

Family and schizophrenia – psychoeducational group in a pilot programme

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Summary

Aim. The paper aims to present the programme, the outcomes and the conclusions of a psychoeducational training series for families with schizophrenia carried out by the Babiński Specialist Hospital in Krakow, Poland. The paper sets out to describe an explorative project based on qualitative study methods. The programme described in the paper adheres to the systemic and narrative approach to therapy.

Methods. The project involved 23 people from 16 families, who attended 14 psychoeducational meetings for 4 months. A variety of methods was applied: lectures, case studies, discussion, interactive workshops, psycho-drawing, multimedia presentations, simulations of crisis situations, training in subgroups.

Results. Upon the completion of the programme, no significant increase in the participants' theoretical knowledge on schizophrenia was observed, which in turn concurred with a decrease in the subjective sense of burden in the family. Even though only 11% of the participants initially expected emotional support from the group, 60% of them identified support as the most important benefit from the programme.

Conclusions. The systemic narrative approach used in the programme has been accepted and assessed well by families of patients with schizophrenia. It seems to provide an effective alternative to traditional psychotherapy. The combination of effective training tools with activities to create a space for participants to exchange their thoughts and experiences has proved to be an effective form of support to families in adversity.

Key words: schizophrenia, family, health education

Introduction

Psychoeducation plays an important role in the multi-modal approach to patients with schizophrenia together with pharmacotherapy, psychotherapy, occupational therapy and cognitive functioning training, [1–3]. As a result of psychoeducational training, members of the family become allies of the therapeutic team and they also learn how to fight their sense of guilt and how to deal with their ill relative; they also undergo problem-solving training and receive crisis support [4, 5]. It is of particular importance to lower negative emotional levels which at times transform into excessive protectiveness towards the patient. As a therapeutic proposition, psychoeducation adheres to the assumption that family can become important partner who lends significant support to the patient in the rehabilitation and the relapse prevention processes [6, 7]. Researchers who described the role of the family environment in the 1970s observed that the strength of expressed emotions (EE indicator) displayed by the close family of the patient proves to have an important effect on the length of remission. Patients living in families with low EE indicator, both, the negative (hostility, critical remarks, emotional overinvolvement) and positive (warmth and positive remarks) had fewer relapses. Clinical research confirm that psychotic patients from families with high EE indicator, have more than twice the baseline recurrence rate of symptoms [8]. The concept of psychoeducation seems to be a natural development of this construct. It seems that the excessive domination of emotions can be restrained by raising awareness and providing practical tools to help the participants to think on their feet when in a crisis [9]. According to research, psychoeducation for families reduces their emotional burden by as much as one third [10]. Decline of emotional burden in caregivers may contribute to reducing the level of expressed emotions in family, which can in turn lower the number and intensity of relapses.

Psychoeducational training for families is adjusted to particular stages of the illness. At the acute stage, it is suggested to relieve emotional strain in the family and to provide information on the illness. At the recovery stage, the family should receive guidance on how to minimise potential relapses in their relative. At the stabilisation stage, all previously mentioned measures are used [5]. Psychoeducation for families with schizophrenia will bring desired results if the following recommendations are used: the rule of partnership, regular meetings, focus on the most crucial problems of the patient and the repetition and the revision of the newly acquired information through homework [6, 7]. The importance of psychoeducation for families with schizophrenia refers to the fact that it gives them valuable cognitive and operative skills to deal with the illness.

The concept of psychoeducation was first described by Carol M. Anderson in the 1980s as a behavioural therapeutic activity which aims to tell the patients about their illness and to provide communication, assertiveness and problem solving training [11]. The positive and restorative effect of psychoeducation has also been identified by psychiatrists treating bipolar patients [12], forensic patients [13] and veterans with PTSD symptoms [14].

Quantitative research on the effects of psychoeducation provided to patients with schizophrenia has shown a significant decline in the number of relapses and

hospital treatments [15], better social functioning and higher satisfaction with health care [16], better knowledge on and insight into the illness and higher self-esteem [13, 17]. Normative research on the effects of psychoeducational groups for families has in turn demonstrated that they lower emotional burden in families of patients [10], improve their sense of self-efficacy [18] and reduce the number of relapses at initial stages of the illness [19]. Psychoeducation for families has been studied in interpretative approach to identify how it promotes knowledge on the illness in families with schizophrenia, how it fosters strategies to support patients with schizophrenia and how it builds social support [7, 10]. Regardless of the approach in psychoeducation for families, it seems that lowering the emotional burden and the expressed emotions level is one of the most important effects, which translates into decline of recurrence ratio.

The effects of various psychoeducational activity models have been tested by a number of projects. These include: Behavioural Family Management [20], Family Psychoeducation Model [21], Relatives Groups [22], Psychoeducational Multi-Family Groups [15, 23,]. Polish studies carried out to evaluate psychoeducational programmes have in turn focused on the ways in which information is provided to families and its restorative effect. The evaluation of families with schizophrenia carried out by Górna et al. [7] demonstrated the importance of psychoeducation for promoting knowledge on the illness, but it also showed that families learnt new skills when confronted with the illness and established new contacts with other families with schizophrenia. A large number of respondents identified higher tranquillity, self-detachment and optimism levels as the major benefit of the programme. The outcomes of the research on psychoeducation combined with pharmacotherapy showed that such a combination reduced the chances of relapse. Popławska et al. indicated that the chance of relapse within 12 months in a group provided with both types of therapy was significantly lower than in a group under exclusive pharmacological treatment [3].

Aim

The paper aims to present the programme, the outcomes and the conclusions of a psychoeducational training series for families with schizophrenia carried out by the Babiński Specialist Hospital in Krakow, Poland. The project adheres to the qualitative approach and is exploratory in character. The process of change in the programme was based on two aspects. The first was to restore natural roles in the family and to relieve members of the family from the role of co-therapists, which puts too much emotional burden on them and often collides with the roles performed by the therapeutic team [24]. The second was to work out ways to externalise the problem [25]. This consisted in the gradual learning of how to differentiate between the symptoms of the illness and the patient's identity, and then to differentiate between problems related to the illness and problems of other origin. This allowed for the identification of both healthy areas and those which were affected by psychosis. The programme adhered to the narrative and systemic approach which resulted in work with family stories and not just on the identity of one of its members [4].

The programme was designed for healthy individuals who were undergoing a crisis brought about by illness in the family and who needed both information and emotional and instrumental support. The aim of the programme was to help the participants to gain a better understanding of schizophrenia and to lower their emotional burden, and, as a far-reaching goal, to lower the expressed emotions indicator in the family. These aims were instrumental in the process of developing the psychoeducational programme, selecting the tools and creating the meeting framework. The materials developed for the programme were to inspire the participants to work on their personal stories and not just to present psychiatric knowledge. Such an organisation of the psychoeducational process was to help the participants to include their knowledge on the illness into their personal mental maps [26].

Material

Study group

23 people from 16 families, including 18 women and 5 men, took part in the programme. While the vast majority of the respondents were parents of a person with schizophrenia, two persons were also their siblings. The mean age of the participants was 48 years (their age varied from 26 to 65 years). 70% of the respondents were secondary school and university graduates.

The programme involved 15 men and 1 woman with schizophrenia aged 19 to 38 years (their mean age was 24 years). The majority of them, i.e. 14 participants, were secondary school graduates (some of them were university students or university drop-outs) while two persons completed professional colleges. The average history of the illness in the family and the resulting treatment ranged from 4 to 5 years and 3 to 4 years, respectively. While all participants with schizophrenia had undergone hospital treatment (usually 2 or 3 times), they had only a partial relapse of symptoms during the programme and received treatment at outpatient clinics.

Method

Psychoeducational programme

The programme involved 14 1.5-hour meetings carried out over the course of 4 months. The entire series was completed by 8 families (13 people).

Prior to their admission to the study group, the candidates went through a qualification process whereby information on the illness in the family, the effect of the illness on its functioning and the illness related problems and requirements was collected. The expectations of the participants from the group and their motivation were also examined. The main criterion for admission was whether the family required such meetings, and their motivation levels served as an additional criterion.

The aim of the programme was to reduce stress and burden levels in families with schizophrenia by providing information on the illness, facilitating the communica-

tion process, lending support and restoring structure in the family whose identity and functioning were significantly reshaped by the illness.

The following teaching methods and techniques were used: lecture, case study, mind map, psychodrawing. The work with case studies created a space for an in-depth analysis of various phenomena which affect the functioning of the patient and his or her family; it also allowed for a better cognitive and emotional understanding of similar processes taking place in the family. At the same time, the method did not disturb the intimate and personal experiences and feelings of the participants, as it allowed them to identify with the situations described in the case study to an extent they themselves felt necessary to feel safe and comfortable with.

The study participants were often encouraged to work on their own and to refer to their own family context. E.g. by drawing a Map of My World [27] (psychodrawing), the participants could examine their social support network (actual and potential), which triggered off their reflection process on social isolation in persons with schizophrenia and their families, and also opened a number of real opportunities for isolation prevention in their own social environment. The study participants created their own “Crisis Plan” in writing in case their relative relapses into illness, which also contributed to the analysis of real and available opportunities for providing support to the family.

The fact that guests from outside of the group were invited was also important. Families could have a Q&A with a professional psychiatrist about the practical side of pharmacotherapy for psychotic patients. Many questions concerning legal, medical and financial issues were also asked, which clearly indicated the need to organise a meeting with a social worker.

Evaluation methods

The programme was evaluated by means of qualitative assessment tools to analyse the dynamics of the group process and by means of quantitative assessment tools including questionnaires completed twice throughout the programme: at the beginning and at the end of the series. The questionnaires were developed specifically for the programme. They covered the following three areas:

- The participants’ needs and expectations versus the degree to which the two were met (16 open-ended questions and 16 close-ended questions);
- The participants’ basic knowledge of schizophrenia and its treatment (35 true/false questions);
- A subjective sense of stress and illness-related burden in individual members of the family (28 close-ended questions designed to verify whether a given symptom was observed in the patient at the time, and if so, how burdensome it was for the respondents).

Since the group was small, only basic statistical methods could be used in the quantitative analysis of the results (mathematical means and percentages).

Results

The assessment of the group work effectiveness based on the dynamics of the therapeutic process

The psychoeducational training series provided by the team can be divided into three stages which led to the formation of the study group and its development.

The first stage was to collect the individual stories of the participants, the circumstances of the incidence of schizophrenia in the family and the participants' expectations and requirements from the programme. It also served to discuss their knowledge on the illness and its aetiology and the way they imagined their roles and their future. It turned out that all participants conditioned their future and their development (including their return to work and their decision to retire) on the recovery of their child and whether he or she took medicines, went to work, set up a family, etc.

The second stage of the programme was to build their clinical knowledge on the illness. The module, which consisted of four consecutive meetings, included lectures, case studies and free discussion. It covered a number of problems, including various concepts of schizophrenia aetiology in the family context (from Frieda Fromm-Reichmann [12] to the systemic concepts proposed by the Milan School) and the expressed emotions indicator. This proved to be stimulating to the emotional atmosphere in the group and opened layers of repressed feelings, mainly anger and guilt.

The third stage, which served to consolidate the group, focused on the individual experience of the illness and the ways to cope with it by the family system. The classes devoted to creating crisis plans and the problem of social exclusion turned out to be a watershed. Each participant received a crisis plan scheme which covered seven points: 1) persons I may contact in a crisis; 2) symptoms of relapse, 3) behaviours that show the patient is doing well; 4) things that help the patient; 5) things that do not help the patient and lead to additional stress; 6) things that are helpful to me and 7) their opposites. Almost all participants indicated a psychiatrist or a psychologist as a person to contact with when in a crisis. However, the majority of them had difficulty indicating someone who they trust and can rely on (even just to speak to) and who does not work in health care. The task to draw the support network of both the patient and the participant not only demonstrated that members of the family had fewer people or institutions supporting them than their ill relative, but it also showed that they themselves often gave up on such a network and only contacted health care to help their ill relative. This was because, as the participants pointed out, they felt distrustful and anxious at the prospect of sharing information of the illness in the family, which in turn was related to their sense of guilt and their fear of social exclusion. It was also observed that it was easier for them to adopt the perspective of the patient than that of one's own. The tasks and their joint analysis allowed the participants to come to the conclusion that not only did they find it difficult to think about themselves as someone in need, but they were more inclined to see themselves as members of the therapeutic team.

The assessment of the group work effectiveness based on questionnaire surveys

The summary of the outcomes focused on the goals that the psychoeducational group for families with schizophrenia was designed to serve [28].

Direct goals

- To provide the family with knowledge and skills to help them to take care of their ill relative

The participants said that by joining the group they could achieve a better ‘understanding of schizophrenia’. Initially, the majority of the participants (81%) considered their knowledge on the illness insufficient and superficial. The comparison of the questionnaires that examined the factual knowledge of the participants in turn demonstrated that the participants learnt more about the illness, but not as much as their facilitators would require (the percentage of correct answers grew from 45% in the pre-test to 46% in the post-test). It is important to mention that the tests verified only theoretical knowledge while a significant proportion of the meetings were devoted to practical knowledge. It is possible that the method to verify the changes was not suited to the object of the study.

- To facilitate the communication process

About 80% of the participants gave a positive opinion on the scope of the subjects proposed and the frequency of the meetings. Most of them (80%) also emphasised the importance of sharing experiences with other families with schizophrenia and the value of speaking out loud about what had previously been kept to their family.

- To build a social support network and to stimulate the family to fight social stigma and isolation

Initially, all participants felt lonely and isolated with their problem, and no one in the group knew other families with schizophrenia while merely 11% initially declared that they needed support. Concurrently, 60% of the participants identified support as the most important benefit from the programme. Thus, it seems justified to claim that families with schizophrenia were not aware of the fact that they had every right to seek and receive support.

- To reduce the emotional burden caused by schizophrenia

The study demonstrated a decline in a subjective sense of burden in the family with schizophrenia. The number of symptoms in the patient which the participants identified as ‘particularly stressful’ dropped from 32% in the pre-test to 16% in the post-test.

Indirect goals

Indirect goals, including reduction of expressed emotions level in family, minimising the risk of relapse, developing skills for life and the ability to cope with problems

caused by the illness in the family and improving rehabilitation efficiency, were achieved to an extent which was noticeable by the therapeutic team (the following estimate was based on feedback provided by the participants several months after the completion of the programme).

The psychoeducational group and the psychiatric hospital structure

In his description of the psychotic process, Franco de Massi refers to its destructive nature which is “like a matrix that confines the patient to a nightmare” and annihilates his or her bonds with other people [29, p. 32]. The restorative ‘anti-matrix’ may be a remedy for the confinement of psychosis. The hospital structure should not only concentrate on the patient and his or her symptoms, but also on the broader social and existential context. This is because the therapeutic effect can be achieved not only by medical or psychological measures, but also through information, education [30], promoting the direct style of conversation with the patient about his or her family and creating a broader network of support that helps to restore the social bonds that have been annihilated by the illness. The psychoeducational formula proposed by our team in this paper opens up a space for the family to express their beliefs, concerns and emotions. Social stigma and isolation affect both the patient and his or her family, which is why both the former and the latter should receive relevant support.

Basic effects of the project

- Family members have learnt how to speak openly about the illness and the illness-related problems they experienced.
- The participants have adopted the roles of both those who need and those who lend support.
- The participants have reflected on their own visions of how to take care of their ill relative and often changed them for more adaptive strategies.
- Family members have gained greater emotional distance towards problems associated with illness, their self-esteem and focus on problem solving have increased, their emotional burden has diminished.

The proposed way to run meetings for families with schizophrenia has turned out to be a good alternative to ‘traditional’ psychoeducation. The combination of effective training tools with activities to create a space for participants to exchange their thoughts and experiences has turned out to be an effective form of support to families in a crisis.

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