



UTS
ePRESS

Gateways:

International Journal
of Community
Research and
Engagement

Vol. 14, No. 1

May 2021



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Citation: Sheehan, L., Ballentine, S., Washington, L., Canser, M., Connor, J., Jones, R., Laster, E., Muhammad, K., Noble, S., Smith, R., Walley, G., Kundert, C. and Corrigan, P. 2021. Implementing Community-Based Participatory Research Among African Americans With Serious and Persistent Mental Illness: A Qualitative Study. *Gateways: International Journal of Community Research and Engagement*, 14:1, 1–19. <http://dx.doi.org/10.5130/ijcre.v14i1.6894>

ISSN 1836-3393 | Published by UTS ePRESS | <http://ijcre.epress.lib.uts.edu.au>

RESEARCH ARTICLE

Implementing Community-Based Participatory Research Among African Americans With Serious and Persistent Mental Illness: A Qualitative Study

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DOI: <http://dx.doi.org/10.5130/ijcre.v14i1.6894>

Article History: Received 13/11/2019; Revised 02/01/2021; Accepted 19/04/2021; Published 05/2021

Abstract

Community-based participatory research (CBPR) is an approach that involves community members in research, not as research participants, but as partners. However, few studies have examined CBPR projects conducted among African Americans with serious and persistent mental illness (SPMI). This article focuses specifically on the Inspiring Change (IC) model, which includes a leadership trio comprised of an academic researcher, health service provider and an African American with lived experience of SPMI. Our purpose is to investigate how the IC model shapes not only how research is conducted but how research is understood and experienced by the community. We achieve this purpose by (1) describing an innovative CBPR model and pilot projects that involved African Americans with SPMI in all stages of the research project; and (2) presenting findings from qualitative interviews conducted with CBPR team members about strengths, challenges and leadership particular to this model of CBPR, an area rarely explored in CBPR literature. With the guidance of an advisory board and the manualised IC curriculum, two CBPR teams initiated and conducted nine-month long research projects focusing on health disparities for African Americans with SPMI. Members of the two CBPR teams ($n = 13$), which included individuals with lived experience, service providers and researchers, completed qualitative interviews. Benefits of CBPR projects included opportunities to

DECLARATION OF CONFLICTING INTEREST The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. **FUNDING** Research reported in this article was funded through a Patient-Centered Outcomes Research Institute (PCORI) Engagement Award (1081-IIT). The statements presented in this article, are solely the responsibility of the author(s) and do not necessarily represent the views of PCORI, its Board of Governors or Methodology Committee.

learn, a sense of purpose in helping others and increased trust of research participants. Challenges pertained to disorganisation of leadership, lack of transparency with compensation, time pressures and interpersonal conflicts. These challenges highlight the importance of preparing and supporting those from both academic and lived experience backgrounds in skills necessary to thrive in leadership roles for CBPR projects.

Keywords

Community-Based Participatory Research; Serious and Persistent Mental Illness; Psychiatric Disability; African American

Introduction

Individuals with a serious and persistent mental illness (SPMI) die about 15 years earlier than same age peers ([Martens 2001](#); [WHO 2003](#)) and have a higher risk of chronic physical disabilities, including heart disease ([Osborn, Nazareth & King 2006](#)), diabetes ([Dixon et al. 2000](#)), stroke ([Hansen, Maciejewski, Yu-Isenberg & Farley 2012](#)), and other illnesses ([Sokal et al. 2004](#)). Difficulty with social skills, problems regulating emotion and disinterest in others ([Li, Shi-ni Hu & Yi, 2011](#)) can interfere with community participation in advocacy, organising and research efforts that seek to address these stark health disparities ([Corrigan, Pickett, Batia & Michaels 2014](#)). In addition, social exclusion related to stigma and disability can lead people with SPMI to become discouraged and give up trying to engage in meaningful life roles ([Corrigan, Larson & Rüsich 2009](#); [Corrigan & Rao 2012](#)). The project we describe here is an effort to engage African Americans with SPMI in solutions to these health disparities through community-based participatory research (CBPR). While CBPR methods are meant to enhance research partnerships with community members, previous CBPR studies have rarely involved African Americans with SPMI in all aspects of the project or in leadership roles, and have not documented the perspectives of these CBPR team members. The model of CBPR described herein (Inspiring Change: *IC*) provides a framework for implementing more inclusive practices in CBPR.

This article focuses specifically on the Inspiring Change (*IC*) model, which includes a leadership trio comprising an academic researcher, a health service provider and an African American with lived experience of SPMI. Our purpose is to investigate how the *IC* model shapes not only how research is conducted but how research is understood and experienced by the community. We achieve this purpose by (1) describing an innovative CBPR model and pilot project that involved African Americans with SPMI in all stages of the research project, and (2) presenting findings from qualitative interviews conducted with CBPR team members about strengths, challenges and leadership issues particular to this model of CBPR, an area rarely explored in CBPR literature.

Literature Review

African Americans are notably under-represented in research samples ([Huang & Coker 2010](#); [Milani et al. 2020](#); [Webb, Khubchandani, Striley & Cottler 2019](#); [Zhang, Tsang, Wijeyesundera & Ko 2013](#)), which is not surprising, given the discrimination, ethical violations and mistreatment committed against African Americans by the research profession ([Brandt 1978](#); [Shavers, Lynch & Burmeister 2000](#)). In the infamous Tuskegee experiments, which persisted over four decades through the early 1970s, researchers withheld life-saving medical treatment from African Americans infected with syphilis ([Brandt 1978](#)). In the 1950s, Henrietta Lacks' cells were harvested without her consent and subsequently utilised in medical research that profited from her cells ([Shah 2010](#)). Collective memories of the Tuskegee study and other research transgressions persist in African American communities despite subsequent protections and safeguards against further abuses, leading to a lack of trust that needs to be re-established by researchers ([Bonevski](#)

et al. 2014; [Gamble 1993](#); [Nooruddin et al. 2020](#); [Shavers, Lynch & Burmeister 2000](#)). Recruitment strategies that neglect African American cultures and make little effort to appeal to African Americans have further limited participation ([Erves et al. 2017](#); [Huang & Coker 2010](#)). Lack of cultural competence in African American research can result in an emphasis on problems and weaknesses rather than strengths and solutions ([Fenwick 2016](#)). To better understand and address the needs of a community, it is vital that community members (in this case, African Americans with SPMI) are involved in developing research ([Bonevski et al. 2014](#); [Huang & Coker 2010](#); [Las Nueces et al. 2012](#)).

Community-based participatory research is one approach to research that can help reduce health disparities and increase the diversity of perspectives in research ([Wallerstein & Duran 2006](#)). In CBPR, academic researchers partner with community members to formulate and investigate research questions that are important to the community. CBPR team members provide vital information on community resources, culturally sensitive recruitment strategies, interpretation of results and translation of findings into practice ([Hatch et al. 1993](#)). CBPR has been successfully implemented to address African American health disparities in HIV ([Berkley-Patton et al. 2010](#); [Griffith et al. 2010](#)), cancer ([Bone et al. 2013](#)), diabetes ([Austin & Clairborne 2011](#)) and hypertension ([Dodani et al. 2011](#)).

Given the heightened risk of disparities for African Americans with SPMI, who face both race-based and disability-based discrimination ([Breslau et al. 2005](#); CDC 2014; [Earl et al. 2016](#); [Orsi, Margellos-Anast & Whitman 2010](#)), a few studies have implemented CBPR for African Americans with SPMI. The studies include development of a peer navigator program to improve health for the homeless ([Corrigan et al. 2017](#)), a family intervention for youth with depression ([Breland-Noble, Burriss & Poole 2010](#)) and a mental health program for young adults ([Mance et al. 2010](#)). The studies describe CBPR team roles as primarily in program development or participant recruitment. For example, [Corrigan and colleagues \(2017\)](#) partnered with a group of African American people with SPMI who were homeless to design a peer navigation curriculum and recruit participants for a randomised controlled trial. Similarly, [Mance and colleagues \(2010\)](#) used a CBPR team to adapt an existing intervention, while [Breland-Noble and colleagues \(2010\)](#) formed an advisory board of parents to give feedback on a youth treatment manual. Unfortunately, these CBPR studies seemed to lack involvement of persons with lived experience throughout the entire span of the research project. Furthermore, they provided only a cursory description of CBPR team involvement and did not describe the experiences or perceptions of the CBPR members themselves.

For people with SPMI, CBPR has been described as a moral imperative – to borrow from the disability rights movement, ‘nothing about us without us’ – that improves research quality and impacts the lives of those who take part in CBPR ([Collins et al. 2018](#); [Hancock, Bundy, Tamsett & McMahon 2012](#)). CBPR might benefit team members in their own mental health recovery by providing structure, purpose and opportunity to help others in the community ([Case et al. 2014](#)). Potential challenges with CBPR have also been well documented, such as the intensive time for training community members who are inexperienced with research, as well as the significant time commitment in joining a CBPR project, which can last months or even years ([Case et al. 2014](#)). Commitments and priorities of researchers (e.g. pressures of publication, teaching and grant-writing obligations) may conflict with those of community members ([Collins et al. 2018](#)). The status and power of academic researchers can discourage the contributions of community members and threaten the principle of equal partnership in CBPR if these are not carefully navigated ([Case et al. 2014](#)). Multiple roles and relationships between individuals in CBPR (e.g. doctor and patient) can be challenging for CBPR team members to manage, as they may be doing research alongside providers or in institutions where they also receive services ([Collins et al. 2018](#)).

Despite the extensive use of CBPR to reduce health disparities ([Minkler & Wallerstein 2011](#)), limited research explores CBPR team members’ perceptions of the collaborative process. While several studies have evaluated CBPR stakeholder perspectives on community-academic partnerships (e.g. [Blevins et al. 2008](#); [LeClair, Lim & Rubin 2018](#)), a review of the literature found no research exploring the experience of

CBPR teams that include African Americans with SPMI, especially those involving people with SPMI in leadership roles. Thus, the goal of this project was to examine the experiences of CBPR members who are working on projects to reduce health disparities for African Americans with SPMI. Specifically, we sought to explore how the *IC* model of CBPR shapes how research is conducted, understood and experienced by the community in terms of benefits, challenges, team engagement and leadership perceptions.

Background Context

Researchers at the Chicago Health Disparities Center, Illinois, USA, had previously received a federal grant to develop and test a health intervention for African Americans with SPMI using CBPR. However, when implementing the project, they found limited resources on CBPR that were specific to this population. Thus, the principal investigator (PC) partnered with a lived experience CBPR member (SB) to refine methods in CBPR for African Americans with SPMI. The first (LS), second (SB) and last author (PC), research associate, lived experience co-investigator and principal investigator respectively, applied for and received funding through Eugene Washington Patient-Centered Outcomes Research Institute (PCORI) Engagement Award (see [Figure 1](#) for the sequence of project milestones). They established a Training and Development Advisory Board (TDAB) to develop the curriculum and help guide implementation of CBPR. The TDAB was recruited through flyers distributed at local mental health agencies and members were selected by the first and second authors through an application and interview process. The board was comprised of mental health providers ($n = 2$), researchers ($n = 2$) and African Americans with SPMI ($n = 8$). The group used a landscape review and stakeholder interviews to design a CBPR training curriculum called Inspiring Change (IC). The African Americans with SPMI who comprised the TDAB elected to call themselves 'people with lived experience' to highlight the importance of their experiences rather than their illness. The IC curriculum used this terminology throughout; thus, CBPR team members with SPMI are described as having 'lived experience' in this article.

In the *IC* model, the CBPR teams are comprised primarily of people with lived experience and are jointly led by a researcher, a healthcare service provider and an African American in recovery from SPMI. Thus, the CBPR team is a unit that includes all three stakeholder groups (researchers, healthcare providers and people with lived experience). For the current study, the TDAB conducted a full-day training (based on the *IC* curriculum) for interested individuals and teams of researchers, healthcare providers and individuals with SPMI from local non-profit agencies. The training included interactive, bi-directional activities aimed at highlighting the important role that people with lived experience have in CBPR projects. Researchers and health care providers on CBPR teams learned how to navigate their role on the project while acknowledging inevitable power differentials and cultural misunderstandings. At the training, the TDAB distributed a request for proposal, inviting CBPR projects that could help reduce health disparities for African Americans with SPMI. The TDAB assisted individuals with lived experience who had completed the *IC* training and who were interested in co-leading a team in recruiting a healthcare provider and a researcher to partner with. The trio of leaders then worked together to submit a research proposal. The TDAB, in conjunction with outside academic reviewers, selected two projects for funding based on the proposal's adherence to CBPR principles and research feasibility. Leadership trios from two local social service agencies were each awarded \$20,000 to carry out time-limited, nine-month research projects embedded within their agencies. Together, these two groups of three leaders developed a preliminary research plan and recruited three to four additional African Americans with SPMI who were service recipients of their organisations. These additional team members with lived experience were selected collaboratively by the leadership trio following an application and interview process with interested individuals. One of the CBPR teams conducted focus groups and surveys with African American male survival sex workers to explore barriers and stigma

experienced in healthcare settings. The second team designed and pilot-tested a series of health self-management workshops for African Americans with SPMI.

Once leaders had recruited the additional CBPR team members, the *IC* curriculum provided activities and worksheets that team leaders used to establish ground rules, develop group decision-making strategies, address power dynamics, help all team members understand basic research design, and disseminate research findings. Team leaders had monthly check-ins and received technical support from the TDAB on implementation of the CBPR projects. Monthly check-ins lasted one hour and had a standing agenda, including: project successes, progress on timeline, anticipated changes in research plan, team engagement, challenges, and next steps. The *IC* curriculum also included resources such as templates for meeting agendas, timelines and research plans. The curriculum is available free at www.chicagohealthdisparities.org. The lived experience leader and team members with lived experience were paid an hourly rate (minimum of \$15 per hour) for attendance at research meetings, recruitment, data collection and other study-related tasks. Researchers and health service providers were paid through their organisation at their regular hourly rate for their percentage of work on the project. To better understand the experiences of participants within the CBPR model, the TDAB designed and conducted qualitative interviews with members of the two CBPR teams ($n = 13$), described in detail below. The TDAB members who wished to be involved in the data analysis and manuscript preparation sessions are co-authors on this article.

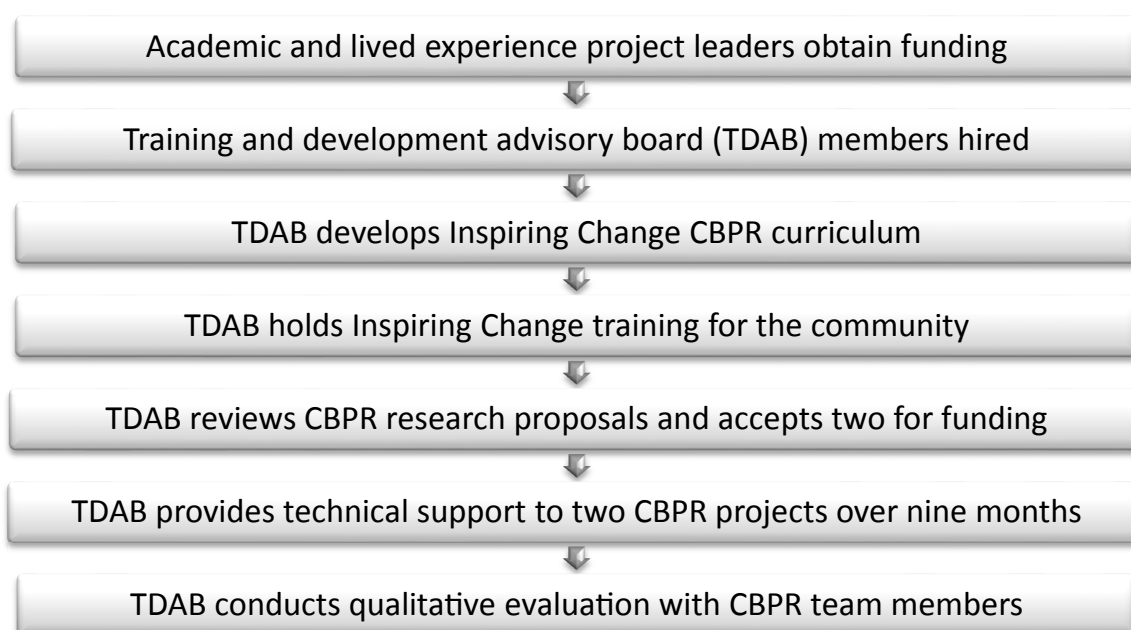


Figure 1. Graphic representation of project sequence.

Method

The twelve-member Training and Development Advisory Board (TDAB), comprised of mental health providers, researchers and African Americans with SPMI, designed qualitative interviews to be conducted with members of two CBPR teams, whose health disparity research projects were funded and guided by the TDAB. Qualitative interviews were aimed at identifying the experiences of participants in CBPR broadly, as well as experiences specific to the *Inspiring Change* model, described above.

PARTICIPANTS

Participants ($n = 13$) in the current study were members of the two CBPR teams who had conducted research projects on health disparities, as described above, including the researcher, healthcare provider and individuals with lived experience. CBPR team members (referred to hereafter as participants) were compensated with a \$50 gift card and all team members (seven from the first team and six from the second) who were involved in the two projects agreed to participate. Most participants had lived experience of mental illness ($n = 10$). Mental health diagnoses included major depression, substance use disorder, PTSD, bipolar disorder and schizoaffective disorder. Both healthcare provider participants and all nine participants with lived experience were Black. For both projects, the lead researcher was White and did not report lived experience of mental illness. Participants ranged in age from 24 to 63 and included four men and nine women. Healthcare providers and researchers were employed full-time by their organisations, while most participants with lived experience were not employed ($n = 7$).

MATERIALS

The interview guide was developed collaboratively by the TDAB, with questions cross-checked against curriculum topics (e.g. inclusion, power differential, group dynamics, benefits, challenges and leadership needs). Example questions were: 'How did your team go about making decisions in the group setting?' and 'How did your team handle conflict in the group?' All interviewees were asked the same questions. (The full interview guide is included in the Appendix.)

PROCEDURE

The research protocol was developed by the TDAB and approved by the institutional review board at the Illinois Institute of Technology. Participants were recruited via a brief presentation during each team's CBPR meeting and interested participants were invited to complete the informed consent, ask any questions about the study and provide their phone number. Interviews were conducted from a private office at the Illinois Institute of Technology during the final month of the nine-month long CBPR project. Two research assistants were trained to conduct and transcribe the semi-structured interviews. The research assistants were briefed on the goals of the project and practised by conducting an interview with a member of the TDAB. Research assistants were instructed to ask questions in order, but to ask relevant follow-up questions or seek clarification on responses as needed. Interviews lasted between 15 minutes and 1 hour.

Data Analysis

The TDAB used an emergent strategy of thematic analysis ([Braun & Clarke 2006](#)) to analyse transcripts in MAXQDA 12, with a goal of generating comprehensive themes and sub-themes for each research question ([Marshall & Rossman 1999](#)). Preliminary codes and a coding system were iteratively developed by the first and second authors after a thorough reading of the transcripts ([Braun & Clarke 2006](#)). The first author, a doctoral-level researcher with experience in qualitative coding, trained the second author (co-investigator with lived experience) and third author (Master's level student with lived experience) in identifying distinct items (bytes of information) for coding. During the process of coding the first three transcripts, the coding structure was reorganised several times by the second and third authors in response to the emerging data. After the larger themes were developed for the first three transcripts, the second and third authors iteratively developed sub-themes by grouping similar items (e.g. 'I learned about research in the group' and 'I learned a lot' would both be categorised into 'self-improvement' within the theme of 'benefits to team members'). After coders reviewed the themes and sub-themes in the first three transcripts, a codebook was established so that the second and third authors could code independently. Two additional transcripts were

coded independently and compared; at which time they reached an 80 per cent interrater reliability. The second and third authors proceeded with coding the remaining transcripts independently. Themes and sub-themes were reviewed by the first and second authors in relationship to the codes and to the overall data, which allowed for discussion and reorganisation of themes (Braun & Clarke 2006). Results were not separated out by role (lived experience, health provider, academic) in order to preserve the anonymity of interviewees. Finally, the authors created tables to name and define themes (Braun & Clarke 2006). Results tables, discussion points and the manuscript itself were presented to all authors for discussion, amendment and final approval.

Results

BENEFITS OF CBPR

Benefits of CBPR were divided into benefits to team members, benefits to community, and benefits to the research. Individual team members reported that CBPR work gave them a chance to improve skills, knowledge, or self-confidence: 'It gave me a chance to overcome my fear and work on the struggles that I have to overcome. I'm just trying to get comfortable with having lived experience.' Other skills included learning about research and leading group sessions. Participants talked about the satisfaction of contributing to a purpose ('being a part of something new that we built from the ground up'), the enhancement of their social interactions ('...everyone was like family, we praised one another, we gave each other feedback, and picked each other up') and the benefit of having income from their work on the project (Table 1).

One important benefit to the community mentioned many times by participants was the chance to help others ('serving the community that was underserved'). On this theme, participants spoke about how the CBPR project allowed for research and services that better reflect the interests of the community, and allocated resources in the form of research funding. Participants also spoke about how the research highlighted the needs and strengths of the Black community, hopefully leading to increased services that are community driven. Themes for benefits to the community also included improvement of the partner agency through a better understanding of the community that they were serving, and the opportunity to challenge stigma ('Well people need to see that African Americans have these issues but they're still working on them').

Participants identified ways that the research process itself could benefit from CBPR. They discussed how they were able to give suggestions based on their lived experience (e.g. providing research participants with more privacy to complete questionnaires), how they helped recruit difficult-to-engage populations in research (e.g. finding male sex workers in local parks), and how they could relate with research participants. One CBPR team member who helped with data collection for one of the projects noted: 'The participants saw value because they were listening to people with similar experience, so that creates a level of trust.' Team members with lived experience said they engaged their potential research participants through shared language (street slang) and built trust with them through a brief disclosure (e.g. 'I been where you are.'). The shared experiences of having mental illness (or being Black, unemployed, homeless, a sex worker, etc.) allowed the research participants to feel less judged and more open to answering questions about mental health or other sensitive topics.

CHALLENGES OF CBPR

Leaders of the CBPR teams sometimes struggled with managing the project, both from their own perspective and from that of the rest of the team. CBPR members reported difficulties with communication, organisation and motivation. One said, 'For me, what was frustrating was, that our [leader], over a period of time, became disinterested in the project.' The leaders with lived experience on the project also expressed some difficulties in feeling like a real leader. As one put it, '... I felt that even though I was a team leader, I

Table 1. Benefits of CBPR

Theme	Sub-theme	# coded items
Benefits to Team Members	Self-improvement	53
	Being able to contribute to a purpose	23
	Social interactions	22
	Income	4
Benefits to Community	Helping others	87
	Good for agency	4
	Challenge stigma	5
Benefits to Research	Give suggestions based on experience	21
	Help with recruitment	3
	Relate with research participants	18

wasn't included for some parts of it.' Leaders felt pressure to get tasks done on time and please other team members, while members of the team sometimes wished they had more guidance and training from leaders ([Table 2](#)).

Participants believed that limited finances and time were significant challenges. Some said that access to a computer, more money and more time would have been helpful. One comment sums up several comments relating to the time pressure: 'Yeah, I think part of the problem... we all felt the same frustration, which was time.' Along with that were annoyances with some team members' lack of participation, in the form of being late, not showing up, or not putting in as much effort as other members.

Other participants related challenges specific to their research project. It was especially difficult for team members to orient themselves to the distinction between doing research and providing help to peers: 'It was just data we collected. We weren't able to give any suggestions or refer them to services.' Others reported challenges understanding the research design or with data collection. Participants noted problems with recruiting enough participants for the research and feeling stressed when their research participants shared their stories of trauma or their current difficulties.

Getting along with members of the team was another reported challenge. Some participants wanted more transparency (e.g. information and updates) on the project, more unity on the team, or had perceived differences in workload ('A couple of us had to step up and do his part.'). Trust amongst team members was sometimes a challenge, but one participant described how this improved: '...in the beginning I thought they [team members] would be judgmental... but later on we got comfortable.' In terms of communication, participants thought that the leaders could be more direct in their communication. Participants also noted specific limitations of team members (e.g. symptoms of mental illness, active addiction, low literacy) that held the team back.

Engagement Strategies

Leaders and team members identified various engagement strategies as crucial to the involvement of lived experience members on CBPR projects. The engagement strategies ([Table 3](#)) employed by team leaders during the CBPR projects were meant to ensure that team members felt a part of the project and were able to meaningfully participate. One way all three team leaders engaged team members with lived experience was by emphasising the importance of their role on the project, which was done by asking for

Table 2. Challenges of CBPR

Theme	Sub-theme	# coded items
Leadership ¹	Communication between leaders	5
	Leader preparation and organization	41
	Leader motivation and engagement	12
	Alienation of leader with lived experience	4
	Pressure on leaders	4
	Lack of guidance and training from leaders	5
Finances	Resources	5
	Compensation	37
Time Pressure	Felt pressured/stressed for time	12
	Other responsibilities interfere with work on project	2
Participation	Late arrivals	8
	No shows	10
	Lack of effort	6
Research	Understanding of research	5
	Data collection	17
Getting Along	Transparency	5
	Unity	6
	Perceptions of fairness	8
	Trust	4
	Communication	23
	Team member limitations	24

¹ Leadership themes refer to project leaders collectively

their input ('We let them know that their opinions are as good as the next person.') and pointing out their individual strengths. Team leaders asking team members to contribute in important ways was also essential ('I administered the surveys, talked, and gave suggestions about locations that I thought we would help to fulfill the quota that we needed to have.'). Participant team members frequently talked about the importance of ongoing contact and support. Team leaders accomplished this by scheduling regular meetings, trainings and social events, and reaching out through phone calls. Given the involvement of people with disabilities in the research, reasonable accommodations were also mentioned as important: '...to see any special needs like wheelchair and going up and down stairs – all of that was factored into finding sites to have these meetings.' Accommodations were provided that were not directly related to disability, such as giving bus cards to those in need. Participants discussed how the structure of the *IC* curriculum, including activities and worksheets, provided ways for team members to become involved.

Decision-making practices also helped to engage the team. Participants recognised many ways that the team made decisions; these included relying on the expertise of a particular member ('if someone had

experience in a specific situation then they would help out'), having the leader make the decision, discussing the decision within the group, or voting. Participants noted that sometimes having the leader(s) resolve a conflict might be appropriate ('Scheduling work sites was difficult, so the project lead handled conflicts'), while at other times taking a break, or planning ahead to avoid conflict-laden situations were suggested as appropriate choices. Other strategies included discussing the conflict outside the meeting time, discussing the conflict within the group, or letting it go ('Some people were totally happy with the outcome, some weren't, but they accepted it.'). Participants said that sometimes deferring to group rules or updating group rules could help with conflicts. A few participants said that allowing or encouraging a team member to leave the group permanently might be necessary if it was a significant conflict, although this strategy was not used on either team.

Table 3. Engagement Strategies

Theme	Sub-theme	# coded items
Emphasize importance of role	Ask for input	6
	Point out individual strengths	4
	Involve in project tasks	41
Ongoing contact and support	Regular meetings	7
	Trainings	9
	Social/team building events	1
	Phone calls	1
Reasonable accommodations	Disability-related	3
	Other-related	3
Structure	Use curriculum	18
	Follow schedule/agenda	11
Decision-making practices	Defer to person with expertise	2
	Leader(s) make(s) the decision	13
	Discuss in group	25
	Vote	4
Conflict resolution	Discuss in group	17
	Leave it to the leader	1
	Take a break	6
	Plan for it	2
	Discuss outside meeting	1
	Let it go	4
	Refer to group rules	2
	Allow group member to leave/resign	2

Desired Characteristics and Responsibilities of CBPR Leaders

Both leaders and team members discussed the desired characteristics and required responsibilities for leaders on CBPR projects. These results are summarised in [Tables 4](#) and [5](#). Characteristics were coded as consistent, assertive, reflective, knowledgeable, hard-working, patient, confident, professional, and effective listeners. In terms of responsibilities, participants said that leaders should be able to select team members who would contribute to the project, and then they would be able to identify and use the strengths of each team member by delegating tasks to them. The CBPR teams for these projects held meetings several times a month; thus, facilitation of meetings was an important task. Further, participants noted that leaders should be able to make decisions, solve problems, communicate effectively and motivate the team. One

Table 4. Desired Characteristics of CBPR Leaders

Characteristics	# coded items
Consistent	4
Kind/compassionate	6
Assertive	8
Reflective	1
Knowledge of topic	6
Hard working	9
Patient	4
Confident	6
Professional	7
Effective listening	3

Table 5. Desired Responsibilities of CBPR Leaders

Responsibilities	# coded items
Solve problems	3
Select appropriate team members	3
Identify strengths of team members	6
Delegate tasks	1
Facilitate meetings	12
Make decisions	10
Communicate effectively	11
Motivate and engage the team	12
Manage time	14
Be organized	12
Manage stress	3

leader stated: 'You need to be able to deliver the message that you have to deliver without having to have that authority figure and without making others feel judgment.' Finally, managing time, being organised and managing stress were also seen as the responsibility of leaders. 'Anticipate that it [the project] is time consuming and will take a lot of planning.... you need to look at each of the steps, resources, team members, responsibilities and how they'll be handled.'

Discussion

Our study highlights the potential benefits of CBPR for the individual team members, a concept that has seldom been empirically examined ([Case et al. 2014](#)). Participants described instances in which they personally benefited from participation in the study, including through developing social connections and feeling a sense of purpose. Of particular salience were the opportunities for self-improvement discussed by participants, suggesting that individuals who participate in CBPR, especially those from marginalised backgrounds, can gain professional skills, self-esteem and knowledge that might improve their lives and translate into future opportunities.

Research shows African Americans with low incomes often report a prominent sense of alienation from the community and the political process ([Washington et al. 2009](#)). Individuals with SPMI experience similar alienation and distance from their communities ([Pelletier et al. 2009](#)). The benefits outlined in this study suggest that CBPR can provide people with SPMI important roles and enhance their civic engagement. Sense of purpose may emerge through being able to tell their stories and being involved in meaningful research that positively impacts the community. Within the theme of 'benefits to the community', a substantial number of items were categorised into the sub-theme 'helping others'. Clearly, participants viewed CBPR as a vehicle for social change, with accompanying actions that could help their community. While participants highlighted the contribution their CBPR projects made to the communities, they also discussed accompanying personal benefits in terms of pride and satisfaction in their ability to contribute.

The ability to help fellow peers who experience a mental illness may allow lived experience team members to turn the difficult experience of SPMI into one that has greater purpose and meaning for them. CBPR team members in this study described feeling a sense of being able to relate with the research participants in the study. This sense of connection may allow for recruitment of marginalised populations within the African American community (e.g. male sex workers) and make research participants more trusting and comfortable sharing potentially stigmatising information about their lives. Future research could explore the potential mental health benefits of participating in CBPR teams, or make comparisons with benefits to other populations engaging in CBPR.

While these CBPR projects seem to have some similar challenges to traditional research projects (e.g. financial and time pressures), the fact that CBPR uses a collaborative process means that interactions are more complex and require skilled leaders who can manage the different personalities and research challenges. Challenges identified by our research participants somewhat overlap with those of past research in CBPR, including time limitations and communication ([Case et al. 2014](#)). Clarity and transparency around compensation for team members and budget allocation for the project emerged as especially important in this data. Historically marginalised individuals with unreliable sources of income may benefit from explicit expectations and communication around compensation, such as set payment schedules and regular budget updates. Specific limitations of team members noted within the challenges of 'getting along', such as symptoms of mental illness, addiction, or low literacy, highlight the need for project leaders to be sensitive to these needs by providing support and accommodation. Communication, another challenge that prominently emerged around 'getting along', indicates the need for leaders to be skilled communicators who can listen and directly address unique needs of team members.

[Schulz and colleagues \(2003\)](#) summarise group dynamics in CBPR, with an emphasis on the need for open communication, conflict resolution, collaborative decision-making, shared power, trust and organised project management ([Schulz, Israel & Lantz 2003](#)). Similar challenges were also present in our data; however, participant responses in our study seemed to emphasise the important role that project leaders played in team dynamics. The CBPR teams examined in this study were unique in their inclusion of African Americans with SPMI in a leadership role. While leaders navigated challenges similar to those of other research projects, leaders with lived experience were new to this role and were in the position of straddling two worlds: the lived experience and the professional realm. For example, lived experience leaders reported that team members asked them for advice, referral to services or to talk about the project during their personal time. Thus, leaders with lived experience had the additional task of connecting with and advocating for the lived experience team members, while fulfilling their professional responsibilities to the project and to the co-leaders. This study provides important information for researchers, healthcare providers and individuals with lived experience as they initiate research projects.

Engagement strategies that emerged as particularly important included involving the team in project tasks, group discussions and use of the *IC* curriculum. Curricula such as *IC* provide a framework for meetings, including activities that encourage involvement of the team in each step of the research project and plans for a prearranged number of meetings and group discussions. The *IC* curriculum recommends that once leaders have established preliminary project goals they then collectively select the remaining members of their team, who should mostly be people with lived experience. Thus, leaders should ensure that they begin with carefully defining the role of each team member, including their time commitment and pay. Leaders need to interview and screen potential members for lived experiences consistent with the project goals, for their commitment and understanding of the project, and to make sure they fully comprehend that they are research partners rather than participants. The team may need extra people to account for drop-out (e.g. the 'starters' and the 'bench'). Use of meeting agendas, consistent meeting times and places (with flexibility for accommodations), and a structured meeting format may help improve team engagement. Teams should understand that they can expect 'bumps in the road' and try to prepare for those.

This study identified meeting facilitation, motivation of team members, time management and organisation as key responsibilities of CBPR leaders. It is interesting to note that participants did not emphasise a need for leaders to have research skills, but rather commonly discussed project management responsibilities that centred mostly on their interactions with the team and ability to move the project forward in an organised and timely way. While this is hardly surprising given the collaborative, participatory nature of these projects, it does suggest that leaders do need the time, dedication and stamina to fulfil these important responsibilities. Further of note was the finding that these key responsibilities were mentioned by participants more often than personal characteristics of the leader (e.g. patience, assertiveness). This suggests that competence in required tasks may take precedence over personality or leadership styles.

Teams that want to pursue CBPR should be prepared for difficulties during project start-up when they are determining the needs of team members and the personalities involved. Agency partners (i.e. health care providers) and academic researchers must invest time in the project and be able to treat the team members as valuable partners in research with unique expert knowledge, while learning how to provide reasonable accommodations. As well, team leaders should discuss with members the potential for traumatic experiences, mental health symptoms, substance use, and other difficult or triggering subject matter that might emerge during research meetings or data collection efforts. Academic researchers also need to take an active role in explaining the project-specific research methods to the rest of the team, ensuring that team members understand and have an opportunity to ask questions.

CBPR team leaders can also take steps to create a welcoming and sensitive environment, to ensure members with lived experience can participate fully and effectively. Given that people with SPMI are among the most marginalised members of the African American community, reasonable accommodations for team

members with lived experience were essential in beginning to address some of their barriers to participation, including substance abuse, symptoms of mental illness, housing instability, incarceration, low literacy and deficits in critical thinking skills. Accommodations included additional breaks during the meetings, check-ins between meetings to ensure understanding, and days off for doctor or therapy appointments or mental health/rest days. Leaders should also work with the team members to establish trauma-informed procedures, identify resources for members in need, and recognise methods of supporting team members when challenging discussions arise.

LIMITATIONS

This was a small, qualitative study that explored the perspectives of CBPR team members from two projects using the *IC* CBPR model. Participants interviewed for this research took part in time-limited (nine-month) projects in the local community that were focused on improving health care for African Americans with SPMI. Thus, the results of this research might not represent the way that all team members experienced CBPR and therefore might be unable to address differential impact of participant characteristics (e.g. gender, race/ethnicity, role on project). Another limitation is that, while 6 of the 13 interviewees had a leadership role on the project, we did not examine leader responses separately from those of other CBPR members and did not explore benefits inherent in each leader type (academic, provider and lived experience). This was done in an effort to protect the anonymity of participants given the small sample size, but limits the specificity of the data. Finally, results presented here do not account for the outcomes of the two research projects and how those outcomes might be related to the process of participating in CBPR.

While CBPR has the potential to produce research outcomes that are more culturally responsive, this is also dependent upon the cultural competence of researcher and research environment (academic or healthcare setting). Experiences of racism and discrimination based on disability were largely absent in our data, as was a discussion of how African American status may have affected the projects. Perhaps these biases were so pervasive and implicitly accepted that participants did not find them worth mentioning. Internalised, Eurocentric white views of leadership could be reflected in our findings on desired leadership characteristics, especially considering that data on leaders were general rather than specific to the leader role (service provider, academic or lived experience). Internalised stigma of mental illness might also impede participant reflection on disability-based discrimination. Future research teams could consider how to elicit responses from participants on these important topics and how to illuminate the unique qualities that lived experience leaders might bring to the team.

While on this project the TDAB provided the initial CBPR training and supported potential lived experience leaders in connecting with researchers and non-profit organisations, the *IC* curriculum recognises that not all CBPR projects might be initiated in this fashion. The curriculum suggests ways for stakeholders to come together organically within the confines of organisations and for lived experience individuals to initiate projects by seeking organisational partners. In real-world settings, the process of initiating projects with strong lived experience input during start-up may be undermined by financial constraints, power imbalances, stigma and lack of organisational support for CBPR. Future work could identify how best to support lived experience leaders on project initiation and equitable partnerships with academic researchers and healthcare organisations.

Conclusion

While CBPR has been widely implemented, rarely has it involved individuals with SPMI as research partners or project leaders. This article describes the *IC* model of CBPR, which involved a group of African Americans with SPMI as partners on a research team, including one person with lived experience in a leadership role. Our qualitative study examined the perceptions of CBPR team members who had

implemented the model, with a particular emphasis on leadership needs. In the *IC* model, a triumvirate of co-leaders (academic researcher, person with lived experience and health service provider) recruited additional CBPR team members with lived experience to conduct the research project. The results presented here can provide important information for potential CBPR project leaders in terms of understanding potential benefits and challenges of CBPR with this and other marginalised communities. The needs of the leadership team that are outlined in this study can aid future projects in choosing leaders and give potential leaders insight into what to expect on such projects. For example, CBPR projects require leaders who can lead a diverse team, navigate reasonable accommodations for team members, and employ engagement strategies to fully involve them in the project in meaningful ways and to highlight the contributions of lived experience team members. Finally, this research points to areas that might need development in the future. The research literature on how to onboard and support research leaders with lived experience who are in SPMI recovery is non-existent; thus, further research is needed to explore factors that will contribute to successful leadership. Leaders with lived experience may need additional preparation and support to meet the demands of leadership on a CBPR project, especially when managing recovery from mental illness. Similarly, academic researchers and healthcare partners can benefit from training, preparation and self-reflection prior to initiating CBPR projects.

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Appendix

INTERVIEW GUIDE QUESTIONS

We are interested in your experiences with community-based participatory research (CBPR).

1. How did you benefit personally from being on the CBPR team?
2. How was being on the CBPR team different from what you expected?
3. What did you like about working on the project?
4. What didn't you like about working on the project?
5. How did your team go about making decisions in the group setting?
6. How did your team handle conflict within the group? Was it handled effectively?
7. How was the manual and workbook used? What parts of the manual/workbook were most helpful?
8. Can you name a couple of things that were frustrating about being on the team?
9. Were you satisfied with your payment on the project? Why or why not?
10. Did each member of the team do about the same amount of work on the project?
11. What impact do you think your project will have on your agency/your community?
12. What do you think that people with lived experience (African Americans with mental illness) brought to the project?
13. Tell me about the work that you personally did on the project.
14. What unique ideas did you bring to the project?
15. What other training or preparation do you think would have been helpful to have at the beginning of the project?
16. What strengths does the leader of a CBPR project need to have?
17. Do you notice any differences between the leaders and the rest of the team?
18. What do you think the leaders could have done differently?
19. Were you able to communicate your frustrations, needs, ideas, etc. effectively in the group?
20. Did you feel that your input was valued? Were your comments respected?
21. Would you want to be on a CBPR team again? Why or why not?