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FULL-LENGTH ARTICLES

The Process and Significance of Convening a Community Advisory Board With Individuals With Severe Mental Illness

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Individuals with lived experience of being diagnosed with severe mental illness and/or substance use disorders have deep and profound knowledge regarding the culture and needs of their community. Historically, these and other vulnerable populations have been excluded from care access, treatment insights, research development and participation, and often society in general. In this paper, we share our experience of convening a community advisory board with vulnerable populations and highlight the expertise these community members provide. We outline our processes of convening the community advisory board, engaging in collaborative meetings, revising the research protocol, and exploring future research needs. Using meeting minutes, conversations, and reflections we share our trauma-informed process of developing relationships with community members, with particular attention to the specific needs and significant value of working with vulnerable populations. Our intention is to outline our processes in the collaborative relationship through which we improved our research protocol due to community advisory board members' thoughtful contributions. Individuals with severe mental illness offer perspectives from a lived experience that is invaluable in the development of significant, useful, trauma-informed, and timely research for vulnerable communities. Based on our findings and experiences, we recommend that researchers convene and collaborate with community members at each stage of the research processes from inception to completion.

Introduction

Convening a community advisory board (CAB) is one method employed to equitably facilitate community input into participatory research methodology. However, there is little research in which individuals with severe mental illness (SMI), such as schizophrenia and schizoaffective disorder, are included in research methodology. This paper explores the processes of working with a CAB comprised of individuals with SMI. Through detailed field notes, we uncover the knowledge provided by the CAB members in enhancing the procedures involving a newly developing research project, and the significance of a collaborative approach to research for and with individuals experiencing SMI.

Many view CABs as an initial process of facilitating community-based participatory action research (CBPAR). Community-based participatory action research presents a research strategy that engages researchers and community members in a partnership in which they collaborate to form nonhierarchical relationships and improve the health outcomes of a community. This may be compared to more customary public health research, which adopts a traditional top-down, or expert-driven, research approach where the researcher, or the 'expert,' designs and conducts research with minimal involvement of the community (Collins et al., 2018; Israel et al., 1998). These top-down research paradigms often center on individual risk factors which, when in combination with minimal community engagement, can obscure the social and environmental factors such as societal inequities that impact communities. Such approaches lead to growing divides in health outcomes as well as research knowledge (Israel et al., 1998). According to Israel and colleagues (2010), CBPAR includes the following key principles: (1) recognize and respecting the community as an identity; (2) identify and build upon existing resources, strengths, and relationships to better identify the communal health concerns; and (3) facilitate collaborative partnerships in all areas of the research process. Implementation of a CBPAR research paradigm requires the identification of a community with a vested interest in a specific topic or interest in relevant phenomena, and the direct involvement and inclusion of community members in all aspects of research in an equitable manner. Furthermore, the research experience and findings should be beneficial to the research team and the community at hand. The processes and efforts of the research should provide relational longevity and ultimately work towards diminishment of disparities (Wallerstein & Duran, 2006).

Background

In general, a community advisory boards (CAB) refers to a body of community members centered around a common identity, culture, language, and/or experience such as a diagnosis or medical condition(s). Community advisory board members partner with the research team to inform the study parameters and advocate for other members of their community. Many view CABs as an ethical opportunity for researchers to explore and address the context in which individuals in a community perceive the risks, benefits, and understanding of their research (Crouse Quinn, 2004). Working in tandem with community consultation throughout the research process is especially crucial to working with marginalized communities such as those with schizophrenia and schizoaffective disorder who often have a history of being subjected to unethical research practices and methodologies (Cramer et al., 2018). Best practices for convening a community advisory board consist of: (1) recruitment and formation of a CAB with a clear purpose, function, and roles; (2) establishing operational procedures, guidelines, as well as leadership; and (3) sustainability and continued engagement in the CAB (Newman et al., 2011).

Two qualitative studies examined CABs and mental illness from the perspective of the CAB members with specific focus on their intent and motivations behind their participation. One study found that community members were motivated to participate in CABs based on their own personal diagnosis or diagnosis of family members, desire to be involved in advocacy, prior role as a health professional, or prior experience with research (Sotto-Santiago et al., 2024). The study by Ortega and colleagues (2018) found that community members were motivated to take part in a CAB by a desire to help the community with the perception that they had insider information and experiences coupled with the desire to bring outside health resources and services to their community. Both studies found that CAB members were motivated by a desire to assist their community and serve as a resource for researchers (Ortega et al., 2018; Sotto-Santiago et al., 2024).

In terms of engagement of CAB members for research with persons with bipolar disorder, Paltin and colleagues (2022) identified early and continual activation of the CAB as most effective as well as clarification of roles and expectations. Moreover, the CAB members made significant contributions to study design, such as strategies for participant recruitment. However, the CAB did not solely include people who had a diagnosis of bipolar disorder but also the family members of persons with bipolar disorder as well as physicians and administrators (Paltin et al., 2022). Another study looking at schizophrenia genomics (Campbell et al., 2015) found that the use of CABs both in developing countries, as well as in research relating to mental illness, resulted in beneficial input related to consent procedures, recruitment, participant perception and illness beliefs, and stigma and bias in the study overall. In this study, CAB members noted that the general population may be under- or mis-educated about SMI, thus contributing to stigmatization and bias. In response to this, CAB members recommended educational contributions, such as a newsletter, to properly inform individuals, promote mental health, and update the community about the processes and progress of the research project (Campbell et al., 2015). Both studies demonstrated the effectiveness of CABs, as indicated by the impactful contributions and, in most cases, improved research methodology, when research with individuals with SMI was facilitated. Furthermore, the studies emphasize the beneficial relationship in reducing stigma and bias when working with vulnerable communities in research.

Through CBPAR, the implementation of CABs has been suggested to bridge the gap between marginalized and previously exploited communities and researchers to improve the ethics of research and gain better community input. Prior research has shown that utilizing CABs in research involving SMI has both had positive motivation and participation from board members to further inform research methodology as well as positive contributions to the research process and novel contributions (Campbell et al., 2015; Ortega et al., 2018; Sotto-Santiago et al., 2024). However, there is a lack of research to date into the creation, incorporation, and benefits of a CAB

comprised of individuals with schizophrenia and schizoaffective disorder, a marginalized group who are the recipients of research outcomes. Therefore, this paper explores and examines the experiences, effectiveness, and impact of a CAB composed entirely of individuals with SMI. Detailed field notes of each CAB meeting detail components of the process and the potential implications for rebuilding trust with marginalized communities, addressing special considerations when working with individuals with schizophrenia and schizoaffective disorder, and reducing stigma and bias in SMI research will be considered.

Convening of the Community Advisory Board

In March 2023, we recruited individuals from an urban non-profit organization in Pennsylvania that provides congregate, permanent, supportive housing across 22 residences for people with SMI and substance use disorder (SUD). This organization has provided services for over 35 years. Individuals with a history of living unsheltered are provided affordable housing options in individual apartments in a common, single building. This approach is a Housing First Initiative, which provides housing and supportive services such as health care, education, mental health and recovery services, and employment opportunities. Housing provisions are not dependent upon utilization of services, nor sobriety of the residents, and believes that everyone deserves a home regardless of extenuating circumstances. The research team acknowledged the vulnerability of individuals with SMI and SUD who also had a history of living unsheltered. Therefore, the decision to convene a community advisory board (CAB) was made to establish rapport, invite individuals with lived experience to guide the research project, and attempt to develop relative safety for the community members. Upon approval from Thomas Jefferson University's Institutional Review Board (IRB) to commence a research project, we recruited individuals with lived experience of SMI, substance use disorders, and a history of living unsheltered to join a CAB. Only CAB members who were also research participants completed Informed Consent in compliance with the IRB. Those CAB members who were not part of the research did not require informed consent as they did not have access to research data.

Our recruitment strategy included posting a flyer in all the building's elevators and the community group room. The flyer simply stated, "We are working on a project about dance/movement therapy groups and body awareness. We are looking for people to join our community advisory board to offer input on our project design." The researcher and research assistant (RA) attended a regularly scheduled community meeting for the residents as invited guests. In the meeting, we spoke about the role of CAB members, and the intention of the CAB in informing the research team about the design of a study that was to take place within their community. We indicated that joining the board would require participation in four meetings throughout the project timeline, lasting approximately two months, and that participants would be compensated for their time. Moreover, the researcher informed the

CAB members that they would be providing lived expertise with which they would be teaching the research team what may work best for and with their community members. The research team determined that compensation for CAB members' time was imperative. Clearly and colleagues (2008) purported that providing individuals with SMI with remuneration for research is "contentious" and "largely ignored" (p. 286). This goes beyond the typical notion of remuneration as coercion and moves towards the perceived and false incapacity of individuals with SMI to manage money (Cleary et al., 2008). Historically, individuals with SMI were deemed incapable of financial responsibility; however, this claim is under-researched and unwarranted (Marson et al., 2006). In alignment with the tenets of CBPAR, particularly respecting the community and engaging in collaborative partnerships in research, CAB members were paid a fair wage, nearly three times above the minimum wage in the state, for their collaborative work. This wage was based on the living wage calculator for the state of Pennsylvania.

The research team explained to CAB members that the intended research study focused on the effects of six dance/movement therapy (DMT) sessions on mind-body connection and physical health awareness for individuals with schizophrenia; however, their expertise was sought to help inform the research processes and protocols. The researcher described the study design and protocol to the CAB members providing the following details: a definition and description of dance/movement therapy, an explanation of what the intervention may look like, an overview of the surveys used in both pre- and post-intervention, and a description of a focus group with possible questions that may be asked following the intervention. The CAB members were informed that through our meetings together, we would collectively evaluate each of the components of the study in addition to points of significance from the CAB members. Eleven individuals in total expressed interest in and joined the CAB. Seven CAB members were present from the project's inception and four more joined after the first meeting. Four of the CAB members were also study participants and seven were not, as they did not meet the full inclusion criteria to participate in the research study. We chose to include individuals who met inclusion criteria for the study as well as those who did not to join the CAB. This provided equitable opportunities for all community members and offered etic (outsider) and emic (insider) perspectives of the processes from general community members and research participants respectively. Community members who did not meet eligibility criteria to participate in the proposed research study were provided with an opportunity to share knowledge and lived expertise as a CAB member. Regarding those who joined as both a research participant and CAB member, we believe that including these individuals amplified their voices in their provisions of care. All of the CAB members have likely experienced stigmatization per their lived experiences; having them collaborate with the research team offered agency in one aspect of their wellness. The site at which the CAB was convened was also the location of our pilot intervention group

for the research project. Additional sites through the organization expressed interest in joining the research study, which would be pursued following the completion of the pilot protocol and implement information provided by the CAB members.

Community Advisory Board Meetings

The CAB members, researcher, and RA met four times total to discuss the research: twice before the research protocol's inception (in April 2023), once halfway through the intervention (in July 2023), and once after the study concluded (in August 2023). The CAB meetings were held in the community group room at the residents' supportive living community and lasted between 60-90 minutes each. Meeting minutes were scribed by the researcher with permission from the CAB members. The researcher chose to keep the first meeting topic innocuous so as not to be too abrupt in inquiring about personal or detailed information prematurely. The subsequent meeting foci progressed to explore more in-depth topics. This was intentionally chosen to provide space and time to develop trust between the CAB members and the research team. There were 16 weeks between the first and fourth meetings. Below, we provide a summary of the meeting minutes. Our intention behind sharing these synopses is to demystify the process of collaborating with CAB members who have a diagnosis of a SMI and have experiences living unsheltered. The meeting minute summaries provide concrete examples of the insight gleaned from working with this population and our process of progressing together from concrete to critical concepts as we established therapeutic rapport and interpersonal relationships. Based on the paucity of research around convening community advisory boards with individuals with SMI and the historical harm perpetrated towards this population, we feel that the following summary can act as a guide for others working with these vulnerable populations.

Meeting 1: Introductions, Explanation of the Research, Rapport Building

The first meeting took place five weeks prior to study recruitment, in the early phase of research development. The priority of the first meeting was to build rapport and begin to create a space of relative safety in which individuals could openly share their thoughts and ideas. The researcher introduced herself and shared her background in working with individuals with SMI. Next, she spoke about her research interests, particularly in creating spaces of belonging and healthcare equity for individuals with SMI, as well as an historical account of the previous research she has facilitated. Finally, the researcher explained the role of CAB members and the importance of their advisement on the present research study. The researcher acknowledged the perceived hierarchy and status difference between herself and the CAB members, highlighted the importance of the knowledge CAB members could provide, and noted that they are the experts the researcher

team can learn from and with. Next, the research assistant introduced herself, then CAB members were asked to introduce themselves and share any information they would like with the researcher and research assistant.

Following introductions, the researcher provided the group members with a brief description of DMT and informed CAB members that this would be the intervention for the research study. The researcher explained that a typical DMT session would last approximately one hour and include (1) a movement warm-up co-led by the group facilitator and participants; (2) movement and dancing to process or move through a theme that is developed by the group members; (3) a movement cool down to physically and emotionally close up the session; and (4) a time for verbal reflection. The researcher explained that music would be played during the sessions and posed a question to the CAB members: Thinking about not only your preferences, what do you think the preferences of the community would be regarding music choices for the groups? The following music genres were provided by the CAB members: (1) Motown; (2) 80s music; (3) Smooth jazz; (4) Salsa, merengue, and bachata; (5) Classical; (6) Heavy metal; and (7) Gospel. We briefly discussed how each of the musical genres may be useful to community members such as using smooth jazz to help soothe and mellow people, and Latin music to be more inclusive of the community members who identify as part of the Latine community.

Meeting 2: Study Logistics

The second CAB meeting took place one week after our initial meeting. We began by introducing the four new members to our group. The researcher recapped topics discussed at the previous meeting and asked returning and new CAB members if they wanted to add any additional comments or thoughts. This meeting was focused on the logistics of three parts of the research protocol: intervention length, completion of forms, and focus group scheduling.

The researcher then posed the first question: "Thinking about commitment and availability, how many sessions would be an appropriate number for the research intervention?" When there was a lull as the conversation advanced, we wanted to ensure that the CAB members knew we valued their perspective. We were also mindful that the CAB members were mostly unfamiliar with what a DMT session would entail. With that, we reminded them of the components of a DMT session and inquired as to whether CAB members had participated in group psychotherapy sessions in the past for a point of reference. The researcher noted that there were currently six sessions scheduled and that we were unsure if that felt like an appropriate number of sessions. We then asked if they would recommend changing that number. All CAB members agreed that six sessions were a suitable number to start with for this study, and that we can re-evaluate after participants had an opportunity to experience, and thus further understand, a DMT session.

The researcher next explained that participants in the research study will be completing forms as part of the research protocol. The group held discussions regarding (1) whether study participants should complete the forms on their own or in a group setting; and (2) whether the research assistant should read the forms to participants or allow the participants to read them individually. Members of the CAB suggested that we assess individual preference regarding reading the forms on their own or having the RA read them to them. They all agreed the RA should be present to answer any questions participants may have. The CAB members also agreed that the forms should be completed in a group format when possible so all participants could benefit from any inquiries clarified by the RA.

The group next discussed the post-intervention focus groups, which were scheduled to take place within 30 days following the last intervention session. Community Advisory Board members advised that this is too long of a period between the final intervention and the focus groups. They recommended that the focus groups should take place within a week of the final intervention session, so the process was still fresh in participants' minds. They noted that the longer the wait period, the less people may retain and thus share in the focus group.

Finally, we spoke about the study outcomes CAB members felt would be most important to consider. The researcher provided the group with a brief overview of the questions asked in the focus groups and the concepts we were interested in measuring before and after the intervention. The CAB members were asked their opinions regarding the areas we were inquiring about and what, if anything, they would change. The primary areas that CAB members suggested were missing were inquiries about symptomatology, physical limitations, motivation, and participants' prior experience with dance. This information prompted the researcher to change the quantitative outcomes measures and add a question to the focus group guide. Original outcomes measures included the Scale of Body Connection (Price & Thompson, 2007), PROMIS Self-Efficacy for Managing Chronic Conditions (Lee et al., 2019), and PROMIS Physical Function (Rose et al., 2008) form. All three instruments were removed, and the following added in their place: Multidimensional Assessment of Interoceptive Awareness (Mehling et al., 2012), Positive and Negative Syndrome Scale: Negative subscale (Kay et al., 1987), and Medical Outcomes Study: 20-Item Short Form Survey Instrument (Tarlov et al., 1989). A question in the qualitative focus group guide was added to inquire about prior dance experience. An amendment was submitted to the IRB to change the outcomes measures.

Meeting 3: Community Recommendations for Therapeutic Support Needs

The third CAB meeting took place 12 weeks after our previous meeting. This date was determined by two circumstances: (1) recommendations from the previous CAB group were submitted as an amendment to the IRB,

and we were awaiting approval to begin the research study; and (2) we agreed to meet at approximately the half-way point through the interventions and scheduling allowed a meeting following the fourth (of six) weekly intervention sessions. We began with a welcome of members, a recap of the last meeting, and a request for any additional comments regarding our previous topic. This meeting then led with an inquiry regarding what the group believed the community needs pertaining to therapeutic sessions. They offered six areas of which they felt would be most beneficial to the community as a whole: (1) Navigating isolation; (2) Communication and community building; (3) Self-care; (4) Developing and maintaining healthy boundaries; (5) Creation and maintenance of relationships; and (6) Motivation. This information would be incorporated into themes explored in the DMT intervention sessions with research participants in ongoing intervention sessions. It was also suggested for future sites that will participate in the ongoing research study.

A discussion ensued around the tendency towards isolation of community members and the limited interaction they have with others. Community advisory board members suggested that working therapeutically on communication and community building could diminish some of the isolative behaviors of community members. This also tied in the suggested theme of self-care, particularly as it related to a DMT intervention. The CAB members noted that individuals who isolate often lack self-care skills and may need support regarding how to ensure they are caring for themselves in a variety of ways including socially, emotionally, and physically. Moreover, a combination of isolative behaviors, lack of self-care practices, and difficulties with interpersonal relationships deter community members from engaging in activities, services, or relationships with one another. This is further compounded by symptomatology that diminishes their motivation.

The discussion turned to the significant role of relationships within community living. Developing and maintaining healthy relationships can be complicated by mental health and substance use symptomatology. This is further compounded by either a lack of clear boundaries by individuals or having community members who do not respect set boundaries. Members of the CAB identified a need for support in developing, maintaining, and respecting personal, physical, and emotional boundaries within and amongst the community.

Meeting 4: Post-Research Processing and Future Study Directions

Our final CAB meeting was held two weeks after the final intervention delivery, and one week following the post-intervention focus group. We began as the previous three had, with a welcoming of group members, a recap of our past session together, and an opportunity to provide additional information to our past discussion. The group members were then informed that in our session, six questions would guide our final meeting. These questions were developed by the research team to glean information that would support successful implementation of the research protocol at additional sites and to

gain clarity in the community needs from the CAB members. The questions were: (1) What are important things to look at regarding future research projects; (2) How do we figure those things out?; (3) How do you know when you are doing or feeling "well," and what does "well" look like?; (4) How important is it for you to participate in things provided to you?; (5) Do you think we should learn from questionnaires, conversations, or a combination of both?; and (6) When I go to the next site, what should I tell people about this research study? All the questions were addressed in our final meeting; however, the CAB members did not directly respond to question three; rather, this question was indirectly responded to throughout the discussion.

Question 1: What are important things to look at regarding future research projects? The conversation began with a suggestion of wanting both researchers and community members to understand the culture of the illness: the mindset, being in "survival mode," understanding how our environment changes or informs our behaviors, and trying not to fall back into old patterns. For example, one participant shared that they sometimes feel isolative and do not socialize with peers due to historically being unsheltered and needing to be unseen and unintrusive to society for safety purposes. This sparked discussion about caring for others and noticing when they fall into maladaptive patterns so the community can contact them with support. We discussed humanity without enabling as it pertains to individuals experience substance use disorders, mental health diagnoses, and those who have been incarcerated or lived unsheltered. We discussed how we can support individuals and provide grace regarding their needs and move towards a harm reduction model of care. Members of the CAB shared that community support is imperative, treating one another like family, and helping decrease judgment, bias, and stigmatization that community members experience. How we treat others in times of need extended the need for human connection as part of the healing process. We spoke about the importance of feeling seen, heard, and respected amongst the community and in therapeutic healing provisions. The community, including staff members, should encourage support and growth of one another.

To achieve progress, CAB members spoke of the importance of meeting people where they are, as each community member has different capacities and needs. They noted clear communication and seeing and respecting one another's boundaries as key roles in growth. Moreover, they suggested conflict resolution skills as necessary in establishing and maintaining a healthy, supportive community that fosters growth and positive achievements.

Question 2: How do we figure those things out? The primary responses to this question by CAB members was for researchers to talk with people in the community and provide them with experiences. They suggested a combination of individual and group discussions in which resources can be shared. Peer specialists were named as a way for community members to feel

heard and have individuals with whom they can relate. They reiterated the importance of professionals being able to meet individuals where they are and having the capacity to be empathic of community members' lived experiences.

Question 4: How important is it for you to participate in things? The CAB members agreed that it is important for community members to participate in experiences offered to them. However, they noted the myriad barriers to participating, namely the isolative behaviors that often accompany mental health and substance use disorders. They noted that when people show up and engage authentically with them, it establishes trust and relationship that are necessary for individuals to feel relative safety that can lead to participation in new experiences.

Question 5: Do you think we should learn from questionnaires, conversations, or a combination? None of the CAB members thought that questionnaires alone were a good idea. However, if questionnaires were implemented, CAB members preferred them to be completed collectively in a group format. This would allow clarifying questions to benefit the entire group and initiate conversations around the premise of the outcomes being examined. Although some of the CAB members felt interviews alone would be sufficient, a majority felt that a combination of interviews or conversations in tandem with questionnaires would give the researchers the most holistic picture of what was being researched. Regarding collection of verbal data, the CAB members preferred focus groups or group conversations over individual interviews, indicating that the community component of the discussion is important.

Question 6: When I go to the next site, what should I tell people? The primary message CAB members wanted future participants to know is that participation in new experiences could provide opportunities for social and emotional growth. They shared that participation in the DMT sessions could provide an opportunity for growth and development both individually and collectively. They stated that participation can provide an understanding about different things such as self-care, your body, and your mental health. They spoke about how participation may provide an opportunity for individuals to combat isolative behaviors through opening up more, having new ideas, and meeting people in your community. Members of the CAB noted that DMT provides an opportunity to move around, moving you out of your comfort zone. They shared that it may be fun, engaging, and proactive in your path to recovery. One CAB member noted, "Dance is good for the body and the soul. It is a way of communication. It's art. It reaches beyond words. It can open the door for community."

Discussion

The processes of convening and collaborating with a CAB comprised of individuals with SMI was beneficial in multiple capacities. First, the research team used their position, which is hierarchical in nature, to invite individuals with lived experience to join their team and collaborate on the research's development. Second, we aimed to diminish stigmatization of

individuals with SMI through collaboration with the CAB members. Third, it provided a platform for and amplification of voices with lived experience, identifying them as experts and offering reclamation of agency. Fourth, the CAB groups became a place of trust and relationship for all involved. Fifth, CAB members provided care and advisement for their communities by guiding the research with their expertise. Sixth, the collaboration included researchers, CAB members, and other members of the staff, who supported the processes and acted as a liaison between researchers and CAB members. And finally, inclusion of the CAB allowed the research team an entry into understanding the culture and community through establishment of authentic and reciprocal interpersonal relationships.

Research as Advocacy

Research as advocacy is a practice that strives to diminish hierarchy amongst communities and collaborators in the research processes. This is in direct alignment with CBPAR tenets (Israel et al., 2010). Historically, individuals with SMI have been excluded from healthcare decisions including treatment planning (Ivanova, 2022), psychosocial interventions (Biondo et al., 2021), and research protocols (Biondo et al., 2021; Chen et al., 2016; Cook et al., 2014; Sailer et al., 2015). Much of the literature acknowledges the profound levels of stigmatization that individuals with SMI, particularly schizophrenia, face (Ivanova, 2022; Kohn et al., 2021; Oud & Meyboom-de Jong, 2009; Rössler, 2016; Sølvhøj et al., 2021; Swildens et al., 2016). Development of a CAB comprised of individuals diagnosed with SMI is, in and of itself, advocacy. It disregards ongoing exclusion of vulnerable individuals and places the expertise of those with lived experience at the forefront, providing them with direct input into the formulation, development, and implementation of the research being conducted within their community (Wallerstein & Duran, 2010). Research as advocacy combats historical dismissal of experiences and ostracism of individuals with SMI. Such exclusionary behaviors tend to exacerbate symptomatology associated with SMI, which, in turn, leads to further ostracization (Reinhard et al., 2020). Lack of inclusion and perpetuation of stigmatization is particularly detrimental to individuals with SMI whose sense of self has been inhibited or disrupted by these very behaviors (Davidson, 2020).

Stigmatization and Ostracization

Both ostracization and stigmatization can be internalized by individuals with SMI, presenting as perpetuation of isolation, self-stigmatization, and dehumanization. Individuals' identities are informed by life experiences and relationships; the identities of individuals diagnosed with schizophrenia and other SMIs are affected by ways in which their diagnoses have informed or influenced their identity development (Cowan et al., 2021; Estroff, 1989; Seeman, 2017; Sugawara & Mori, 2018). Being in receipt of high levels of stigmatizing and ostracizing behaviors can lead to internalizing processes that result in self-stigmatizing behaviors, thus perpetuating poor self-esteem

and diminished self-efficacy (Rössler, 2016; Yen et al., 2020), complicating both self-identity and social identity (Estroff, 1989). These disruptions in healthy self- and social identity can lead to the process of depersonalization or dehumanization for individuals with schizophrenia (Sugawara & Mori, 2018). Therefore, participating in, and thus being empowered by, a CAB could address the ostracization and stigmatization often experienced by individuals with SMI. The CAB can provide an opportunity for these individuals to see themselves as valued and valuable members of a CAB.

Rehumanization

Convening a CAB is one way to engage in inclusive practices with individuals diagnosed with SMI, moving towards a rehumanization process. Jenkins et al. (2023) defined rehumanization as "the attempt to restore [a] sense of humanity" and focuses on "positive social connection, contrasting thwarted belonging, as well as a sense of purposefulness and sacredness of life, remedying perceptions of burdensomeness, [which] may provide a sense of interconnection toward humanity" (p. 3-4). Loneliness and isolation are more prevalent in individuals with schizophrenia than in general populations (Trémeau et al., 2016). Inclusion in a CAB can foster wellness in individuals with SMI, particularly those diagnosed with schizophrenia. One of the primary contributing factors to mental health recovery is a sense of belonging developed through social support and interpersonal relationships (Davidson, 2020; Soundy et al., 2015). Notably, such support and community development are sought through non-familial interpersonal relationships with others experiencing comparable life experiences. Members of our CAB could relate to one another through shared experiences of community living, diagnoses of SMIs and SUD, and a history of living unsheltered. The CAB members became part of the research team and were named experts in the subject matter. Establishing a community in which the CAB members provided insights and knowledge to a group who valued their opinions and could engage in shared dialogue provides an avenue to agency, belonging, trust, and wellness (Davidson, 2020; Soundy et al., 2015).

Therapeutic Rapport Building

Trust and relationship building are imperative when working with vulnerable populations. This is due, in part, to historical harm that has been perpetuated towards individuals who experience severe mental illness, coupled with the internalized perception of being less than human based on demeaning and diminishing behaviors by others (Jenkins et al., 2023). Ho (2023) noted that circumstances such as historical inequities, structural racism, and stigmatization due to mental illness or substance use constitute vulnerability in a population. A CBPAR approach strives to diminish the hierarchy associated with research relationships. Moreover, inclusion into the decision-making processes as they relate to the research protocol provides agency and expertise status to the CAB members. Relative safety, a phrase coined by St. Just, accounts for the current and historical trauma experienced

by individuals and how that will inform perceptions of safety (Gray, 2019). Community members, and thus CAB members, have multilayered contributing factors that may lead to the potential for having experienced trauma: (1) a diagnosis of an SMI; (2) a history of living unsheltered; and (3) racial and ethnic minoritization. All the CAB members experienced at least the first two indicators, many experiencing all three. Knowing that these individuals may never truly feel absolute safety, based on historical or current traumatic experiences, we strive to establish a sense of feeling safe enough in the CAB members' relationship with the research team. It is widely known that individuals with SMI and SUD benefit from trauma-informed approaches that place relationship building, trust, and safety at the forefront of their care (Isobel et al., 2021). A trauma-informed approach considers the life experiences of individuals that may make them hesitant to develop relationships and prioritizes the establishment of trust and safety.

Topical progression in our CAB meetings began on a more superficial level and delved deeper as the therapeutic rapport and relative safety were established amongst the group. The research team began by providing transparency of our intentions—collaborating with and acquiring knowledge from the CAB members—and progressed into inquiring primarily about music choices that may support and align with the community needs and preferences. The goal was to diminish perceived and historical hierarchy between the researcher, research assistant, and CAB members. Inquiring about community music preferences was an entry into acknowledging CAB members' expertise and allowed sequential progression based on their comfort levels (Paquette & Derrington, 2018). The progression of topics—music, to study logistics, to community therapeutic support needs, to future research—unfolded organically as the group established relationship. Relational trust is imperative to rehabilitation efforts, as it provides a space for honesty, and thus depth within the relationship (Soundy et al., 2015). Once such trust is developed, interpersonal relational work can begin both amongst CAB members, between CAB members and the research team, and between CAB members and their community.

Care Amongst Community Members and Research Champions

Soundry and colleagues (2015) named "caring for others" as a valuable aspect of mental health recovery, providing a platform for being a contributing member of society (p. 6). An aspect of how caring for others fosters healing and growth was apparent in the development of the CAB. This was largely due to one of the program managers who had lived experience and joined our efforts as a research champion. Champions are those who "dedicate themselves to supporting, marketing, and driving through an implementation, overcoming indifference or resistance that the intervention may provoke in an organization" (Powell et al., 2015, p. 9). Perhaps having their own lived experience fostered the role of champion for the program manager, as those who not only understand social justice work, but also have been historical recipients of services provide depth

of understanding the profound impact services can have on vulnerable populations (Corrigan & Shapiro, 2010). This individual was instrumental in ensuring that community members were aware of this opportunity and encouraged them to consider ways in which they could act as leaders, adopting the role of both research champion and champion of advancing well-being. Our champion posted and handed out CAB flyers to all community members, helped schedule CAB meetings to ensure they were convenient for the members, and reminded community members of the meeting days and times in passing. As our only connection within the community, the research champion is an instrumental component to the team. They act as a bridge between emic and etic viewpoints providing great insight to both potential participants and the outside research team.

Research champions should be sought out when developing CBPAR research, as they certainly contribute to the success of implementation. Often in community settings, organizations are under supported financially and understaffed as a result. Identifying and aligning with a research champion can ensure clear communication amongst all parties and additional support for community members to receive the benefits associated with participation. We recommend a strong collaborative relationship that includes research champions who are acknowledged and compensated for their temporal and energetic investment. Moreover, there needs to be a reciprocal relationship established between research teams, community sites, and community members.

Conclusions

As discussed in the final CAB meeting, it is imperative for research teams to understand the culture of the community and phenomenon under inquiry. This can happen when the research team collaborates with the community members as experts. Through our processes, the CAB members provided important information regarding the research protocol through recommendations of music and improved outcomes measures. Diminished hierarchies through CABs can highlight the knowledge of individuals with lived experience supporting both rehabilitation and rehumanization. We move towards humanization and equity through conversation, community building, and creation of spaces of belonging. Community-based participatory action research and convening of CABs provides a framework for a more just, equitable, inclusive, and collaborative research plan that places humanity at the forefront of the agenda.

Inclusion in a CAB can be an entry point into research with vulnerable populations, as it provides the opportunity for these individuals to develop research parameters, positioning them in a place of agency. As vulnerable populations have been subject to cruel and inhumane treatment historically—namely the Tuskegee syphilis study, among many others—CAB development and implementation can support these individuals in regaining power over their experiences (Paquette & Derrington, 2018). Furthermore, such agency over the development of research can provide individuals with

self-efficacy, self-value, and giving back to society through the betterment of individuals who are experiencing comparable circumstances to their own. Providing knowledge that can lead to equitable care for peers can diminish isolative behaviors and provide opportunities for contributing to de-stigmatization of historically and currently marginalized populations (Davidson, 2020).

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