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A community-academic collaboration supporting persons of color with chronic health conditions in their recovery journey

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**Abstract**

**Background: Persons of color (POC) face disproportionate risk of chronic disease and substance misuse (SM). There is little information on how chronic disease impacts SM recovery.**

**Objectives: T**o understand experiences of POC in SM recovery and intersection with chronic health condition management; identify community priorities for reducing challenges; and develop program ideas.

**Methods: Community-academic partnership hosted listening and dialogue sessions identifying barriers, facilitators, and priorities to support POC with chronic conditions in SM recovery.**

**Results: Health management is important SM recovery.** We found that POC in recovery with chronic health conditions face multiple challenges to effectively managing their chronic conditions. Low-income, racism, and SM recovery intersect to create unique challenges. **Prioritized needs are education, capacity building and advocacy. Preferred strategies include educating health care providers/systems, advocacy for health care access and peer-to-peer support.**

**Conclusions**: This work provides a foundation for program development, potentially increasing feasibility and acceptability of new efforts.

**Background**

**Heart disease, cancer, stroke and diabetes are leading causes of death for US adults.1 In the US, persons of color (POC)** [[1]](#footnote-1) **are at disproportionate risk for developing these conditions.2 The cause of such disparities are rooted in social and economic disadvantage fed by structural racism.3 Substance misuse**[[2]](#footnote-2) **(SM) is another chronic health condition that disproportionately affects POC.4 Racial and ethnic disparities in SM also have roots in systemic racism.5**

**POC in SM recovery face may face additional burdens compared to their White counter parts including less access to treatment services including medication for opioid use disorder (MOUD), and less access to health insurance to pay for treatment services than their White counterparts.5 One additional barrier to achieving recovery for POC with SM may be the high burden of chronic disease experienced by POC. The disproportionate burden of chronic conditions and other health problems experienced by POC may be exacerbated by SM which can cause long term damage to health including cardiovascular disease, lung disease, cancer, stroke, HIV/AIDS, mental health problems, and Hepatitis C.6 Recommendations are to treat all conditions, including SM concurrently.6**

**We are specifically interested in how the presence of one or more chronic health condition(s) may influence the recovery journey for POC in SM recovery. We expect that the disproportionate burden of chronic health conditions experienced by POC and systemic racism, that shapes all aspects of health including health care access, trust of health care providers, and quality of health care delivery7 are likely to create burdens to maintaining recovery for POC.**

**To our surprise, a review of the literature has turned up few studies examining ways in which the presence of multiple chronic health conditions in persons with SM may influence their recovery and chronic condition management. One study found those who received care for chronic conditions in addition to SM treatment had fewer readmissions to SM treatment five years after initial intake but more frequent health visits were associated with higher rates of readmission to treatment at the five-year point.8 Another study examined perceived needs of people in recovery by length of time in recovery found that managing health conditions emerged as a need in mid- and long-term phases of recovery, while more immediate survival issues such as employment and housing were emergent in early phases of recovery.9 Several studies examining clinical models for treating SM in primary care settings using chronic disease management models of treatment indicated that primary care may be a preferred source of on-going recovery management but offered little insight into the concurrent management of other chronic conditions or how that may interact with the recovery management process.10 Ultimately we could find very little on how the experience of being in SM recovery may influence health care and treatment desires and needs for those with chronic disease comorbidities.**

**Objective**

Our community-engaged partnership11 aims to bring together community organizations, government representatives, policy makers, service providers, researchers, and POC in SM recovery. Our goals are to understand the experiences of POC in SM recovery as they relate to chronic health condition management; identify community priorities for reducing challenges to chronic health condition management for this population; and develop ideas for programs that address priorities.

**Methods**

***Partnership development***

**The Northern Illinois Recovery Community Organization (NIRCO), located in Lake County, Illinois is a member of Faces and Voices of Recovery and the only recognized Recovery Community Organization in Northern Illinois. NIRCO provides recovery support services, advocacy and education to persons in recovery. NIRCO leaders have lived recovery experience and careers in SM recovery services. NIRCO’s leadership identified health conditions as a potential barrier to beginning or maintaining recovery among POC in Lake County, Illinois. NIRCO’s Executive Director (MR) and Program Coordinator (DL) reached out to Northwestern University’s Feinberg School of Medicine to seek a partnership with a public health professional with similar interests.**

**Through a matchmaking process led by the Northwestern University Clinical and Translational Sciences Institute’s (NUCATS) Alliance for Research in Chicagoland Communities (ARCC), MR, DL and MM matched based on common interests. MR, MM and DL met in person at NIRCO’s offices (prior to the pandemic closures) and online twice more to discuss potential scope, goals and activities. These conversations involved sharing personal and professional backgrounds, observations, research findings in the literature, insights and visions for the future. Once we determined that a partnership was feasible and desired, we drafted a seed grant funding proposal to support partnership development through NUCATS’ ARCC program. We collaboratively developed the proposal, sending drafts back and forth for clarification and elaboration of the partnership development activities. We submitted a proposal in March 2020, and approved for funding in June 2020. The one-year grant began September 2020.**

**The project took place in Lake County, Illinois. Lake County is a populous county of approximately 760,000 residents located directly north of Cook County, IL where Chicago is located. Lake County boarders Wisconsin and is diverse with rural, suburban and urban areas and an economically and racially/ethnically mixed population. Lake County is racially/ethnically and economically segregated with higher populations of lower income and POC in Northeast municipalities such as Waukegan, Zion and North Chicago. The project’s in-person community dialogue session took place in Waukegan and drew participants from nearby areas.**

**Bi-weekly partnership meetings**

**Starting in June 2020, partners (MR, MM and DL) met bi-weekly to develop a partnership agreement, work plans, discussion guides, and a detailed calendar of activities. Later, we used these meetings to prepare for, and debrief from our community dialogue sessions and review draft reports.**

We did not seek IRB review for this project because the intent was partnership development and we gathered information solely to support program development; our activities did not meet the definition of research under 45 CFR 46 subpart A.

***Three community listening sessions***

**We held three community listening sessions to gather input from POC with lived experience, SM treatment and recovery service providers, community coalitions, policy makers and community services (police, library, State’s Attorney’s office) between** fall 2020 and spring 2021. Session one focused on breast cancer as a health concern for women in recovery and had nine participants, all of whom were POC. Session two, featured discussion on the intersection of health and recovery, health considerations in SM recovery service delivery, and perceived needs relative to health for POC in SM recovery living and/or receiving services in Lake County. There were18 participants, 12 POC. The third session expanded on challenges and facilitators to health during SM recovery and ideas reducing barriers. There were 11 participants, nine were POC.

***Community dialogue and prioritization session***

**Our last session was a community dialogue presenting feedback from the three listening sessions and offered opportunities for participants to prioritize topics and approaches to barrier reduction. There were 48 participants, 40 of which were POC. All participants received a $10 gift card.**

***Data analysis*. We analyzed transcripts and notes from the listening and dialogue sessions by starting with a framework tied to our project purpose and organized information into thematic “buckets” such as connection between recovery and health, health issues, barriers to health management. Once organized thematically, we looked for common sub themes and summarized data accordingly. At each step along the way MM, MR, and DL met to discuss the data fit with themes and whether they adequately reflected the information. MM led data analysis.** We present the feedback obtained as overarching themes and program development priorities. We intend this to be the start of a road map for program development to address the prioritized needs of community members.

**Community engagement**

**A wide variety of community representatives were engaged throughout the process including persons in recovery, recovery service providers, faith-based organizations, community institutions, emergency services and health care providers. Partnership engagement took several forms. The most involved was consultation with potential listening session and community dialogue participants prior to sessions to learn more about their interest in the topic and gather feedback on discussion guides. We also engaged participants by asking them to recruit additional participants for these events and encouraged community members to make presentations or share experiences during the events. We encouraged all participants who attended listening sessions to share opinions, experiences and knowledge during the events. At the community dialogue event, we asked participants for opinions, feedback and priorities on health issues, challenges and potential solutions identified in earlier listening sessions and used priority voting to determine common and main concerns. At the community dialogue session, we intentionally sought additional feedback on issues not surfaced during listening session as an additional engagement opportunity.**

**Findings.**

**Health and recovery are connected.** Many participants described managing chronic conditions as an important issue within their recovery journey.

***The initiation of addressing health conditions varied by recovery phase.*** Some participants reported health issues prompted their entry into treatment. In contrast, for others, the process of recovery surfaced health issues.

***Service providers endorsed connection between recovery and health.*** Recovery service providers universally believed that addressing health concerns is critical to the success of people in their recovery journey.

***Substance use treatment and recovery service providers believe they have a role to play in supporting health management of people in recovery*.** Treatment and recovery service providers all emphasized their role in referring persons in recovery to health management services.

***Common health conditions experienced by participants*.** Participants identified hypertension, diabetes and depression as the most common health conditions among POC in recovery in Lake County. Table 1 includes the list of health issues identified by participants.

**Recovery-related challenges to health management.** Most participants were able to identify issues that interfere with their health management that are specific to being a person in recovery. There were:

Self-blame/shame for behavior during SM that may have contributed to development of a health condition and/or not managing health conditions during SM.

Experience of stigma/prejudice –for example, a provider judging them for their using history, treating them less compassionately, “writing them off”

Fear that treatment options may be limited to avoid certain medications due to past misuse and worry about pain, especially dental pain.

Delayed development of self-insight/self-care skills due to clouded perceptions/judgement, and/or different priorities while in SM. As a result, some people in recovery did not feel that they were where others of similar age/life stage or similar chronic illnesses with respect to these skills.

Fear that “bad” health news may trigger relapse. This can lead to avoidance of receiving health news.

“Having a lot on their plate.” Managing recovery is a lot for some; adding chronic health conditions may overwhelm their focus on recovery. For example, having many appointments, medications, lifestyle changes to manage.

**Intersection with additional challenges.** For many, these recovery-related challenges are compounded when they intersect with their experiences as a POC and/or as a person with limited income. See Figure 1 for a depiction of the relationship of identity aligned challenges. For example, many but not all participants expressed that they already faced issues of discrimination as POC seeking health care and this worsened when they experienced stigma upon disclosure of their recovery status. Others explained that not having resources for transportation made travel to multiple health care providers in the region much more difficult and that, added to the work of recovery, was sometime overwhelming.

Some of the challenges discussed related tolack of access to health care insurance, a problem fundamentally based in the challenges of having a low income. Participants explained that even with access to health care insurance through the Affordable Healthcare Act (e.g. Obama Care), many lacked the income to purchase even the most basic plans or the plans that they could afford had very limited benefits and onerous processes for approval of health care services. Participants also raised concerns about transportation to health care appointments, and access to and affordability of healthier foods.

Another set of issues discussed were cultural differences between patients and providers based on differences in education and race and ethnicity. Participants reported communication difficulties due to unfamiliarity with health and health care terminology used in health care settings. Others reported feeling unwelcome at certain providers due to perceived prejudice based on racial identity. As one participant commented, “you walk in there and can just see they don’t want to be bothered with you”.

Finally, persons with multiple chronic health conditions faced challenges to health management. Those discussed at our listening sessions included having to appointments with multiple providers in multiple locations, having to acquire and manage multiple medications and learning and sticking to new behaviors such as exercise and diet.

**Prioritized Challenges**

In a culminating dialogue session (July 2021) we convened policy makers, government representatives, service providers, persons with lived experience, faith based representatives and health care providers to present these findings and then identify priorities for next steps. Each participant selected priorities in three areas: health conditions, challenges to address, and solution strategies. Table 2 includes a prioritized list of challenges to address. The top three challenges identified were lack of health care insurance, lack of trust in health care providers in treating persons in recovery and persons in recovery not prioritizing their own health.

**Solution strategies**

Table 3 includes the Full List of Prioritized Solution Strategies. The top priorities were education of health care providers regarding the needs of POC in recovery, and capacity building and advocacy supports to help POC in recovery meet their health needs. These strategies rely on dialogue and skill development to share perspectives, meet needs and encourage self-advocacy.

*Strengths and Limitations*

This is a small, qualitative study and may not apply to locations outside of Lake County. However, by engaging persons with lived experience, we captured issues important to this population and these perspectives can be helpful to those working in other locations as a starting point for reflection on the intersection of chronic health conditions and recovery.

**Conclusions**

Our focus on management of chronic health conditions for persons in recovery is reflective of the Substance Abuse and Mental Health Services Administration (SAMHSA) approach to health and wellness.12 The emphasis on recovery as a journey aligns well with the philosophy and model of Recovery Community as put forth by Faces and Voices of Recovery (https://facesandvoicesofrecovery.org/services/), a national convener of local recovery communities with a mission to support people in recovery in their local communities. These alignments support this work and provide a framework for its continuation.

This work contributes to the field by highlighting the connections between management of chronic health conditions and SM recovery, a topic not well documented in the literature. As the opioid crisis enters its third decade, the needs of people in recovery should generate more interest and research. Our efforts in this area have benefited from the perspectives of persons with lived experience. We found that POC in recovery with chronic health conditions face multiple challenges to effectively managing their chronic conditions and that low income, racism, and issues related to being in recovery intersect to create unique challenges.

Participants suggested and prioritized several potential programmatic directions to address these challenges. One is adaptation of an existing community health worker (CHW) initiative by adding a training component specific to supporting health during recovery. This may be a fruitful approach as it leverages an accepted and well-regarded model already operating in the community. Examples of successful CHW adaptations are plentiful.13 In Lake County, a CHW program has adapted to provide pandemic training to their staff in addition to routine training components.

Another promising approach suggested and prioritized through listening and dialogue sessions was the education of health care providers about the needs and concerns of POC in recovery. We are aware of several anti-racism initiatives in health care systems with the goal reducing bias in health care delivery.14 We are also aware of emerging models to address recovery in health care settings such as recovery management services in primary care settings and, locally, the location of recovery coaches in emergency department settings.10,15 However, we are unaware of any existing initiatives that specifically address the intersection of race/ethnicity and SM recovery with health care systems and providers. Participants’ vision for such an initiative includes assisting providers in developing productive “bedside manner”, providing examples of preferred and consistent (across recovery and health services) language, building awareness of the array of recovery assistance services available locally, and sharing common health care concerns of POC in recovery so that providers can anticipate and respond accordingly.

Listening and community dialogue sessions yielded benefits for this community-academic engaged partnership. The process built shared purpose and common goals. This enabled diverse community members and academics to unite around a topic of initial interest and generate excitement and good will to move forward. We gained the perspective on the ways aspects of identities of people with lived experience intersect and the ways that intersection of these identities contributed to the challenges experienced. Through dialogue and reflection, we were able to gain a more nuanced understanding of challenges and how they may interfere with chronic condition management. Through dialogue, we shared findings from earlier sessions and gathered feedback. This enabled us to generate a prioritized list of acceptable approaches that focused on reducing challenges experienced by people with lived experience. This provides a foundation for program development and in particular, ways to think about program development in the context of services currently available, potentially increasing feasibility and acceptability of new efforts.

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1. We use “persons of color” based on community member input as it best reflected how they self-identify. This term reflects an understanding that POC includes a wider range of identities than the label “Black” and thus is consciously reflective of a broader range of diversity. In our context community members pointed out that this applied to “Black AND brown” people including African Americans, Africans, Latinx, Asian and Native peoples. [↑](#footnote-ref-1)
2. There are multiple terms for this in the literature and in use in the community. We have chosen “substance misuse” based on input from community members who felt this best reflected how the issue is understood in their recovery community. [↑](#footnote-ref-2)