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1-1-2018

The effectiveness of support groups: a literature review

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Recommended Citation

Worrall, Hugh; Schweizer, Richard; Marks, Ellen; Yuan, Lin; Lloyd, Chris; and Ramjan, Rob, "The effectiveness of support groups: a literature review" (2018). *Faculty of Science, Medicine and Health - Papers: part A*. 5441.

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The effectiveness of support groups: a literature review

Abstract

Purpose: Support groups are a common feature of the mental health support engaged by carers and consumers. The purpose of this paper is to update and consolidate the knowledge and the evidence for the effectiveness of mental health support groups.

Design/methodology/approach: This paper is based on a systematic literature review of relevant databases around support groups for mental health. Support groups are defined as meetings of people with similar experiences, such as those defined as carers of a person living with a mental illness or a person living with a mental illness. These meetings aim to provide support and companionship to one another.

Findings: The results show that there is a consistent pattern of evidence, over a long period of time, which confirms the effectiveness of mental health support groups for carers and people living with mental illness. There is strong, scientifically rigorous evidence which shows the effectiveness of professionally facilitated, family-led support groups, psychoeducation carers support groups, and professionally facilitated, program-based support groups for people living with mental illness.

Research limitations/implications: This research implies the use of support groups is an important adjunct to the support of carers and people with mental illness, including severe mental illness.

Originality/value: This research brings together a range of studies indicating the usefulness of support groups as an adjunct to mental health therapy.

Disciplines

Medicine and Health Sciences | Social and Behavioral Sciences

Publication Details

Worrall, H., Schweizer, R., Marks, E., Yuan, L., Lloyd, C. & Ramjan, R. (2018). The effectiveness of support groups: a literature review. Mental Health and Social Inclusion, 22 (2), 85-93.

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The Effectiveness of Support Groups: A Literature Review

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Abstract

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Keywords: Support groups, carers, consumers, mental illness

Paper Type: Literature review

Introduction

Support groups have been used in mental health for many decades as a means of providing a forum to discuss problems and share experiences and information(Heller *et al.*, 1997). Support groups offered assistance at times when fewer services were available for people with mental illness and the satisfaction that people expressed with those services was low. The move to deinstitutionalise people from psychiatric hospitals into the community, from the 1970s until now, also played a role in the popularity of support groups, whereby families were reimagined as participants in support and recovery rather than the cause of mental illness (Heller *et al.*, 1997; MacFarlane, 2004).

Many support groups were set up absent a scientific evidence-base. This literature review aims to investigate current research regarding the effectiveness of support groups for families and carers of people living with mental illness and people who have experienced mental illness themselves.

While online support is mentioned, this is not a thorough study of online support groups or forums.

Method

Literature searches were conducted using Ovid Medline(R), PsychInfo and Proquest Central databases. The subject headings 'mutual support', 'self-help groups' and 'support groups' were filtered using various combinations of the subject headings psychotic disorders, schizophrenia, bipolar disorder, Community Mental Health Services, Social support, Grow program, hearing voices, anxiety, caregivers, carer, family, depression. These searches resulted in a harvest of 57 relevant articles.

Findings

Support groups can also be known as mutual-aid groups, self-help groups, peer-led support groups, consumer-led support groups, multi-family groups or family-led support groups. There is a diversity in the way in which support groups are organised and the content of their meetings (Seebohm 2013; MacFarlane 2004; Ahmed *et al.* 2012). Throughout the literature there is a variety in the definition of what constitutes a support group. This makes a study of the effectiveness of support groups challenging.

Peer-led, self-help, mutual-help or mutual-aid groups

Peer work in the mental health sector is becoming more recognised and professionalised (NSW Mental Health Commission, 2014). The concept of 'peer-led' usually means that a group is led by people who have had the experience of a mental illness. Peer-led, however can also be applied to carers and family members who lead support groups as 'peers' for other carers and family members. Provision of peer led services has been emphasised as critical to integrating consumers' perspectives in recovery based mental health services (Fukui *et al.*, 2010).

'Mutual support', or 'mutual aid' groups operate to support people across a whole range of health and welfare issues. Mutual support and mutual aid are the names more likely to refer to volunteer-based groups. In the mental health sector these groups tend to be organised and run by carers and family members of people living with a mental illness or people who have experienced mental health problems, not by mental health professionals.

Sometimes these distinctions are hard to maintain when support groups have mixed membership or are supported by employees of organisations who may, or may not, be carers or people with lived experience themselves.

A qualitative study by Seebohm *et al.* (2013) explores the contribution of selfhelp/mutual-aid groups to mental wellbeing using the UK National Mental Health Development Unit (NMHDU) indicators. Whilst five of the groups in their study are mental health specific groups, most of the groups in their study are interested in other health and social issues; for example, cancer. Using thematic analysis they compared the experiences and mental wellbeing of participants before and after they began participating in their group. They note that the core protective factors for mental wellbeing are:

- Enhancing control;
- Increasing resilience and community assets;
- Facilitating participation and promoting inclusion (NMHDU, 2011; Seebohm *et al.*, 2013).

They found that prior to joining their groups many participants felt isolated, lacked hope and were at risk of mental ill-health. They conclude that self-help/mutual-aid groups can be measured against the NMHDU mental wellbeing protective factors and that these factors do correspond with people's experience of improved mental wellbeing.

Support groups for people with the lived experience of mental illness

The literature demonstrates that support groups for people with lived experience of mental illness are effective and have positive outcomes (Corrigan *et al.*, 2002; Knight, 2006; Mancini *et al.*, 2013). Mutual help programs such as GROW have been extensively studied. GROW is an international organisation which supports a network of mental health support groups using the GROW model. The support groups use standardised meeting procedures developed from the 12-step format of AA and standardised literature as references to be read by "Growers" individually and at meetings.

GROW was attributed with significant improvement in the quality of life and related factors of members who have serious mental illness (Corrigan *et al.*, 2002), significantly reduced number of days hospitalised compared with similar people in an Illinois psychiatric facility (49 for GROW members compared to 123 in controls), improvements to self-esteem, self-efficacy, social support, spiritual well-being, and psychiatric symptoms. Growers identified self-reliance, industriousness and self-esteem as key ingredients of recovery.

The success of GROW has also been evaluated in the Australian context. A study by Finn *et al.* (2009) found that the group community plays a vital role in supporting, encouraging and holding group members during times of crisis and difficulty.

A survey conducted in 2013 by the Australian GROW organization (GROW, 2017) found that:

- 85% felt an improved sense of personal value;
- 77% experienced an improved sense of belonging and connection with the community;
- 81% reported an improved network of friends and personal supports;
- 67% said that GROW had directly contributed to their recovery from mental illness.

Mancini *et al.* (2013) conducted a validated evaluation questionnaire of the Procovery program in the US. Procovery is a voluntary program focused on consumer choice and respect delivering discussion on a variety of topics from hope and insight to addressing practical matters such as managing medications, developing support networks, engaging in meaningful activities, self-care and getting a job. Facilitators were either peer facilitators or mental health workers who were trained to be neutral coordinators, allowing for other members of the group to participate as equals.

Participants in the Procovery treatment group displayed an increased positive perception of psychiatric staff and overall quality of life measures. However, no effects were found for social relationships, consumer recovery attitudes or quality of life subscales. Almost all Procovery facilitators believed that Procovery improved consumers' recovery attributes such as motivation, problem solving, hope, socialization, communication, self-esteem, and confidence.

An extensive review of six 2-point-in-time studies conducted by Knight (2006) examined the effectiveness of self-help groups for people with a serious mental illness. Knight concluded these studies demonstrated reduced symptoms and substance abuse over time; concomitant reduction in crises, hospitalisations and use of services; improved social competence and social networks; and increased healthy behaviours and perceptions of well-being. These healthy behaviours and perception of wellbeing included: medication compliance, acceptance of illness, better coping skills, quality of life, greater sense of security and self-esteem, creation of one's own meaningful structure, and changes in what healthcare consumers wanted from time spent with their family.

It is worth noting that all of the studies included in the Knight review, with the exception of the study of the GROW program (Kennedy, 1990) are closely associated with mental health services, and staff from those services organise and facilitate or co-facilitate the programs. Knight attributes the success of these programs to increased social networks, the role of the facilitator acting as a support for participants, peer-to-peer learning and role modelling, and the creation of group-led meaningful structures.

Support groups for people living with a psychotic illness have a normative function as members compare themselves to each other, learn from each other and incorporate the culture of the group. Referent power, which is the identification with group leaders and members, is a distinguishing factor of mutual help from professional assistance, but is not necessary for people to identify the group as helpful. Expert power refers to valuing the knowledge of group members, leaders and support workers.

The social influence that expert power affords has been identified as a major factor in determining the perception of the helpfulness of a group (Salem *et al.*, 2000). Outcome variations exist within groups which may be attributed to the strength of the social network. For example, people who attend support groups more often attain a better quality of life score and lower use levels of healthcare resources than people that attend less frequently (Terzian *et al.*, 2013). The activation of social networks should be considered a mandatory component of the care and rehabilitation of patients with schizophrenia (Terzian *et al.*, 2013).

The internet provides an alternative medium for mutual support and support groups. However, studies evaluating unmoderated, unstructured internet peer support by Kaplan *et al.* (2011) and Bauer *et al.* (2013) suggest that the internet cannot replace health professionals and other traditional psychoeducational approaches. Rather, the use of the internet may be a useful adjunct to traditional self-help groups.

Support groups for people with lived experience of bi-polar disorder

A number of different support group models have been demonstrated to be effective for people living with bi-polar disorder. For example, Castle *et al.* (2010) demonstrated that manualised, group-based therapy can be an effective adjunct to treatment as usual for people. A randomised controlled trial in Victoria, Australia, was used to evaluate a group program based on the "Collaborative Therapy Framework". This program was designed to help participants with their coping strategies, to address their vulnerabilities and manage stress. Participants received a workbook, information book and collaborative therapy journal. People in the treatment groups had fewer relapses of any type (manic, depressive or mixed) and spent less time unwell than those in the control group. There was, however, no significant difference detected in the severity of symptoms between the treatment and control groups (Castle *et al.*, 2010)

Psychoeducation programs for people living with bipolar have also been shown to be effective for a number of measures (Castle *et al.*, 2010; Poole *et al.*, 2012). A randomised controlled trial evaluating the "Beating Bipolar" online psychoeducation program demonstrated that the program was easy to deliver, engaging for the participants and provided a modest effect on psychological quality of life (Poole *et al.*, 2004). Half the participants in this study reported that they would prefer a face-to-face group rather than online, while the other half prefer the online environment. Similarly, Bipolar Education Program Cymru (BEP-Cymru), which is a 10 session program facilitated by two mental health workers, enabled people to therapeutically share their experiences with their illness, care, treating professionals and hospital treatment. Participants gained insight into ways of coping, particularly with stigma associated with the illness through the program (Poole *et al.*, 2015).

Groups for substance abuse or dual diagnosis

The 12 step approach adopted by Alcoholics Anonymous (AA) is established as one of the leading, empirically validated treatments for drug and alcohol dependence (Borganschutz, 2005). However, only a minority of people with a dual diagnosis attend self-help groups despite sustained encouragement by health services personnel to attend.

Specially designed groups for dual diagnosis have an advantage (e.g. Double Trouble for Recovery) (Noordsy *et al.*, 1996). A number of factors influence attendance including social ability and diagnosis, with attendance particularly low for those whose dual diagnosis includes a psychotic illness. Furthermore, forceful referral of people to 12 step self-help groups without respecting their own explanatory models of understanding their addictions and illness was counterproductive.

Support groups for carers

The diagnosis of a severe mental illness in a family member can have a major impact not only on the individual but on the family as well. Mutual support groups have been used as an effective modality of family intervention to improve care, family and patient functioning (Chien *et al.*, 2005). The objectives of caregiver support groups include:

- To provide education and information in order to increase knowledge and understanding of the disorder;
- To encourage an atmosphere of mutual trust in which to explore strategies for coping;
- To provide emotional support conducive to open, honest sharing of feelings (Chou *et al.*, 2002).

Monking (1994) is one of the earliest studies to attempt to provide rigorous measures for the effect of mutual support groups on both the participant living with a mental illness and their families who joined the carer mutual support groups set up for their study. Monking concluded that participation in self-help groups is effective in helping relatives. Although not statistically significant, Monking found that decreased levels of emotion and physical complaints were concurrent with the increased contact frequency between the person they care for and their contact with other group members. In this paper, Monking put weight on the social (community) impact of a successful self-help group.

Heller *et al.* (1997) conducted a statistical analysis of 14 family mental health support groups from Chicago and Illinois. Of these groups, 4 were led by professionals and the other 10 were led by family members. Heller *et al.* described an increase in two outcome factors for support group participants. Firstly, information benefit increased, which involved knowing how to advocate for the person they care for more effectively, increased ability to cope emotionally and having more knowledge about mental illness, the services available and the latest interventions. Secondly, relationship benefit was increased, which involved an improved ability to cope with

social stigma, less anger toward the person they care for and better relationships with both their person living with mental illness and other members of the family.

It is worth noting that negative factors were also reported by up to 30% of participants as a result of participation in the group including an increase in the feeling of being overwhelmed and less able to meet the needs of the person with mental illness (Heller *et al.*, 1997). It's also worth noting that this study did not distinguish the outcomes between the groups facilitated by professionals or family members.

A number of other studies have also demonstrated the benefits of caregiver support groups (Chou *et al.*, 2002; Chiu *et al.*, 2013; Chien and Norman, 2009). In one study in Taiwan (Chou *et al.*, 2002), members of the support group demonstrated less depression and less of a sense of burden than controls by creating a sense of commonality, validation of the caregiver's experiences and opportunities to give and receive help. Similarly, family psycho-education programs were found to be effective in reducing worry and displeasure, significantly improving intra-psychic strain, depression and empowerment (Chiu *et al.*, 2013).

Support groups have also been shown to be more effective than standard care alone in some settings (Chien *et al.*, 2004; Chien *et al.*, 2006). A randomised control trial of family-led mutual support groups for Chinese caregivers demonstrated that support group participants experienced significantly greater improvement in families' burden, functioning and number of support persons than those receiving standard psychiatric care alone (Chien *et al.*, 2008; Chien and Chen, 2004). Multivariate analyses have also shown that, in conjunction with routine psychiatric care, family-led mutual support groups are more effective than family psychoeducation groups in improving the psychosocial health conditions of patients and their family members (Chien *et al.*, 2004; Chien and Thomson, 2013).

Multifamily support groups

Multifamily groups include people living with a mental illness, the people who are their carers and other people in their family group.

McFarlane (2001) reviewed a unique model of multifamily groups for the treatment of severe psychiatric disorders. These were long-term closed groups, in which new members are unable to join the group once it starts. The group leaders were 2 clinicians who aimed to keep the group members attending. Rather than viewed as a support group, they are referred to as "therapeutic social networks" or a "healing community".

The therapeutic effectiveness of multifamily groups resembles those described in other support group studies and includes increased social networks, improved coping and problem-solving capacities, increased ability to absorb anxiety and a shift in identity from stigma to mastery (McFarlane, 2011).

McFarlane also describes how senior people in families begin to pay attention to the person living with mental illness in other families. It is this multifamily aspect, particularly the increased social network, which forms a multilevel intervention that is linked to better long-term outcomes.

Support groups for families of people with lived experience of psychotic illness

There is consistent evidence of the immediate or short-term positive effects of mutual support groups on the physical and psychosocial health conditions of patients and their families(Chien and Norman, 2009; Chien and Chan, 2004).

Chien *et al.* (2008) and Chien and Chan (2004) undertook a long-term program of study including a randomised controlled trial with 106 families over a 3 year period. They conclude that family-led mutual support groups are an effective intervention for Chinese people with schizophrenia, resulting in long-term effects of improving patient and family functioning and reducing rehospitalisations. Family mutual support was shown to be more effective in improving self-maintenance, social functioning and community living skills of patients with schizophrenia than either psycho-education or standard care alone.

These effects were not limited to the people living with schizophrenia. The families caring for the relative with schizophrenia also showed improved measures for mutual support, acceptance of the caregiver role, increased knowledge of the illness, adoption of new coping skills, perceived social climate of the group, informational support, empowerment and psychosocial functioning (Chien *et al.*, 2014). Chien *et al.* (2006) noted that poorer group outcomes were experienced with low group attendance, negative pressure from dominant members, and over-expression of intense and negative feelings.

Discussion

Across many types of support groups, there is a strong, scientifically rigorous evidence base for the effectiveness of support groups in providing positive improvements to wellbeing and the recovery of participants. Outcomes include reduced symptoms, substance abuse, number of crises, hospitalisations and use of services, as well as improved social competence and social networks, increased healthy behaviours and perceptions of wellbeing.

Regardless of the type of support group, participants report many of the same perceived benefits from participation:

- Fostering hope;
- Learning about the issue that brings them to the support group;
- Learning coping strategies;
- Overcoming isolation;
- Building social and support networks;
- Learning from successful role models;
- Feeling more in control over the situation
- Overcoming stigma;
- Learning about the services available and being able to advocate more effectively.

The exact mechanisms by which support groups achieve these perceived benefits are, however, not always clear. For most mental health support groups there is professional mental health worker involvement in the development and facilitation of the group. Commonly, workers provide assistance to set up groups, to support the group leaders and maintain their contacts with, and knowledge of, the mental health system.

There are a range of matters that affect the success of the use of a support group program and the involvement of professionals health workers. These include:

- The value placed on, and the techniques used, to promote the involvement of participants and peer-leaders;
- Professional worker rigidness or flexibility with the program and willingness to let participants contribute to the process rather than being 'lectured';
- Co-facilitation of a group by a professional mental health worker with a group participant (peer leader) can contribute to the effectiveness of support groups. Peer leadership has been identified as an important component by participants.

This doesn't mean that support groups without professional leadership and programmed materials are not effective. Studies aiming to reach rigorous standards of scientific evidence usually require controlled variables and professionally-led, programmed-based groups to enable this kind of study. It is less likely that community-based, unfunded programs are going to be suitable for rigorous scientific study or attract the funding that is required to confirm a program as evidence-based.

Barriers to achieving positive outcomes include the person's diagnosis, irregular group attendance, negative pressure from dominant, experienced members, and the overexpression of intense and negative feelings during group meetings.

Regardless of the model of support group, there are some consistent challenges to the functioning of the groups. These include the management of disagreements between participants, having to repeatedly talk about your problems, the idea of spending a lot of time with other people living with mental illness, resources, the personal energy required to maintain the group and the difficulties of getting people to attend and maintain attendance at the groups. Training professional workers, peer leaders and volunteer group leaders is crucial for overcoming these challenges.

Conclusions

The results show that there is a consistent pattern of evidence, over a long period of time, which confirms the effectiveness of mental health support groups for carers and people living with mental illness. There is strong, scientifically-rigorous evidence which shows the effectiveness of professionally facilitated, family-led support groups, psycho-education carers support groups, and professionally facilitated, programbased support groups for people living with mental illness.

This review has identified a number of elements that may contribute to the success of support groups, such as peer leadership, family involvement, professional facilitation or co-facilitation, and the use of manualised programs. The studies in this review describe a range of outcome factors and the benefits experienced by support group participants. Further studies elucidating the mechanisms by which the benefits are achieved and, in particular, the contribution to the effectiveness of groups by professionals would be beneficial. This field would also benefit from further research on whether people living with mental illness use other types of community groups for support such as writing and music groups and sport clubs, and how the effectiveness of this compares with recognised support groups.

Limitations of the conclusions drawn here and by others include the low number of studies with a rigorous statistical base. Challenges to conducting research in this area include the lack of attention to treatment, poor follow-up, the lack of testing around the involvement of psychiatric nurses or other health professionals and consideration of social-cultural conditions.

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