk et al., 2008).

In Turkish culture, patients with schizophrenia mostly live with their families and care of these patients is provided by family members. In addition, women are generally those who are responsible for health and care of the family in Turkish culture. Providing care to patient with schizophrenia by family members brings along positive contributions such as increase of emotional communication, development of close relationships, receiving social support from other members, and providing personal psychosocial satisfaction as well as numerous problems and difficulties. In Turkish culture, implementation of care-giving task by family members may cause caregivers to experience various difficulties and to receive professional help (Atagün, Balaban, Atagün, Elagöz, & Özpolat, 2011).

To establish a holistic care for the patients with a chronic mental disorder and their families, it is fundamental to consider patients and their families as a whole. FFSP primarily serve to cover the needs of families for information and support. Therefore, the efficacy of the program should also be evaluated with qualitative data derived from the experiences of the caregivers besides the quantitative data obtained in surveys and researches. Although there are plenty of qualitative studies in regard to the experiences of the caregivers of patient with schizophrenia in the scientific literature worldwide, there is a growing need to analyze the ideas, emotions and experiences of the caregivers in Turkey, partly because of the fact that the program has just been initiated with Turkish groups. This study, accordingly, was conducted to investigate the ideas, emotions and experiences of the caregivers of patient with schizophrenia about the program who participated in FFSP.

METHOD

Design

The study was conducted with a qualitative method, phenomenological method, to analyze and study the ideas, emotions, and experiences of the caregivers of patient with schizophrenia who participated in the program (Streubert & Carpenter, 1999). Phenomenological method focuses on cases which we are aware of but do not have a thoroughly and detailed understanding about. For the studies aiming to investigate cases that are not only strange to us completely but also we have not exactly made sense of, phenomenological method constitutes an appropriate research basis. Phenomenology, also called as case science, is a method searching for an answer to the question "What is real?" Individual experiences constitute the basis of phenomenological approach. In this approach, researcher deals with individual experiences of the participant and examines perceptions of the individual and the meanings assigned to events by him/her (Yıldırım, & Şimşek, 2005).

FFSP consists of eight sessions. The purpose of the development and implementation of the FFS program is to create environments where caregivers can interact with and receive emotional support from each other, increase their knowledge about the causes and treatment of mental illnesses, better cope with their difficulties and protect their own mental health. Caregivers in the FFS group were provided with a support program by the caregivers who had previously completed the

"train the trainer" course to maintain the FFS program. The FFS program was completed in 8 weeks with each group participating 2 hours a week on the designated day.

Sample

FFSP consisting of 8 weeks was carried out in the İzmir Schizophrenia Support Association; a total of 20 caregivers participated and completed this program. Therefore, these 20 caregivers who participated and completed FFSP constituted the sample of the study in order to determine their feelings, thoughts and experiences related to the program.

Ethical Concerns

The Board of Ethics at Dokuz Eylül University Nursing School granted the permission to conduct the study. The participants were instructed about the name, purpose, duration and format of the study. The participant caregivers were also reminded that they could leave the study at will. Additionally, the administrative body of İzmir Şizofreni Dayanışma Derneği (İzmir Solidarity Association with the Patients of Schizophrenia) was also informed about the study and legal permissions were obtained.

Data Collection

The study data were collected with a semi-structured interview questionnaire in two parts which was specially designed. The first part included demographic questions about age, sex, educational status, relation to the patient and duration of their responsibility as the caregiver. The second part of the questionnaire involved four open-ended questions where the caregivers were asked to write freely about their emotions, thoughts and experiences of FFSP. Questionnaire contained open ended questions like

1. Can you tell us about the reasons why you have chosen to participate in "Family to Family Support Program"?
2. What has changed in you and your life if you compare before and after you have joined the program?
3. How has your decision to participate in the program influenced your life?
4. What would you recommend to the caregivers of patient with schizophrenia who have not participated in "Family to Family Support Programs"?

The interviews with the caregivers were conducted in the İzmir Solidarity Association with the Patients of Schizophrenia. The caregivers were informed about the study, and their written consent was obtained. The caregivers completed the survey in 20–30 min, though they were allocated more time. The researcher did not have any interference with the answers of caregivers during the interview. The researcher made statements when there were questions which the caregivers did not understand or asked for an explanation. The researcher and an academic member experienced on qualitative research made separate codings regarding data obtained from interview and consistency was examined by comparing the codings. In the assessment, it was observed that there was a perfect consistency between raters and it was decided that coding was reliable. All of the results were given directly without any comment in order to increase the internal reliability of the study. In addition, confirmation of participant was provided by confirming the obtained results and comments with the caregivers participating into study.

Data Analysis

The study data were analyzed as suggested by Colaizzi (1978) (Streubert & Carpenter, 1999). The feedbacks of the caregivers were read by both researchers. The reports were discussed and analyzed in detail until researchers came to an agreement and these reports were

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