

Creating a Supportive Environment: Peer Support Groups for Psychotic Disorders

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People with psychotic disorders frequently experience significant mental and social limitations that may result in persisting social isolation. Research has shown that a supportive social environment is crucial for the process of personal recovery. Peer support groups can provide an opportunity to reduce isolation and enhance the process of personal recovery. It encourages people to express their thoughts, feelings, and personal concerns in a peer-to-peer learning environment. Although the importance of peer support groups for various chronic diseases is widely acknowledged, they do not generally form part of routine care for people with psychotic disorders. The evidence base is promising, but the field could benefit from more rigorous, pragmatic trials with follow-up measurements to establish a solid evidence-base. This article briefly reviews the literature and discusses the barriers to implementation of a peer-support learning environment in routine care, as well as ways to overcome these.

Key words: psychotic disorders/schizophrenia/peer support/social support/recovery

Peer Support for Persons With Psychotic Disorders

People with psychotic disorders frequently experience multiple mental and social limitations that, as a result of their condition, may lead to social and emotional isolation. In addition, due to social stigma and the extreme nature of their experiences—such as delusions and hallucinations—they may find it difficult to reveal and discuss this part of their lives with others who have not had similar experiences. Many studies confirm this and show high rates of social isolation (44%–64%),¹ one study reporting that 76% of patients with chronic mental problems indicate that a mental health professional is the most important person in their lives.² For this dire situation

to improve, persons diagnosed with a psychotic disorder need to be able to share their experiences with others who will understand and accept them as their peers. Peer support groups offer such an opportunity.

Although the value of peer support groups for different chronic diseases is widely acknowledged,³ such groups are not yet offered as a standard component of care for people with a psychotic disorder. There is a rich history of mutual support groups that are at the core of the mental health consumer/service user movement, and a body of research that suggests that participation in these groups (such as GROW, Recovery, Inc, and Schizophrenics Anonymous) produced several benefits, including reduced hospitalizations and enhanced social inclusion and quality of life (for reviews see Davidson et al^{3,4}). A peer-to-peer learning environment encourages people to express their thoughts, feelings, and personal concerns, and to learn from each others' efforts to cope with daily life after a psychotic episode. A supportive social environment also has been found to play an important role in the recovery of people with a psychotic disorder.⁵ Social and emotional support from family members, friends, and significant others, including peers, can be crucial.^{6,7}

Given the social isolation of many persons with psychosis and the reported benefits of peer support groups, making such groups more readily accessible and encouraging attendance would seem to offer the potential for enhancing the social lives of patients and establishing a more secure foundation for their recovery. Recent meta-analytic work supports this observation.⁸

In an effort to promote the development and broader use of this form of social support, this article reviews some of the barriers faced in developing and sustaining peer support groups and describes recent approaches to overcome these barriers.^{9,10}

Literature Update

What is the evidence of peer support studies worldwide? Recently, a meta-analysis of randomized controlled trials (RCTs) of peer support for people with severe mental illness was published.⁸ It distinguished 3 types of peer support: (1) mutual peer support groups, where the support is reciprocal in nature; (2) peer support services, in which the support is primarily uni-directional with 1 or more clearly defined peer supporters offering support to others and is organized separately from or in addition to the care provided by mental health services; and (3) peer mental health service providers; ie, people who have used mental health services themselves and are employed to provide part or all standard care delivered by a mental health care service.⁸

The overall conclusion was that there is some evidence that these 3 forms of peer support are associated with positive effects on measures of hope, recovery, and empowerment at and beyond the end of the intervention. However, this was not consistent within or across the different types of peer support.

For mutual peer support groups, the pooled effects were based on 4 studies ($n = 2369$). Most patients had a mood disorder and a minority had a diagnosis of schizophrenia ($\leq 50\%$). Significant effects were found for empowerment (standardized mean difference (SMD) = -1.44 ($-2.79, -0.09$)) and quality of life (SMD = -1.42 ($-1.69, -1.16$)), but all studies were of low methodological quality.⁸ The effect of mutual support groups on personal recovery was studied in only one of the 4 studies ($n = 300$)¹¹ showing no effect (SMD = -0.11 ($-0.35, 0.13$)).⁸ However, the literature indicates that personal recovery is correlated with a number of related constructs, including empowerment, quality of life,¹² and size and satisfaction of one's social support network.¹³ Given positive effects of mutual support groups on both empowerment and quality of life in the meta-analysis of Lloyd-Evans,⁸ and an effect on the social support network in a recent European RCT,⁹ there are indications that peer support groups may also impact personal recovery. Also, for "peer support services" there was a small effect (SMD = -0.24 ($-0.39, -0.09$)) on recovery in 4 RCTs in the meta-analysis ($n = 1066$).⁸

Recovery-oriented interventions should be given high priority. Personal recovery is a process that may take multiple years, future studies should also focus on long term effects of peer support groups on personal recovery (the longest follow-up period so far is 12 months). Another interesting starting point for future studies is to integrate the new concept of health defined by Huber et al¹⁴ as "the ability to adapt and to self-manage". In this concept "sense of coherence" is important in the definition of mental health. It is seen as a factor that contributes to a successful capacity to cope, recover from strong psychological stress, and prevent post-traumatic stress disorder by enhancing the comprehensibility,

manageability, and meaningfulness of a difficult situation. This new concept fits in well with the active ingredients of peer support groups reported by the participants in taking part in a recent RCT (eg, I recognized myself in others, I got time and the opportunity to tell my story, I saw that I was not the only one with this problem and other peers understood me very well).¹⁵

Barriers to Implementation

There are, unfortunately, factors associated with the nature of psychotic disorder itself that may make developing and sustaining peer support groups difficult over time. In addition to stigma and social withdrawal, negative symptoms and neurocognitive alterations experienced by many persons with a diagnosis of schizophrenia^{16,17} may pose additional barriers to their leading or even participating in peer support groups. Negative symptoms like poverty of speech, lack of initiative, and lack of energy or motivation can be refractory to treatment and make it difficult for people to join in social activities, even when they express the desire to do so. As peer support groups focus on social contact with peers, alterations in social cognition can impede the group process,¹⁸ just as concentration and memory alterations may make it difficult to carry on a simple conversation. At least for persons facing these prominent features of psychosis—people who would not necessarily seek out or choose to attend a peer support group on their own—modifications may be needed to group leadership and structure to overcome these challenges.

Modifications to Enhance Peer Support Groups

In medicine, support groups usually are established and facilitated by patient associations. However, many people with a diagnosis of schizophrenia report a perceived lack of self-organizing capabilities to plan.¹⁹ They encounter problems in social interaction and taking initiative (negative symptoms). This makes it difficult for patients to initiate peer support groups themselves. Establishing and facilitating support groups over a longer period of time often becomes too much of a burden for peer experts. These experiences suggest that perhaps peer support groups may become more accessible and sustainable if they are co-facilitated by mental health professionals.

In a recent randomized trial in the Netherlands, minimal guidance was used to facilitate mutual support in persons with psychosis, showing that support groups are a useful intervention in enabling and strengthening mutual relationships and social support.⁹ The minimal guidance was to facilitate structure by helping to set an agenda, secure continuity by organizing the meetings, and providing security in the group.¹⁰ The participants themselves clearly indicated that recognition and self-expression

were the active ingredients of the group and implementation of the intervention could be accomplished without additional costs.^{20,21}

Conclusions

Peer support in many medical conditions has been shown to enhance functioning by fostering acceptance, coping and formulation of novel adapted goals that provide meaning and identity. In schizophrenia, peer support is emerging as a new and potentially effective complement to existing care, aiming to enhance social support among a socially isolated population. It has the potential to enhance personal recovery in the sense of pursuing and attaining new goals and starting to live beyond the disorder. However, this is barely studied in peer support groups for psychotic disorders. The evidence base is promising, but the field needs more rigorous, pragmatic trials with follow-up measurements to establish a solid evidence-base. Also, procedures must be developed to guarantee continuity, to compensate for cognitive problems and negative symptoms, and to improve the tolerability of group approaches in people with alterations in social cognition and rapidly exhausted cognitive resources, especially in social environments.

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