Community Mental Health Journal
https://doi.org/10.1007/s10597-024-01326-y

ORIGINAL PAPER

Operational Mechanisms of Peer Support Groups and Support for Caregivers of People Living with Serious Mental Illness

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Received: 23 June 2024 / Accepted: 13 July 2024

Abstract

The challenges faced by caregivers of people living with serious mental illness in Canada are well documented in the literature including emotional distress, financial strain, social isolation, and concerns about their physical health following the impact of caregiving. Peer support programs (including peer support groups) emerged as a promising method to attempt to address these challenges. While there is evidence on the positive impacts of peer support groups in providing support for caregivers, the mechanisms by which peer support groups operate and influence support for caregivers of people living with serious mental illness are less understood. This qualitative study took on a co-designed participatory research approach. Fifteen adult caregivers of people living with serious mental illness across Canada were engaged through key informant interviews that lasted for 45 – 60 min each. A thematic analysis was carried out to help understand the operational mechanisms of peer support groups in influencing support for caregivers. The key informant interviews allowed for the identification and description of the following operational mechanisms that influenced the support caregivers received from peer support groups: (1) Group dynamics; (2) Messaging/content; (3) Equity and inclusion, (4) Group philosophy; and (5) Privacy concerns. Findings from this study showed that caregivers identified a number of operational mechanisms of peer support groups that explained how they felt supported when they participated in peer support groups. Among other operational mechanisms, group dynamics in terms of the gathering of caregivers of different age brackets and varying caregiving experience negatively influenced the peer support experience of caregivers. This pointed to the need for group dynamics that consider close age ranges and similar caregiving experience during group meetings to enhance support for caregivers. Caregivers also identified a gap in equity and inclusion in peer support groups that could have otherwise enriched their experience and enhanced the support they looked to receive from the group. Practical examples to enhance equity and inclusion include promoting active listening, using inclusive language, encouraging diverse representation and asking for feedback from peer support group members. While peer support groups in Canada exist independently of one another, it may help to consolidate evidence-based recommendations in the operational mechanisms of these groups, for the benefit of caregivers who turn to these groups for support, having been left on their own by an otherwise fractured mental health system.

Keywords Family caregivers · Support · Serious mental illness · Peer support · Peer support groups · Bipolar · Schizophrenia · Psychosis · Group operational mechanisms · Mental illness

Introduction

Serious mental illnesses (SMIs), including schizophrenia, bipolar disorder and psychosis, lead to challenges for both individuals living with SMIs and their family caregivers (Harries et al., 2023). The challenges faced by caregivers of people living with SMIs in Canada are well documented in the literature including emotional distress, financial strain, social isolation, and concerns about their physical health following the impact of caregiving (Blok et al., 2023;

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Phillips et al., 2023; Guan et al., 2023). Peer support programs emerged as a promising method to attempt to address these challenges (Griffin et al., 2017; Otero et al., 2019; Phillips et al., 2023). Peer support refers to the provision of support and assistance by individuals who have lived experience with a similar condition or situation (Stefancic et al., 2021). Peer support for caregivers of individuals with SMIs facilitate shared understanding and empowerment improved well-being, and enhanced coping abilities (Chinman et al., 2014; Stefancic et al., 2021). Caregivers often rely on their families as the primary source of care due to the lack of support from healthcare systems (Azman et al., 2017). Peers can relate to the experiences, emotions, and challenges faced by caregivers, fostering a sense of understanding. Interactions with peers can empower caregivers by providing them with practical advice, coping strategies, and a sense of control over their situations. Additionally, peer support interventions have been found to have positive impacts on caregivers and individuals living with mental illnesses (Chinman et al., 2014; Rebeiro Gruhl et al., 2016; Stefancic et al., 2021; Smit et al., 2023). Bhatia et al. (2020) categorized the available caregiver initiatives into: one-on-one peer support (peer mentoring), or group-based support (support groups, online fora, and recreational activities). One-on-one support provides support to caregivers on an individual basis by connecting them with persons who can comprehend their challenges (Interior Health Authority, 2018; Bhatia et al., 2020). In Canada, group-based support is the commonly used means of delivering peer support initiatives but is mostly spearheaded by health-based grassroots organizations, in response to the dire need for support for caregivers who often rely on peer support (Interior Health Authority, 2018; Bhatia et al., 2020). Many group-based peer support initiatives run independently of one another, although, some mental health organizations and hospitals offer group-based support generally referred to as family/peer support programs, specifically designed for caregivers (Bhatia et al., 2020). Some sessions of group-based support are conducted in the form of educational workshops that offer relief for caregivers of people living with mental illnesses by providing lectures and group activities including meditation sessions (Ami Quebec, 2020). These group sessions are often facilitated by trained volunteers with lived experiences of caregiving (AKA peer support workers) and in some cases health professionals; they are often delivered through physical or digital means (Bhatia et al., 2020; Baycrest, 2020). Over the past decade, Canada has recognized the importance of peer support for caregivers, leading to the development of training for peer support workers/facilitators of peer support initiatives across the country (O'Hagan et al., 2010; Peer Support Canada, 2022). Peer support Canada – the national voice for peer support for mental health in Canada, organizes and oversees the certification and accreditation of mental health peer support workers across Canada (Peer Support Canada, 2022). Evidence shows that peer support workers who most often have lived experience of mental illness play a key role in open dialogue models of crises and continuing mental healthcare, enhancing shared understanding and providing a sense of belonging and social inclusion for caregivers (Turuba et al., 2023). The training for peer support workers aim to equip individuals with the necessary skills and knowledge to effectively support caregivers and individuals living with mental illness (Rebeiro Gruhl et al., 2023). Several Canadian studies and initiatives have reported the benefits of peer support initiatives for caregivers of people with mental illness and those with SMIs in Canada (Ami Quebec, 2020; Baycrest, 2020). While the positive impacts of group-based peer support in providing support for caregivers is documented, the mechanisms by which group cohesion and operations influence the support for caregivers of people living with SMIs are less understood. In this qualitative study, we set to identify the operational mechanisms of peer support groups and how they influence support for caregivers of people living with SMIs, by exploring caregivers' perspectives of peer support groups.

Methods

Upon identifying the research gaps to be addressed, our research team contacted caregiver organizations across all 5 distinct regions in Canada, leveraging our networks, to inform them of our study. We held an initial meeting with attendees where we presented the proposed study. At the meeting, we received feedback from caregivers on the study objectives and further direction on the proposed study design including the key informant interview questions. We also received suggestions/contact information to contact more caregivers for the study. We purposively sampled the study participants across Canadian regions. This co-design component of the study was in line with the participatory research approach adopted by the study to enhance participation and co-learning for the benefit of the study population who were caregivers of people living with bipolar disorder, psychosis and schizophrenia (Denzin & Lincoln, 2011; Chen et al., 2020). To meet the criteria for participation in the study, the caregiver must be 18 years of age and above, and be a spouse, other relative or a close friend who is also a caregiver of the person living with SMI. Fifteen adult caregivers were engaged through key informant interviews that lasted for 45 – 60 min each. Participation was on a voluntary basis. Participants were made aware of their rights to decline at any time even during the interview. Participants signed a written informed consent form and agreed to be interviewed through videoconferencing. The interviews were carried out by two research team members of the Canadian Institute for Advancements in Mental Health (IAM), and in English language. All audio recordings were transcribed verbatim, and the anonymity of participants was maintained through the removal of identifying information of participants.

The de-identified data was validated by participants. All datasets were reviewed and coded in a codebook maintained with code names and definitions. Data was analyzed using NVivo software version 12. After extensive review of the codes, similar codes were formulated into five main themes according to the tenets of qualitative research (Braune & Clarke, 2006), with the aim of effectively identifying and summarizing caregivers' experience of how operational mechanisms of peer support group influenced the support they received from peer-support groups.

Results

The study involved a total of 15 caregivers among whom were a few peer support group facilitators ($n=4$). Caregivers were parents ($n=7$), spouses ($n=5$), and siblings ($n=3$) of people living with SMIs. The key-informant interviews allowed for the identification and description of the following operational mechanisms that influenced the support they received from the peer support group: (1) Group dynamics; (2) Messaging/content; (3) Equity and inclusion, (4) Group philosophy; and (5) Privacy concerns. The identified operational mechanisms were mentioned by caregivers and the definitions of these mechanisms in the context captured by participants, are presented in Table 1.

Group Dynamics

The operational mechanism of group dynamics among caregivers in peer support groups was often mentioned, taking the forms of age and varying experience of caregiving. Participants expressed how age and the varying experience of caregiving were important considerations in how they felt supported in peer support groups. They pointed out the need for peer support groups to have participants of similar age and caregiving experience to enhance the *peer* experience that groups of these nature aim to achieve.

Table 1 Operational mechanisms emergent from the analysis that influence peer support groups for caregivers of people living with SMIs

Mechanism	Emergent Definition
Group dynamics	Factors surrounding interactions and behaviour of group participants/members
Messaging/content	The message/information/communication that the group conveys
Equity and inclusion	Factors surrounding equity and inclusion as it pertains to meaningful participation in the group
Group philosophy	Involves the accepted/purported beliefs of the group
Privacy concerns	Concerns with privacy of group participants/members

> I did go to one support group, and I found it was not as supportive because there's various stages of illness and not everybody understands the (caregiving) experience that you have and so it got to be a little bit frustrating (KI-4).
> One of the things we discovered from people coming in (to peer support groups)… we realized, oh, my goodness, you cannot bring certain people together. It was destructive, it was not healthy. And the goals were not achieved. So, an example of people we would not mix together in a group would be a mother who is 55, 60 or say 70, because the age difference is not so much as it is when you pair younger families with older families in the system (KI-2).

Messaging/Content

In addition to group dynamics, messaging/content conveyed in peer support groups was mentioned as an operational mechanism. Many spoke about their experience with the messaging/content in support groups in ways that determined their continued participation in the group or not, as one caregiver described how "alienated" some caregivers felt with the messaging of "recovery":

> The problem is they (support group) keep talking about the recovery journey and a few people said to me, "They need to stop calling it a recovery journey because there is no recovery." And I try to explain to them that, "You know what, no, there's no recovery like if you have the flu you recover, no. With a serious mental illness you still have that illness, but the idea is that you can recover to the best health available to you through the treatment and the therapy." But they find that very alienating (KI-12).

Another caregiver described their preference for a "validation" style messaging that was "less judgemental", saying the message they received in the support group may have accounted for their current held back approach to participation in support groups.

> Basically, a validation. More expression of interest and caring and less of judgement. (Instead of) "well

> you should've done this, or you should've done that and why didn't you" and that sort of thing. There's a way to express that without sort of pointing an accusing finger, without acting like you have all the answers. You know, like I just felt there was too much of that and not enough empathy. Again, it could be just the people that were there at the time, or it could be my state of mind at the time, I don't know. I don't know what it was exactly that caused this reticence in me (KI-4).

> It was amazing to hear from other parents, but tough love (messaging) was not helpful and should be banned in meetings especially for people caring for those with schizophrenia. (KI-15)

Equity and Inclusion

The operational mechanism of the group revolving around equity and inclusion was expressed by participants as contributory to how they experienced support from peer support groups. Participants highlighted their experiences in support groups where limited support exist for racialized people (who already grapple with the "taboo around mental illness") and those who do not speak English as their first language. A caregiver summarily described this in a cultural context, saying:

> In order to make a connection, you have to make a cultural connection too, you know. I think there's a lot of work to do in that domain (KI-1).

Furthermore, facilitators/leaders of support groups could encourage more support for group participants if they "took control of the meeting… and made it more inclusive."

Group Philosophy

With group philosophy operational mechanism, caregivers signaled the importance of the groups' purported beliefs and overarching goal (be it "advocacy" or "education-based") as considerations for how they felt supported in peer support groups. Caregivers noted that they only felt a sense of belonging in the group (and by extension support from the group) when there was an alignment in goals with what the groups stand for. In some cases, being forward about one's caregiving experience was not received well as described by a caregiver:

> We went to one session a long time ago; we were invited by another parent. When my husband just started being honest to people, letting them know that be prepared for the long haul, that this is not a temporary thing, like he was actually told not to come back because I guess we were too honest. And I don't understand (KI-10).

Privacy Concerns

Participants noted privacy concerns as an operations mechanism that influence the support they would hope to receive from a peer support group. They indicated the need for privacy during meetings as captured by a caregiver:

> One of the things families need is a place where we can meet where we can have a certain degree of privacy (KI-11).

An aspect of privacy concern that emerged from the study was of caregivers noting that privacy was getting in the way of the interactions among group participants.

> But the difficult thing was, you know, you hear someone else's story, and they might be further along the journey than you are, and then it's like, "oh my gosh, wow." And then the meeting is over, I don't know that person's name, I don't have their email, I can't see what happened with their daughter, nothing. I think people are so worried about privacy. If you pass a page around and people choose to share their email, there's nothing wrong with that but they (peer support group facilitators) absolutely did not encourage that. So, I don't know if that's like government policy or what that is, but I just thought, "Oh I wonder what happened with the caregiver and her daughter? (KI-15).

Discussion

The study findings revealed a number of mechanisms surrounding the operations of peer support groups and how they influence support for caregivers of people living with SMIs. The study showed that group dynamics i.e., factors surrounding the interactions and behaviour of peer support group participants mostly influenced the support received by caregivers from peer support groups. The study showed that the pairing/gathering of caregivers of different age brackets and varying caregiving experience negatively influenced the peer support experience of caregivers. This finding was in relation to the lack of relatability in peer experience of caregivers who typically rely on each other for support. Grouping caregivers who were further along in their caregiver journey with those who had much less years of caregiving experience may have created a divide that did not translate to the desired support for caregivers, as our study found. But the opposite was found to be of more value among caregivers of people with chronic physical illness where younger caregivers learned more from those who were far along in caregiving (Anderson & White, 2018). However, given the delicate nature of caregiving for people with SMIs as opposed to physical illnesses in this case, the expectations of support from peer support groups may be realized when support groups pair caregivers of people living with SMIs by closer age brackets as well similar caregiving experience. Additionally, the study revealed that the information content/message conveyed in peers support groups was a notable influence in the kind of support caregivers received in peer support groups. Caregivers who participated in this study described how they negatively felt supported in peer support groups they attended, noting that the messaging received during group meetings made them feel judged and by extension, less supported. One participant called for the "ban of tough love" messaging for caregivers of people living with schizophrenia, saying they did not find it helpful, while another encouraged a validation type of messaging during peer support meetings. The burden of caregiving for people living with SMIs is hard enough with most of them already living with the guilt associated with the helplessness of caregiving in a fractured health system. A validation messaging/information content conveyed in peer support groups may likely enhance the support caregivers receive as our study has shown.

Equity and inclusion was found in the study to influence the support caregivers received from peer support groups. Ranging from language barriers experienced in groups where only English was spoken, to a lack of cultural considerations for racialized people who are caregivers of people living with SMIs. Historically, there exists a misunderstanding and openness about mental illness among racialized groups/culture (Department of Health and Human Services, 2001). Turning to peer support groups for support should be much more encouraged for caregivers from racialized backgrounds, by making accessible language translation services, as well as culturally sensitive considerations during group meetings. Practical examples to enhance equity and inclusion include, promoting active listening, using inclusive language, encouraging diverse representation and asking for feedback from peer support group members. Furthermore, group philosophy emerged as an operational mechanism of peer support groups that caregivers of people living with SMIs found to influence the support received from peer support groups. While some support groups stood as caregiver advocacy groups, others were education-focused to mainly help caregivers with information for caregiving. The education-focused philosophy of peer support groups emerged in response to caregivers of people living with SMIs who typically start their journey not knowing where to look for information (Port City Home Services; No Date; Obegu et al., 2024). The present study found that caregivers' felt a sense of belonging when their goals were in alignment with the philosophy of the group/what the group stands for. However, group philosophy took a different direction in the study as a caregiver noted that being "honest" about their caregiver experience to other caregivers in the group was not received well, leading to their unwelcome presence in the support group. This misalignment in accepted beliefs/philosophy of the group led to the negative support received by a caregiver in the group. To encourage alignment of group philosophy in enhancing support for caregivers, we suggest an open communication of the group's philosophy so that participants are aware/reminded of the beliefs of the group and what it stands for. This way, individuals will understand their roles in the overall objective of the group. For example, if the group makes it clear through printed materials and during discussions that there are an advocacy group with a mission to get government's buy-in on the subject of their advocacy, it will help new and even existing members align themselves with the group philosophy as they support one another.

Lastly, an operational mechanism of group-based support that emerged from the study was privacy concerns. Caregivers noted mixed opinions about privacy concerns as some called for more privacy during meetings which should enrich the peer support group experience. This finding is similar to a report that points to the discouragement of people with SMIs and their caregivers by extension in seeking help where there is an uncertainty of privacy (Felt-Lisk et al., 2003). Others described their experience of privacy concerns noting that privacy was getting in the way of the interactions among group participants, wherein they were unable to contact each other after support meetings. Given the interplay of personal struggles of caring for a person living with SMI and the associated stigma that still very much exists, privacy concerns are not far-fetched. Despite peer support groups operating independently of one another in Canada, the peer support group experience will be enriched if privacy is prioritized, thereby enhancing the desired support caregivers look to receive from these groups. In cases where associated stigma tends to inform privacy concerns, we encourage reassurance of privacy to group participants by group facilitators (in relation to applicable privacy laws), with total respect for participants' privacy within and outside of peer group settings.

Strengths and Limitations

In the present qualitative study, we employed a co-design participatory design, with members of the study population (caregivers) directly working with the research team to guide and produce more meaningful research questions and methods. Another strength of the study is our nationwide study participation, capturing caregivers' perspectives of peer support group operational mechanisms in all regions in Canada. This elicited unique and rich findings around the research topic that as of the time of publication of this paper, had not been explored. The study sampling was purposive to enable a more detailed exploration of caregivers' perspectives of peer support group operational mechanisms. However, we understand that this may limit generalizability of the study findings and may not be applicable to other groups like caregivers of people with other conditions.

Conclusion

The burden of caregivers of people living with serious mental illness is sufficiently documented and much is known about the benefits of peer support groups in helping caregivers cope with the burden of caregiving. However, how peer support groups operate to lend support to caregivers is less understood. Findings from this study show that caregivers identified a number of operational mechanisms of peer support groups that explained how they felt supported when they participated in these groups. The pairing/gathering of caregivers of different age brackets and varying caregiving experience negatively influenced the peer support experience of caregivers, hence the need for group dynamics that consider closer age brackets and similar caregiving experience during group meetings to enhance support for caregivers. Caregivers also identified a gap in equity and inclusion in peer support groups, that could have otherwise enriched their experience and enhanced the support they looked to receive from the group. Caregivers from racialized backgrounds pointed out the need for more culturally sensitive content, and representation in groups to encourage inclusion. The present study found that caregivers felt a sense of belonging and ultimately supported when their personal goals were in alignment with the philosophy of the group/what the group stands for. Those who looked to groups to advocate on their behalf felt supported when the group's philosophy was advocacy as opposed to say, education only. While peer support groups in Canada exist independently of one another, it will help to consolidate evidence-based recommendations such as those of this study in the operational mechanisms of peer-support groups, for the benefit of caregivers who turn to these groups for support, having been left on their own by an otherwise fractured mental health system. While this is a first of a kind study on the operational mechanisms of peer support groups of people living with SMIs in Canada, we recognize that there is room for more exploration of this topic utilizing study designs that are more generalizable including quantitative studies. Also, exploring other aspects of this topic including the role of peer workers in the operational mechanisms of peer support groups and how they influence support for caregivers will increase and strengthen the knowledge base.

Acknowledgements We would like to thank the study participants for their participation including the co-design of this first of its kind study. We appreciate the staff of IAM who were involved in the administrative coordination of this study including Sophie Hwang. We also appreciate Erin Boudreau who was a key supporter of this study in its inception.

Funding This study was funded with grants received from Petro Canada's CareMakers' Foundation.

Data Availability The qualitative dataset generated and analyzed during the current study are not publicly available due to not compromising individual privacy and legal restrictions.

Declarations

Ethics approval and consent to participate In accordance with the Declaration of Helsinki, ADVARRA Institutional Review Board Services approved this study on the 13th of July 2023 (Pro00072543). Participants signed a written informed consent form before taking part in the study.

Competing Interests There are no competing interests to this manuscript publication.

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