

The Qualitative Report

Volume 22 Number 1

Article 12

1-16-2017

Depression/Bipolar Peer Support Groups: Perceptions of Group Members about Effectiveness and Differences from Other Mental Health Services

Joe Behler Union Institute & University

Allen Daniels Health Care Consultant

Jennifer Scott
Union Institute & University

Lewis Mehl-Madrona

Coyote Institute, mehlmadrona@gmail.com

Follow this and additional works at: https://nsuworks.nova.edu/tqr

Part of the Quantitative, Qualitative, Comparative, and Historical Methodologies Commons, and the Social Statistics Commons

Recommended APA Citation

Behler, J., Daniels, A., Scott, J., & Mehl-Madrona, L. (2017). Depression/Bipolar Peer Support Groups: Perceptions of Group Members about Effectiveness and Differences from Other Mental Health Services. *The Qualitative Report*, 22(1), 213-236. Retrieved from https://nsuworks.nova.edu/tqr/vol22/iss1/12

This Article is brought to you for free and open access by the The Qualitative Report at NSUWorks. It has been accepted for inclusion in The Qualitative Report by an authorized administrator of NSUWorks. For more information, please contact nsuworks@nova.edu.



Depression/Bipolar Peer Support Groups: Perceptions of Group Members about Effectiveness and Differences from Other Mental Health Services

Abstract

Peer support services remain poorly understood by many mental health service providers. In this study we explored the views of people who use peer led support groups. We asked how adding peer support groups changed, balanced, or augmented the use of conventional mental health services. Participants were 43 adults attending 4 peer led support groups for depression/bipolar disorder. Data consisted of observations of all 43 participants interacting in their group, in-depth interviews of 20 participants, and results from 2 standardized questionnaires to ballpark the level of symptom severity relative to other groups. Through constant comparative analysis, 12 categories emerged. The most salient features of our findings consisted of the shared perception that groups promoted recovery and augmented conventional services. Members felt acceptance due to their shared diagnoses. Groups provided an experience of community in which recovery skills could be practiced, practical advice received, and hope and empowerment encouraged. Groups appeared to provide participants with important support and healing unavailable from psychotherapy and psychiatry. Peer support groups appeared to be an important addition and sometimes an adequate substitute for psychotherapy and/or psychiatry. Further research is indicated and quantitative students should build on the insights of qualitative studies in developing their protocols.

Keywords

Peer Support, Bipolar Disorder, Depression, Group Psychotherapy, Peer Counseling, Mood Disorders, Grounded Theory, Constant Comparative Analysis, Mutual Aid

Creative Commons License



This work is licensed under a Creative Commons Attribution-Noncommercial-Share Alike 4.0 License.



Depression/Bipolar Peer Support Groups: Perceptions of Group Members about Effectiveness and Differences from Other Mental Health Services

Joe Behler

Union Institute & University, Brattleboro, Vermont and Cincinnati, Ohio, USA
Catholic Charities, Covington, Kentucky, USA
Community Mental Health Center, Lawrenceburg, Indiana, USA

Allen Daniels Health Care Consultant, Cincinnati, Ohio, USA

Jennifer Scott

Union Institute & University, Brattleboro, Vermont and Cincinnati, Ohio, USA

Lewis Mehl-Madrona

Coyote Institute, Orono, Maine, USA Eastern Maine Medical Center Family Medicine Residency, Bangor, Maine, USA Acadia Hospital, Bangor, Maine, USA

Peer support services remain poorly understood by many mental health service providers. In this study we explored the views of people who use peer led support groups. We asked how adding peer support groups changed, balanced, or augmented the use of conventional mental health services. Participants were 43 adults attending 4 peer led support groups for depression/bipolar disorder. Data consisted of observations of all 43 participants interacting in their group, in-depth interviews of 20 participants, and results from 2 standardized questionnaires to ballpark the level of symptom severity relative to other groups. Through constant comparative analysis, 12 categories emerged. The most salient features of our findings consisted of the shared perception that groups promoted recovery and augmented conventional services. Members felt acceptance due to their shared diagnoses. Groups provided an experience of community in which recovery skills could be practiced, practical advice received, and hope and empowerment encouraged. Groups appeared to provide participants with important support and healing unavailable from psychotherapy and psychiatry. Peer support groups appeared to be an important addition and sometimes an adequate substitute for psychotherapy and/or psychiatry. Further research is indicated and quantitative students should build on the insights of qualitative studies in developing their protocols. Keywords: Peer Support, Bipolar Disorder, Depression, Group Psychotherapy, Peer Counseling, Mood Disorders, Grounded Theory, Constant Comparative Analysis, Mutual Aid

Consumer-operated or peer-led programs consist of groups of people with similar problems who come together in places they own and control to learn from each other without experts (Chamberlin, Rogers, & Ellison, 1996; Davidson, Chinman, Kloos, Weingarten, Stayner, & Tebes, 1999; Lieberman & Snowden, 1994). Consumer-operated programs are not

clinical treatment and tend to use the language of recovery more than that of maintenance (Davidson et al., 1999).

Consumer groups such as Mental Health America, National Alliance for Mental Illness, and the Depression Bipolar Support Alliance (DBSA) recommend support groups in addition to other services for mood disorders (Depression Bipolar Support Alliance, 2012; Mental Health America, 2011; National Alliance on Mental Illness, 2012). The Substance Abuse and Mental Health Services Administration promotes peer support (SAMHSA, 2004). "The American Psychiatric Association recognizes, supports and promotes peer support services as an important part of the continuum of mental health and substance use disorder services" (American Association of Community Psychiatrists, 2010).

Peer support comes in many forms. Davidson et al. (1999) have described three types of peer support: informal (naturally occurring), peers participating in peer/consumer run programs, and consumers employed as peer providers (Peer Support Workers [PSWs] or Peer Specialists). Repper and Carter (2011), in a review of 38 studies published between 1995 and 2010 on peer support in mental health services, identify the growth of the employment of PSWs in the US, Australia, and New Zealand over the last decade, and more recently in the UK.

The idea of recovery has been intimately linked to peer support and came to the forefront when The President's New Freedom Commission recognized it as an essential focus of service programs for persons with serious mental illness (Hogan, 2003; New Freedom Commission on Mental Health, 2003). Services that promote recovery and include the person with disabilities in all facets of intervention appear to yield greater success in helping people to meet their vocational and independent living goals (Corrigan, Faber, Rashid, & Leary, 1999; Rogers, Chamberlin, Ellison, & Crean, 1997). Peer-support, peer-counseling, and consumeroperated services are considered integral to the recovery process (Corrigan, Calabrese, Diwan, Keogh, Keck, & Mussey, 2002) and appear to facilitate recovery from serious mental illness (Corrigan, Slopen, Gracia, Keogh, & Keck, 2005). Gaining a sense of personal value is fostered by peer support and believed to be important for recovery (Corrigan, Slopen, Gracia, Keogh, & Keck, 2005). Laudet, Magura, Vogel, and Knight (2000) analyzed 310 interviews with people attending Double Trouble Recovery (DTR) in New York City and found that people diagnosed with both substance abuse disorders and mental illnesses reported less substance abuse, mental distress, and greater levels of emotional wellbeing when they participated in these type of peer support groups.

Cabral, Muhr, and Savageau (2013) showed that peer counseling was useful for mental health patients who were deaf, commenting on how those who are deaf feel marginalized and how peer support can offset this. Peer support was shown to provide useful social networks for Latino Migrant Day Laborers who otherwise had no access to services (Negi, Michalopoulis, Boyas, & Overdorff, 2013). Peer-to-peer learning and teaching were shown to be an effective and underutilized strategy for preventing pressure ulcers in surgical patients (Meehan & Beinlich, 2014).

Mehl-Madrona and Mainguy (2014) found that peer-led talking circles (an Aboriginal form of peer support) in family medicine waiting rooms after hours had larger effect sizes in reducing the rated level of distress of common family medicine complaints than seeing the physician during hours. Group medical care is becoming more common in North America and contains some elements of peer group interaction. Among Canadian Aboriginal people, Mehl-Madrona (2010) showed that group medical care for diabetes that was inclusive of a traditional elder, a behavioral health specialist, and a physician was more effective in improving diabetes than the group without the elder and much more effective than individualized treatment as usual with health education groups. Gwozdziewycz and Mehl-Madrona (2013) found that peers made more effective counselors for war-traumatized refugees than professionals when using the technique of narrative exposure therapy.

Chinman et al. (2014) reviewed 20 studies across three service types: peers added to traditional services, peers in existing clinical roles, and peers delivering structured curricula. The level of evidence for each type of peer support service was moderate. Many studies had methodological shortcomings and outcome measures varied. "For example, sample sizes in various studies often were small, outcome measures with unknown reliability or validity were used, data collectors usually were not blind to the treatment group (raising the issue of possible bias), self-reported data on symptomatology did not have corroborating reports from other sources, and research designs involved wait-list control groups rather than active control groups" (p. 433). The effectiveness varied by service type. Across the range of methodological rigor, a majority of studies of two service types—peers added and peers delivering curricula—showed some improvement that favored peers over professionals. Compared with professional staff, peers were better able to reduce inpatient use and improve a range of recovery outcomes, although one study found a negative impact. Effectiveness of peers in existing clinical roles was mixed.

In a systemic review and meta-analysis of 18 trials with 5597 participants (Lloyd-Evans et al., 2014), including 4 trials of mutual support programs, 11 trials of peer support services, and 3 trials of peer-delivered services, substantial variation was found between participants' characteristics and program content. Outcomes were incompletely reported; there was high risk of bias. These authors found little or no evidence that peer support was associated with positive effects on hospitalization, overall symptoms, or satisfaction with services. There was some evidence that peer support was associated with positive effects on measures of hope, recovery, and empowerment at and beyond the end of the intervention, although this was not consistent within or across different types of peer support. They concluded that current evidence does not support recommendations or mandatory requirements from policy makers for mental health services to provide peer support programs.

This study took place in a context of debate about the value of peer support groups within mental health services. Our curiosity about what people gained from these support groups that caused them to continue to go over months and years guided our approach.

The Researchers

Joe Behler is currently on internship on his way to psychology licensure after receiving his Doctor of Psychology degree from Union Institute & University. This study served as his dissertation. He was introduced to peer support and peer groups for mood disorders during his course on qualitative research and became interested in their effectiveness and how members negotiated their experiences in peer support with their involvement in the mental health system. With the help of his Committee, he designed this study.

Dr. Allen Daniels is an internationally recognized scholar in the area of peer support and peer counseling who has been studying this area for years and has accumulated information and knowledge about the operation of peer counseling groups and their effectiveness for a wide variety of problems. He serves as a consultant to a number of peer counseling organizations. Dr. Jennifer Scott is a Core Faculty in the Psychology Graduate Program at Union Institute & University in Cincinnati, and is interested in testing and measurement. She teaches the core classes in psychological assessment at Union. Drs. Daniels and Scott served as consultants for this study. Drs. Daniels and Scott served as advisors on design of the study and commented on the interpretation of the results. Dr. Lewis Mehl-Madrona is currently Executive Director of Coyote Institute in Orono, Maine, which is dedicated to exploring how indigenous wisdom can influence contemporary health care. He is also a faculty member in the Eastern Maine Medical Center Family Medicine Residency and is an Associate Professor of Family Medicine at the University of New England. He has written elsewhere about the use of talking circles as

peer support among Aboriginal people and has been involved in providing group therapy services and training people to be peer support group leaders. He worked with Dr. Behler in designing the study and analyzed and interpreted the results with Dr. Behler.

Methods

Theoretical Position

Kenny and Fourie (2014) have written an excellent article about what it was like to study with Glaser and Strauss, both together and separately in the San Francisco Bay Area in the 1970s and 1980s. LMM was one of those students who became excited by the methodology. Like Charmaz, he was disillusioned by the type of theorizing that remained in grounded theory. Charmaz (2006, p. 5) wrote that Glaser and Strauss had pioneered a systematic procedure for qualitative research, demonstrating that qualitative analysis could be methodical, rigorous, and structured. They inspired generations of qualitative researchers (p. 7), though they believed in the eventual discovery of an implicit theory in the data, an idea which we and Charmaz reject. She insisted that neither the data nor the theories are discovered, but that both are co-constructed "through our past and present involvements and interactions with people, perspectives, and research practices" (p. 10). Kenny and Fourie (2014) note that constructivist grounded theorists continue to embrace a number of the original techniques, including theoretical sampling, saturation, constant comparison, and memo writing. They focus on a mutual construction of knowledge by the researcher and participant with the ability to develop subjective understandings of participants' meaning (Charmaz, 2000, p. 510).

During this time LMM was exploring indigenous knowledge and the ways in which it is obtained. Through this line of investigation he became interested in stories and narrative analysis and inquiry. He came to believe that the basic unit of human knowledge is the story and that the role of the researcher is to elicit the stories related to a question, since the stories people hold and tell, guide their behavior (Bryman, 2008; Sarantakos, 2005). Phenomenology became his friend, since he was interested in finding ways for people to tell their stories. Phenomenology facilitates researchers being able to identify both common and unique experiences in people's discourse and facilitates an understanding of the lived experiences of people. His goal has been to explicate a uniquely North American Aboriginal approach to research that is story-based, rigorous in its observations, systematic in its approach, and reflective of the meanings and structures that people co-create through interaction with the story. The perspective that he brought to this methodology was to invite people to tell their stories about what peer support groups meant to them. The goal was to find what was common among the participants. Why was the group important to them? What were their stories about its importance? What were their stories about how groups should function and who should lead them? The goal was to facilitate the stories of the participants in this study to emerge in a composite form to create a story with which all could agree to explain why this group was important. Dr. Behler was in agreement with this perspective.

Description of Methodology

We used the constant comparative method, as well as theoretical memo writing (starting with whatever ideas the text inspired), then theoretical coding to come to a higher level of understanding of what common areas might exist in the stories people told, and then theoretical sorting in which these memos were organized into similar themes. We used a possibly archaic method of cutting out the memos and arranging them on the floor in piles that seemed to group together and then placing the piles in relative distances from each other to indicate potential

similarity and repeating the process iteratively until we arrived at the themes which all could endorse. Inevitably some idiosyncratic categories remained as orphans, since they referred to individual experiences not shared by other the participants and therefore, while interesting, were not relevant to our aim of finding the common elements that drew people to peer support groups and kept them coming. We differed from classical grounded theory in the sense that we were not trying to develop a theory of peer-support groups (Charmaz, 2000), so much as to create an opportunity for participants in peer support groups to tell the story of what drew them and kept them coming. In that regard, we also repeatedly returned to participants to share our developing understanding and to make sure it fit their understanding. In this regard, our methodology was decidedly narrative and influenced by writings about narrative inquiry (Clandinin, 2013). We were really most interested in presenting what participants would say was the value of peer support groups and not drawing conclusions on our own or generating theory about peer support.

Recruitment and Inclusion

We received approval to proceed from the Union Institute & University's Institutional Review Board. We recruited groups for participation by contacting the leaders from a directory of peer support groups compiled by the local mental health services agencies in the greater Cincinnati area. The leaders of eight groups were approached, and four agreed to participate. Dr. Behler then attended the group to be introduced, to present his study, and to invite all present to participate. Once invited by the leader, no group refused. Out of 43 potential participants, 20 volunteered to be interviewed.

The four support groups gathered at three Christian churches and one County mental health center location, one evening per week for 2 hours. One group was an affiliate Depression Bipolar Support Alliance (DBSA) group, two were former Depression Bipolar Support Alliance (DBSA) groups, and the fourth group was affiliated with Recovery International. The DBSA, founded in 1985, includes as part of its mission, an intention to provide peer support groups for mental health consumers in a network of affiliate groups across the United States (Depression Bipolar Support Alliance, 2012). Recovery International was established in 1937 by Abraham Low, MD, as a peer-to-peer, self-help training system (Recovery International, 2014).

The Participants

JB interviewed 20 individuals out of 43 total people who were attending 4 peer led support groups from two states in the greater Cincinnati metropolitan area, ranging in age from 32 to 76, with a mean age of 52.3 (standard deviation, 13.95 years) with 11 females and 9 males. Nineteen participants were of European-American ancestry and 1 was South Asian American. Diagnoses of participants were bipolar disorder (8); major depressive disorder (7); dysthymic disorder (2); and schizoaffective disorder (1); two people had not received a formal diagnosis. Participants had been attending group for an average of 6.6 years (S.D. = 3.15 years). Fourteen were taking psychiatric medications and 6 were not.

Questionnaires

We gave participants two questionnaires to gain some comparative awareness of the level of distress and symptomatology among the people we were interviewing. Participants completed the Outcome Rating Scale (ORS), which assesses wellbeing. The ORS has high test-retest reliability and strong internal consistency reliability (Miller, Duncan, Brown, Sparks, &

Claud, 2003). Participants were also administered the Measure Yourself Medical Outcome Profile, Second Edition (MYMOP2). The Health Services Research Collaboration of the UK's Medical Research Council created this individualized self-report measure in which the patient selects two symptoms to monitor—things that matter to him/her. They also monitor an activity, medications, and general sense of wellbeing (Reilly, Mercer, Bikker, & Harrison, 2007). The ORS and MYMOP2, collected once, established a benchmark for average of symptom severity among our participants to aid comparison to other studies. We were satisfied with simply noting whether or participants fell within the mild, moderate, or severe level of clinical symptom severity.

The ORS mean was 23.78 and the standard deviation was 9.36. The clinical range is less than 25. Typical clinical sample means are 19.6 with standard deviation of 8.7 (Duncan, 2012; Miller et al., 2003). Our population appears to be on the higher-end of the clinical range, moving toward higher levels of overall wellbeing. The MYMOP2 mean score was 2.58 with a standard deviation of 1.61. This can be compared to the norms from a UK general medical clinical practice where the patients' mean score was 4.7 (Paterson, 1996). These results are consistent with the results on the ORS with the MYMOP2 scores being on the low end of the symptom scale of 0 to 6, again suggesting that the participants in our study have fewer symptoms and a higher sense of overall wellbeing.

Interviews

We envisioned the interviews as the creation of opportunities for people to tell their stories about their illness and what the groups meant as described by Ollerenshaw and Creswell (2002). Our interview questions were conceived as guidelines for creating a conversation in which a story emerged ideally touching upon all the areas that interested us. In doing this we followed the ideas of narrative inquiry (Clandinin, 2013; Merriam, 2014) as exemplified in completed studies (Craig, Zou, & Poimbeauf, 2014). The questions themselves were collaboratively created with another peer-support group that Dr. Behler visited during his graduate course on qualitative methodology. He asked people in that group to help him formulate questions that he could ask to help understand the value that peer support had for others. The Appendix contains the full range of possible questions which could be asked. Disagreements exist within the qualitative research community about the practice of asking every question versus the goal of interviewing for the purpose of eliciting a conversation, which becomes a story. This controversy has been discussed since at least 1990 (Clandinin & Connelly, 1990). We followed the practice of using the questions as a loose outline, attempting to cover all the material that would be accessed by the questions, but allowing the interviewees to tell the story as the story came to them, returning to the questions when natural pauses occurred, consistent with the methods of narrative inquiry. Interviews were recorded with the permission of participants. Transcripts were made and shared with participants who could make clarifications or changes if they wished.

Group Observation

JB engaged in casual conversations with leaders and members of the groups before group, during breaks, and afterwards. These observations were meant to complement the interviews and to provide a further perspective (that of the group interaction) to understand the individual's comments. JB wrote down his observations immediately after the group ended. For example, JB wrote during one group about how the members asked the leader about people who had not come for several weeks and the leader reported on her phone calls to check on these missing members. This further confirmed what members reported in the interviews—

that leaders could reach out to members and care about them in a different way than professionals do. JB attended group sessions to recruit participants and made his observations during the course of recruitment and interviewing. Other than the behavior of the leader, he made no comments on individual members, but rather on the group process and the topics of discussion.

JB and LMM reviewed and reflected upon his observations as part of the iterative process of going through the transcripts. His notes gave JB and LMM an additional sense of the context in which participants' statements were made. To the extent possible, we strove to be theory-free and to allow the observations to emerge with a minimum of interpretation as described by Charmaz (2000).

Data Analysis

Transcripts were analyzed by JB and LMM together. We began by reading the transcript with an eye to the question of "What is being said here?" We used a variety of colors to highlight text that interested us as saying something about the person, about his or her experience with peer support groups, about his or her diagnosis and experience with the psychiatric care system, and more. The colors denoted our earliest separation of the data into broad categories, such as statements about self (blue), statements about group (green), statements about mental health professionals (yellow), statements about the group leader (violet), and so on. When we had gone through the transcripts twice to find everything of potential value, we began again to review our highlighted comments, asking the question, what area of concern is this person addressing? Observations of group process were included in this iterative process primarily to help us contextualize the transcripts we would be analyzing and to make sure we had not missed any important details. As an example, JB commented in one interview on a process he observed during the group and used his observation as a stimulus for gathering more information. He said,

That kind of thing that happened the other day when I was observing and how you were helping a group member deal with that issue and the way her drinking was an issue and the way you handled that. . I thought that was quite impressive the way you just stayed with her and listened and tried to help her see what she can do. Does that kind of thing happen all the time in the group, different kinds of things like that where you help somebody?

We used the constant comparison method to assure that all data were systematically compared to all other data in the data set (Fram, 2013). This assures that all data produced will be analyzed rather than potentially disregarded on thematic grounds.

We wrote memos in the margins of the text to signify the areas we thought the participants were addressing and what their comments implied. We used the constant comparator analysis method to continue to iteratively go through all the transcripts to arrive at a set of organizing themes to describe the experiences and perceptions of participants and what emerged to us about their experiences and perspectives. We aimed to allow these themes to emerge through the dialogue among the two of us with the transcript. We shared our ongoing observations with the participants themselves and provided the opportunity for them to critique and comment upon what we were developing, thereby enabling them to provide input at all stages.

Here are some examples of memos:

From Participant 1 (describing what is important about the group to him): The group is more at ease, laid-back, um- I am not sure if I am going to say this right but there is camaraderie of the people, and after you are here so long, and you don't come, you miss that. You miss being in a room full of people that are bipolar, or people that have depression. When you are not in the room you are out there and you feel isolated, like there's a glass wall around you. So coming to the groups you can chill out, you can relax, you can say what's on your mind, and no one is going to - I haven't personally had anybody or felt like I've been judged. It is longer than a doctor session usually. It is longer because everybody takes a turn-and with that, those other people that are taking their turns you may relate exactly to it and the situation may come up in the future that you can learn by, by the person telling about the experience. Um, so it is longer and more laid-back [than a doctor's appointment].

Memo: Apparently the world outside the groups doesn't feel very safe? Or friendly? Or Supportive? Or accepting? Maybe of people who are different?

The above memo was coded initially as "things the group provides that aren't available in the outer world" and eventually became part of the broader theme "How is Group Different from the Support of Family and Friends."

Memo: Apparently outside of the company of other similarly diagnosed people, this woman feels isolated and judged. In the company of people with her same diagnosis, she feels she can relax, chill out, and say what's on her mind.

The above memo was initially coded as "What's different about being in the company of people with the same diagnosis?" and eventually was placed in the category of "Acceptance and Empathy."

From Participant 7: I know I've mentioned it but I think the most important thing about recovery was my family a lot of people don't have that and that's a shame. This was more so than the medication even or anything. The way my family would rally around me made all the difference.

Memo: He feels grateful to have a supportive family as many group members do not have this support. ???? Does the group become their family?????

The above memo was originally coded as "Functions of the group that family does not provide." It eventually became part of the category "Community."

From Participant 14: R: Has the support group been helpful to you? If so, talk about how it has helped you.

P: Tremendously helpful, just the knowledge that you gain from people who have lived through it and even if you are just starting and it's become new to you there is always someone who's been through it, something similar, just the feeling that you are not alone and this is something that's only happening to you. It is tremendous support and you never feel like an outcast or unwanted.

Memo: The group is tremendously helpful, with knowledge that you gain from people who have lived through it and even if you are just starting and it's become new to you there is always someone who's been through it, something similar, just the feeling that you are not alone and this is something that's only happening to you. It is tremendous support and you never feel like

an outcast or unwanted. Sometimes our initial memos appeared to simply repeat what the person said to us.

The above memo was originally coded as "Positive benefits from being in the group" and eventually came to be placed into the category 'Hope and Empowerment."

R: What other kinds of help have you received to manage your diagnosis?

P: I have been to my psychiatrist regularly. I have not done therapy with the therapist. My psychiatrist offers it but we have an agreement at this time that with the support from the group it is not needed. She is a tremendous support and between her and the group so far this has been able to cover what I need.

Memo: The group and her medication are enough to sustain her needs. She does not see a therapist but talks to her psychiatrist if needed in more depth but only during medication check appointments.

The above memo was originally coded as "The ways in which people optimize services" and eventually came to be part of the category, "Mental Health Professionals."

In each iteration, we commented further upon memos and added questions and notes. During each iteration we asked what similarities existed across participant responses. We continued in an iterative process in which transcripts were repeatedly reviewed until we came to consensus about what was common to the responses of participants.

We included the field notes of group observations in the iterative process to make sure that our observations were grounded in the larger context of the group and that interviews had not missed important topics of discussion. For example, once we had developed all our themes, we combed through the group observation notes to make sure that we did not miss any themes. We recognize that our results are embedded within our process and enculturation and that others may have seen different categories in this data. The results to follow are our best synthesis of what emerged from the data. We were drawn to agree with Minkler (2000) that quality in qualitative research could be linked back to the participants agreeing with what we concluded about their reports, and this was what we emphasized.

Results

We present the results of our question about what peer support provides differently from conventional mental health services. The following themes emerged consistently from the interviews and observations.

1. Being with peers who have shared the same experiences of mental illness and can relate in a more direct way than family and professionals who have only observed others having these experiences, provides a unique and desirable benefit toward wellness, functionality, and recovery.

Participants experienced a kind of acceptance and empathy in the peer support group that they did not feel from their family members or professionals. Group members repeatedly used the words acceptance, care, support, encouragement, understanding, and safety to describe how they felt and what they received from the group, saying that feeling this way promoted recovery and improved functioning. Attending group reduced feelings of being stigmatized and feeling isolated.

Participants repeatedly stated that Peer Support provided an experience of mutual understanding from people who shared similar experiences without the perceived constraints inherent in the formal boundaries existing in most professional relationships. Regardless of whether or not they had supportive family and friends, group members described receiving an importantly different kind of support from peers who had been there and had "walked the walk and talked the talk" than from what they received from family and friends. A participant shared a story in which she drove her vehicle over 100 miles an hour during a manic episode. Two other members related having done the same during their prior manic episode. She said this sharing promoted understanding of what it is like to experience a manic episode. Observation of other group interactions revealed similar interchanges that led to a mutual understanding of a depressive episode, understanding suicidal feelings, medication side effects, and other mutually experienced symptoms and behaviors. During the interviews, several people used the "boiled frog metaphor." If a frog is placed in boiling water it will jump out. However, if the frog is put in cold water and the water is slowly heated then it is less likely to experience the danger and will be boiled to death. They used this metaphor to describe the difficulty people experience when change occurs gradually. A 38-year-old man who attended group every other week for the last 3 years said that "people who are around you every day may not notice that you are changing, but the people who see you every two weeks, weekly, or once per month might notice." This provides a safety net for the fear of being hospitalized again or regressing. Members stated that a family member who sees you daily may not recognize increasing symptom whereas the group would be able to tell. One man invited his wife to a group and after she attended asked her not to return because he valued the experience of interacting with the group alone, without her input. He reported a strong and positive relationship with her, denying marital problems or difficulties, but did not want her to intrude upon the comeraderie of the group.

A 46-year-old man who had attended the group for 6 years said,

I trust the group implicitly, you know, excuse me (getting teary-eyed and holding back his tears), we. . .(taking time to collect himself). . .I have a pretty close bond with people and there are some that don't come anymore and I called one of them once. It just makes you feel like you're not alone.

A 32-year-old woman who had attended group for 3 years said, "If I'm not here, they wonder where I am and that kind of stuff." A 63-year-old woman said, "I find there are other people in the world like me and I know when I am at my worst there is someone that cares because I don't have that at home." She said further,

I have only been here with them since July [8 months], but they have really grown fondly in my heart and they are a support to me. They take me as I am and not how they want or expect me to be, and that helps.

A 41-year-old woman said, "I was able to come here and explain what was going on and I felt like the people are really sincere here and truly do know what is going on."

Group members frequently reported meeting outside of group and developing friendships, calling each other during the week, checking on each other, all of which could combat the loneliness and isolation of coping with mental illness. In one group two men became friends and met outside the group to play guitars or go to a concert. Women described shopping together or walking in the park. At two groups, members sponsored dinners or picnics once or twice a year. The 65-year-old leader of one of these groups said,

We have a mini potluck usually in June or July and then we have a big Christmas potluck in the first part of December, but we are starting to do all the Christmas stuff in between Thanksgiving and Christmas and we do that upstairs [in the kitchen]. We actually cook for that. I actually make turkeys and all kinds stuff like that. I'll make turkeys here but heat stuff up in the kitchen. We actually use the kitchen when we do that and we had probably at least 25 people the last time during Christmas.

We interpreted these comments as saying that peer support groups provide a strong social network, friendships, a sense of belonging, a sense of family, and facilitate gathering outside the group differently from one-to-one relationships, which can feel like a friendship but do not provide a communal experience and cannot occur outside session due to the formal boundaries and hierarchical relationships inherent in the contemporary practice of psychotherapy.

The members who did not have a supportive family reported that the sense of community and friendships from the group was especially important. The group community included family members without a diagnosis, since they were welcome to attend annual dinners and picnics. A 62-year-old father attended the group with his wife due to their concern about their 22-year-old son who had been diagnosed with major depression and social phobia. He said,

I was pleasantly surprised when my son got to know a few people at the group and made some friends with some of the people. He socialized outside of the DBSA sessions and they came over his place and he goes over to their place. So that is positive since he has depression and social phobia.

2. Peer support facilitates social identification with others who share the same diagnoses, thereby promoting wellness, function, and recovery.

Group members said that sharing the same diagnosis provided camaraderie, unity, a bond, and the use of a shared language that is different from what professionals gain from their use of the DSM-IV-TR. They reported feeling relaxed, safe, and able to speak about what was happening in their mind because they shared the same diagnoses. One member said she could "chill out" in group in contrast to feeling judged, stigmatized, and isolated on the outside of group. A 74-year-old man said,

I kept everything inside because I thought people are going to think I am wacko, that I am nuts if I share these feelings that I have depression, anxiety, and anger. I guess the first thing I was aware of was that everyone had symptoms like me and some of them had more symptoms. All of a sudden I started opening up and found that I was not the only one.

Group members were comforted to discover they were not the "odd ball" or the exception and were not alone with their symptoms. This feeling of shared diagnosis normalized their experience and created camaraderie and unity. A 48-year-old woman described it as "the camaraderie of the people." She said,

After you are here so long and you don't come, you miss that. You miss being in a room full of people that have bipolar or people that have depression. When you are not in the room you are out there and you feel isolated, like there's a glass wall around you.

People with the same diagnosis knew how it felt to have done similar things, so it was not embarrassing to talk to them, whereas professionals may not know how it felt, and it was embarrassing to talk to them. Sharing the same diagnosis created a bond which seemed important to recovery. In further describing her experience of the group this woman said,

It is not as embarrassing because I know they've felt we've done the same thing so they know where I'm coming from; whereas a psychiatrist is not necessarily bipolar. She has read about it and studied it and seen it and put people in the hospital for it but she doesn't know how it feels.

Participants frequently remarked on how helpful it was to see others as not so "well," which appeared to apply between group members as well as between mental health professionals and group members.

3. Watching other people help themselves and get well encouraged and promoted normalization of one's own behavior.

Participants reported that watching others help themselves within the peer support group was encouraging and normalized behavior in a mutually respectful way as compared to the hierarchical experience received with professional experts through role-play or review of skills. They stated that an important function of group was to practice and model skills that came directly from other members. Group members commented frequently about the changes in themselves or in other group members due to learning from each other and practicing skills.

As an example of normalization, one of our respondents said,

Coming to the group and seeing all these people with the different behaviors and kind of comparing yourself and learning from them and then you start finding out, well gee, my sister has this and it is in the family. It kind of normalizes it or something.

Another respondent said,

Before I went to the first meeting I kept everything inside because I thought people are going to think I am wacko; I am nuts if I share these feelings that I have—depression, anxiety, anger, and I guess the first thing I was aware of when I got in recovery was that I noticed that everyone had symptoms like me and some of them had worse symptoms. So then, all of a sudden I started opening up and talking according to the way recovery is structured; we give the example of the four steps and I found that I wasn't exceptional anymore. I was not the only one, and I think that was the first thing that made an impression on me.

She continues to say that this awareness of not being the only one and others being worse than she contributed to her believing that she could function better and could recover. A third respondent talked about practicing skills at his job as a roofer that he had learned in group:

I would get all upset on the roof and carry on and argue. . . . Eventually after about 6 months I started getting insights into how to help myself and realized that recovery was working, even though at first I had to be satisfied with small

gains. Probably the four steps of the example helped me more than anything else. . .giving examples at recovery meetings and then trying my best to apply them on the job, like when I was roofing. I guess one of the things that I did was I started slowing down when the boss wasn't looking. When the boss was looking you had to speed up or else you are the next one to go, you know. Here's your second check, sorry to let you go but really you knew that they let you go because you weren't going fast enough. But, anyway I learned to slow down in spots where the boss wasn't looking or he wasn't around, and then I might go to the bathroom a time or two. All of this was to settle myself down so I could handle situations. I guess doing things and small acts and I picked up on the endorsement, endorsing myself for small gains. You know, if I went to the porta-let I wouldn't stay there long. I would stay there 2 or 3 minutes and just rest and run a few recovery actions through my mind. If I would leave there I would endorse myself, facing the situation with courage and more or less resting and getting some objectivity and more or less settling myself down. You might say that the state was similar to meditation but instead of meditating I was running the right recovery actions through my mind. I read the book and I read the book and Dr. Low, everything he says in there is the secure thoughts that he wants you to replace your insecure thoughts with. So I practically memorized the original book, which is Mental Health Through Will Training, not really memorized it but I knew it pretty well. You know, when I get in situations I can remember all the secure thoughts that he would tell me such as this is an average situation and almost anyone would be as upset as you are. Maybe not quite as upset because as a nervous patient your intensity and duration with symptoms is longer but you can build nerve resistance by practicing recovery and the longer you do it you get to the point where your nervous system begins to become stronger so the symptoms don't last quite as small or the duration.

This man used the group as an opportunity to keep learning new skills and practicing and reporting on the ones he was cultivating, all the while getting encouragement and feedback from other group members.

4. People within peer support groups provide suggestions, share experiences, and give tips that are more meaningful than those which come from professionals who do not have lived experiences.

Participants reported that these practical experiences and tips were easier to incorporate into their lives due to the security of the relationships that developed in the group. In some cases the information was about non-mental health issues. One participant recommended a good physical therapist to another. Another group member helped five others through the detailed process of getting approval for Social Security Disability Income (SSDI), since he had successfully navigated the process for himself. A 35-year-old man said that regular exercise reduced his anxiety and depression. This had been recommended by another group member. He said,

Anxiety, a lot of times, is connected to cortisol and cortisol is usually higher in the morning so you might like to try exercise in the morning. That's when I started running and it's been the greatest thing that I've ever done. It has absolutely changed my life.

This man had taken anti-depressant medication for a major depressive disorder but over time stopped it, continuing with supportive psychotherapy, the peer support group, and exercise. Participants said that these simple interventions were more powerful because they were suggested by trusted peers who understood the value of practical actions that made a difference. In another example, a participant suggested that a distraught father take his son to the park to walk the dog, as a way to connect with him, since this member was so upset that his 9-year-old son was diagnosed with bipolar disorder, just like him, his father. The man said this suggestion helped tremendously.

Several members appreciated literature, information, and trainings offered through DBSA about how to manage their diagnoses. The Recovery International groups referenced *Mental Health through Will Training* by Abraham Low (1950), the founder of the recovery group, as a main resource as well as literature available on their web site and provided as handouts at group meetings. This literature was available at three of four of the meetings. Another member reported learning to recognize triggers for a manic episode by listening to other members share their experiences. A couple attended their first peer led support group after the husband had been hospitalized twice for Major Depressive Disorder and reported in the interview that a group member shared an insight that helped them reflect on how depression had been affecting them. The wife said,

One of the girls mentioned that she used to do all kinds of things like [Ben], but she stopped and she realized that she was punishing herself, taking all the good things away to punish herself and [Ben] said he never thought about that before, so it just gives him something to think about.

Participants mentioned that the group provided an outlet when the doctor was not available, and was less expensive than professional services (sometimes free or by suggested donation); they mentioned that you can only go so often to a psychiatrist or therapist for low or no cost. Members reported that family members learned about depression and its symptoms and how it affects their loved ones by attending group. Members believed that they could not obtain this same knowledge by simply reading about depression or consulting with an expert. Members stated that observing and meeting group members with a diagnosis provided a valuable experience. Most members felt the attendance of their loved ones in group was essential not only for their support but for their loved one to obtain knowledge and information about their diagnosis.

5. Participants shared information and experiences with psychiatric medications and used the groups to become more informed consumers and to take more agency in managing their medications.

Even those who were pleased with their psychiatrists mentioned that psychiatrists pushed medication compliance from a power differential without room for people to make different choices. Although none of the four groups observed gave medical advice, members shared information about their experiences with medication and provided medication related referrals. Practical medication management occurred in which people compared notes about which drugs were working and explored how to manage side effects. Sometimes this information was taken to their psychiatrist, and sometimes not.

Participants reported many complaints about psychiatrists. They frequently complained that psychiatrists were "pill pushers" and wanted to "throw medication at you." Numerous group members met with several different psychiatrists until they found one whom they felt could help them. They compared their psychiatrists and rated them and helped each other

decide whether to continue with a psychiatrist or to find a new one if they were not having a positive experience. Three members took medications for years but were doing so well with psychotherapy and group that in consultation with their psychiatrists, they stopped medication.

A 44-year-old woman who was diagnosed with bipolar disorder at age 38 said she saw four psychiatrists before she was finally diagnosed. Several group members complained that their previous psychiatrists were "pill pushers" until they found a doctor that handled their medication management well. One group member said, "The group is almost as important to me as my actual medication."

6. Group members shared information about positive and negative experiences with mental health professionals and used the group to become more informed and selective consumers of psychotherapy and psychiatry services, educating each other in what good services were and how to recognize bad services.

A few group members discussed ethical violations by psychotherapists that led to mistrust. A psychotherapist was described whose license was revoked due to a conviction of sexual abuse of a client. A female member described being sexually abused by two different male therapists; she reported that she had finally developed a positive relationship with a female therapist. Despite these difficulties most group members had received or were receiving psychotherapy. However, a number of group members saw a psychiatrist for medication management and attended the group and reported this was all they needed. Numerous group members wished that their mental health professionals would self-disclose whether or not they were also suffering from a mental health diagnosis. Group members reported that this would help them feel understood by their professional, similarly to how they felt in the peer support group. One member from the Recovery International group said that 60 to 70% of people he had met used the program alone and did not use a psychologist or psychiatrist.

Overall, the majority of group members recommended a combination of medication from a psychiatrist, psychotherapy, and peer led support group. Several participants expressed that the group was more helpful than a psychotherapist because there was more time (2 hours) and because a therapist was not as astute about mental illness. They said that people who have had the same experiences are more attuned to what can happen and therefore more helpful than professionals who have not had these experiences. Another group member commented that some people who have benefited from the group have used it as a substitute for psychotherapy because they have had no insurance or were underinsured and could not afford a therapist. We frequently heard that "one must walk in the other's shoes to have true empathy," implying that only peer support supplied this critical factor.

7. Good peer group leaders are in recovery from mental illness; they welcome, accept, support, are nonjudgmental, understand, listen, attend to group tasks, and have good people skills, whereas clinicians do not generally reveal personal attributes or tell personal experiences and may or may not have had experience with mental illness.

Separately from our questions about what people gained from peer support, people uniformly spoke about their peer group leader. They told us that peer group leaders provide understanding and empathy, keep the group on task, and make sure that members have equal time to speak. The peer leader must be able to self-disclose, set limits and boundaries for the group and group members, and manage overall group details. One participant said the group leader must be like a good company manager, looking out for the whole team, but also keeping the group on task. Participants emphasized that peer group leaders must also be in recovery from mental illness. They believed this was crucial for group members to feel comfortable and

understood not only by other members who are diagnosed with a mental illness or have a family member with mental illness but also by the group leader. "Being in recovery or having a family/friend with mental illness is the credential that creates something different that promotes a better group," according to one participant. This 32-year-old woman said,

They've got to be levelheaded when things blow up, just like a manager would be able to do. So they have to have a lot of management skills and they have to have the people skills and be able to talk to people and defuse situations. For a peer led group obviously experience is important because you can't come in and start running a group and you can't run it as efficiently as you can if you haven't been there.

Participants reported that peer group leaders expressed their concern both within the group and outside the group, checked on former group members, and reported on them to members of the group. They told us that clinicians could reach out only within the session but must remain within professional boundaries, while peer group leaders could call group members to make sure they were not in crisis. Other peer members could also do this, but they said that the leader modeled how to reach out. We noted that all four leaders had a list of names and numbers of former members to facilitate keeping track of all of them. Periodically group members would ask the leader about a former member and the leader would contact that person for follow-up and would report back to the group. This was often in response to group members worrying or being concerned about a member who had stopped coming. Leaders had visited group members in the hospital or responded to a text or phone at the group. One of the leaders presented himself as a shepherd caring for his flock, thinking about group members and whether they were well or would come back to the group. He missed them. One woman who had led group for 22 years kept lists of names and numbers in case any members might want to return. One of the groups held a yearly dinner at the church where they met and the leader contacted people who had stopped attending and inviting them to dinner. Often they would come. A 48-year-old woman who had attended the group for 15 months described this process:

The people that don't come on a regular basis come to that dinner, because the sponsor, the leader, will call everyone that is on our list that has ever come to group. She has everybody's name and address and number, and contact information and the very first time they come they fill that out. So, she has the list. She tries to invite everybody that comes or that has been here.

8. Peer groups do not last forever; the lifecycle of a group depends on the leader and the group dynamics and can change frequently, unlike professional services which are more consistent unless a provider relocates.

Each of the four groups had its own history. We learned that the leader of the Recovery International group had led for 22 years. She was in her mid-70s and was concerned about who might lead when she retired. In the interview done with her, she reported having seen a decline in the region of the number of groups that were sustained and wondered what might be changing to cause this. The group leaders from two other groups were ages 65 and 70 and although they did not express any concerns to us about ending their role, they also reported seeing changes in the ebb and flow of attendance at the groups. We learned that a charismatic woman had led one of the groups for 6 months and had just retired. During her tenure as a leader, over 50 people attended at her location. At one point participants were divided into four separate groups to accommodate everyone. Since her departure the new leader had one group

that averaged about eight members each week from a total pool of 25 to 30 attendees. In the interview with her, she was unsure if the group might further grow, but having attended the group for 6 years, she described some anxiety about making sure the group would flourish. The last of the four groups observed was led by a 32-year-old woman who reported that she was building the group and expanding it. She had started the group 7 years previously and had met 155 people during this time. She was considering expanding this group from the criteria of depression and bipolar disorders to include all mental health diagnoses.

One respondent was both a participant and a group leader. He said,

I have had four or five meetings all over town, 2 years here, 5 years there, but the groups eventually close down. But actually the handwriting was on the wall when I started the groups because I was, like a supplementary or fill-in leader at that point and they would send me to groups that were deteriorating so I almost knew that with one or two people that if people didn't come very shortly that they wouldn't last. I would go to these groups and they would last 3 months, 6 months. I would be down to one person besides myself. It is hard to lead a meeting with just one person present. So I would close the groups but at least tried to keep them going.

Although the requirement that the peer leader must be in recovery from mental illness was identified consistently in three of the four groups while one of the four groups established a norm that varied from this standard. The 70-year-old leader of this group was invited to the group by a former leader who was moving to another state. The two of them overlapped for several months. He was accepted by the group as their leader when the original leader departed, but he freely shared information about a family member who had been diagnosed with a mental illness. This was mentioned frequently as what made him an exception to the idea that the leader must have had a mental illness personally. Participants reported that he was well-liked and respected even though he was not personally recovering from a mental illness due to his compassion for group members, his leadership skills, and his positive history with the group.

Some group members discussed Peer Specialists, and one group leader had a goal of becoming one. She had been hospitalized 15 times and had frightening experiences when she first entered the hospital. One of her goals in becoming a Peer Specialist was not only to lead groups but to accompany those first entering a psychiatric hospital and support them and provide them information due to her negative experience. She was also interested in providing the services typically conducted by Peer Specialists. JB interviewed another man who had not formally pursued the role but had led several groups and was considering becoming a formal Peer Specialist. The majority of other members was not familiar with this title but felt that if a peer leader had additional training and became a Peer Specialist this could only be beneficial to group. They did not see any conflicts with a Peer specialist being paid for their services.

9. These groups are a positive, helpful, and powerful force in the lives of the participants (who continue in these groups).

One respondent said,

Using the recovery language helps, rubbing shoulders with other people that you know of is an experience very similar to what you're going through because I think on average most nervous patients, you feel like you are the exception to the rule and say you are the only one that is as sick as you are because you keep

all of this to yourself before recovery and then when you get in there you're a little surprised that there are other people like you.

He goes on to say how incredibly useful being in the group has been for him. Another respondent said,

It [the group] helps you open up for that reason because you know they are not going to ridicule you and so on and so forth and they're going to use recovery language and secure thoughts to help you think and do your way out of the situation you are in.

He continues to say how positive and helpful participating in the group has been for him.

A third respondent said,

I think it helps because you are able to practice by example, meaning that you see other people help themselves and get well. In other words there is a very sick lady that is depressed, with the black hair:

R: yeah, she was kind of down on my end of the table?

P: yeah, I know her name but I can't think of it. But you know who I am talking about?

R: yeah I know who you're talking about.

P: She just started maybe 4-6 weeks ago and I can see the difference now. She hasn't made any big steps and that is not what you're looking for in recovery. You're looking for the small steps and being satisfied, the small gains. If I was a new person in recovery, say I started the last time I was at Margie's and I started that night and the lady was there for 5 or 6 weeks and I watched her mature a little bit, maybe not so much weekly but maybe by monthly that gives you more hopeful anticipation about helping yourself.

R: Watching somebody else progress and seeing how that encourages you...

P: right

This respondent continues to say how powerful the group has been in his and others' recovery.

Discussion

We did not anticipate the depth of the group members' beliefs about the group's effectiveness and its importance in their recovery. We were also surprisingly impressed at the importance of sharing of personal experience and how participants viewed professional distance as working against recovery. Participants reported that the groups provided something different from other available services.

Criticism of groups did exist. We describe them under theme 8—that groups do not last forever. Leaders can become too dominating or press their own agenda on others. Several of our respondents had left peer support groups for this reason and had found other groups.

Presumably related to the nature of our sampling strategy, we did not encounter anyone who gave up on peer support; just some who left a group because it no longer worked for them and found another group that did.

We were surprised at the findings for different reasons. LMM was surprised because group members appeared to have created a microcosm for themselves of the kind of support that is found in indigenous communities, which he did not think was possible among non-indigenous people, especially in the greater Cincinnati area, the place where he attended high school. Dr. Behler was surprised because he had not been trained to believe that peer support could be so effective or so engaging. Of course the depth of our surprise could be reflective of the depth of our acculturation in a biomedical model of mental health service delivery.

We hypothesize that participation in peer support groups is one important way that people find community, a broad concept that captures a sense of belonging, a feeling of acceptance, and a social identification. Community is harder to experience through professionals or when one must pay for it. We are referring to a non-hierarchical relatedness that involves a form of radical acceptance that is hard to find in the contemporary non-indigenous world. Some people find it through belonging to churches, some to workplaces, and others through peer support groups. Being part of community is empowering and instills hope. This sense of community forms the basis for much of indigenous healing (Mehl-Madrona, 2009).

The other available mental health services follow a professional model of hierarchy and expertise, which perhaps works against healing and recovery. Peer support emerges from shared or similar experiences, with a shared language. Watching others help themselves can encourage and normalize behavior. It is not limited socially or communally as are professional services due to the need for professional roles and boundaries. Hope may emerge from watching others recover. Peer support appears to be a different experience for group members than what traditional mental health services provide, one that augments traditional services.

People who use peer support appear to benefit greatly and differently from other mental health services. The discrepancies between our small qualitative study and larger quantitative studies are important. The medical approach to research rushes to large, randomized, controlled trials (RCT), sometimes in advance of understanding the subtleties of the phenomenon under investigation. Most of the RCTs are short duration (6 to 12 weeks) given their high cost. The average duration of group attendance of our participants was 6.6 years. Perhaps people need to come longer than 12 weeks to show significant benefit. RCTs apply the drug model (which is what they were developed to study) over short periods of time, and may not be the optimal way to explore peer support groups, which may not be helpful for some people and may be extraordinarily helpful for others. When this occurs, the net effect could be small because those who have strong benefits are offset by those who have no benefit. Longerterm outcome studies of at least 2 years may be necessary to gain insight into how peer support helps in the overall management of serious mental illness. We could also inquire about where people would be in their process of recovery to be able to use peer support. It may be that randomizing people to peer support or no peer support will fail to capture the usefulness of this therapy because it is not for everyone or is most useful at different stages of the recovery process. However, for those who gravitate to it, it could be life-saving. Small, qualitative studies like ours can help determine who peer support most benefits. This kind of data can provide a rational basis for subject selection for RCTs—by knowing what populations of subjects are most likely to benefit and at what stage of their recovery and knowing how far they must come to show an effect.

Study Limitations

Our study looked at people who appeared to be successfully using peer support groups as a positive force in their recovery. We do not know what percentage of people who come to peer support, they represent. We do not know what percent of people who are referred for peer support actually go and, of those, what percent continue to go to make the referral worthwhile. We do not know what happens to people who come to peer support and do not last. We do not know what the people who declined to be interviewed would have said. We were not able to recruit people who were dissatisfied with peer support. Perhaps dissatisfied people do not enroll in research studies. Perhaps they do not stay in groups long enough to be encountered.

There are conversations we would like to have. We'd like to interview people who came once and left. We'd like to interview people who dropped out because they didn't feel connected or respected or included, or because they could not identify with the other group members. For now, we can say that those who continue in peer support for at least 6 months reported significant gains on symptoms and felt that peer support was a uniquely positive influence in their recovery and different from what they received from professionals or family.

References

- American Association of Community Psychiatrists. (2010). *Position statement regarding peer support services*. Retrieved from http://www.communitypsychiatry.org
- Bryman, A. (2008). Social research methods (3rd ed.). Oxford, UK: Oxford University Press.
- Cabral, L., Muhr, K., & Savageau, J. (2013). Perspectives of people who are deaf and hard of hearing on mental health, recovery, and peer support. *Community Mental Health Journal*, 49(6), 649-657.
- Chamberlin, J., Rogers, E., & Ellison, M. L. (1996). Self-help programs: A description of their characteristics and their members. *Psychiatric Rehabilitation Journal*, 19(3), 33–42.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 509-536). London, UK: Sage.
- Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative analysis. Thousand Oaks, CA: Sage.
- Chinman, M., Daniels, A. S., Delphin-Rittmon, M. E., Dougherty, R. H., George, P., Ghose, S. S., & Swift, A. (2014). Peer support services for individuals with serious mental illnesses: Assessing the evidence. *Psychiatric Services*, 65(4), 429-441.
- Clandinin, D. J. (2013). Engaging in narrative inquiry. New York, NY: Routledge.
- Clandinin, D. J., & Connelly, F. M. (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2-14.
- Corrigan, P. W., Calabrese, J. D., Diwan, S. E., Keogh, C. B., Keck, L., & Mussey, C. (2002). Some recovery processes in mutual-help groups for persons with mental illness: Qualitative analysis of program materials and testimonies. *Community Mental Health Journal*, 38(4), 287–301.
- Corrigan, P. W., Faber, D., Rashid, F., & Leary, M. (1999). The construct validity of empowerment among consumers of mental health services. *Schizophrenia Research*, 38(1), 77–84.
- Corrigan, P. W., Slopen, N., Gracia, G., Keogh, C. B., & Keck, L. (2005). Some recovery processes in mutual-help for persons with mental illness: Qualitative analysis of participant interviews. *Community Mental Health Journal*, 41(6), 721-735. doi 10.1007/s10597-005-6429-0
- Craig, C. J., Zou, Y., & Poimbeauf, R. (2014). Narrative inquiry as travel study method:

- Affordances and constraints. *Asia Pacific Education Review*, 15(1), 127-140.
- Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. K. (1999). Peer support among individuals with severe mental illness: A review of the evidence. *Clinical Psychology: Science and Practice*, 6(2), 165-187.
- Depression Bipolar Support Alliance. (2012). *Find a support group*. Retrieved from www.dbsalliance.org/
- Duncan, B. L. (2012). The Partners for Change Outcome Management System (PCOMS): The heart and soul of change project. *Canadian Psychology/Psychologie Canadienne*, 53(2), 93.
- Fram, S. M. (2013). The constant comparative analysis method outside of grounded theory. *The Qualitative Report*, 18, 1-25. Retrieved from http://nsuworks.nova.edu/tqr/vol18/iss1/1
- Gwozdziewycz, N., & Mehl-Madrona, L. (2013). Meta-analysis of the use of narrative exposure therapy for the effects of trauma among refugee populations. *The Permanente Journal*, 17(1), 70-76.
- Hogan, M. F. (2003). New freedom commission report: The President's New Freedom Commission: Recommendations to transform mental health care in America. *Psychiatric Services*, *54*, 1467–1474.
- Kenny, M., & Fourie, R. (2014). Tracing the history of grounded theory methodology: From formation to fragmentation. *The Qualitative Report*, 19(52), 1-9. Retrieved from http://nsuworks.nova.edu/tqr/vol19/iss52/1
- Laudet, A. B., Magura, S., Vogel, H. S., & Knight, E. (2000). Addictions services: Support, mutual aid, and recovery from dual diagnosis. *Community Mental Health Journal*, 36(5), 457-476.
- Lieberman, M. A., & Snowden, L. R. (1994). Problems in assessing prevalence and membership characteristics of self-help group participants. In T. J. Powell (Ed.), *Understanding the self-help organization: Frameworks and findings* (pp. 32-49). Thousand Oaks, CA: Sage.
- Lloyd-Evans, B., Mayo-Wilson, E., Harrison, B., Istead, H., Brown, E., Pilling, S., & Kendall, T. (2014). A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. *BMC psychiatry*, *14*(1), 39, doi:10.1186/1471-244X-14-39
- Low, A. (1950). *Mental health through will training*. Chicago, II: Recovery International, Inc. Meehan, A., & Beinlich, N. (2014). Peer-to-peer learning/teaching: An effective strategy for changing practice and preventing pressure ulcers in the surgical patient. *International Journal of Orthopaedic and Trauma Nursing*, 18(3), 122-128.
- Mehl-Madrona, L. (2009). What traditional indigenous elders say about cross-cultural mental health training. *Explore: The Journal of Science and Healing*, *5*(1), 20-29.
- Mehl-Madrona, L. (2010). Comparisons of health education, group medical care, and collaborative health care for controlling diabetes. *The Permanente Journal*, 14(2), 4-10.
- Mehl-Madrona, L., & Mainguy, B. (2014). Introducing healing circles and talking circles into primary care. *The Permanente Journal*, 18(2), 4-9.
- Mental Health America. (2011). Support group clearinghouse. Retrieved from http://www.mentalhealthamerica.net/
- Merriam, S. B. (2014). *Qualitative research: A guide to design and implementation*. New York, NY: John Wiley.
- Miller, S. D., Duncan, B. L., Brown, J., Sparks, J. A., & Claud, M. S. (2003). The outcome rating scale: The preliminary study of the reliability, validity, and feasibility of brief visual analog measure. *Journal of Brief Therapy*, 2(2), 91-100.

- Minkler, M. (2000). Using participatory action research to build healthy communities. *Public Health Reports*, 115(2-3), 191-197.
- National Alliance on Mental Illness. (2012). *Support and programs*. Retrieved from http://www.nami.org/
- Negi, N. J., Michalopoulis, L., Boyas, J., & Overdorff, A. (2013). Social networks that promote well-being among Latino migrant day laborers. *Advances in Social Work, 14*(1), 247-259.
- New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America*. Final report. (DHHS pub no SMA-03–3832). Rockville, MD: Department of Health and Human Services.
- Ollerenshaw, J., & Creswell, J. W. (2002). Narrative research: A comparison of two restorying data analysis approaches. *Qualitative Inquiry*, 8, 329-350.
- Paterson, C. (1996). Measuring outcomes in primary care: A patient generated measure, MYMOP2, compared with SF-36 health survey. *British Medical Journal*, *312*, 1016–1020.
- Recovery International. (2014). *Recovery International one day training manual*. Chicago, IL: Recovery International. Retrieved from https://www.recoveryinternational.org/wp-content/uploads/2014/11/final_one_day_training_manual_6_5_2014.pdf
- Reilly, D., Mercer, S. W., Bikker, A. P., & Harrison, T. (2007). Outcome related to impact on daily living: Preliminary validation of the ORIDL instrument. *BMC Health Services Research*, 7, 139.
- Repper, J., & Carter, T. (2011). A review of the literature on peer support in mental health services. *Journal of Mental Health*, 20(4), 392-411.
- Rogers, E. S., Chamberlin, E. M., & Crean, T. (1997). A consumer-constructed scale to measure empowerment. *Psychiatric Services*, 48(8), 1042–1047.
- SAMHSA. (Substance Abuse and Mental Health Services Administration: Center for Mental Health Services). (2004). *National consensus statement on mental health recovery*. Washington, D.C.: U.S. Department of Health and Human Services. Retrieved from www.samhsa.gov
- Sarantakos, S. (2005). Social research (3rd ed.). Basingstoke, UK: Palgrave MacMillan.

Appendix

Interview Questions for Depression/Bipolar Support Groups

- 1. Why did you decide to join this support group?
- 2. How did you learn about the group?
- 3. How long have you attended the group?
- 4. Have you attended other support groups and if so can you talk about your experiences there?
- 5. Can you talk about your experiences in a support group and if you have a preference for other groups you may have attended?
- 6. Has the support group been helpful to you? If so, talk about how it has helped you. What do you think has changed as a result of being in this group?
- 7. How is it that people come to support groups, what do they get out of them, and how do these groups relate to professional services?
- 8. Has participating in these activities changed the way you have handled your medical problems or changed the way you use health care?
- 9. Has anything changed in your overall health and well-being since you have been in a group?

- 10. Has anything changed in the way you manage your health problems or psychological issues, or the way you relate to people since you have been in a group?
- 11. What do you think makes for a good leader of a support group? What kind of attributes or qualities makes a good leader?
- 12. How would you feel about the peer leader of your support group if he/she had extra training?
- 13. How would you feel if you knew that a peer leader, one who is also in recovery was getting paid to lead the group? Would he/she still be a good leader?
- 14. What other kinds of help have you received to manage your diagnosis?
- 15. If you have received help from a psychiatrist can you talk about this experience?
- 16. If you're taking medication can you talk about this experience?
- 17. Was it difficult to find a psychiatrist?
- 18. Once you found a doctor did you remain with that doctor or did you see other doctors?
- 19. How long did it take for you to receive a diagnosis?
- 20. Once you began medicines how long did it take before you felt you had a medicine that helped you?
- 21. If you pursued psychotherapy, can you describe your experience, and was psychotherapy helpful?
- 22. Can you describe your experience in navigating the mental health system?
- 23. Was there a long wait for a therapist or psychiatrist?
- 24. Did you try to find a therapist through the community mental health system or through a private practitioner?
- 25. How would you compare your experience in a support group with your experience in psychotherapy?
- 26. Did you find a support group or psychotherapy to be more helpful in your recovery?
- 27. Do you think that attending a support group along with medication would be enough to help you feel better or do you feel you need something more?
- 28. Have you investigated any on line support groups for depression or bipolar and if so can you talk about your experiences with them?
- 29. If a friend of yours was diagnosed with bipolar, what advice would you give that person?

Author Note

Joe Behler, PsyD, is in private practice in Edgewood, Kentucky. He obtained a master's degree in Clinical Psychology from Xavier University in Ohio and a doctoral degree in Clinical Psychology from the Union Institute and University. He is a licensed Clinical Psychologist in Kentucky. He has worked in Ohio, Kentucky, and Indiana at hospitals and residential treatment facilities for children, social service agencies and early childhood centers, domestic relations court, community mental health centers, and in private practice. He is interested in psychotherapeutic interventions for depression, anxiety, and neurodevelopmental disorders, peer support, family therapy, and collaborative partnerships with health care providers.

Dr. Allen Daniels is an independent behavioral healthcare consultant and also serves as Senior Study Director for Westat and consulting Clinical Director for InfoMC. He has been Professor of Clinical Psychiatry and Public Health Sciences at the University of Cincinnati, College of Medicine. He has also served as the Executive Vice President and Director of Scientific Affairs for the Depression and Bipolar Support Alliance (DBSA). He is a graduate of The University of Chicago School of Social Services Administration, and The University of Cincinnati College of Education. He has extensively published in the area of behavioral health policy including: managed care and group practice operations, quality improvement and

clinical outcomes, behavioral healthcare workforce development, behavioral health and primary care integration, and peer support and person-centered care. Dr. Daniels served on the National Advisory Committee for SAMHSA's Center for Mental Health Services. He is active on a number of other boards and professional organizations.

Jennifer L. Scott, PsyD, ABPP is a licensed and board certified clinical psychologist. She received her doctoral degree in Clinical Psychology, along with a graduate certificate in Organizational Concepts and Management, from Xavier University in Cincinnati, Ohio. She is full-time faculty in the graduate college at Union Institute & University and has been recognized at state and local levels for excellence as a practitioner and educator. She has published and presented scholarly work in the areas of psychological assessment, professional ethics, clinical supervision, self-care, and teaching in technology mediated learning environments. Dr. Scott also maintains a private psychology practice, providing clinical assessment and consultation services to rural and marginalized communities in southwestern Ohio.

Lewis Mehl-Madrona, MD, PhD, is Faculty at the Family Medicine Residency at Eastern Maine Medical Center and is Associate Professor of Family Medicine at the University of New England. He is also Executive Director of Coyote Institute in Orono, Maine. He is board-certified in family medicine, geriatric medicine, and psychiatry, and has a Ph.D. in clinical psychology with a specialization in neuropsychology. He is a graduate of Stanford University School of Medicine, the Psychological Studies Institute in Palo Alto, the narrative studies post-graduate program at Massey University, Palmerston North, New Zealand, and completed his residencies in family medicine and in psychiatry at the University of Vermont College of Medicine. He is interested in narrative medicine, indigenous knowledge, and the incorporation of indigenous ideas into contemporary health care. Correspondence regarding this article can also be addressed directly to: Dr. Mehl-Madrona, 802-451-0311, mehlmadrona@gmail.com, fax 207-973-6109, address: Coyote Institute, P.O. Box 39, Orono, ME 04473.

Copyright 2017: Joe Behler, Allen Daniels, Jennifer Scott, Lewis Mehl-Madrona, and Nova Southeastern University.

Article Citation

Behler, J., Daniels, A., Scott, J., & Mehl-Madrona, L. (2017). Depression/bipolar peer support groups: Perceptions of group members about effectiveness and differences from other mental health services. *The Qualitative Report*, 22(1), 213-236. Retrieved from http://nsuworks.nova.edu/tqr/vol22/iss1/12