

Peer-to-Peer Psychoeducation in Schizophrenia: A New Approach

Christine B. Rummel, M.D.; Wulf-Peter Hansen; Alexandra Helbig;
Gabriele Pitschel-Walz, Ph.D.; and Werner Kissling, M.D.

Objective: To evaluate the feasibility of the first peer-to-peer psychoeducation program in schizophrenia.

Method: We developed a 5-step curriculum for structured training of peer moderators. In step 1, peer moderators participate in regular psychoeducation, and in step 2, they participate in workshops on knowledge about schizophrenia and moderation techniques. In step 3, peer moderators conduct peer-to-peer groups in the presence of a mental health professional, and in step 4, they conduct the groups independently with regular supervision. Further peer moderators are recruited in step 5. Psychoeducation by trained peer moderators comprises 8 60-minute group sessions (warm-up, symptoms, diagnosis, causes, medication, psychosocial therapy, warning signs, coping with schizophrenia) with 6 to 10 patients per group. The feasibility of the 5-step curriculum was evaluated by conducting a pilot study of 7 peer groups with 2 peer moderators. Evaluation of peer-moderated groups was done from January 2003 to July 2004 using inpatients of a university hospital who had schizophrenia or schizoaffective disorder according to ICD-10. The primary outcomes of interest were change in knowledge and concept of illness from baseline to endpoint.

Results: Two peer moderators conducted psychoeducational groups with a total of 49 patients in the presence of a physician (step 3). On the whole, conduction of peer-moderated groups worked well. Knowledge of illness increased significantly ($N = 44$, $p < .001$), and concept of illness changed significantly in 3 subscales: trust in physician ($N = 40$, $p = .002$) and trust in medication ($N = 40$, $p = .001$) increased, and negative treatment expectations decreased ($N = 40$, $p = .001$). Subjective assessments of peer moderators by participating patients were positive.

Conclusion: First results suggest that peer-to-peer psychoeducation in schizophrenia according to the 5-step curriculum is feasible and may be comparable to professional psychoeducation in regard to short-term outcomes.

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Corresponding author and reprints: Christine B. Rummel, M.D., Möhlstrasse 26, 81675 München, Germany (e-mail: christine.rummel@lrz.tum.de).

Rehospitalization rates of patients with schizophrenia on oral antipsychotic medication average 42% within the first year.¹ More than 50% of these rehospitalizations may be attributable to medication noncompliance.^{2,3} Improvement of efficacy and tolerability of new-generation antipsychotics compared to first-generation antipsychotics⁴ has not led to a significant increase of compliance.^{5–10} Therefore, additional strategies for enhancing compliance with currently available antipsychotic medication should be considered. Psychoeducation is just such a strategy. It provides both information about the disease and emotional relief as well as help in coping with the disease.¹¹ There is evidence that rehospitalization rates of psychotic patients receiving psychoeducational or family interventions improve significantly compared to those of patients not receiving such interventions.^{12–14} Hence, education regarding schizophrenia and its treatment was incorporated into several treatment guidelines for schizophrenia.^{15,16}

Still, only 10% to 30% of the patients with schizophrenia are provided with psychoeducational interventions, as a recent survey of psychoeducation in Germany, Austria, and Switzerland showed.¹⁷ According to the responding professionals, the main reasons are lack of manpower and lack of time. On the other hand, as clinical experience suggests, some patients are reluctant to take part in professionally moderated psychoeducational groups.

To improve availability and patients' acceptance of psychoeducation in schizophrenia, it appears reasonable to include other persons in the moderation of psychoeducational groups. A new approach is to train recovered patients who are personally experienced with schizophrenia to become psychoeducational group moderators themselves. This "peer-to-peer" idea has been used in many different medical areas during the last decade, e.g., for human immunodeficiency virus (HIV) prevention, pa-

tients with diabetes, and cancer prevention.^{18–21} This approach has also found its way into psychiatric fields, e.g., with the concept of Alcoholics Anonymous²² and the National Alliance for the Mentally Ill (NAMI),²³ who offer family-to-family and peer-to-peer education programs on general psychiatric disorders, which are taught by trained family members and trained consumers, respectively. Although some of the peer-to-peer concepts described above are widespread, few scientific evaluations of such programs have as yet been made.^{24–26} In addition, peer-to-peer groups specifically designed for patients with schizophrenia and related disorders are still lacking.

Therefore, a psychoeducational “peer-to-peer” training concept using a 5-step model was developed and implemented in order to qualify recovered patients as moderators of psychoeducational groups on schizophrenia. The present article describes the curriculum (5-step model) and presents preliminary results from step 3.

METHOD

Description of Peer-to-Peer Psychoeducation

Training of peer moderators. We developed a 5-step curriculum for the structured training of patients in moderating psychoeducational groups. The future peer moderators are introduced step-by-step, beginning with participation in a psychoeducational group, extending over training workshops and comoderation up to independent moderation of psychoeducational group sessions.

In step 1, future peer moderators take part in a regular psychoeducational group, conducted by mental health professionals. In step 2, 4 half-day training workshops with physicians and psychologists are conducted within a period of about 2 months. The future moderators obtain a general introduction into group moderation and deepen their knowledge of schizophrenia. Training in the moderation of each individual group session proceeds via video-documented role playing. Specific manuals provide additional information and support. After this training, the peer moderators begin moderating psychoeducational groups themselves. In step 3, 2 peer moderators conduct the psychoeducational group program for patients. A physician is present but is involved actively only if requested by the peer moderators. Beginning with step 3, the peer moderators are paid for their work. From step 4 on, 2 trained peer moderators are independently conducting psychoeducational groups with supervision by mental health professionals after completion of the group sessions. Update and repetition workshops take place on a regular basis. Step 5 includes the recruitment of new patients interested in peer moderation, who will then be trained according to the curriculum described above.

Structure of peer-moderated psychoeducational groups. Six to 10 patients take part in a peer-moderated group that convenes twice a week. These groups comprise

8 group sessions, each lasting about 60 minutes. The first group session serves for getting acquainted, evaluating the expectations of the participants, and introducing the program. The other topics are as follows: symptoms of schizophrenia, diagnosis of schizophrenia, causes of schizophrenia, medication effect and side effects, psychosocial therapy, warning signs and contingency plan, dealing with schizophrenia, and the influence of family members and friends.

Pilot-Evaluation Study of the Feasibility of Peer-to-Peer Psychoeducation

Participants in peer-moderated groups. To evaluate the feasibility of peer-to-peer psychoeducation, 7 groups were conducted by 2 peer moderators in the presence of a physician (step 3). Participants in this pilot study had a diagnosis of schizophrenia or schizoaffective disorder according to ICD-10. Participants were included in the peer-to-peer groups as early as clinically reasonable, as judged by the treating physician. As there is evidence that particularly patients with a diagnosis of schizophrenia are generally rather unwilling to join self-help groups as outpatients, we tried to recruit participants while they were still in an inpatient setting.²⁷ Participants of these groups were considered completers and were included in the data analysis if they had taken part in at least 4 group sessions (50% of the group sessions). All participants received standard psychiatric care with naturalistic pharmacologic treatment. Written informed consent and institutional review board approval were not obtained for this feasibility pilot study, as a physician was always present, which was considered comparable to “routine” psychoeducation.

Evaluation

The following scales were used to assess change of knowledge about the illness and concept of the illness from baseline to endpoint: the Knowledge of Illness About Schizophrenia Questionnaire²⁸ and the Disease Concept Scale (KK Scale).²⁹ A feedback questionnaire (modified PEGASUS questionnaire)³⁰ was used for subjective assessments.

The Knowledge of Illness About Schizophrenia Questionnaire was used for data acquisition on the knowledge of illness through testing on the different topics imparted in the group sessions. It comprises 21 questions with 107 single items; the maximum score is 70 points.²⁸

The KK Scale, a validated scale with 29 questions for the assessment of the concept of illness, comprises 7 subscales: trust in medication, trust in treating physician, negative treatment expectations, guilt, chance control, susceptibility, and idiosyncratic assumptions.²⁹

Questions from the PEGASUS questionnaire for the assessment of the capabilities of the peer moderators and of the program (4 multiple-choice questions on knowledge, empathy, pedagogical abilities, practical experience

of the moderators; 2 multiple-choice questions on the assessment of the program) were modified for applicability to the peer moderators.

Statistical Analysis

Descriptive methods were used for statistical analyses of sociodemographic data and feedback by participants. Comparisons of baseline and endpoint assessments of knowledge of illness and concept of illness were made using nonparametric Wilcoxon tests for combined samples. A Bonferroni correction for multiple testing was applied and the initial level of significance ($p < .05$) was adjusted to $p < .006$. All calculations were done with SPSS for Windows, version 11.5.1 (SPSS Inc., Chicago, Ill.).

RESULTS

Description of the Peer Moderators

Two recovered patients were chosen in October 2002 to become peer-to-peer moderators for this pilot study. After attending a regular psychoeducational group moderated by mental health professionals (step 1), the 2 future moderators advanced to step 2 and participated in detailed training workshops. One of the 2 peer moderators was a 42-year-old man who had experience in living with schizoaffective disorder for over 20 years and had become eligible for a pension in the meantime. He began studying economics but did not finish his studies due to the schizoaffective disorder. He had been taking typical antipsychotics and a mood stabilizer for over 15 years and had not been hospitalized during the last 6 years. Earlier, he had been hospitalized several times because of multiple episodes of his schizoaffective disorder. The other moderator was a 41-year-old woman who was diagnosed with schizophrenia 4 years previous and had been currently working in her own practice for physiotherapy. She had been taking atypical antipsychotic medication for 4 years and had not been hospitalized since her first episode. Having taken part in the training workshops, the peer moderators began moderating group sessions for patients with schizophrenia or schizoaffective disorders in the presence of a physician (step 3); this physician attended all peer-moderated group sessions in the 7 groups conducted. The 2 moderators described here were the only ones who began their training during this pilot study; in the meantime, a third patient began training for peer moderation.

Participants in Peer-Moderated Groups

Most participants were recruited while they were inpatients of an open psychiatric ward in a university psychiatric hospital; 4 participants were outpatients, referred by their treating physicians for psychoeducation. All participants were diagnosed with schizophrenia or schizoaffective disorder according to ICD-10. Fifty-eight patients were included in 7 groups of 8 sessions each in this pilot

Table 1. Sociodemographic Data of Participants (N = 49) in Peer-to-Peer Psychoeducation

Characteristic	Value
Gender, N (%)	
Male	25 (51.0)
Female	24 (49.0)
Age, mean (SD), y	33.7 (12.2)
Diagnosis (ICD-10), N (%)	
Schizophrenia	38 (77.6)
Schizoaffective disorder	11 (22.4)
Duration of treatment, mean (SD), y	5.9 (7.3)
No. of hospitalizations, mean (SD)	2.2 (2.9)
Current employment status, N (%)	
Unemployed	20 (40.8)
In training	11 (22.4)
Competitive employment	12 (24.5)
Noncompetitive employment	1 (2.0)
Retired	5 (10.2)
Living situation, N (%)	
Independently	19 (38.8)
With parents/siblings	13 (26.5)
With partner/children	10 (20.4)
With others	1 (2.0)
In rehabilitation institution	6 (12.2)

study lasting from January 2003 to July 2004. Forty-nine patients completed the pilot study; 9 patients failed to attend at least 4 sessions for various reasons (4 patients were discharged, 2 patients were transferred to a locked ward, 3 patients were not interested in further psychoeducation) and were therefore excluded. Sociodemographic data of the completers of the 7 psychoeducational groups (N = 49) are shown in Table 1. Participants were typical of patients treated in our institution in regard to age, duration of illness, employment status, etc. On the average, participants took part in 7 out of 8 group sessions (mean = 6.5; range, 4–8).

Knowledge and Concept of Illness Evaluations

The baseline-to-endpoint evaluation of knowledge of illness and concept of illness is shown in Table 2. There was a significant increase in knowledge of illness after participation in the psychoeducational peer-to-peer program ($p < .001$, $Z = -5.648$). Patients' scores on 3 of the 7 subscales of the KK Scale changed significantly, namely: trust in treating physician ($p = .002$, $Z = -3.165$), trust in medication ($p = .001$, $Z = -3.358$), and negative treatment expectations ($p = .001$, $Z = -3.334$). Patients' scores on the subscales guilt, chance control, susceptibility, and idiosyncratic assumptions did not show any significant changes.

In addition to these objective evaluations, participants were asked for subjective feedback on the abilities of the peer moderators. The vast majority of participants were satisfied with the peer moderators' knowledge, empathy, and pedagogical abilities and with the information given. Ninety-four percent of the participants claimed they would definitely recommend a peer-to-peer group to other patients. Results from subjective assessments (feed-

Table 2. Knowledge of Illness About Schizophrenia Questionnaire^a and Disease Concept Scale (KK Scale) Subscale Scores (N = 49)

Measure	Baseline, Mean (SD)	Endpoint, Mean (SD)	p ^b
Knowledge of Illness About Schizophrenia Questionnaire (N = 44)	46.61 (14.54)	56.73 (10.09)	< .001
KK Scale subscale (N = 40)			
Trust in treating physician	11.33 (2.68)	12.78 (2.55)	.002
Trust in medication	15.25 (3.33)	16.93 (3.43)	.001
Negative treatment expectations	8.40 (4.15)	5.95 (3.77)	.001
Guilt	5.00 (2.42)	4.40 (2.46)	.183
Chance control	8.38 (3.74)	7.55 (4.39)	.272
Susceptibility	7.10 (2.46)	7.25 (2.56)	.387
Idiosyncratic assumptions	6.88 (3.18)	5.65 (3.63)	.013

^aMaximum score on the Knowledge of Illness About Schizophrenia Questionnaire is 70.

^bA Bonferroni correction for multiple testing was applied and the initial level of significance ($p < .05$) was adjusted to $p < .006$.

back of participants) after participation in the program are shown in Table 3 (N = 49).

DISCUSSION

To our knowledge, this is the first description of a peer-to-peer program specifically designed for patients with schizophrenia and related disorders. The aim of this pilot study was to examine the feasibility of peer-to-peer psychoeducation in schizophrenia using a newly developed program. The results suggest that peer-to-peer psychoeducation is feasible and may be comparable to psychoeducation conducted by mental health care professionals. In the peer-to-peer study described, knowledge of illness increased significantly from 67% to 81%; in a professionally led psychoeducational study carried out in our department, which was comparable in terms of content, number of sessions, and participants, knowledge increased significantly from 64% to 76%.³¹ In both studies, trust in medication and trust in the treating physician increased significantly, and negative treatment expectations decreased significantly. Trust in medication and in the treating physician have an important impact on compliance with psychiatric medication.^{32,33}

The results show that the peer moderators have a high credibility among other patients and can serve as role models.³⁴ Because of their own experiences with schizophrenia, peer moderators may help other patients in coping with their schizophrenic disorder. In addition, peer-to-peer moderation may be a new approach for increasing the number of potential moderators of psychoeducational groups; as a recent survey on psychoeducation shows,¹⁷ the great need for more psychoeducation in schizophrenia cannot be fulfilled by mental health professionals alone. Furthermore, peer moderators themselves can be empowered by their function as experts in coping with a chronic

psychiatric disorder. Moderating peer-to-peer groups can even have positive therapeutic outcomes, such as a return to work, enhancing self-esteem, and providing new insight into one's own problems, as other studies have shown.³⁵⁻³⁷ Peer moderators are paid for their work as soon as they begin conducting psychoeducational groups (step 3), which they recognize as an appreciation for their commitment.

Several points should be taken into consideration when training peer moderators. The training according to the 5-step curriculum for psychoeducational peer moderators is similar to that for professional moderators. In clinical settings, professionals are introduced step-by-step into the conduction of psychoeducational groups, namely via participation in a regular group, potential participation in a training workshop, comoderation of a group, and moderation of a psychoeducational group. Supervision of this work during the step-by-step training is necessary to guarantee the high quality of the resultant psychoeducational groups. This is particularly true for peer moderators. The supervisor must ensure that the peer moderator is giving correct information to participants and, in addition, that this peer moderator will not be unduly stressed by psychoeducation. Choosing the "right" remitted patients as peer moderators is essential for this concept. Several characteristics seem to be essential for peer moderators. They should have recovered from an acute episode and should be in a stable state of their illness. Peer moderators should have accepted their diagnosis and should have experience in living with schizophrenia or schizoaffective disorder in order to be able to report these experiences during the group sessions. Peer moderators should have a biological concept of the illness and accept modern treatment recommendations such as antipsychotic medication and psychotherapeutic and psychosocial strategies. In addition, peer moderators must be able to speak in front of a group and should be interested in other people.

In the event of a relapse of one of the peer moderators, the second moderator might bridge this gap and would be assisted by an additional moderator. The 2 peer moderators chosen for this study were able to give structured information about schizophrenia, to answer questions adequately and correctly, and to share experiences with medication, medication side effects, and living with schizophrenia in general. Participants of these peer-moderated groups respected the peer moderators as experts, yet at the same time regarded them as peers.

Obviously there are a number of limitations to this pilot study. A first clear limitation is that only 2 peer moderators were involved in this study. Secondly, data on steps 4 (group moderation by peer moderators alone) and 5 (recruitment of further peer moderators) are not yet available. A physician was always present during the sessions (step 3) and provided assistance if requested by the peer moderators. He may have provided a certain amount

Table 3. Subjective Assessments (feedback from participants) After Participation in Peer-to-Peer Psychoeducation (N = 49)

Feedback	Very Satisfied or Very Important, N (%)	Satisfied or Important, N (%)	Rather Not Satisfied or Rather Not Important, N (%)	Not Satisfied or Not Important, N (%)
Satisfaction with the knowledge of the peer moderators	26 (53)	23 (47)	0 (0)	0 (0)
Satisfaction with the empathy of the peer moderators	19 (39)	30 (61)	0 (0)	0 (0)
Satisfaction with the pedagogical abilities of the peer moderators	22 (45)	26 (53)	1 (2)	0 (0)
Satisfaction with the practical experience of the peer moderators	24 (49)	24 (49)	1 (2)	0 (0)
Importance of the information given by the peer moderators	24 (49)	25 (51)	0 (0)	0 (0)
Importance of learning about experiences of other group members	15 (31)	29 (59)	5 (10)	0 (0)

of authority to the conducting of the groups simply by his physical presence. Thirdly, data on knowledge and concept of illness were not available for all included patients. Some of our included patients were able to participate in the group sessions, but were not able to complete the self-report questionnaires at baseline, mainly due to a lack of concentration or motivation. Missing data is a common problem in most clinical studies, even when questionnaires are completed by physicians or psychologists, and is particularly common in self-report questionnaires completed by patients with schizophrenia or schizoaffective disorder. Fourthly, there is no comparison group that received psychoeducation from a professional. Fifthly, there are no outcome data on rehospitalization rates.

Future studies are needed for the evaluation of steps 4 and 5 of this curriculum and especially its long-term outcomes concerning rehospitalization rates. A randomized controlled clinical trial has been planned in order to compare peer-to-peer psychoeducation with psychoeducation conducted by mental health care professionals.

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