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The effectiveness of peer support groups in psychosis: a randomized controlled trial

Castelein S, Bruggeman R, van Busschbach JT, van der Gaag M, Stant AD, Knegtering H, Wiersma D. The effectiveness of peer support groups in psychosis: a randomized controlled trial.

Objective: To investigate the effect of a (minimally) guided peer support group (GPSG) for people with psychosis on social network, social support, self-efficacy, self-esteem, and quality of life, and to evaluate the intervention and its economic consequences.
Method: In a multi-center randomized controlled trial with 56 patients in the peer support group and 50 patients in the control condition, patients were assessed at baseline and after the last meeting at 8 months.
Results: The experimental group showed GPSG to have a positive effect on social network and social support compared with the control condition. In the experimental condition, high attenders favored over low attenders on increased social support, self-efficacy, and quality of life. Economic evaluation demonstrated groups to be without financial consequences. The GPSG-intervention was positively evaluated.
Conclusion: Peer support groups are a useful intervention for people suffering from psychosis by improving their social network.

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Significant outcomes

- This first randomized controlled trial showed that peer support groups are a useful intervention for people suffering from psychosis by enabling and strengthening mutual relationships.
- Intervention adherence, i.e. group attendance, turned out to be an important condition for its effect.
- Of clinical importance are the development of the guided peer support group-intervention – which seemed to fit well within this patient group – and the lack of financial consequences.

Limitations

- The absence of an attention-placebo control condition is a limitation. The waiting-list control condition may have improved from anticipation-effect.
- The results may not generalize to in-patient or substance-misusing patients as our participants were all clinically stable, non-substance-misusing out-patients.
- Our results are related to the guided peer support group-intervention. The effects of another design (i.e. weekly meetings, open group, peer guided) are on the outcomes are not known.
- The chosen instruments are all self-reporting.

Introduction

Peer support is based on the assumption that people who share similar experiences can offer each other emotional, appraisal, and informational support and hope (1, 2). Peer support groups for many chronic diseases like diabetes, cancer and asthma are well accepted. However, studies on the effectiveness of such groups report conflicting findings and the question as to what conditions peer support works best under await a definitive answer (3).

For mental health care, several studies have established the need for peer support groups for adults with psychosis and have suggested their potential effect on relapse, symptoms, social network, and quality of life (4, 5) This need may be even more pressing given the negative and

restrictive influence of psychotic disorders on one's social life. So far, the effectiveness of peer support groups on, e.g. an individual's social network, social support, self-efficacy, self-esteem, and quality of life has not yet been established in this patient population (2).

In the 1990s, the University Center for Psychiatry in Groningen initiated peer support groups for people with psychosis. A nurse, together with a patient who would take over the guidance as soon as the group process had taken effect, led them. In the absence of initial guidance by a professional, the groups tended to peter out, even though the participants themselves highlighted their importance. This prompted us to create a slight variation on peer support groups with a 'minimally guided' group structure. These groups are in essence consistent with the principles of peer support, but the intervention acknowledges the problems schizophrenia patients encounter when they participate in a group session because of their cognitive and social disabilities (6).

Of note, peer support interventions fall on a wide continuum from those that are member driven, to those that are professionally driven (3). To date, the effects of various designs on the outcomes are not known (3).

Aims of the study

The aim of the study was to investigate the effect of a guided peer support group (GPSG) for people with psychosis on social network, social support, self-efficacy, self-esteem, and quality of life, and to evaluate the intervention and its economic consequences. We hypothesized that the group would have a direct positive effect on the patients' social life adding indirectly to their quality of life.

Material and methods

Design

The study was a randomized controlled trial (RCT) comparing the effects of care as usual plus minimally GPSG with a waiting-list condition (WLC) consisting of usual care alone (ISRCTN: 02457313). The duration of the study was 8 months with assessments conducted at baseline and at the end of the trial.

Subjects

Patients were included if they had a clinical diagnosis (by psychiatrists trained in applying the Schedules for Clinical Assessment in Neuropsychi-

atry according to DSM-IV criteria (7) of schizophrenia or a related psychotic disorder and were 18 years of age or older. Potential participants with drug and/or alcohol dependency known by their psychiatrist were not included at beforehand.

A screening interview was used to detect other exclusion criteria that would have impeded the assessments or could possibly hamper communication with peers, i.e. possible language difficulties and severe psychotic symptoms.

In four mental healthcare centers in the Netherlands, participants were recruited from January through August 2003. In total, 106 participants were randomly allocated per center to the GPSG or WLC condition by a person not involved in the study or recruitment using numbered, sealed envelopes. Patients were randomized by computer-generated random block number to insure an equal balance per center (see Fig. 1). Because of successful recruitment, each center could start a peer support group, one center even two. The design of the study did not allow for masking researchers to service assignment. However, we expect this to interfere only minimally with the study results as all questionnaires used were of the self-report type.

All patients provided written informed consent. The Medical Ethics Committee of the University Medical Center Groningen approved the study (reference number: METC 2003/053).

Treatment condition

The intervention is described in more detail elsewhere (6). Briefly, the closed peer support group included approximately 10 patients and involved 16 sessions of 90 min biweekly over 8 months. Participants decided the topic of each session. Each session had the same structure discussing daily life experiences in pairs as well as group wise.

The key point was to provide peer-to-peer interaction (3). For that reason, nurses needed to guide the groups with minimal involvement. This required training in the intervention and 'the minimal guidance' attitude: offering structure, continuity, and a sense of security without actively interfering with the group process. The nurse had a facilitating role to avoid professionalization of the groups.

Patients in the experimental condition participated in these groups and received care as usual consisting of medication monitoring, psycho-education, and supportive counseling.

Patients in the control condition were put on a waiting list expecting to participate in their peer support group 8 months later. In the meantime,
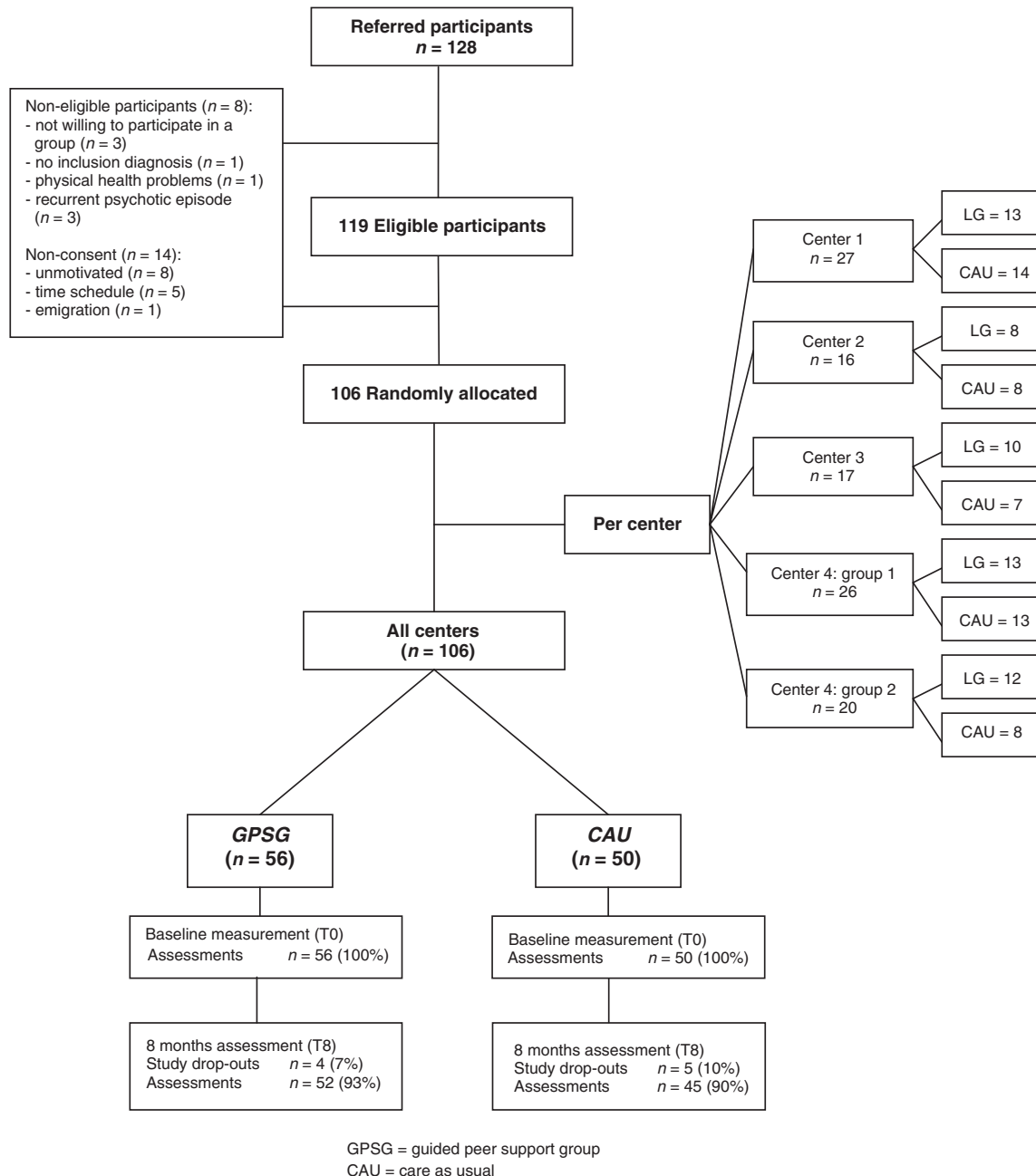
Fig. 1. Trial profile.

they did not follow a prescribed treatment protocol, but received care as usual.

Outcome measures

All outcomes were self-reported, and were measured before the group started and after the last meeting at 8 months. The participants filled out all questionnaires during a separate group session where assistance from an independent professional – blinded to study condition – was available.

Size and content of the social network was assessed by a self-developed list [Personal Network Questionnaire (PNQ)] asking for information on the frequency of contacts with named family, friends, and members of the peer support group.

The Social Support List (SSL) (8, 9) measures not only positive social interactions but also the discrepancies between the support people want and what they actually receive. The SSL consists of six subscales: everyday emotional support, emotional support with problems, esteem support,

instrumental support, social companionship, and informative support. By adding the scores of the subscales, the total score for positive interactions (range, 34–136) and the total score for discrepancies (range, 34–102) are calculated. Higher scores on interaction indicate more support; higher scores on discrepancy indicate a greater deficit in desired support. The interaction dimension has an additional subscale measuring 'negative interactions' on a 7-item subscale (range, 7–32) with higher scores indicating more negative interactions. The score on this subscale is not part of the total score.

Self-efficacy was assessed by the Mental Health Confidence Scale (MHCS) (10) which is a 16-item scale with three factors: optimism, coping, and advocacy. The sum of the items provides the total score, ranging from 16 to 96 with higher scores indicating more empowerment.

Self-esteem was assessed by the Rosenberg scale (11) which has two subscales: positive and negative self-esteem. The total score ranges from 10 to 40: the higher the score, the higher the level of self-esteem.

Quality of life was assessed with the 26-item WHO Quality of Life (WHO QoL) Bref (12) which contains four major domains ranging from 4 to 20 (physical, psychological, social relationships, and environment) and two individual items on 'overall quality of life' and 'general health'. Scores on these two items and four scales create an overall quality of life score (ranging from 18 to 90).

To control outcome data for confounding and mediating effects, we collected information on gender, age, marital state, occupational status and illness characteristics, duration of illness, and frequency of episodes. The severity of psychopathology was assessed by the Community Assessment of Psychic Experiences (CAPE) (13, 14) with the last 2 weeks as the reference period. Although the CAPE is designed for the lifetime assessment of psychotic experiences in a general population, it can also be used as a self-report questionnaire in our population (J. van Os, personal communication, 2003). The nurse collected the adherence data by noting the presence of each participant after each session.

At the end of the study, participants and professionals evaluated the use and appreciation of the group sessions by a self-developed list. In addition, an economic evaluation questionnaire assessed the healthcare costs in euros (€). Costs were prospectively registered for all the patients and included costs related to in-patient and day patient care, outpatient and community care, general health care, visits to day activity centers, and medication use (prescribed and non-prescribed).

Treatment fidelity

A professional specialized in the guidance of peer support groups and the 'minimal guidance' structure trained the guidance nurses, and provided individual supervision by telephone to all nurses after each session. After each supervision, fidelity to the prescribed protocol was rated on a 4-point scale with higher scores indicating better fidelity. Score 1 indicated that the nurse did not follow the protocol; at score 2 the nurse hardly followed the protocol; with score 3 the protocol is followed, but exceptionally deviated from; at score 4 the group is guided in complete accordance with the protocol.

Statistical analysis

Analyses were conducted in line with the CONSORT guidelines with patients analyzed in the condition to which they were randomized irrespective of treatment adherence ('intention to treat').

Supplementary to this, a 'completer analysis' studied *post hoc* the influence of intervention adherence (15). In the literature, there were no prescribed procedures as to how to divide participants in different groups.

In this RCT, we used a cut-off point of nine or more sessions to define good adherence and eight or less sessions to define poor adherence primarily based on the total number of 16 sessions.

The Student's *t*-tests for continuous variables and Pearson chi-squared tests for categorical variables analyzed between-condition baseline characteristics. Mixed model methodology and general linear model analyses (univariate), adjusted for baseline values with treatment condition as a fixed effect, were used in the main analyses of outcome (SSL, MHCS, Rosenberg, and WHO QoL). The Student's *t*-test evaluated differences in proportion positive changes on the PNQ (network) between conditions.

Logistic regressions were calculated to determine whether gender, age, duration of illness, psychotic episodes, severity of psychopathology, peer contact, self-esteem, and treatment location were predictors of positive outcomes on quality of life. Mixed model methodology was used to analyze costs, correcting for baseline differences in costs.

Using spss (version 14; SPSS Inc., Chicago, IL, USA), significance levels were set at 0.05 with all tests two-tailed. Based on the results of a comparable study with quality of life as the main outcome measure, we calculated that 30 patients in each condition were needed to detect relevant differences with a power of 0.80 and a conventional alpha level of 0.05 (16).

Results

Sample characteristics

Of 128 referred patients who completed the application forms, 106 were included (see Fig. 1). Nine participants (8%) did not complete the follow-up, but these participants did not differ significantly at baseline from those in the study with regard to age, gender, psychotic episodes, duration of illness, educational level, occupational status, or self-reported quality of life scores.

There were no differences between both conditions regarding the baseline demographic and clinical characteristics of participants (see Table 1). At baseline, the mean level of psychopathology assessed by the CAPE (14) was relatively low: mean total score on frequency was about 78 and on distress about 74.

Table 1. Baseline demographic and clinical characteristics of participants of guided peer support groups (GPSG) and waiting-list controls (WLC)

	GPSG, $n = 56$	WLC, $n = 50$	P-value*
Age, years: mean (SD)	37.8 (10.5)	39.4 (11.6)	0.45
Gender: male, %	68	63	0.53
Living alone, %	64	56	0.92
Education: university level, %	12	6	0.37
No partner: %	73	74	0.42
DSM IV-diagnosis: %			
Schizophrenia	77	72	0.57
Other psychotic disorders	23	28	
Number of self-reported psychotic episodes, %			
1	18	10	0.91
2	34	34	
>3	48	56	
Duration of illness, years: mean (SD)	9.5 (8.6)	10.2 (9.4)	0.71
CAPE: mean (SD)			
Frequency score	77.5 (15.2)	78.7 (14.5)	0.69
Distress score	73.4 (17.3)	75.2 (17.0)	0.61

GPSG, guided peer support groups; WLC, waiting-list control; CAPE, community assessment of psychic experiences.
*Chi-squared or t-test.

Results on the outcome measures at baseline showed that the whole study population reported comparable frequencies of interactions on the social support questionnaire (SSL-I), but many more discrepancies (SSL-D) which equated to a greater deficit in desired support compared with respondents in healthy populations (9) (see baseline data of both conditions in Table 2). Participants had relatively high scores on quality of life in comparison with other studies in schizophrenia, except for the social relations domain on which they scored lower (17). Scores on self-efficacy were in line with other self-help and out-patient treatment settings (10). Self-esteem was also comparable with other studies in schizophrenia (18).

Intention to treat

Participants had a significant increase in contact with peers outside of the sessions ($P = 0.03$) and on esteem support (i.e. asked for advice, received a compliment, asked for help; $P = 0.02$) in comparison with the WLC condition (Table 2). The positive effect on peer contact did not generalize to other relationships; for instance, contact with family and friends. Regarding self-efficacy, self-esteem, and self-reported quality of life, no between-condition differences were found, but participants in both conditions improved over the study period. Mixed model analyses showed no other relevant differences between conditions over time or in interaction effects between intervention and time.

The influence of adherence

A comparison between high (≥9 sessions) and low attenders (<9 sessions) at baseline showed no differences on outcomes, except for the advocacy subscale of the MHCS, on which low attenders scored significantly better.

Table 2. Intention to treat analyses of outcome of guided peer support groups vs. waiting-list control (mean, SD)

	GPSG ($n = 56$)		WLC ($n = 50$)		Condition Effect
	T0	T8	T0	T8	P-value*
PNQ					
Proportion improved peer contact	*	56%	*	31%	0.03
SSL-I total score	74.9 (12.4)	74.0 (15.6)	69.7 (14.8)	68.4 (16.4)	0.42
SSL-D total score	60.2 (15.9)	55.5 (16.1)	58.7 (13.9)	57.0 (15.8)	0.42
SSL-D Esteem support	10.5 (3.3)	9.0 (2.7)	10.2 (3.4)	10.2 (3.4)	0.02
MHCS total score	66.4 (12.0)	67.5 (12.0)	62.2 (12.0)	64.8 (14.5)	0.84
Rosenberg total score	26.4 (4.3)	27.0 (3.9)	25.4 (5.1)	26.5 (5.0)	0.97
WHO QoL total score	60.2 (8.9)	60.9 (10.0)	56.7 (10.3)	59.2 (11.0)	0.87

GPSG, guided peer support groups; WLC, waiting-list control; PNQ, Personal Network Questionnaire; SSL, Social Support List; MHCS, Mental Health Confidence Scale; WHO QoL, WHO Quality of Life.
*GLM analysis (univariate) adjusting for baseline values.

Table 3. Completer analyses of outcome of high vs. low attenders (mean, SD)

	High attenders (n = 31)		Low attenders (n = 25)		Condition Effect
	T0	T8	T0	T8	P-value*
PNQ					
Proportion improved on having a partner	N/A	13%	N/A	0%	0.08
SSL-I total score	77.7 (12.2)	78.7 (14.9)	71.4 (11.9)	66.6 (13.9)	0.13
SSL-I Esteem support	13.1 (2.8)	13.7 (3.4)	13.3 (2.6)	11.8 (2.9)	0.03
SSL-I Social companionship	11.4 (2.5)	11.9 (2.6)	10.4 (3.1)	9.7 (2.4)	0.01
SSL-D total score	58.2 (16.9)	55.0 (15.4)	62.7 (14.5)	56.4 (17.4)	0.75
MHCS total score	65.0 (10.6)	69.6 (11.0)	68.0 (13.5)	64.3 (13.1)	0.01
Optimism	25.2 (4.4)	26.7 (5.2)	25.7 (6.2)	23.7 (5.4)	0.01
Advocacy	12.6 (2.5)	13.9 (2.0)	14.2 (2.9)	13.3 (2.6)	0.01
Rosenberg total score	26.2 (4.4)	27.1 (3.8)	26.6 (4.4)	26.8 (4.1)	0.62
WHO QoL total score	59.9 (8.2)	63.4 (8.9)	60.5 (9.8)	57.2 (10.5)	0.01
Physical health	13.3 (2.0)	14.4 (2.2)	13.6 (2.9)	13.1 (3.1)	0.02
Social relations	12.6 (3.7)	13.5 (3.3)	12.6 (3.2)	11.1 (3.2)	0.00

PNQ, Personal Network Questionnaire; SSL, Social Support List; MHCS, Mental Health Confidence Scale; WHO QoL, WHO Quality of Life; N/A, not applicable.
*GLM analysis (univariate) adjusting for baseline values.

Neither age nor gender, duration of illness, psychotic episodes, severity of psychopathology, or treatment location predicted which participants would complete the intervention.

The results of the completer analyses are shown in Table 3. The high attender group did significantly improve on social support, self-efficacy, and quality of life compared with the low attender group.

Predictors of positive outcome

To determine which participants benefited most from this intervention, we compared participants who improved at least 0.2 SD (19) on overall quality of life at follow-up with the remaining participants. No demographic or clinical characteristics predicted the improvement of overall quality of life except for some effects on the domain scores of the quality of life scale.

More negative symptoms at baseline ($P = 0.02$) and more distress caused by these symptoms ($P = 0.05$) predicted improved psychological health, but not on social relations ($P = 0.01$). More distress caused by positive symptoms ($P = 0.05$) and a longer duration of illness ($P = 0.06$) predicted improved social relations. Those with higher distress from negative symptoms had significantly less chance of improving on social relations ($P = 0.01$). Positive change in peer support did not predict a better quality of life score.

Positive additive effects

Results on psychopathology showed additional effects of participation in peer support groups. In fact, the participants in the experimental condition had statistically significant, fewer negative symptoms ($P = 0.02$) and less distress from these symptoms ($P = 0.04$) in comparison with the participants in the control condition. In addition, no between-condition differences were found in hospitalization rates ($P = 0.28$) during the intervention.

Evaluation of the intervention

Almost all participants (85%) reported that the intervention fulfilled their expectations. They felt supported by other participants (82%) and were satisfied with the guidance of the nurse (93%) who, from their perspective, was indispensable (89%). They preferred the guidance of a nurse (74%) to the guidance of a peer (13%) or any other discipline (13%). The bi-weekly meetings were considered to be convenient and the sessions to be of sufficient length. Participants positively evaluated the structure of the sessions (working in pairs alternating with group discussions).

In addition, the nurses were very satisfied and well engaged in this intervention. They appreciated the groups as a valuable intervention for the patients, feasible to implement, and as a positive professional experience for themselves. They were observed to have high commitment rates to the developed GPSG-intervention. The scores ranged from 3 to 4, with a mean of 3.5.

Economic aspects of peer support groups

The mean costs of the minimally GPSG mounted up to €250 per patient over the course of the study

(2003–2004). This included the costs of an individual's contact with a nurse prior to the start of the peer support groups and the costs of the meetings attended (about €20 per meeting per patient). The estimated mean total costs of the two conditions were close to €5750 over the 8 months of the study. The costs of admissions to psychiatric hospitals (approximately one-third of the total costs in each condition) largely influenced the mean total costs of healthcare use in both conditions. Differences in healthcare costs prior to the study complicated the interpretation of the differences in mean total costs between the peer support group and the control condition. Results of the mixed model analyses demonstrated no relevant differences between mean total costs of the two conditions.

Discussion

This first RCT on peer support groups for people with psychosis demonstrates that this intervention is effective in improving their social network by encouraging mutual relationships and in enhancing their appraisal support. Intention to treat analysis showed no significant benefit on the outcomes self-efficacy, self-esteem, and quality of life. However, the high attender group did significantly improve on social support, self-efficacy, and quality of life. The intervention had the greatest impact on the quality of life of participants with a longer duration of illness and more positive and negative symptoms at baseline.

The GPSG-intervention, which was tailored to the specific needs of this patient group with cognitive impairments, is fully applicable and implementation of the intervention can occur without additional costs.

The finding that peer support groups lead to more mutual relationships is essential, as most people with psychotic disorders have small social networks with few opportunities to share their experiences with other people. The deficits we found in desired support and social relations, when compared with other affected and healthy subjects, highlighted even more the need for such an intervention. Peers can therefore play an important role in compensating for this deficiency in their social network, preventing both social and emotional isolation of other members in this group as they report feeling more appreciated. The finding is all the more striking given the chronic character of our population. Thus, this study demonstrates that the peer group improved social contacts within an existing group.

The lack of effect on other relationships, such as family or friends outside of the mental health environment, may reflect the impoverished social environment commonly experienced by schizophrenic patients. This is also illustrated in this study where 74% of the patients had no partner.

Participants tolerated the intervention very well. Hospitalization rates during the study did not differ between the experimental and control condition. In the experimental condition, we even found positive additive effects of the intervention as participants reported fewer (distress of) negative symptoms at the end of the study. From the patients' perspective, the presence of the nurse was indispensable: the 'minimal guidance' structure creates the opportunity for patients to have peer-to-peer contact without having to take charge of the further organization of the sessions and the recruitment of participants over a longer period.

Treatment adherence in schizophrenia (20, 21) is a well-known problem, but rarely studied in psychosocial intervention studies. In our study, adherence could not be explained by demographic and clinical characteristics. Therefore, other factors, such as goal attainment of expectations and intrinsic motivation at entrance (e.g. to see how others cope with their problems, recognition of own problems) require further study. This also pertains to the active ingredients of the GPSG-intervention.

To date, related research into peer support groups for mental disorders with a RCT-design is scarce. Peer support has been studied in RCTs, but in interventions that were based on the principle of peers as service-providers in mental health (22–25). For psychosis, only one study on peer support groups per se has been published (4). The author of this study suggested a possible effect on relapse and symptoms.

An explanation for the modest effect on quality of life in our study may be the relatively high score on the individual item 'overall quality of life' at baseline (ceiling effect) as only 16% of the respondents rated their quality of life as poor. One may argue that quality of life is too indirect and broad an outcome measure for this type of intervention with only three of the 26 items on the WHO QoL measuring social aspects.

New studies on peer support should focus on the instruments relating more specifically to the three types of support that peer supporters generally offer each other: emotional, appraisal, and informational support (1).

One of the limitations of our study is the absence of an attention-placebo control condition. The waiting-list control group may have improved from anticipation-effect. Second, our results may not generalize to in-patient or substance-misusing

patients as our participants were all clinically stable, non-substance-misusing out-patients. Third, the results are related to the GPSG-intervention. The effects of another design (i.e. weekly meetings, open group, peer guided) on the outcomes are not known. Fourth, the chosen instruments are all self-reporting. Some might say that the credibility of self-reports is questionable in schizophrenia research because of their lack of insight into their illness. However, we see no reason why this choice would have affected the main results or their interpretation as all questionnaires were filled out under the same circumstances by participants in both conditions. In addition, a strength is that self-report takes into account patients' own perceptions which are of value even if they differ somewhat from clinician-rated assessments (26).

To insure the further implementation of the GPSG-intervention, a manual, training curricula, and supervision for nurses were developed. The manual sets out the recruitment procedures, logistics, and the protocol for each meeting in detail. Training and supervision highlight and secure the minimal guidance attitude of the professional.

In conclusion, our study enriches previous work on peer support as the first in psychotic patients evaluating the effectiveness, intervention, and economic aspects of this approach. Contact with peers can play an important role in the prevention of social and emotional isolation. Future studies on peer support groups should evaluate the factors that influence intervention adherence and should explore instruments measuring the support itself.

Acknowledgements

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