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# Witnessing for Black mental health: Formative steps for designing a community-based mental health education intervention

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#### Abstract

Following the May 14, 2022, racially motivated mass shooting killing 10 Black members of the Buffalo, New York, community, mental health care was found to be the most frequently endorsed unmet need among Black community members surveyed. In response, a community-university partnership formed in pursuit of developing culturally and racially sensitive mental health programming. The partnership conducted community-engaged research to understand diverse stakeholders' relevant concerns, beliefs, and preferences. In Study 1, experienced community health workers (n=13; 92% Black; 100% women; 23–78 years old) participated in one-on-one semi-structured interviews. In Study 2, community members (n=54; 100% Black; 63% women, 31% men, 6% gender not reported; 18–91 years old) participated in focus groups. In both studies, transcripts were coded using descriptive, semantic, realist thematic analysis. Across both studies, participants described cultural and material barriers to mental health care; systematic and interpersonal mental health risks; willingness to discuss mental health; and preferences and needs for mental health education and services. Results informed the partnership's development of a pilot mental health education program, "Witnessing for Mental Health." The community health worker-delivered program addresses participant-identified barriers to mental health care and leverages community preferences for mental health programming.

**Keywords:** qualitative, mental health, social determinants of health, community health workers, African American, Black

On May 14, 2022, Buffalo, New York, was the site of a racially motivated massacre that claimed the lives of 10 Black individuals. In response to deep community pain among Black Buffalonians, National Witness Project (NWP), a national community-based health organization founded in Arkansas in 1991 and headquartered in Buffalo since 2006, surveyed members of Buffalo's Black East Side to identify urgent community needs. NWP leaders were surprised to find 38% of 200 community members surveyed indicated mental health was their most important unmet need. The willingness of Black community members to disclose this vulnerability was perceived by NWP leaders to be paradigm-shifting given longstanding community stigma around mental health treatment 1-3, Black adults' likelihood to believe that mental health problems will resolve on their own 4, and to avoid mental health treatment due to concerns other community members will find out 5. This led to the development of a community-academic partnership between NWP and the University at Buffalo (UB) to address these needs.

## **Context of Mental Health Disparities**

NWP's findings of a great need for mental health services reflects extreme stressors facing Buffalo's Black community as well as Black Americans broadly. Unfortunately, stressors (negative events, chronic strains, and trauma) are unevenly distributed across different racial groups, exacerbated by discrimination stress in marginalized groups, and compounded across individual lifetimes and generations to create ever-widening gaps in mental health disparities<sup>6</sup>. For example, mass incarceration of Black men<sup>7</sup> and health disparities leading to early mortality<sup>8</sup> have ripple effects on the mental health of individuals, families, and communities<sup>9</sup>.

Although Black individuals experience more life stressors and worse physical health outcomes than White individuals, they are often reported to have lower rates of mental health problems than White individuals—this finding has been referred to as the "Black-White mental"

health paradox"<sup>10</sup>. Importantly, it is unknown whether this paradox represents true differences in prevalence rates versus other factors such as cultural idioms of distress that may not pattern neatly onto diagnostic criteria<sup>11,12</sup>. The finding of lower depression rates among Black adults, for example, has often been used as evidence of enhanced resilience in the population<sup>13</sup>. And while the enduring resilience of Black Americans is a vital cultural asset that may facilitate mental health maintenance, such an explanation has also been used to undermine the need for research and treatment related to Black mental health<sup>14</sup>.

Indeed, decades of research on mental health disparities support NWP's findings that mental health care is a substantial and unmet need for Black individuals, and in need of innovative solutions. The U.S. Office of the Surgeon General first acknowledged mental health treatment disparities in 1999—reporting that half the number of Black adults in need of mental health services received them compared with White adults<sup>15</sup>. There has been *no improvement* in the past 25 years<sup>16</sup>. Compared to White Americans, Black Americans are less likely to receive mental health treatment, especially evidence-based or culturally competent treatment; are more likely to be misdiagnosed; experience higher severity and chronicity of mental illness; and are more likely to have police involvement in mental health crises<sup>15,17</sup>. Lack of access is institutionalized as well: Black communities tend to have lower availability of mental health services<sup>18</sup> and Black families have lower rates of insurance<sup>19</sup>. Other social determinants of health, such as increased poverty, limited access to childcare, and less access to transportation, also contribute to disparities in access<sup>15,20</sup>.

In addition, the United States has a long history of medical racism and exploitation of Black communities.<sup>21</sup> One salient contemporary example is the *underdiagnosis* of depression and *overdiagnosis* of schizophrenia among Black adults<sup>22–24</sup>. There is evidence that this is likely

influenced by factors such as diagnosticians' beliefs about clients' race or perceptions of patients' honesty<sup>25,26</sup> or systematic disregard for the first-person testimonies of Black patients<sup>27</sup> rather than true group differences. Such skepticism and invalidation Black individuals often encounter in healthcare settings is layered onto historical medical mistrust, leading to a likely adaptive mistrust of White medical providers among Black communities.

Unfortunately, there is a shortage of Black providers that might provide services where trust is otherwise lacking. Though 14.4% of the U.S. population is Black<sup>28</sup>, Black providers are underrepresented in most mental health professions, making up just 4% of psychologists, 2% of psychiatrists, 7% marriage and family therapists, and 11% of counselors<sup>29</sup>. Additionally, there are disparities in access to evidence-based treatments for Black individuals<sup>30,31</sup>, and there is further concern about the cultural appropriateness of such evidence-based interventions<sup>32</sup> and validated clinical measures<sup>33</sup>. Further, when Black adults do seek treatment, they are disproportionately likely to be subject to inpatient care that removes them from their communities and social support network, or conversely, not offered treatment at all<sup>16</sup>.

# **The Present Study**

The present research is one outcome of a community-academic partnership which emerged in response to the need to address ongoing mental health disparities in our community. The community partner, NWP, reduces Black health disparities through a spiritual "witness" storytelling model in which community health workers educate community members and navigate them to services<sup>34,35</sup>. Author DOE, NWP co-founder, and author DJ, NWP National Executive Director, are founding members of the UB Psychological Services Center's Community Advisory Board, established in February 2022 by authors SMT and RLA to better serve the mental health needs of Buffalo's Black community. Following the May 14 shooting and

subsequent needs assessment surveys, DJ and DOE invited SMT and RLA to support NWP's consideration of mental health as a feasible new service line.

Our team includes White and Black cisgender women who have lived in Buffalo ranging from 3–30 years. Our education ranges from bachelor's degree to doctorate. Across the group we have expertise in clinical psychology, community health science, and intervention development, implementation, and dissemination. Approximately half of the research team have novice to expert knowledge of mental health, but relatively limited knowledge of the community in focus; the other half have expert knowledge of the community in focus and community health, but relatively little mental health expertise.

Though NWP's content expertise lies in [DISEASE], their work has expanded over time to include additional targets of health equity dictated by community needs. NWP has an extensive history of maintaining successful community-based participatory research (CBPR) partnerships for behavioral health intervention development <sup>36,37</sup> and important elements of CBPR are employed in this research. Accordingly, our first step in program development was to understand stakeholder perspectives on mental health and associated needs, desires, barriers, and opportunities. We first interviewed NWP community health workers (CHWs) (Study 1), then conducted focus group with community members (Study 2). UB-NWP partners collaborated at every stage of the research process, with an emphasis on shared power and decision-making related to study design, funding, and dissemination. We collaborated to develop and revise study materials and procedures, to share ongoing reflexive reflection, and to analyze data. Feedback on tentative findings was solicited and integrated from stakeholders iteratively: from NWP leaders, a CHW, and in two community listening sessions.

## Study 1

CHWs are trusted community members who serve as frontline representatives of community-based health organizations like NWP and bridge research-to-practice gaps by effectively delivering evidence-based therapies with high cultural competence<sup>38,39</sup>. We sought to understand CHW's experiences with mental health and invite programming ideas.

#### Method

#### **Ethics**

This study was deemed exempt by the UB IRB (STUDY00006930).

#### Recruitment

Active NWP CHWs (≈60) were invited to participate in interviews about their experiences related to community mental health. We set an initial target of 15 interviews, and CHWs with interest and availability were scheduled on a rolling basis. The study team met weekly during data collection to share initial impressions of interview themes and representative diversity of perspectives. Data collection was halted once the team agreed saturation was reached.

## **Participants**

Participants were 13 CHWs with at least five years of NWP experience. Participants were  $M_{\text{age}}$ =52 (SD=19.87; 23–78); 100% cisgender women; 92% Black, and 8% White.

## Interviews

Interview questions (https://osf.io/tafcq/?view\_only=162b7c39ae8f4972ae528fea0e9ab8ac) ranged from "What does 'mental health' or 'mental illness' mean to you?" to "How can we increase awareness of mental health services and encourage community members to seek out mental health care when needed? What should we avoid?" Interviewers were three White women in their 30s and 40s (authors HNR, SMT, and RLA). Prior to interviews, participants received consent forms to review; key consent issues were reviewed face-to-face before interviews began.

Individual semi-structured interviews were 50–109 minutes (M=67, SD=19) and conducted virtually (n=11) or in person (n=2). Participants were compensated \$25.

## Analysis

Interview recordings were transcribed automatically and checked for accuracy prior to analysis. Interviewers served as coders. Coders used a descriptive, semantic, realist reflexive thematic analysis approach to analysis<sup>40</sup>, noting potential key themes and paradigmatic interview examples. Each transcript was reviewed in its entirety by two coders. Following open coding, coders met to compare notes, identify common themes, and explore interpretive differences.

#### **Results**

CHWs were asked to focus on their own experiences and the experiences of the communities they live in and serve as CHWs, which they described as "underserved and never-served," mostly Black Americans, and mostly low-income. Findings are presented under four broad topics: 1) mental health needs, 2) barriers to mental health care, 3) willingness to discuss mental health, and 4) critical components for future mental health programming.

# Mental Health Needs Shaped by Community, Global, and Developmental Factors

CHWs perceived community members' mental health concerns to be anxiety, depression, loneliness, isolation, grief, anger, fear, and substance dependence and abuse. These problems were described as affecting adults across the lifespan and were understood to arise in response to acute or chronic exposure to trauma, unmanaged or unmodifiable life stressors, and lack of social and instrumental resources. CHWs also encountered community members struggling with suicidality, psychosis, and mania, though these problems were seen as less prevalent. In addition, CHWs described community members as frequently exposed to racial violence (e.g., disproportionate incarceration rates) and interpersonal violence (e.g., intimate partner violence),

leading to persistent fear ("Fear, fear, fear. Just being afraid all the time," Ellen, 73) and grief ("It's kind of hard to be positive when everything around you is so negative," Mary, 64).

Mental Health Tipping Points. CHWs saw recent, unprecedented events as exacerbating baseline distress. Having endured nearly three years of social isolation, illness and loss, and increased internal and external health surveillance during the COVID-19 pandemic, many community members were "angry because of what they've been through—the lockdown that they were in. They already was going through issues [before the pandemic], and [the pandemic] just didn't help it. It may be a bit more people are into their feelings" (Brenda, 69).

Just as the U.S. began to lift pandemic restrictions, Buffalo was visited by racially motivated mass gun violence. CHW interviews took place less than one year following the May 14, 2022, massacre in Buffalo, which they identified as another possible mental health tipping point. Ellen, 73, explained a community member had been interviewed following the massacre:

He said this young man that did the shooting, he sat on a bench and talked with him like the day before. Can you imagine?...That messes with your psyche a little bit. So now I'm afraid to talk to people. I'm afraid to be friendly...It makes you closed off from people.

Noticing the distress of community members as well as their own mental health challenges was also a tipping point within organizational culture. Carmen, 32, described it vividly: "You're witnessing family members die from COVID. You're scared to have your sons out in the street at certain times...It just became too much." Carmen explained that prior to this tipping point, NWP was "so focused on...other aspects of social determinants of health...[and] knew the stigma in our community" that "mental health didn't come up as much....But....it became such an identifiable need....we knew we had to do something."

Finally, in December 2022, a historic blizzard brought power outages, cold injuries, hunger,

and tragically, 47 lost lives, further traumatizing Buffalo and surrounding towns. A disproportionate number of the deceased and injured were Black and low-income<sup>41</sup>, underscoring the under-resourced, marginalized status of Buffalo's Black community. This series of extreme events were described by CHWs as contributing to an overall sense of loneliness and isolation among Buffalo's Black community members. In turn, loneliness and isolation were conceptualized as both symptomatic of and causing further mental health distress.

Antecedent Risk Factors and Causes. Brenda, 69, described how loneliness and isolation exacerbated mental health problems: "You going through something. Maybe [you do] not know how to deal with it. Holding stuff inside. Silence. Silence. Breakdown!" Similarly, individuals transitioning into the community following incarceration were seen as having no support in adjusting to community life, resulting in increased interpersonal problems and difficulty establishing personal stability. CHWs identified fewer available services for low-income individuals, LGBTQ individuals, people with disabilities, and homeless individuals. Lack of social support and mental health education were also described as root causes of widespread use of alcohol and street drugs to self-medicate in response to trauma or psychopathology. As Carmen, 32, put it, "People just know to go to what they're comfortable with—there's a liquor store on every street, even if you can't find a psychologist."

CHWs were particularly concerned with untreated mental health problems among younger adults (adolescents and twenties) and older adults (roughly sixty and up). Several CHWs identified a tendency toward short-term thinking among *younger adults*. While late adolescence and early adulthood are generally characterized by more short-term thinking<sup>42</sup>, CHWs described this phenomenon as paired with a hopelessness consistent with a foreshortened future. Ellen, 73, explained, "I think that the reason a lot of these kids do the things that they do—is because they

don't plan for the future. They just live for today." CHWs of all ages attributed this to a lack of positive support as children, high exposure to violence, and urgent concerns associated with childrening, financial insecurity, and interpersonal domestic problems.

Older adults were also highlighted as in greater need of mental health services. Ellen, 73, described observing a pattern of overwhelming stressors and fear leading to mutually reinforcing and escalating social isolation and confusion: "You're not thinking clearly. You're thinking in so many different patterns...to the point where...you might harm yourself." When "confusion of why things that you want for your life [aren't] falling into place" arises,

You kind of grasp on to something that is not reality, and I think that contributes to your confusion....So then you're like, "I don't feel good...I don't know what's wrong with me." But physically you're not really hurting anywhere. I think part of it is...they are embarrassed....

[When] you say, "Well, maybe you need to talk to somebody," [they say,] "I don't need to talk to anybody—I'm not crazy!"

## Barriers to Mental Health Care: Cultural and Material

CHWs identified intertwined cultural and material barriers to receiving mental health care operating on individual, family, and community levels.

Cultural Hesitance to Disclose Problems to Outsiders. CHWs described long-standing community hesitance to engage outside of the family to resolve mental health concerns. Worries centered around emotional safety and threats to future medical care if providers were to weaponize patients' mental health help-seeking. These concerns arose in the context of community members' awareness of historical medical racism, as well as first and second-hand negative personal experiences. Revealing mental health concerns was also understood by some to carry risk of being labeled with a stigmatized identity amplified in the context of minoritized

racial identity<sup>1</sup>. Gloria, 78, described an interaction with a community member she was urging to seek mental health care:

She says, "I don't want that on my medical record, because then they're going to look at me like...I'm not worthy"...She used the word *worthy*, and I was surprised...because that should have nothing to do with your mental health....I says, "No, you could only get help if you express what you need"....That's the issue [I see] in most of the underserved communities.

Further, interactions with outsiders were sometimes seen as intrusive and threatening to personal agency. Jessica, 32, explained that for some community members, the idea of talking to a therapist is "like a death sentence for them....'There's gonna be this person who's gonna get like super close and personal with my life, and they're gonna tell me what to do.'" CHWs also described community members' worries that treatment would be ineffective or low-quality, given their awareness of the limited availability of providers with racial concordance, shared lived experience, or cultural competence. Many CHWs had themselves experienced and heard stories about mental health providers failing to listen to clients or follow up appropriately. Concerns about psychiatric medication were also prominent, including worries about inappropriate prescriptions and that prescribed medication could lead to dependence or addiction.

Importantly, the tendency for Black Americans to keep mental health problems private or shared with trusted confidantes reflects not just skepticism toward providers, but also the sense that one's family, particularly elders, could provide adequate mental health support. Taylor, 32, shared that when she and her friends were teens struggling with suicidal thoughts,

The best coping for us was..."praying grandmothers"...We knew somebody was in our corner...And for me, I would say what really kept me from spiraling super to rock bottom was...I didn't want to hurt my family by hurting myself....[I knew] somebody's listening.

Somebody is watching. [The message is] "I recognize something is going on. I'm not going to force you to talk about it. I'm not going to force you to take the help. But I'm here."

Material. Four material barriers to accessing treatment were described frequently across CHW interviews. First, a belief that there are *too few providers* reflected both a modest number of local providers and a lack of awareness of all providers. In particular, certain large local providers were often perceived by community members to provide only substance use treatment rather than broader mental health services, which led to reluctance to engage with such providers due to substance use treatment stigma. Second, lack of personal *transportation* or cost of parking, limited public transportation, and unreliability of paratransit for older or disabled adults made scheduling in-person healthcare appointments onerous. Third, *time constraints* arose around low provider availability outside of the traditional workday; taking time off work, especially on a regular basis, is not feasible for many. Lack of childcare at any time of day posed further constraints. Finally, *financial* barriers applied to both psychotherapy and medication, and included individuals being uninsured or underinsured and a limited number of providers accepting insurance or offering sliding scale fees. These material concerns were seen as mental health stressors unto themselves. Taylor, 32, explained that individuals sometimes feel:

The weight of the world on their shoulders. But if they stop to acknowledge it, it feels like it's gonna crush them...They're like..."I just got this diagnosis...My dad just passed...My kids need this paid for. I'm trying to keep food in the house." They're... either ignoring their issues...which is causing them to...become numb...and in a depressive state, or they...[don't] have that mental capacity to...stop, take a moment, think things through.

These stressors were described as feeling insurmountable. As Bianca, 24, described, "They've been through so much, they done tried so much, so they at they [wit's] ends like, 'Hey,

this doesn't work for me.' You know? They've been disappointed so much."

# Increased Willingness to Discuss Mental Health: A New Trend

CHWs described the need for community members to have opportunities to "just be heard" and "be with others," and that they had recently observed an increase in community members' willingness to talk about mental health and seek support. Carmen, 32, described the shift as:

In the past...it was really more of a hush, hush thing...It would be like maybe 85–95% of people are like, "I'm not interested in talking to *anybody* about *anything*." It's more like 50/50 now, or like even...60% are like, "No, I wouldn't mind talking to someone if you can get me connected to somebody that I feel like I can build that conversation with."

Two potential causes were identified. First is the mental health tipping point as described above. Second, CHWs observed *generational differences* in perceptions of mental health; those in their 30s and younger seemed to hold less stigmatized views of mental illness and have greater willingness to discuss mental health topics openly. This was attributed to more education around mental health as well as young parents' desires to "break the cycle" for the next generation.

Taylor, 32, described this evolution as building on foundations of family and faith:

We depend on each other. We lean on each other...The community aspect is very important...You handle it, you know, "in house." So you go talk to your grandmother, your grandfather...your pastor, your missionaries, your elders at church....Prayer is absolutely a necessity. But I also believe God gives us tools [such as psychotherapy] to manage and maintain this walk that we have to take.

## Trust, Accessibility, and Visibility: Keys to Successful Mental Health Programming

CHWs were clear that future programming should "meet people where they're at," both psychologically and physically. CHWs reported too many instances of organizations and

individuals coming to "help" the community, but with agendas that were out-of-sync with community needs or time-limited due to lack of sustained funding or staffing.

**Provider Credibility.** Establishing the trustworthiness of mental health providers was described as paramount. CHWs stated "warm hand-offs" from trusted sources, such as one's primary care provider, community center staff, church leader, or friend, are valuable—and building credibility through behavior is necessary. Ellen, 73, stated it is crucial for providers to center clients' lived experiences and refrain from imposing their own beliefs:

Doctors used to tell me all the time, "People tell you stuff that they don't tell me. Why is that?" Because they feel like you're not listening to them! When I'm talking to a [community member], I listen...I wait...to give a suggestion [and make it clear], "This is not a path you have to go down. This is just something you can think about."

Gloria, 78, asserted that such problems were widespread; that "in the Black community...people feel there isn't a relationship [with providers]—[that] they're just doing their job. 'They don't care about me.'" She described how provider inattentiveness can have deleterious effects, relaying an encounter with a young community member who "needed someone to really sit and talk with her" but felt "no one wanted to be bothered at her primary care. She says, 'Nobody is interested in my well-being...I just wanna go in the corner and not talk to anybody anymore.'"

**Keep Showing Up Authentically.** CHWs noted that in their current roles as [DISEASE] care educators and navigators, relationships are cultivated through listening to others authentically and sharing authentically of themselves, and this is similarly important in the context of mental health. Geraldine, 72, explained:

I just tell them some of my business from my past .... [and] sometimes they...walk away

saying, "Her? She went through that." And that's what it's all about—getting them to know that "it's not only you." You know, I can't make them come out of hiding; I can't make them share. But as long as they leave with a different head space and knowledge for better, they'll go home and they're better, too, whether they realize it or not.

CHWs also made clear that dependability is key to developing trust. Carmen, 32, urged clear expectations, such as publicizing regular availability. She asked the interviewer to imagine:

You show up every third Thursday. And nobody comes. Then it means *still* showing up every third Thursday until people start to come....It's not that they don't want it. It's just like they don't know who you are, and...don't know if you're here for one time and...not coming back...[It's about] meeting people where they are...like, 'This is *your* neighborhood clinic.'

She added that *showing up* meant simply listening "until that trust and rapport is built. And then you can start to kind of incrementally add....'I'm here...just checking in with you. See how you're doing. Are there different things you want to address now?""

Bringing Care to the Community. CHWs urged creativity and attentiveness to cultural and practical preferences when considering locations for mental health care delivery. For example, they suggested bringing care to non-traditional settings such as salons and barber shops, corner stores, senior housing residences, and high-stress workplaces. Taylor, 32, offered, "Even if it was like a kitchen [setting]...That's where we gather to meet, hang out...We break bread together, and then we talk about what's going on." Some CHWs suggested engaging community members through volunteerism, such as implementing a block club model in which community members would check in on their neighbors or through person-to-person door-knocking campaigns—both strategies already utilized by NWP.

Finally, CHWs advised that meeting people "where they are" involves avoiding alienating or

excluding community members through highfalutin language or burdensome program requirements. For example, some warned that program recruitment material drawing attention to the university might deter community members. They also stressed the importance of brief, simple recruitment and clinic materials and processes to decrease time and cognitive burdens.

# Study 2

We next invited community members who had been or could be served by NWP to participate in focus groups. The format echoed familiar NWP group programming.

#### Method

## **Ethics**

This study was deemed exempt by the UB IRB (STUDY00006930).

## Recruitment

We aimed to recruit 10–15 participants per focus group, seeking diversity in age and life experience. Prior to focus group meetings, CHWs and residential/program staff invited all Black adult (18+) members of a given constituency (e.g., building residents) to participate in a focus group about Black mental health led by an NWP-UB team. Sample size was determined by the number of those invited who were interested and available to participate.

# **Participants**

Across four focus groups ranging from 7–23 participants each, participants (n=54) were 18–91 years old, 100% Black, and were 63% cisgender women, 31% cisgender men, and 6% gender not reported. No other demographic information was collected.

#### **Procedure**

Two focus groups with residents of low-income housing were held in building community rooms. One focus group with women experiencing housing instability took place in a social

service agency's residential building, and one focus group with community-dwelling young adults was held in the community engagement center where NWP is headquartered. Open-ended focus group questions (https://osf.io/tafcq/?view\_only=162b7c39ae8f4972ae528fea0e9ab8ac) were informed by analyses of Study 1 CHW interviews and a community needs assessment survey. Groups were facilitated by two young Black women psychology research assistants (ET and BG) with support from NWP-UB leaders and staff. Prior to beginning, participants were reminded participation was voluntary and they could leave at any time without consequences. They were informed staying in the group was tantamount to consent to participate, including being audio recorded. Focus groups were 1–1.5 hours each; participants were compensated \$30.

## Analysis

Study 1 analytic procedures were followed.

#### Results

Results related to the development of novel mental health programming are presented below.

Unless indicated otherwise, results were common across all focus groups.

## Barriers to Mental Health Care

Focus group participants identified a variety of structural and interpersonal challenges as relevant to the development and maintenance of mental health problems.

**Social Determinants of Health.** Significant systemic stressors or lack of access to basic resources were core concerns. Tina, 51, stated:

As soon as I go to my doctor, I drop a tear that quick because I be in so much pain. He looks at me and he goes, "Tina, you're stressed. You're literally stressed...Go up to [the hospital psychiatric ward] in a white jacket truck." Don't even worry about the white jacket! Just give me the key where I can let myself in. If I don't call you, don't call me.... That's how I feel

because...I'm taking care of 10,000 different things....I'm so stressed half the time I'm just confused.... I feel my mind just stuck in one spot and I can't think, and I cry so bad.

Participants pointed to lack of tangible resources (e.g., money, housing, and transportation) as hampering their ability to bring about desired changes. For example, Sylvia, 86, stated, "boredom—not having enough to do" was a major challenge made worse by lack of transportation: "Even though we're seniors and retired, sometimes we just want to be more active and do more things and...if we don't have cars, we can't do a lot of stuff." Similarly, a lack of power to gather together with other building residents in community spaces was described by Martha, 63, as "not fair to us and our community. It's very, very depressing too. It keeps you from being able to be social."

Harmful Interpersonal Relationships. Participants sometimes felt mental health problems were exacerbated by invalidating peers and family members. Parent and grandparent participants were concerned about growing mental health concerns among their children and grandchildren resulting from bullying, infrequent opportunities for positive socialization, and little support from school staff and other professionals. Further, participants described fear of being alone as linked to the maintenance of mental health problems. For example, Ernest, 73, explained that when people try to get support from friends, "They get judged by somebody that's—they straight, they clean—and they judge, 'Man, you shouldn't do this or you shouldn't do that because I don't do that'....And then you float away...because he gave you negative vibes." He then described how this leads to seeking "positive vibes" from "the wrong person, but birds of the feather flock together." Vincent, 70, agreed: "I've been through the gangs....I lived it all...I've seen the separation in people. Because why? Because every time somebody seen somebody get up, it was like...they could pull them back down like a barrel of crabs."

Tina, 51, described the seeming intractability of such patterns: "Nine times out of 10, when you bring [someone who had been receiving treatment] back into [their previous environment], they're going to relapse anyway because of the environment, their loved ones, and so-called friends." Many participants were wary of seeking support from friends and family members. When prompted to describe who they might ask for mental health support from, Keith, 66, noted, "It takes a lot of courage to reach out for help. A person would just rather try to deal with it on their own." Other participants described themselves as "too prideful" and concerned about becoming "a burden" to ask for help (Samuel, 21), or worried others might "end up rubbing it in my face" (Monica, 26). Tammy, 62, expressed that her sister had previously gossiped about Tammy's problems when she had risked opening up. Tammy was deeply hurt by these actions, reflecting, "They want to talk to me dirty. I'm not a dog. I'm a human being."

**Mistrust of Providers.** Healthcare providers were also seen as dehumanizing to vulnerable people in their care. Barry, 70, powerfully described his fury after doctors kept changing his diagnoses and prescriptions:

I said..."This is *my* body, why y'all playing with me? Why y'all doing this to me? I'm taking 13 pills a day!" I take so many pills I don't even think about eating no food sometimes...

They done had me on a ping-pong table for years. It does something to you, mentally *and* physically...They. Don't. Care! They make you out of a guinea pig. They don't care!

Unfortunately, Barry's experience was not unique. Most participants described having healthcare experiences that led them to believe many providers do not care about patients or about providing good care, and that treatment decisions were motivated by selfish interests such as making money. As Paula, 64, quipped, "It's all about that mighty dollar. The more

prescriptions he writes, the fatter his pocket gets. He's...more concerned about that than he is

about people's lives."

Providers were also described as often being *out of sync with patients' lived experience*. Ernest, 73, described his frustration after attending many community health fairs and programs that felt ineffective, and then seeing the providers "coming out, getting in they Mercedes and they Audis and stuff. Because it was just their job....'Let me get back in the suburbs."

Concerns about medication were particularly prominent. Participants saw many providers as prescribing medications as a first line treatment, without considering alternatives. Robin, 56, stated the hospital she works at is "short staffed, [so] they have people not trained to deal with mental health" working in mental health care. As a result, "they just push the pills." Participants worried about side effects such as mental fog and worsening mental health problems (e.g., increased suicidal ideation). Barry, who described feeling like a guinea pig above, described doctors behaving as if prescribed new medications with the thinking, "If it works with him, I'll give it to somebody else. But if it don't work with him, and he start getting the shakes...I'm not going to give it to that other person [that] got that excellent insurance." Medication concerns were one of several types of inappropriate care described, including differential treatment by income/insurance status; not enough time for appointments; and a "revolving door" that simply pushes people out without follow-up care.

## Hopes and Preferences for Future Community-Based Mental Health Programming

Participants described features they would like to see in future mental health programming.

Community-Based, Creative Care. Participants requested greater access to providers within their own communities. Robin, 56, shared, "If...I'm like, 'Lord, I don't know which way to go. I'm stressed with the life, the job, the home. I'm stranded," she would prefer help from a community-based organization because staff are more likely to "have integrity [and] empathy."

Virtual mental health visits were suggested by some participants as promoting greater access, and most were more open to this idea. Some raised the possibility of home visits to increase opportunities for care, especially for children and adolescents. Participants also suggested alternative forms of care including nature walks, music therapy, and support groups in informal settings such as barber shops.

Education on Identifying Warning Signs. Many participants were interested in increasing basic mental health knowledge, including signs that someone may need support or be experiencing a crisis, and where to go for help. Russell, 78, offered:

Most of us, we wouldn't recognize the red flags even within ourselves. Which is why this mental health thing is so prevalent....Just like they give you the warning signs for strokes....

You might have to set up some of the guidelines so that people can see it...enough to recognize, "Oh! Well. That sounds like me a little bit."

Participants were also interested in learning how to distinguish mental health problems from personality quirks or developmentally normative behaviors. Sylvia, 86, observed people will "see somebody acting up" and incorrectly assume "because they're living in a senior citizens apartment building...'She's just old.' They don't think that maybe that person needs help."

Authentically Caring Providers. Most of all, participants described a desire for providers to genuinely care about the community and provide high-quality care, highlighting that participants were not wary of mental health care altogether, but rather of being disappointed or harmed through poor care. Vincent, 70, was direct: "Got to teach health professionals to really come to care, not *act* like they care, but really care." Denise, 73, offered an impromptu testimony about the power of working with a mental health provider who authentically cared:

Now I'm going to say this and I thank God for it. The psychiatrist that I used to go to when I

was a kid....She said, "You could come in here and you could talk to me. Your mother can stay out there...What we talk about, it'll be between me and you"....If you can get that relationship with that one person, I'm telling y'all, I was so free. I couldn't wait to go see my psychiatrist to talk to her and tell her what I was experiencing, what I was feeling. It helps.

Community Dialogue Opportunities. There was variation in perspectives around the idea of community dialogues. While some participants indicated they would feel more comfortable sharing mental health concerns among friends, others preferred the idea of dialoguing with strangers. Some participants were concerned that listening to others' problems could trigger problems in listeners; others noted listeners could be motivated to seek needed support.

Participants observed sharing one's story could be *healing to the storyteller*, which we witnessed play out in real time. Within each focus group, there were a handful of participants who shared their personal, difficult experiences with mental health or other life stressors. Other focus group members tended to be supportive. Tina, 51, shared several personal stories. At the end of the group she reflected, "This right here has helped me. It has helped me vent and bring out a lot of stressful things that was bothering me. Not just in the community but in my life as well." Her peers responded with words of affirmation: "I know I was there before!" and "Your story might stop [others] from doing something similar."

The atmosphere of the focus groups was nonjudgmental, seemingly holding those group members who shared personal experiences in equal esteem with those who shared little or were silent. This echoed encouragement from Denise, 73, for implementing programming that creates space for those community members who were not obviously engaged: "Putting that information out there whether [attendees] receive it or not, it might be…like, 'You know what? I was at a meeting the other day and they gave out some information,' and they'll go pick it up and use it."

#### **General Discussion**

## **Areas of Convergence Across Studies**

Findings from CHW interviews and community focus groups were largely aligned. Both samples identified similar segments of the community particularly in need of support (young adults, older adults, those coping with multiple forms of oppression) and similar barriers to care (distrust of outsiders, medical mistrust, significant wariness around psychiatric medication).

There were also several areas of convergence relating to planning for future programming.

First was the idea that trust is built over time, accrued through dependability and willingness on the part of providers to *meet participants where they are*, including respect for individuals' readiness for mental health support. This was also a practical concern about increasing effectiveness: meeting community members in the spaces they live, work, and play increases convenience and feelings of psychological safety. In addition, participants advised providers have a responsibility to not just flee "back to the suburbs" after making an appearance. This point was dramatically illustrated in the following exchange with a focus group member, Carl, 68:

CARL: Do y'all know the next time you all come here, just offhand?

MODERATOR: We don't have a date yet, but we will be back.

CARL: So y'all don't have a date?

MODERATOR: We don't have a date yet, but we will be back.

CARL: That's a killer right there—that's a killer right there.

Though a productive conversation followed, including providing readily available resources and referrals, Carl's response reflected the frustration many participants had with past providers they perceived to be uncommitted to the community. At the same time, participants conveyed a lack of shared community membership and lived experience could be mitigated through

cultivating authentic care and genuine empathy.

Finally, both samples described a benefit to *just being together* and *witnessing and being witnessed*. While there was mixed interest in sharing personal stories, there was more uniform support shown for those who made sensitive personal disclosures—through the nonjudgmental way CHWs described their experiences with community members, and through the validation and respect focus group participants gave to each other.

# **Areas of Nuance or Divergence Across Studies**

There were subtle differences in how CHWs versus focus group participants tended to describe or contextualize their responses. CHWs tended speculate more on the *why*s of various phenomena and place greater emphasis on systematic concerns, likely because of the "outsider/insider" perspective invited during interviews, their knowledge of social determinants of health, and more extensive speaking turns in interviews. For example, where focus group participants described individual consequences of internalized stigma and social stigma, CHWs raised more concern about institutional discrimination (e.g., through healthcare providers), likely because of their experiences witnessing such discrimination first- and second-hand.

Although the topic of *trust* was prominent across both samples, CHWs tended to focus on how institutional mistrust is maintained within the community while focus group participants were more focused on interpersonal mistrust. Several CHWs provided vivid personal examples of feeling supported by friends and family in their own mental health struggles. In contrast, many focus group members described personal relationships characterized by mistrust and lack of support, noting that experiences with negligent or even malicious friends and family perpetuated a fear of disclosing mental health concerns.

# Setting the Stage for "Witnessing for Mental Health"

Our findings suggested the basic structure of existing NWP programming could be adapted to the topic of mental health to fulfill at least some community needs and allow CHWs to "hit the ground running" because of their familiarity with program structure. Discovering the insights of CHWs who have experience and perspective on community health education, balanced by community members' concerns and experiences, informed the path to develop the program structure in collaboration with the community.

The adapted NWP program, Witnessing for Mental Health, will follow the NWP program structure. Programs are delivered in community settings, such as community rooms of senior housing buildings or in places of worship. Prayers or hymns, offered by a CHW or community member volunteer, always open and close programs, which is particularly transferable to the context of mental health given that Black adults consistently report a preference to cope with mental health problems through religious and spiritual practices<sup>43</sup>, with 90% of Black adults endorsing relying on prayer and God as a source of strength in coping with stressful situations<sup>44</sup>. During the program, a CHW trained in personal storytelling will serve as a "witness role model," sharing their lived experience with mental health challenges and successes. Focus group participant Denise's testimony about her childhood psychiatrist is paradigmatic of such "witnessing." The bulk of the program involves an interactive CHW-led educational presentation about mental health (e.g., mental health basics, coping with stress, and understanding psychiatric medication). At the conclusion of the program, attendees will complete a brief mental health screener and interest form for mental health care navigation. All attendees will receive resource lists related to Black mental health and local mental health services.

Consistent with the literature<sup>2,4,45</sup>, NWP has found it is crucial to offer evidence-based health education paired with resource navigation. Therefore, prior to launching Witnessing for Mental

Health, CHWs will receive extensive training in Psychological First Aid, mental health education, and navigation for mental health needs. Our team is working to develop a stepped-care model that connects individuals to the appropriate level of care using "warm hand-offs" to culturally competent providers<sup>46</sup>. This includes navigation to community resources, single-session interventions<sup>47</sup>, traditional psychotherapy, psychiatric care<sup>48</sup>, or acute crisis care.

## **Limitations and Future Directions**

Our ability to engage with diverse stakeholders was a key strength. However, we had relative difficulty recruiting young adults (n=7) and did not meet our recruitment goal for that age group. While this echoes the broader age distribution of adults served by NWP, it limits generalizability. In addition, by virtue of their interest and ability to attend focus groups, Study 2 participants may be more willing than other community members to discuss mental health. Looking ahead, our team will continue to seek and learn from community voices we have not yet heard. We will also continue to explore programming to meet community members' need to "just be heard" and "just be together" in more open, relaxed settings, and to learn from existing mental health programming tailored to diverse Black American communities  $^{49-51}$ .

#### Conclusion

Our partnership of community-based health experts and academic clinical psychologists embarked on a year-long process of identifying the mental health needs and preferences of low-income Black adults in Buffalo. We found participants' first-person perspectives added important depth and specificity to past research about racial inequities in mental health treatment, severity, and chronicity. Through gathering and validating first-person perspectives as we conduct research, and by being accountable to those perspectives in the development and delivery of Witnessing for Mental Health, we aspire to demonstrate to Black Buffalonians that their lived

experiences matter deeply. We further hope to underscore the value of these lived experiences by ensuring they are represented in the scientific literature, informing research and practice to improve mental health disparities.

As with most community-engaged, qualitative research, our aim was to produce research that both reflects community members' lived experiences and resonates meaningfully in a way that is "recognizable" to a broader audience. The present research was conceived of, collected, and interpreted through a local lens; indeed, it was prompted by a heinous act of violence that left permanent scars on the history of Black Buffalo. Even with these deep wounds, NWP leaders were surprised that in the immediate aftermath, so many community members would forthrightly acknowledge their desire for mental health support. Our research suggests this disclosure may have been brought about by unprecedented stressors (i.e., mass shooting; pandemic) layered on top of ongoing inequities, as well as cultural and generational shifts toward a more positive view of talking about mental health. In some ways these factors are plainly—and importantly—local, allowing us to gain an understanding of the local instantiation of broader patterns in Black

American mental health. At the same time, we suggest these same findings might reverberate in unique ways among other researchers and community leaders, leading to culturally grounded mental health research urgently needed in so many communities.

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#### **Statements and Declarations**

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# **Competing Interests**

The authors have no competing interests to declare.

# **Compliance with Ethical Standards**

# **Ethics Approval**

Both Studies 1 and 2 were deemed exempt by the University at Buffalo Institutional Review Board (STUDY00006930).

# **Informed Consent**

Participants who took part in one-on-one interviews received a consent form for review several days prior to the interview and were invited to ask questions about its content prior to the interview. Focus group participants received a verbal explanation of key components of informed consent and given the opportunity to leave if desired prior to the start of the focus group.

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