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# Community-based Participatory Research Examining the Health Care Needs of African Americans who are Homeless with Mental Illness

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# **Abstract**

African Americans with mental illness who are homeless experience significant health risks and illnesses leading to high mortality and morbidity rates. A community-based participatory research (CBPR) team conducted a qualitative study to begin to describe these problems. Results from focus groups and key informant interviews of 42 individuals yielded 98 themes which were sorted into three categories: problems, solutions, and peer navigators. Results included a review of the problems and solutions which the community or people might adopt. An additional goal was to understand and develop impact of peer navigators for addressing health problems in this group. Results yielded a list of values in hiring peer navigators as well as skills and resources they might need to successfully do their job. Findings from the study are currently being used by the CBPR team to develop a peer navigator program for this community.

# Keywords

Homelessness; mental illness; health care; African Americans

People with serious mental illnesses such as schizophrenia or bipolar disorder experience significantly higher rates of morbidity and mortality compared to similar aged individuals.<sup>1,2</sup> As a result, they are hospitalized for physical health problems at much higher rates<sup>3</sup> and die, on average, 15 to 30 years younger than their same-aged cohort.<sup>4</sup> People with serious mental illnesses are at greater risk for homelessness, which clearly compounds their health problems.<sup>1</sup> As a group, they have prolonged periods of unemployment, making workforce re-entry problematic,<sup>5</sup> and are three times more likely to be a member of a family in poverty.<sup>6</sup> People with mental illness are more likely to be involved with the criminal justice system<sup>7</sup> and be victims of or generally more exposed to crime.<sup>8</sup>

These problems are even more complicated by ethnicity. Compared with European Americans, twice as many African Americans are below the poverty level. <sup>9</sup> African

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Americans are three times more likely to experience homelessness. <sup>10</sup> Health care for people of color is limited by lack of available services or cultural competence. 11 Both mental and primary care services are less available to African Americans than others because of poverty. <sup>12</sup> People from ethnic minority groups are less insured than the majority culture <sup>13</sup> and services that should be provided by the government safety net are often in fact lacking. 14 Clinics are not geographically available 15 and access to those that can be found are hindered by inadequate public transportation <sup>16</sup> or may be located in high-crime areas. <sup>17</sup> These barriers impede African Americans from forming ongoing relationships with primary care providers necessary to promote engagement between patient, family, and provider team, especially for chronic disorders. 15 Systems of health care often fail to engage patients in a manner that is culturally attuned to those patients. Factors leading to alienation from health care clinics and providers in many North American settings include: preferences for Western healing beliefs<sup>18</sup> to the point that alternative, non-Western treatments may be denigrated; <sup>19,20</sup> diminished trust; <sup>21</sup> culturally-specific mental illness stigma; <sup>22</sup> diverse understandings of mental illness;<sup>23</sup> and providers missing culturally-specific symptom expression.<sup>24</sup> Exacerbating these differences may be a lack of culturally-matched providers though research on the size of this effect continues to be mixed.<sup>25</sup>

Health disparities due to the intersection of ethnicity, homelessness, and mental illness are complex and yield thorny outcomes. Understanding problems that emerge from this intersection and generating solutions to identified problems has become a primary public health priority. We found several studies over the past decade that examined issues of homelessness and health. Some gathered information from providers; one suggested physicians and nurses viewed themselves as mostly unprepared to deal with the health needs of people who are homeless, especially issues related to safety and criminal involvement.<sup>26</sup> A second sought to uncover characteristics of nurse practitioners that readied them for effective care for the homeless.<sup>27</sup> These included basic values and beliefs ("respect for social injustice" and personal empowerment), communication skills ("learning to listen"), and personality traits (patience and openness). Both suggested provider efforts are further hampered by differences in ethnic background of patients and providers. Other qualitative research addressed questions of homelessness and health by conducting focus groups or keyinformant interviews with people who were living on the streets. Results suggested health care needs are undermined by absence of financial resources, shelter, and access to services. <sup>28, 29, 30</sup> Health is worsened by exposure to sick others and being victimized. <sup>31</sup>

Despite the breadth of prior research, there are notable limitations that drive our study. The impact of mental illness on homelessness and ethnicity has not been considered very often; only one such study suggested cultural competencies were often ignored in health settings and shelters.<sup>32</sup> The research there is tends to focus on problems but to remain mum about solutions: only one solution-oriented study was found and it mostly focused on what shelter staff might do to improve health care for women and children.<sup>33</sup> Finally, these studies have not often embraced community-based participatory research (CBPR) in their design. Community-based participatory research to science that believes research on any group can only be valid when professional researchers make partnerships with members of the group (in our case, African Americans who are homeless with serious mental illness). As partners, co-investigators with lived experience have shared leadership roles in all

elements of research design and implementation: defining research questions and subsequent hypotheses, developing interventions meant to reflect hypotheses, describing measures and designs that will test interventions, conducting statistical analyses to make sense of data collected per design, and interpreting findings leading to recommendations with public health significance. Co-investigators have especially noticeable roles at the onset and conclusion of discrete research projects.<sup>34</sup> At the onset, the special insights of people with lived experience can form the key research questions and corresponding hypotheses. This groundwork is central to subsequent design and measurement decisions. The conclusion is when information from the research is used to impact the public health arena. Typically, people with lived experience are the advocates on the team with the enduring interest and motivation to take what is found and change the community. Thus, CBPR is essential to understanding and resolving health disparities due to homelessness, ethnicity and mental illness.<sup>35</sup>

Community-based participatory research with African Americans who are homeless with serious mental illness might seem to pose significant barriers. First, the kind of social disadvantage that describes this disenfranchised group, especially in terms of homelessness, seems to challenge notions of "community" in CBPR. By virtue of their alienation, people who are homeless do not seem to constitute an organization or discrete community (unlike, for example, Native American tribes or ethnic community organizations that are partners in other program development efforts). Existing research, however, shows that homeless people constitute unique and diverse communities in their own right that have worked collaboratively with researchers seeking to improve their capacities and resources. <sup>36, 37</sup>

Second, might the deficits of serious mental illness undermine a CBPR process? For example, do the cognitive dysfunctions or interpersonal difficulties experienced by some people with serious mental illnesses undermine participation in the partnership? A recent review suggests that people with serious mental illnesses are able to participate fully in and add to the CBPR process, especially when provided reasonable accommodations. The purpose of our study was to show how CBPR and qualitative interviews with African Americans who are homeless and with mental illness can generate useful answers to questions of illness and health care for this group. We sought to ask questions and organize responses to make sense of the breadth of problems as well as a panoply of solutions. The work here is stage one of a three-part CBPR-project funded by NIMHD meant to understand, develop, and implement a peer navigator program for this population.

#### Methods

#### **CBPR** team

This project is being conducted in the Edgewater-Uptown neighborhood of Chicago, an area on the city's north side along Lake Michigan with high rates of homelessness. A CBPR team was convened at start-up to guide the project. *Via* flyers and word-of-mouth, a call was put out to the neighborhood for African Americans who are homeless and with serious mental illness to join a research team charged with understanding and impacting the health of peers in their community. Prospective team members were further informed that participation in CBPR would require two-hour meetings, weekly for up to a year. A total of 49 people

responded; each was interviewed by project coordinators and eight individuals were selected to serve on the CPBR team. Given the focus of the project, although all CBPR team members are African American and homeless, members were selected for further diversity: gender (50% female), and history of various physical illnesses (especially HIV-AIDS), military duty, substance abuse, and/or involvement with the criminal justice system.

Team members are paid \$25 per hour plus travel expenses. This price was determined in consultation with a Chicago area coalition of services to people who are homeless to decrease coercion in CBPR participation. The CBPR team is convened by two leaders: a health services researcher (PC) and an African American who was homeless and has lived experience with mental illness (RB). The CBPR team also includes a service provider from a local community health center. He is African American, was homeless and challenged by mental illness, and now supervises a treatment program for people with mental illness with substance abuse problems. He was included as an active member to provide immediate feedback to the team regarding feasibility of any of its proposals related to the service community (e.g., CBPR team says: "Let's require all neighborhood clinics to stay open until midnight." Service provider's response: "No, that won't work because clinics do not have staff for those hours").

#### Defining the problem and possible solutions: CBPR consensus work and focus groups

The CBPR team began by coming to consensus about the nature of health care problems for people in Edgewater-Uptown and ways ethnicity, homelessness, and mental illness compound them. The CBPR team then came to consensus about plans to address these problems. The team believes that peer navigators offer special promise; in our project, peer navigators are paraprofessionals who are African American, previously homeless and now in recovery that help others—homeless African Americans with mental illness—access health care clinics to address their health needs. Initial groundwork on problems and solutions was necessary for subsequent development of an interview guide that engaged focus groups of community residents. The interview guide was developed over a three month period with multiple iterations of research questions to represent the breadth of concerns about health within a manageable list of questions. The interview guide addressed four areas.

- **1.** What are the health care needs for people who are homeless in Edgewater-Uptown?
  - O What hurdles prevent people from taking advantage of existing resources?
  - O Is health care better or worse for people who are homeless who also have a mental illness?
  - O Is health care impacted by a patient's ethnicity?
- 2. What might be done in Edgewater-Uptown to improve services for people who are homeless with serious mental illness?
  - O What might health care agencies do? ... the community do?... the government do?... peers do?... people do for themselves?

3. Peer navigators are paraprofessionals who were homeless and are now in recovery and who assist others in engaging with health care clinics to address their health needs. What do you think of peer navigators as a possible solution to the health problem?

- O What skills would navigators need to learn to do this successfully?
- **4.** How does poverty, crime, gender, and/or sexual orientation further impact health care for people who are homeless with serious mental illness in Edgewater-Uptown?

The last area – on how health care problems are compounded by poverty, race, crime, etc. – generated a large and fruitful set of responses which will be examined in a future paper. The goal here was to get a sense of the nature of problems and strategies that might impact them.

The CBPR team agreed that focus groups comprised of key stakeholders should be convened to address these questions. The team defined key stakeholders as people with lived experience: African Americans who are homeless, currently challenged by mental illness, and struggling with physical illness. We believed this group should be recruited from the ample population of people who are homeless in the Edgewater-Uptown neighborhood. The CBPR team also thought key stakeholders should be expanded to others whose perspectives would increase our appreciation of the health problem and possible solutions: providers of health, shelter and advocacy services. Again, the CBPR team believed the latter group should be drawn from people who work in the Edgewater-Uptown neighborhood.

The CBPR team decided focus groups should be heterogeneous including both people with lived experience and providers in the same group; in this way, each group could react to the insights of others. Groups were scheduled at various days and times (e.g., Monday afternoon, Tuesday morning) so as to be convenient to the varied availabilities of all. To recruit people with lived experience, each of the eight CBPR team members distributed 25 flyers throughout the Edgewater-Uptown neighborhood with specific focus on homeless shelters, food pantries, on-the-streets per se, and clinics. Flyers included a 24-hour contact number and participants were screened until focus groups were filled. The CBPR team generated a list of provider candidates to recruit to complete the focus groups. All were invited and agreed to participate.

### Results

Focus groups were convened with 42 individuals (33 people with lived experience and nine providers) and key informant interviews were conducted with four providers whose schedules did not allow them to attend focus group sessions. The interview guide described above was used in focus groups and key informant interviews. Focus groups were co-led by an investigator with considerable experience in qualitative research and a member of the CBPR team. Each group included 8–10 participants and lasted 60–90 minutes; people with lived experience were reimbursed \$25 for their time. A scribe attended groups and took copious notes including *verbatim* quotations. Key informant interviews were approximately 60 minutes in length and conducted by phone by the project coordinator with a scribe taking notes and quotations in similar fashion. Four of the focus groups were mixed—i.e., included

both people with lived experience and service providers; the fifth group included only people with lived experience. All of the 33 participants with lived experience were African American; 12 were female. The CBPR team decided it did not want to collect additional information about focus group participants in order to not be personally intrusive. Mental illness was determined solely by self-report.

The 13 providers were ethnically diverse (8 European Americans, 4 African Americans, and 1 Asian American); 7 were female. The provider group represented a variety of roles: medical doctors, shelter staff, nurses, clinic secretaries, social workers, food pantry worker, and CEO of integrated care agency. Although two providers offer clinical services to people who are homeless, at no time were these providers in the same focus group as current or past patients.

Overall themes were gleaned from transcripts of focus groups and key informant interviews using a grounded theory approach to qualitative analysis. Open coding by independent raters yielded 98 discrete themes suggesting saturation was reached after five focus groups and four key informant interviews. A second set of raters then sorted themes into subsequent groups and concepts. A summary of themes and concepts was then provided to the CBPR team for feedback. The CBPR team considered contrasting themes generated by people with lived experience versus providers but decided not to do so. First, information from focus groups does not neatly sort into consumer or provider because we chose a heterogeneous format. Moreover, the dynamic nature of focus groups yields information that represents group process and not an individual *per se*. Finally, some providers are people that were once homeless. Hence, information represents the sum of knowledge provided by the 46 research participants. It is summarized in terms of the three tasks that give shape to this project—define the problem, suggest solutions, and understand peer navigators as a solution—and related subthemes. Results are illustrated with focus group quotations where useful.

#### The nature of the problem

The first subtheme summarized the medical conditions that were especially of concern to participants. These included diabetes, digestive disorders, heart and circulatory problems, and arthritis. People expressed concerns about managing illnesses during their acute stage and that failure to do so made relatively minor health challenges into chronic and disabling conditions. In addition, significant mention was given to conditions ancillary to primary care. Participants were concerned about the relative absence of eye, dental, and foot care.

I don't know what happened with my teeth but I bit down and half my teeth broke out and nerve was exposed; I couldn't eat. It was very painful... I told them how much pain I was in and they still gave me an appointment for the next week. A lot of places don't take my medical card for dental; dental for people with medical cards is really nonexistent. [participant with lived experience]

Participants noted services for women's health were also lacking, as were specialty services for HIV-AIDS. Agencies either lacked mental health programs altogether or failed to provide the kind of evidence-based interventions shown effective for those with the most serious of illness. Integration of mental health and primary care strategies were largely

absent. Concurrent substance abuse often undermined health care because providers were unable to treat these problems in an integrated fashion.

As trends in health care generally show in the American population as a whole, participants were mindful of the need of preventive care: promoting diet, exercise, and other means towards wellness. Nutrition is especially important for people who are homeless as is exposure to weather and elements because of poor housing. "If you're diabetic you have to eat certain food. If you have food stamps you're going to run out if you're trying to buy certain foods' [participant with lived experience]. Many people who are homeless also struggle with personal hygiene because of limited resources. Participants said they lack showers or do not have laundry facilities, making it difficult to keep wounds clean and/or prevent infections from occurring.

The second theme focus related to the nature of the problem represented barriers to obtaining and using existing resources. Many focus group participants noted too few resources, along with long waits. Those programs that are available typically are located in places hard to reach by public transportation. Bus or train routes are not in clinic neighborhoods. Other agencies are located in high crime areas making people hesitate to walk the streets to access them. The payer system is underfunded such that many homeless people are not covered. Services that do exist tend to be crisis oriented so that people wait for a relatively benign condition to become an emergency. As a result, people use emergency rooms as primary care providers.

The third subtheme summarized how these problems are exponentially worsened by homelessness, mental illness, and ethnic disparity. Clinics frequently fail to coordinate with homeless programs. "In shelter system, timing plays a huge part. Have to get into shelter by certain times, basic needs (food shelter) takes precedence over medical care" [participant with lived experience]. The medical staff of programs that do exist are often insensitive to the special needs of people of color who are homeless or with mental illness. This is often observed as stigma or general discomfort with the population. "That's one of the problems I had getting into services was feeling judged, stigmatized, less than, looked down upon, herded like cattle, feeling like I'm a number or a dollar" [participant with lived experience].

Many people who are homeless lack identification documents that are often needed to register or otherwise receive care. They may have lost driver's licenses or state ID cards. "I went to jail when I was homeless and when I got out I didn't have any ID. So I ended up for eight months I didn't have any ID. I couldn't apply for my social security. I couldn't get any kind of assistance, go see a doctor. I had no documents" [participant with lived experience].

Some are wary of signing up with the government even for ID cards; people with immigration concerns are especially hesitant here.

Participants often felt people who are homeless may have different perceptions about health or wellness. They may be unaware of health needs or do not consider them carefully when symptoms emerge.

A lot of time when you're homeless you don't realize how sick you are until you get here and see a doctor, I didn't realize I had two located discs in my back; I knew I had pain but I didn't realize the pain I was walking around with. [participant with lived experience]

They may procrastinate and wait until symptoms become overwhelming crises. As a result, they use emergency rooms as primary care clinics.

Unfortunately unless it's an emergency, they're not going to do it, they don't want to leave because they're terrified if they leave someone's going to come and steal their stuff or the city's going to do a sweep and take their stuff. We've had people who even if they're three blocks from here, they're afraid they're going to lose their blankets so they can't come and access medical care. [participant with lived experience]

Sometimes, health problems pale in light of other challenges. Many study participants said illness is often trumped by living safely in a home out of the elements. Many people who are homeless are also overwhelmed by concerns for the health and safety of children or elderly family members too. Dealing with the police or courts can outweigh health concerns too.

All of this is complicated by the confusion of mental illness. Some symptoms of psychosis or cognitive slowing of depression can impair a person's ability to fully comprehend health challenges or interventions that might address them.

For me I just go into a state where – I'm bipolar so it depends – sometimes I'm highly manic and I feel like I'm on top of the world. Nothing wrong with me. I don't need medication, and really in essence I really do need them. [participant with lived experience]

Living on the street may be traumatic which causes additional mental health problems that may undermine participation in health care.

Health care for people who are homeless seems to be getting worse. In part, this occurs because urban life is changing. The goals of urban gentrification influence a community's perceptions of people who are homeless. As suburbanites move back into the city, they build more expensive housing thereby pushing out people with low incomes.

All of these high priced apartments for people to live. Many people that I see, their rents are going up and they're getting to a place that they can't afford anymore. Less and less places, less disposable money that makes you tighter as far as income is concerned. Housing is health care as far as I'm concerned. [provider]

#### Possible solutions

Two subthemes emerged as solutions to these problems what providers, agencies, and communities might do versus solutions people might consider for themselves. At the agency and community level, participants called for more clinics, drop-in programs, and housing options. They realized this is contingent on government priorities which often are lacking and may be getting worse given budgetary concerns of many states. Agencies and communities need to consider how to improve existing resources. Prominent among these

was the call to integrate behavioral and primary care. Medical errors and incomplete care often occur because psychiatric and primary care is conducted on separate tracks. Related to coordinated care is streamlining services overall. This means much shorter wait time and reminder calls for appointments.

When I first started coming to Heartland [clinic], the social workers will call you and let you know a day in advance that you have an appointment, and they don't do that anymore. They give you a sheet and you put it on your fridge, but if you don't open your fridge, you forget you have an appointment and then you'll have to wait a month. [participant with lived experience]

Participants thought clinics should provide case management support so patients can avail Medicaid and other insurance entitlements.

Service engagement is often hampered by stigma: by the disrespect that accompanies homelessness, mental illness, as well as some physical illnesses such as HIV-AIDS. The obverse of stigma is personal empowerment. Participants believed staff should be trained to promote self-determination. More broadly, study participants thought communities should also be "trained" in self-determination. Citizens should be helped to recognize health care for the homeless as a community's problem and that health care for all is a priority. Community leaders need to be motivated to address health problems for people who are homeless in empowering ways. Citizens and leaders of areas in which homeless people are served need to be especially vigilant here.

Politicians need to have courage, worry less about re-election and more about doing right thing for the communities they serve. Really understand the challenges facing agencies and help advocate. [Politicians are] too often swayed by elections and special interests. Money gets thrown in for specific interests rather than serving the people of the community. Need politicians to be a supportive as possible in area of health care reform. Will be bumpy but they need to make new legislation work. [provider]

These goals need to be discussed aloud in the neighborhoods with part of the discussion concerning affordable housing.

Not being housed, just being homeless; I know for myself every year I was getting pneumonia. For five years straight I was getting it because I didn't have a place to stay. Once I had a place to stay I wasn't getting it; the cold and you have to run around, it's something I can't stand to have. [participant with lived experience]

The second theme included ideas people might do for themselves to better manage their health. People should take responsibility for their health. This might mean learning how to identify indicators of illness. They should be mindful of the pernicious effects of stigma, learning how to respond to it rather than letting it drive them away from care. Failure to get health care needs met sometimes occurs because the patient is not able to adequately communicate with providers. Some people might want to acquire better interpersonal skills. "People need to be reeducated – even homeless people themselves – there are some very disrespectful homeless people and it affects other people. They put everyone in that same category" [provider]. In a similar fashion, people should become their own advocate. They

are empowered to ask questions and provide feedback to providers through all steps of service delivery. At a broader level, participants recommended people who are homeless become community advocates too.

So, the realization that health care doesn't just happen in the doctor's office. Instead of making people come in for diabetes screening, we should be doing this at barber shops (or other places like this). [participant with lived experience]

One especially important focus of the interviews was to understand how people of color, especially African Americans, view health for people who are homeless. Although this question was asked of all focus groups and key informants, rarely did respondents believe ethnicity *per se* worsened health troubles. In part, they said poverty and crime, over-experienced among African Americans, was more likely to be causal. Partly, they believed homelessness effects are equally egregious across groups. Still, some participants with lived experience noted the extra impact of being a person of color. "…like a pre-judgment, most of the people that's on the system, they're minorities'" [participant with lived experience].

# The potential of peer navigators

Two subthemes comprised participant thoughts about peer navigators. First, participants listed assets of effective peer navigators. They said, for example, that personal experience with mental illness and homelessness brings a special intimacy. Peer navigators know useful tricks-of-the-trade to manage the challenges of living on the streets and can help the person be especially alert to problems that might imminently undermine health. Sometimes, seemingly simple things emerged as strategies to cope.

I've learned a ton about homelessness from participants, just things like take off your shoes at night, it actually keeps your feet warmer; which food trucks have the better meals; people really like it here they don't like it there. These things are useful, these aren't; here's what we really need, learning about what people want and need has been really helpful. [provider]

Having been homeless brings tolerance, dedication, passion, and motivation.

One thing I found as a most valuable asset is ability to tell the whole story without shame, not ashamed to tell people I was homeless, struggled with mental health issues, substance abuse issues, criminal behavior. I've been to prison but I also don't shy away from the fact of telling people I live indoors, have a family, job, career, car, a lot of people in my life I care for and care for me, you have to be willing to tell that story. [participant with lived experience]

Peers are likely to be especially tolerant of the kinds of challenges people who are currently homeless and with mental illness might pose to their health problems. Peers are street wise; they understand the same unspoken rules and skills as those currently living without a home.

I just think obviously people with lived experienced can give people going through it a lot of help knowing there are possibilities to live normal productive lives, but also one thing that I've noticed and the more beautiful thing is the sharing of resources. Once a person finds out that, Hey! This person helped me here, to share these resources, there are limited resources but there are some here, and believe it

or not some of those resources are still somewhat underused. [participant with lived experience]

The second subtheme represented broad categories of knowledge and skills that would help peer navigators do their jobs. Navigators need to learn resources available to peers to address health challenges as well as practical approaches to access these resources.

It's hard to get info when you live on the street. You don't know who to talk to about getting care. You know you don't have Medicaid or you don't have no insurance, so it's just difficult when you on the street. [participant with lived experience]

This would need to be fluid information because resources and access strategies change often. This might mean peer navigators would need to master computer skills to be able to search for the most current list of available resources.

Navigators need to have an array of communication skills to optimally engage peers in addressing health problems. Finally, they would need crisis and stress management skills, especially relevant given the challenges of homelessness and mental illness.

But I find out there are certain things that calm me down, putting on the vacuum cleaner, having a cup of cold water in my left hand, a cup of hot water in the right hand. The reason I think this will work better is people find out what's working for them, what's not working; they find out what should I eat and what not. [participant with lived experience]

### **Discussion**

Several important themes and subthemes emerged from this investigation. Acute illnesses in almost every organ system were noted and failure to attend to onset frequently led to chronic course and more disabling outcomes. As the U.S. Department of Housing and Urban Development has found, <sup>10</sup> homelessness undermines the person's ability to tend to health problems. Having no shelter throws up several challenges that outweigh health *per se*. Exposure to the elements, poor nutrition and hygiene, dealing with addictions, and criminal victimization are frequently more compelling than illnesses, at least until sequellae of the illnesses become overwhelming because they were not tended to in a timely manner. The stigma and disrespect of experiencing homelessness worsens engagement with the health care system.

Add to this the troubles of a concurrent psychiatric disorder. The confusion and disorientation of many serious mental illnesses makes it difficult for people to track their illnesses and treatments which may further explain the high rates of morbidity and mortality in this population. <sup>1,2</sup> Another goal of the study was to examine how health issues and homelessness are experienced by people because of their African American ethnicity. Perhaps surprisingly, most participants did not believe being African American worsened the course of their health troubles. This does not invalidate the goal of CBPR to develop health care programs for African Americans; although the group believed ethnic discrimination did not seem to worsen the course of health care for people with mental illness who are

homeless, results of the study still benefitted from being steeped in the perspective of this important ethnic group. Moreover, our findings are especially germane to developing solutions relevant to African Americans in this Chicago neighborhood.

An equally important goal of this study was to identify strategies that might facilitate the health goals of African Americans who are homeless with mental illness. Almost no studies were found in the literature suggestion solutions to these problems. Our participants said many solutions required action by governments, agencies, and communities. Greater policy priority needs to be made to health care for people who are homeless, recognizing that system needs vary when psychiatric needs are added to health care challenges. Obvious solutions were posed: more clinics, more providers, and more financial aid for ancillary services including dental, eye, and foot care as well as pharmacy benefits. Services need to be crafted knowing the demands of being homeless; e.g., providing schedules and places that are convenient, training staff to engage with this group, and modeling communities open to these goals. Solutions also rested with people themselves. Survey participants noted that many people who are homeless may need to be educated about illness, the risks of living on the streets given these illnesses, and interventions/clinics that help to manage health. The group of people who are homeless might also need to be organized to improve their advocacy skills. This includes communication activities that entice communities and governments into the discussion rather than appear angry and perhaps alienate potential allies.

One explicit goal of this NIMHD-funded project was to determine the potential of peernavigators for addressing the health needs of African Americans who are homeless with mental illness. Peer was defined by the group as African Americans who have been homeless but now are able to sustain residence. Peers are also people in recovery, individuals who struggled with significant mental illness and/or substance abuse and now manage the symptoms and disabilities of these disorders so they are able to fully assume the responsibilities of a competitive job, such as a navigator, with reasonable accommodations. Additionally, preference might be given to peers who have struggled with significant physical illness of their own and who were homeless and/or currently reside in the neighborhood in which navigators services will occur. Navigator services are meant to facilitate health care needs by helping the person to more fully avail and engage with primary, specialty, and mental health care. This typically begins where the person is at: on the streets, in the shelters, in the criminal justice system, or wherever else African Americans who are homeless and with mental illnesses may be found. Navigators are committed to time and relationship, recognizing that a quality working relationship takes time and requires one-on-one relationship. Navigators help people get to their appointments and engage with their providers. This may require navigators to accompany the person into the examining room. Navigators help people access their entitlements and do what is needed to fill prescriptions. Navigators realize health problems are not neatly compartmentalized, that shelter, nutrition, and personal safety worsen health. Hence, navigators liaise with other service organizations to address these needs as they arise.

There are limitations to consider about this study. Like any qualitative research, it is unclear whether findings here saturated to the possible domain of responses. Future research might

uncover additional, important themes in understanding health problems and solutions. Because focus groups were heterogeneous, we were unable to discern whether people with lived experience viewed problems and solutions differently than providers. In addition, responses of some people with lived experience might have been suppressed in heterogeneous groups because providers in the group might disapprove. This information is useful for the CBPR team trying to decide how to progress on health care programs. Moreover, our sample was not sufficiently big to examine other variables that might influence perceptions about problems and solutions. People with different types of illness might view problems and solutions in varied ways. Results from our survey suggested, for example, that the problems and services for HIV-AIDS are unique. Providers often view people with HIV-AIDS with stigma. Despite this, more services are often available for people with HIV-AIDS because of special government programs.

Homelessness is a local phenomenon varying with the exigencies of the community, city, and state in which it occurs. The findings here represent the perspective of a large Midwest urban area which may generalize to other areas of the country. Still, these views also represent a distinct Chicago neighborhood with its own history with people who are homeless and with people with mental illness. Additional research needs to determine how findings appear in other neighborhoods. Also, keeping in mind that CBPR has a local program goal as well as broad science mission, findings here suggest the framework of health care for this group in this neighborhood focusing on real world and grassroots insights. A similar CBPR effort would be needed to, for example, craft a program in Detroit or Cleveland.

This study has implications for future research and practice. The next step is to use the information herein to develop a peer navigator program and evaluate its effectiveness on the health care needs of this population. The research literature has begun to yield suggestions about the outlines of these programs; <sup>39, 40</sup> one study shows a California version of peer navigators yielded significantly fewer reports of pain and health symptoms after six months compared to a control group. <sup>41</sup> Our CBPR team is combining these insights with findings from the qualitative research herein to develop a peer navigator program for people in Chicago's Edgewater-Uptown neighborhood.

# References

- 1. Martens WH. Homelessness and mental disorders: a comparative review of populations in various countries. Int J Ment Health. 2001; 30(4):79–76.
- 2. World Health Organization [Internet]. Geneva, Switzerland: 2005. [cited 2014 Jan 10] Available from: http://www.euro.who.int/\_\_data/assets/pdf\_file/0009/74682/E85482.pdf
- 3. Mai Q, Holman CDA, Sanfilippo F, et al. The impact of mental illness on potentially preventable hospitalisations: a population-based cohort study. BMC Psychiatry. 2011 Oct.11(1):163.doi: 10.1186/1471-244X-11-163 [PubMed: 21985082]
- Saha S, Chant D, McGrath J. A systematic review of mortality in schizophrenia: is the differential mortality gap worsening over time? Arch Gen Psychiatry. 2007 Oct; 64(10):1123–1131. DOI: 10.1001/archpsyc.64.10.1123 [PubMed: 17909124]
- 5. Nordt C, Müller B, Rössler W, et al. Predictors and course of vocational status, income, and quality of life in people with severe mental illness: a naturalistic study. Soc Sci Med. 2007 Oct; 65(7): 1420–1429. DOI: 10.1016/j.socscimed.2007.05.024 [PubMed: 17583402]

 Vick B, Jones K, Mitra S. Poverty and severe psychiatric disorder in the US: evidence from the medical expenditure panel survey. J Ment Health Policy Econ. 2012 Jun; 15(2):83–96. [PubMed: 22813941]

- 7. Warf CW, Clark LF, Herz DC, et al. The continuity of care to nowhere: poverty, child protective services, juvenile justice, homelessness, and incarceration: the disproportionate representation of African American children and youth. Int J Child Adolesc Health. 2009; 2(1):49–64.
- Biafora F, Warheit G. Self-reported violent victimization among young adults in Miami, Florida: immigration, race/ethnic and gender contrasts. Int Rev Victimology. 2007 Jan; 14(1):29–55. DOI: 10.1016/j.socscimed.2007.05.024
- U.S Census Bureau [Internet]. Washington D.C: 2012. [Cited 2014 Jan 10]. Available from: http://www.census.gov/prod/2013pubs/acsbr12-01.pdf
- U.S Housing Urban Development [Internet]. Washington D.C: 2010. [Cited 2014 Jan 13] Available from: https://www.onecpd.info/resources/documents/2010HomelessAssessmentReport.pdf
- Rivera LM. Ethnic-racial stigma and health disparities: From psychological theory and evidence to public policy solutions. J Soc Issues. 2014 Jun; 70(2):198–205. DOI: 10.1111/josi.12055 [PubMed: 25530632]
- Lanouette NM, Folsom DP, Sciolla A, et al. Psychotropic medication nonadherence among United States Latinos: a comprehensive review of the literature. Psychiatric Serv. 2009; 60(2):157–174.
   DOI: 10.1176/appi.ps.60.2.157
- 13. Lee S, O'Neill A, Park J, et al. Health insurance moderates the association between immigrant length of stay and health status. J Immigrant Minority Health. 2012 Apr; 14(2):345–349. DOI: 10.1007/s10903-010-9411-z
- Darnell J. What is the role of free clinics in the safety net? Med Care. 2011 Nov; 49(11):978–84.
  DOI: 10.1097/MLR.0b013e3182358e6d. [PubMed: 22005605]
- 15. Jerant A, Fenton JJ, Franks P. Primary care attributes and mortality: a national person-level study. Ann Fam Med. 2012 Jan-Feb;10(1):34–41. DOI: 10.1370/afm.1314 [PubMed: 22230828]
- Bazzoli GJ, Woolton L, Hsieh HM, et al. The effects of safety net hospital closures and conversions on patient travel distance to hospital services. Health Services Research. 2012 Feb; 47(1):129–150. DOI: 10.1111/j.1475-6773.2011.01318.x [PubMed: 22091871]
- 17. Hanson RF, Self-Brown S. Screening and assessment of crime victimization and its effects. J Traumatic Stress. 2010 Apr; 23(2):207–214. DOI: 10.1002/jts.20503
- Padela AI, Gunter K, Killawi A, et al. Religious values and health care accommodations: voices from the American Muslim community. J Gen Intern Med. 2012 Jun; 27(6):708–715. DOI: 10.1007/s11606-011-1965-5 [PubMed: 22215274]
- 19. Bartels SJ. Caring for the whole person: Integrated health care for the older adults with severe mental illness and medical comorbidity. J Am Geriatr Soc. 2004 Dec; 52(Suppl12):S249–S257. DOI: 10.1111/j.1532-5415.2004.52601.x [PubMed: 15541165]
- Su D, Li L. Trends in the use of contemporary and alternative medicine in the United States: 2002–2007. J Health Care Poor Underserved. 2011 Feb; 22(1):296–310. DOI: 10.1353/hpu.2011.0002 [PubMed: 21317523]
- Musa D, Schulz R, Harris R, et al. Trust in the health care system and the use of preventive health services by older black and white adults. J Public Health. 2009 Jul; 99(7):1293–1299. DOI: 10.2105/AJPH.2007.123927
- 22. Abdullah T, Brown TL. Mental illness stigma and ethnocultural beliefs, values, and norms: an integrative review. Clin Psychol Rev. 2011 Aug; 31(6):934–948. doi: http://dx.doi.org/10.1016/j.cpr.2011.05.003. [PubMed: 21683671]
- 23. Martin S. Illness of the mind or illness of the spirit? Mental health-related conceptualization and practices of older Iranian immigrants. Health Soc Work. 2009 May; 34(2):117–126. [PubMed: 19425341]
- 24. Tófoli LF, Andrade LH, Fortes S. Somatization in Latin America: a review on the classification of somatoform disorders, functional syndromes, and medically unexplained symptoms. Rev Bras Psiquiatr. 2011 May; 33(Suppl1):S70–S80. DOI: 10.1590/S1516-44462011000500006

 Cabral RR, Smith TB. Racial/ethnic matching of clients and therapists in mental health services: a meta-analytic review of preferences, perceptions, and outcomes. J Couns Psychol. 2011 Oct; 58(4):537–554. DOI: 10.1037/a0025266 [PubMed: 21875181]

- 26. McNeil R, Guirguis-Younger M, Dilley LB, et al. Learning to account for the social determinants of health affecting homeless persons. Med Educ. 2013 May; 47(5):485–494. DOI: 10.1111/medu. 12132 [PubMed: 23574061]
- 27. Seiler AJ, Moss VA. The experience of nurse practitioners providing health care to the homeless. J Am Acad Nurs Pract. 2012 May; 24(5):303–312. DOI: 10.1111/j.1745-7599.2011.00672.x
- 28. Hudson AL, Nyamathi A, Greengold B, et al. Health-seeking challenges among homeless youth. Nurs Res. 2010 May-Jun;59(3):212–218. DOI: 10.1097/NNR.0b013e3181d1a8a9 [PubMed: 20404776]
- Nickasch B, Marnocha SK. Health care experiences of the homeless. J Am Acad Nurs Pract. 2009 Jan; 21(1):39–46. DOI: 10.1111/j.1745-7599.2008.00371.x
- 30. Thompson SJ, McManus H, Lantry J, et al. Insights from the street: Perceptions of services and providers by homeless young adults. Eval Program Plann. 2006 Feb; 29(1):34–43. DOI: 10.1016/j.evalprogplan.2005.09.001
- 31. Daiski I. Perspectives of homeless people on their health and health needs priorities. J Adv Nurs. 2007 May; 58(3):273–281. DOI: 10.1111/j.1365-2648.2007.04234.x [PubMed: 17474916]
- 32. Christiani A, Hudson AL, Nyamathi A, et al. Attitudes of homeless and drug-using youth regarding barriers and facilitators in delivery of quality and culturally sensitive health care. J Child Adolesc Psychiatr Nurs. 2008 Aug; 21(3):154–163. DOI: 10.1111/j.1744-6171.2008.00139.x [PubMed: 18667048]
- 33. Hatton DC, Kleffel D, Bennett S, et al. Homeless women and children's access to health care: a paradox. J Community Health Nurs. 2001; 18(1):25–34. DOI: 10.1207/S15327655JCHN1801\_03 [PubMed: 11293195]
- 34. Corrigan PW, Shapiro JR. Measuring the impact of programs that challenge the public stigma of mental illness. Clin Psychol Rev. 2010 Dec; 30(8):907–922. DOI: 10.1016/j.cpr.2010.06.004 [PubMed: 20674114]
- 35. Wallerstein, N., Duron, B. The theoretical, historical, and practice roots of CBPR. In: Minkler, M., Wallerstein, N., editors. Community-based participatory research for health: From processes to outcomes. 2nd. San Francisco: Wiley; 2008.
- 36. Ravenell JE, Whitaker EE, Johnson WE. According to him: Barriers to health care among African American men. J Natl Med Assoc. 2008; 100(10):1153–1160. [PubMed: 18942276]
- 37. Washington OM, Moxley DP, Gariott L, et al. Building a responsive network of support and advocacy for older African American homeless women through developmental action research. Contemp Nurse. 2009; 33(2):140–160. [PubMed: 19929159]
- 38. Strauss, AL., Corbin, J. Basics of qualitative research: Techniques and procedures for developing grounded theory. 2nd. Thousand Oaks (CA): Sage; 1998.
- 39. Brekke JS, Siantz E, Rohini P, et al. Reducing health disparities for people with serious mental illness: Development and feasibility of a peer health navigation intervention. Best Practice Ment Health. 2013 Mar; 9(1):62–82.
- 40. Corrigan PW, Pickett S, Batia K, et al. Peer navigators and integrated care to address ethnic health disparities. Soc Work Public Health. In Press.
- 41. Kelly E, Fulginiti A, Pahwa R, et al. A pilot test of a peer navigator intervention for improving the health of individuals with serious mental illness. Community Ment Health J. 2013 Jun.:1–12. DOI: 10.1007/s10597-013-9616-4