

6. Schizophrenia and family

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Summary

Family represents an important supportive social network for most patients with schizophrenia. In order to provide safe and low-stress environment, necessary for the successful long-term treatment of schizophrenia the family must be helped. Family members suffer both emotionally and financially. Their burden is high and quality of life is low. Relatives change their life values and preferences when a severe mental illness occurs in the family and are ready to cooperate. Family interventions constitute an integral part of complex schizophrenia treatment. To be successful interventions must take into account relatives' beliefs, perspectives and issues of concern. The goal of this paper is to 1) overview studies on family burden, 2) provide theoretical background for family interventions, 3) describe a family psychoeducational approach as an optimal treatment modification.

6.1. Introduction

Schizophrenia is a severe mental illness that influences the whole family life. Mental health care re-organization, namely de-institutionalization and emphasis on short hospital stays and community care returns patients with schizophrenia to the community. As a result, relatives of patients with schizophrenia are expected to provide informal care as well as support to their men-

tally ill family members, because the ability to care of themselves, to take care of financial and other personal issues could be compromised in schizophrenia. Also, health care systems count upon relatives as competent persons who can ensure patients' cooperation and prevent expensive hospitalizations (Sales, 2003). It is well known that reaction of relatives to patients' symptoms could influence long-term schizophrenia outcomes and lead to high relapse rates (Barrowclough and Lobban, 2001).

Schizophrenia places an enormous strain on relatives because of its symptoms. Violence against family caregivers by their adult relatives with severe mental illness is a neglected topic as a result of being a taboo area of public discourse and no a subject to scientific research because of fears of further stigmatizing this population. Families of people with schizophrenia experience violence at a rate estimated to be between 10% and 40%, which is considerably higher than the rate of violence experienced by the general population (Solomon et al., 2005). Being exposed to positive, negative and cognitive symptoms could worsen mental as well as somatic health of caregivers (Dyck et al., 1999).

What is the patients' opinion about their family members' involvement in care?

This quite important question is unfortunately not very frequently addressed. Perrault et al. (1999) investigated the preferences of acutely ill patients hospitalized in short-term psychiatric units about the involvement of their relatives in treatment. Majority of patients preferred their relatives to be involved, and 36% of the patients were dissatisfied with the lack of information their relatives received about changes in their treatment. We investigated opinions of patients-participants of family psychoeducation program about involvement of their relatives. Contrary to popular belief, patients welcomed and even required their relatives' participation in the program (Motlova et al, 2006).

Taken together, these facts indicate that comprehensive treatment of schizophrenia should focus both on patients' symptoms and relatives' well-being.

6.2. Schizophrenia, family burden and quality of life of caregivers

Family burden is a multidimensional concept consisting of all the difficulties and challenges experienced by families as a consequence of illness. Objective burden consists of patients' economic dependence, disruption of family routines, behavioral management, time and energy required to negotiate the mental health system, confusing or humiliating interactions with service providers, financial cost of illness, deprivation of needs of other family members, curtailment of social activities, impaired relations with outside world and inability to find satisfactory care settings (Lefley, 1996). Subjective burden is defined as the distress experienced by the caregiver in dealing with the objective stressors described above (Sales, 2003).

Burden is modified by outside circumstances such as patients' symptoms, duration of the illness, frequency of hospitalization, compliance with treatment and level of support provided by health care professionals. Among internal factors that modify burden are individual coping abilities, perceived causes of the illness and expectations from psychiatric services. The relationship between perceived severity and responsibility, attribution of symptoms and levels of caregivers' burden was investigated by Provencher and Mueser (1997). Caregivers who perceived patients as being less responsible for their negative symptom behaviors reported higher levels of objective burden. Severity of positive symptom behaviors was not related to burden. Caregivers who perceive patients as incapable of altering their negative symptom behaviors and of meeting certain role obligations may assume extra responsibilities, leading to higher levels of objective burden. This finding has implications for family psychoeducation program development as it is important to explain the nature of negative schizophrenic symptoms and to teach relatives how to cope with them. The emotional strain imposed on family members with patients who are at an early stage of illness and admitted for the first time was investigated in Sweden (Ostman, 2004). Relatives of patients in acute psychiatric wards, both those admitted for the first time and those re-admitted, were interviewed concerning their experience of family burden and their participation in care. There were relatively few differences found in burden measures and participation in care, however relatives of re-admitted patients experienced more often psychological aspects of burden, equivalent to associated stigma. Moreover, caregiving may be not only burdensome, but actually hazardous to the caregivers' health. Dyck et al (1999) reported an association between amount of burden and number of infectious illnesses experienced by those providing care for a person with schizophrenia and the severity and

type of symptoms exhibited by the patient. More severe negative symptoms were associated with increased caregivers' burden, while increased positive symptoms were associated with more episodes of infectious illness in caregivers (Grant, 1999).

While burden has been studied extensively, little is known about quality of life of relatives. Quality of life (QOL) is a broad-ranging concept that consists of four elements: physical health, psychological state, social relationships and relationship to salient features of the environment (WHOQOL Group, 1998). In a study of 58 relatives we found no significant differences between relatives and controls in the overall QOL score but the quality of life profiles measured by SQUALA (Subjective Quality of Life Scale) were different. The relatives were less satisfied with Mental Well-being and more satisfied with Safety and Money domains as compared to controls. Also, they attached more importance to Hobbies, Beauty and Arts and Self-care, while the controls valued Money and Work more (Motlova et al., 2003). The experience with severe illness in the family probably lead to re-structuring life values and preferences of the relatives.

Not only the aspects of family burden but also interventions designed to reduce it have been assessed. A European study analyzing the burden on the families of patients with schizophrenia found that in all centers relatives experienced higher levels of burden when they had poor coping resources and reduced social support. This finding points to the importance of a social focus that aims to increase the family social network and to reduce stigma. A reduction of burden over time was found among relatives who adopted fewer emotion - focused coping strategies and received more practical support from their social networks (Magliano et al., 1998).

In an experimental group that combined group psychotherapy, lectures, and group discussions, it was found that at the end of the second year, participation in group family programs led to less care burden, better mental and physical health status, and more knowledge about caring for people with schizophrenia (Zhang et al., 1998). Reduced family caregiver burden, however, was not found in multiple-family group participants compared to a standard-care condition over 2 years (Pitschel-Walz et al., 2001). Multiple-family group treatment reduced caregivers' distress but did not increase caregivers' resources relative to standard psychiatric care (Hazel et al., 2004). It should be also pointed out that caregivers reported not only negative impacts but also some beneficial effects of caregiving, such as feelings of gratification, love, and

pride (Veltman et al., 2002). The emerging literature on the positive aspects of caregiving underscores the importance of professional help that is provided to families. Such help is designed to help families improve the challenging situations they face with regard to this disease, and to enable them to identify the rewards of caregiving.

In summary, it seems that it is possible to achieve positive family involvement: relatives are ready to cooperate, they re-structure their life values and preferences to help the patients and patients welcome their participation. In order to ensure relatives' sometimes lifelong support and cooperation specific interventions should be available for them.

6.3. Family interventions: background and theoretical framework

Family involvement in the treatment of schizophrenia is important for both reduction of relatives' burden and for patients' long-term outcomes. As schizophrenia affects the ability to socialize and form new relationships and contacts a psychosocial intervention aimed at improvement of social skills, as well as programs designed to help patients build their social network, is crucial for the well-being of patients. Most patients are in contact with their family members who naturally constitute important social networks. The involvement of close family members is important early in the course of the illness in order to achieve favorable treatment outcomes and minimize the adverse social consequences of schizophrenia. The existence of social support network consisting of patients' relatives and close friends predicts better long-term treatment outcomes (WHO International Study of Schizophrenia, DoSMED, Jablensky et al. 1992, Jablensky, 2000), and family environment and psychosocial factors are important for patients' well-being (Rittsner, 2002). Involvement of relatives influences quality of life of patients (Mubarak, 2003).

Also, participation of relatives in the treatment could modify relapse frequency: when relatives are involved the relapse rate is almost 20% lower (Pitschel-Walz, 2001). This finding has important implications. Even if the cornerstone of relapse prevention is long-term pharmacotherapy with antipsychotic medication (Gilbert et al., 1995; Leucht et al., 2003), relapse is relatively frequent even though patients receive medication: the one-year relapse rate for patients who received oral medication was 42%, compared with 27% for long-acting depot medication (Schooler, 2003).

Different types of family interventions have been proposed:

- Behavioral family management (Falloon et al., 1984)
- Family psychoeducation (Anderson et al., 1980)
- Psychoeducational multifamily groups (McFarlane 2004)
- Individual family psychoeducation supplemented with group psychoeducation for relatives only (Leff, 1989)
- Family consultation (Wynne, 1994)
- Family group education (self-help groups) (Family to Family Program; NAMI, 2003; www.nami.org/family/)

The theoretical framework for most family interventions is based on vulnerability-stress model that was supported by studies on intra-family interactions and atmosphere. According to vulnerability-stress model, certain information-processing deficits, autonomic reactivity anomalies, and social competence and coping limitations are viewed as potential vulnerability factors (Nuechterlein and Dawson, 1984). These problems predispose patients to be vulnerable towards stressors such as discrete life events as well as the prevailing level of social environmental stress which might provoke relapse (Hogarty and Ulrich, 1998). It is hypothesized that family interactions might be stressful for the patient, therefore possibly influence patients' outcomes and could be modified. The interaction of neurocognitive vulnerability and psychosocial stress factors has been confirmed; the combination of patients' working memory deficits and interpersonal criticism jointly predicted psychotic thinking (Rosenfarb et al., 2000).

In order to examine the quality of relationship between patients and their relatives, and the course of psychiatric illness the measure of interpersonal attitudes called Expressed Emotion (EE) was developed. EE is a construct that includes measurement of criticism, hostility, warmth, positive comments, and emotional over-involvement, and is rated from a semi-structured interview known as Camberwell Family Interview (CFI), or Five-Minute Speech Sample (FMSS) (Wearden et al., 2000). The course of the illness was negatively influenced in patients living in stressful environments with relatives exhibiting High Expressed Emotions (HEE): hostility, highly critical comments, and overinvolvement (Leff et al., 1985; Možný and Votýpková, 1992; Kavanagh, 1992; Butzlaff and Hooley 1998). However, all of the above mentioned studies come from Western societies and it is not certain whether the findings can be replicated in other cultural and societal background. For example Japanese/Chinese relatives require more time to reach the point of their criticism and may be more reticent and indirect in criticizing the patient compared

with English relatives reflecting significant differences in terms of communication style that exists between East and West (Nomura et al., 2005). Yang et al. (2004) examined the spontaneous causal attributions made by 54 relatives of schizophrenia patients during the Camberwell Family Interview. Chinese relatives made few controllable and personal attributions overall. Highly critical and/or hostile EE relatives attributed patients' negative behaviors to more controllable and personal factors. High EE and controllable attributions positively predicted relapse, whereas personal attributions unexpectedly protected against relapse. Relatives' use of a particular Chinese characteristic (narrow-mindedness) was integral to the personal dimension's protective effect (Yang et al., 2004). Studies of Mexican American and Anglo-American patients and families indicated that for Mexican Americans, family warmth is a significant protective factor, whereas for Anglo-Americans family criticism is a significant risk factor (Lopez et al., 2004). It is obvious from these findings that in order to provide interventions aimed at creating low-stress environment these cultural differences must be respected.

Results from research on EE in families with schizophrenia was an impetus for research of intra-family interactions in other psychiatric diagnoses. For example, in bipolar disorder high levels of critical, hostile, or emotionally overinvolved attitudes in parents or spouses were associated with high rates of relapse, poor symptomatic outcomes or both (Miklowitz et al., 2000).

6.4. Psychoeducation of the family

Family psychoeducation is one of the most promising relapse preventing psychosocial interventions. It is hypothesized that it can reduce family burden and distress by improving patients' functioning and family coping and by increasing social networking. Family psychoeducation provides a combination of education about mental illness, family support, crisis intervention, and problem-solving-skills training. Mechanism of action is complex. We suggest a model that summarizes the techniques and expected outcomes of family psychoeducation (Figure 9.1.).

The theoretical orientation of this intervention is a broad-based support using a cognitive-behavioral approach. Supportive therapy offers the patient support by an authority figure during a period of illness, turmoil, or temporary de-compensation. It aims to restore and strengthen the patients' defenses and

integrating capacities that have been impaired. Supportive therapy-also called relationship-oriented therapy- uses a number of methods, including:

- warm, friendly strong leadership
- gratification of dependence needs
- help in the development of pleasurable sublimation (e.g. hobbies)
- removal of excessive external strain if possible
- guidance and advice in dealing with current issues, etc.

Delivery of information about the illness and its treatment to both patients and relatives is the cornerstone of psychoeducation. Emphasis is placed on practical, everyday problems with medication adherence.

This focus is important because:

- treatment non-adherence is a significant problem resulting in high relapse rates and
- a significant proportion of patients recognize the difficulties of medication adherence and desire to avoid the adverse consequences of missing their medicine (Irani et al., 2004).

Better treatment adherence as a result of the delivery of information regarding antipsychotic medication to both patients and relatives can be expected. While most patients and relatives appreciate short-term effects of medication resulting in amelioration of positive schizophrenic symptoms, the long-term benefits for cognitive and negative symptoms and prevention of relapse are less obvious to them. Careful explanation is therefore warranted to ensure long-term cooperation. For this purpose the "Iceberg" metaphor could be used: medication targets not only the visible top of the iceberg (positive symptoms) but also its hidden base (the pathophysiological processes); therefore for most patients it is beneficial to stay on medication for years. Being informed about the side effects of antipsychotics does not negatively affect compliance and is essential for establishing patients' confidence in physicians and in the medications (Motlova, 2000). On the other hand it is important to place an emphasis on positive aspects of medication. Mi-A and Sung-Kil (2005) identified medication knowledge, social support and perceived benefits to have significant effects on medication compliance. In a 2-year prospective study of 254 patients recovering from first episode schizophrenia spectrum disorders the likelihood of becoming medication non-adherent for 1 week or longer was greater in subjects whose belief in need for treatment was less or who believed

medications were of low benefit. Beliefs about need for treatment and the benefits of antipsychotic medication may be intervention targets to improve likelihood of long-term medication (Perkins et al, 2006). Another intervention target are early warning signs of relapse. Patients and relatives are taught how to identify them and receive practical advice on what to do after they had recognized them.

While medication knowledge and illness management are intervention targets for both patients and relatives, information about the importance of creating low-stress environment is useful for relatives. Key features of family behavior and attitudes that predict high relapse rate (hostility, critical comments, lack of warmth and over-involvement) are identified and the participants are taught how to implement effective strategies for modifying them. Also, they are instructed how to provide a safe, predictable, stimuli-controlled environment. The expected outcomes in relatives resulting from psychoeducation are lowering of anxiety, self-blaming, expectations and high expressed emotions. Guilt conscience as a result of misconceptions regarding aetiology of the disorder is associated with overprotective and controlling rearing attitudes which are undesirable and therefore should be targeted in family intervention programs. Unrealistic expectations especially of the first episode patients' relatives could increase anxiety in patients. It is possible that the disillusion of relatives with high expectations leads to lower satisfaction and could influence patients' outcomes. The complementary part of this intervention is social-skills-training approach that modifies those patient behaviors that elicit negative feedback from family members (Hogarth and Ulrich,1998) and strengthen patients' capabilities to confront environmental stressors.

Short-term programs usually lead to improvement in knowledge and family burden with limited impact on the severity or course (Merinder et al., 1999; Mueser, 2003). However there are studies that found significant reduction of readmission days in a 4-year follow-up even after a short-term program (Basan et al., 2000), and significant reduction of the rehospitalization rate after 12 and 24 months in patients who attended brief program of 8 psycho-

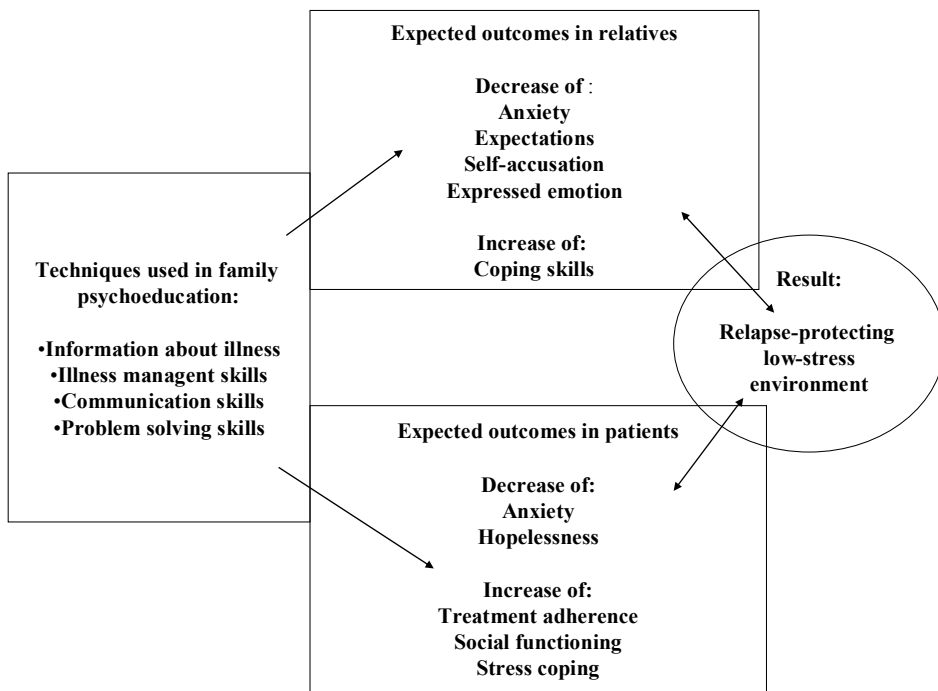


Figure 6.1: Family Psychoeducation: Techniques used in family psychoeducation and expected outcomes in patients, relatives and the family environment.

educational sessions compared with those receiving routine care (Pitscher-Waltz et al., 2006). Longer-term programs (more than 6 months) have a significant effect on reducing relapse rates and rehospitalization over 2 or more years (Dixon et al., 2000, 2001; Ran, 2003) without increasing the overall volume of outpatient mental health services (Dyck et al., 2002).

6.5. Conclusions

Inviting family members for active participation in the treatment of their ill relative has many implications: it is beneficial for the patients' long-term outcomes and reduces relatives' strain and burden. In this context, stress reduction could prevent somatic health complications in relatives. From broader perspective family members' involvement in treatment might have also policy and economic implications. Based on our previous observations, family members seem willing to share their experiences of mental illness with people in their broader social network after the psychoeducational program but

not before the program. When family members share their acquired knowledge with their close social contacts, they can positively influence broader public attitudes towards the mentally ill. Therefore, we suspect that such sharing of experiences increases the potential to create a broader mental-illness-friendly environment and become an important part of successful destigmatization of schizophrenia.

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