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ORIGINAL ARTICLE

Stress, coping and the acceptability of mindfulness skills among pregnant and parenting women living with HIV in the United States: A focus group study

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Abstract

Pregnant and parenting women living with HIV (WLWH) face high levels of psychological stress and mental illness but lack tailored and acceptable psychosocial treatments. The research team sought to inform the adaptation of a mindfulness intervention for pregnant and parenting WLWH through focus groups exploring psychosocial treatment needs and mindfulness intervention preferences. The research team conducted focus groups with pregnant and parenting WLWH ($n = 16$) and case managers ($n = 6$) recruited from a community-based enhanced case management program. The research team utilised an iterative inductive approach to coding of the transcripts from these focus groups. Five themes emerged: stressors, signs of stress, coping, lack of access and acceptability of care, and motivation and trust in care engagement. These focus groups revealed a desire for a group intervention that could decrease isolation while protecting against involuntary disclosure of HIV status. Participants expressed openness to mindfulness skills for coping with stress. The focus group participants' preference for a non-stigmatising group intervention supports the potential of a mindfulness-based group intervention to reduce stress and improve the mental health of pregnant and parenting women living with HIV.

KEYWORDS
female, focus groups, HIV, mindfulness, parenting, pregnancy, stress

1 | INTRODUCTION

Women living with HIV (WLWH) are at high-risk for mental health concerns and psychiatric disorders (Kapetanovic et al., 2009; Orza et al., 2015; Waldron et al., 2021). Approximately one-third of WLWH in the U.S. experience depression (Do et al., 2014), 20%–30% have met the criteria for PTSD (Machtinger et al., 2012; Malee et al., 2014), and up to 40% have reported clinical levels of anxiety (Ivanova et al., 2012; Kaplan et al., 1997). WLWH experience unique familial, social and economic stressors that contribute to the high rates of mental illness and distress in this population (Orza et al., 2015). Some of these stressors include perceived health

status, limitations in their ability to fulfil responsibilities due to their health (McIntosh & Rosselli, 2012), and issues with access to and acceptability of community-based health services for HIV (Hellinger, 1993; Orza et al., 2015; Palacio et al., 1999). WLWH also face stress related to disclosing their HIV status, interpersonal difficulties (Ashaba et al., 2017), and a high prevalence of intimate partner violence (Li et al., 2014; Pantalone et al., 2014). These difficulties are often coupled with HIV-related stigma (Baugher et al., 2017; Emlet et al., 2013). More than four-fifths of WLWH in the U.S. identify as racial/ethnic minority women (Ion et al., 2017); HIV-related stigma can be exacerbated by intersectional stressors of racism, sexism and discrimination that racial/ethnic minority women face (Logie et al., 2011; Logie et al., 2013).

Pregnant and postpartum WLWH are especially vulnerable to mental health concerns due to the significant biological, social and psychological changes during pregnancy and childbirth (Shi & MacBeth, 2017). Pregnant and postpartum mothers are at increased risk for depression, anxiety, obsessions/compulsions and postpartum psychosis (Sit et al., 2006; Zambaldi et al., 2009). For pregnant and postpartum WLWH, these changes may be coupled with additional psychosocial challenges, including stress regarding the prevention of HIV transmission to the infant, HIV status disclosure related to the pregnancy, and potential perceived stigma from obstetric healthcare providers (Ashaba et al., 2017), plus the aforementioned stressors faced by WLWH in general. Research has found that approximately one-third of pregnant or postpartum WLWH have experienced perinatal depression (Kapetanovic et al., 2009; Sowa et al., 2015). High stress (Blaney et al., 2004), low social support (Blaney et al., 2004; Brittain et al., 2017; Ross et al., 2009), and stigma (Brittain et al., 2017; Ion et al., 2017) are all associated with perinatal depression among WLWH.

Recognising and reducing mental health concerns in pregnant and parenting WLWH is critical not only for the mothers' health but also for their children's health. Perinatal depression and anxiety may negatively affect a mother's self-care, care of her baby and prevention of perinatal transmission of HIV (Turan et al., 2014). Depression during pregnancy and the postpartum period is associated with a lower rate of HIV care initiation (Turan et al., 2014), substance misuse during pregnancy, and suboptimal antiretroviral adherence among WLWH (Kapetanovic et al., 2009). Therefore, treatments to reduce depression and other mental health concerns among pregnant and parenting WLWH have the potential to improve both the mental and the physical health of mothers and babies.

Despite the profound mental health needs of perinatal WLWH, available treatments specific to this population are lacking (Waldron et al., 2021). Most published research on mental health treatments for this population has been conducted as part of interventions to prevent perinatal transmission or as an adjunctive piece to usual HIV care (Ishola & Chipps, 2015;Kaaya et al., 2013; Rotheram-Borus et al., 2014). The majority of studies that do exist utilised psychosocial support and noted reductions in depressive symptom severity following participation in their interventions (Kaaya et al., 2013; Ross et al., 2013; Rotheram-Borus et al., 2014). However, several studies noted issues with participant attrition (Kaaya et al., 2013; Rotheram-Borus et al., 2014). Further, the evidence that these interventions could be effective for perinatal WLWH in the United States if specifically focused on mental health is missing (Waldron et al., 2021).

One potential avenue for improving the mental health of pregnant WLWH is mindfulness-based interventions. Mindfulness-based interventions employ formal and informal mindfulness practices that involve intentionally paying sustained attention to sensory, cognitive and emotional experiences without judgement (Kabat-Zinn, 2005). This type of intervention has proven to be effective in aiding individuals living with chronic health conditions better manage their healthcare and improve their quality of life (Gu et al., 2015; Merkes, 2010; Veehof et al., 2016). Mindfulness-based interventions are acceptable and potentially less stigmatising among populations traditionally underserved with mental health treatment like socioeconomically disadvantaged, racial/ethnic minority women due to the emphasis on wellness, stress reduction and group support versus mental illness treatment (Burnett-Zeigler, Satyshur, et al., 2019; Dutton, 2015; Dutton et al., 2013). Of note, the majority of WLWH in the U.S. identify as socioeconomically disadvantaged, racial/ethnic minority women (amfAR, 2018). They show promise for improving the mental health and well-being of people living with HIV (Creswell et al., 2009; Duncan et al., 2012; Hecht et al., 2018), pregnant and parenting women (Vieten & Astin, 2008; Zhang & Emory, 2015) and socioeconomically disadvantaged racial/ethnic minority women

What is known about this topic

- Of the quarter of a million women living with HIV (WLWH) in the United States, more than one-third are of childbearing age.
- Pregnant and parenting WLWH face intersecting social, economic and medical stressors and experience high rates of psychiatric disorders and mental health concerns.

What this paper adds

- Little is known about the acceptability of psychosocial treatments for pregnant and parenting women living with HIV, including their attitudes toward mindfulness-based interventions.
- Pregnant and parenting WLWH expressed a preference for a group psychosocial intervention that could decrease isolation by connecting them with other mothers living with HIV. They also desired an intervention that would be conducted in a way that minimised the risk of unintentional disclosure of their HIV status.
- Enhanced case managers and the pregnant and parenting WLWH with whom they worked expressed an openness to using mindfulness to cope with psychosocial stress.

(Burnett-Zeigler et al., 2016; Burnett-Zeigler, Hong, et al., 2019). Thus, a mindfulness-based intervention designed and delivered specifically for WLWH may fill a gap in needed mental health care for this population.

M-Body is a mindfulness-based intervention shown to be acceptable (Burnett-Zeigler, Satyshur, et al., 2019) and have preliminary effectiveness in reducing stress and depressive symptoms for socioeconomically disadvantaged racial/ethnic minority women (Burnett-Zeigler et al., 2016; Burnett-Zeigler, Hong, et al., 2019). The M-Body intervention was adapted from the evidence-based mindfulness intervention Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 2005). Like MBSR, M-Body is an eight-week group intervention that includes didactics on formal and informal practices of mindfulness, sitting meditation, body scan, yoga and group discussions on the participants' experiences of mindfulness. M-Body was modified from MBSR to enhance acceptability and accessibility in a community-based setting for socioeconomically disadvantaged racial/ethnic minority women. The modifications included: (a) shortening the duration of each class from 180 to 90 min, (b) offering the intervention at no cost at a community health centre, and (c) having a health educator from the community health centre who underwent a streamlined training lead the group. Given the high level of unmet mental health needs among pregnant and parenting women WLWH, the research team sought to adapt M-Body to meet the specific needs of this population. To this end, they partnered with a community-based organisation that provides enhanced case management to pregnant and postpartum WLWH and has the existing infrastructure to deliver a mindfulness-based intervention for this population.

Mother & Child Alliance is a not-for-profit organisation with a mission to end perinatal transmission of HIV in Illinois (Mother and Child Alliance, 2020). Mother & Child Alliance offers enhanced case management (ECM) for pregnant WLWH who need extra support. The ECM services include biweekly face-to-face meetings with a case manager during pregnancy and up to 2 years postpartum, monthly monitoring of HIV risk behaviours and adherence to HIV care and treatment, ongoing review of client progress, linkage to support services, including access to healthcare and benefits, housing, social services and basic infant care. The ECM program aims to link high-risk pregnant WLWH to appropriate health services resulting in the delivery of healthy babies who are HIV-negative and overall improved quality of life.

The ultimate goal of this research is to adapt, test and disseminate a mindfulness-based mental health intervention based on M-Body for pregnant and parenting WLWH across the United States. As a first step toward this goal, this study aimed to collect and analyse data from focus groups of pregnant and parenting WLWH and their case managers to inform the development of this mindfulness intervention. The focus groups intended to (a) gather information on key stressors and responses to psychosocial stress to maximise the relevance and acceptability of intervention content and (b) obtain feedback on preferred modes of delivery, frequency, duration and barriers and facilitators of participation. This paper reports on the results of those focus groups.

2 | METHODS

2.1 | Recruitment

Current and former Mother & Child Alliance clients and enhanced case managers were recruited to participate in focus groups. Enhanced case managers were provided information about the study and asked to share a brief verbal overview of the focus groups and an informational flyer with their clients during regularly scheduled home and clinic visits. If the client expressed interest in participating in the focus groups and provided verbal consent, the case managers provided her first name and contact information to the research coordinator. The research coordinator called these interested clients and invited them to a focus group. Case managers were invited to their own focus group, irrespective of whether they helped recruit clients for focus groups. Per the eligibility requirements for Mother & Child Alliance services, client participants had been diagnosed with HIV and were either pregnant or parenting at least one child under the age of 2 years. Individuals who did not speak English or were under 18 years of age were not eligible to participate.

2.2 | Study design

The senior and second authors (IB and EM) developed a focus group guide for the client focus groups that covered the following topics: (a) identification of key stressors; (b) existing strategies for coping with stressors; (c) knowledge of mindfulness-based approaches for mental health; (d) review of potential intervention content and (e) acceptable frequency, duration and modes of delivery of the intervention. Likewise, they developed a focus group guide for the case manager focus group that covered: (a) key mental health challenges experienced by Mother & Child Alliance clients; (b) mental health services, supports and strategies currently used by Mother & Child Alliance clients and critical gaps; (c) knowledge and experience with mindfulness-based approaches for mental health and (d) review of a potential mindfulness intervention in the context of the current Mother & Child Alliance enhanced case management model. Sample questions from the focus group guide are provided in Table 1. Three groups were conducted in total: one group included six Mother & Child Alliance case managers, and two additional groups included eight current or former Mother & Child Alliance clients each ($N = 22$). The senior author of the study (I.B.) led the focus groups. In addition to the senior author, who identifies as an African American woman, three authors who identify as white women were present at the groups to provide logistical support. Each group lasted approximately 90 min. Focus groups took place in a discreet conference room of a downtown academic medical centre. Clients and case managers received a $50 gift card for participating in the focus group. Childcare, transportation and refreshments were provided. Focus groups were audio-recorded and transcribed verbatim by a professional transcription company. Due to concerns around disclosure

TABLE 1 Selection of focus group interview questions

Questions from client focus group guide	What are some of the things in your day-to-day life that make you "stressed out"?
	What do you do to feel better when you are stressed?
	Do you think something like this [mindfulness intervention] might be beneficial for you during pregnancy? What about after you delivered?
Questions from Case Manager Focus Group Guide	What are some of the common stressors that your clients face?
	What supports currently exist to help your clients cope with stress?
	Do you think these [mindfulness] skills would be beneficial for your clients?

of HIV status and confidentiality brought up by the enhanced case management organisation during study design, no socioeconomic or demographic data of participants were collected.

2.3 | Analyses

The analyses include data from three focus group transcripts. An iterative inductive approach to coding was utilised. All research team members individually reviewed the three transcripts using line-by-line descriptive coding, and each created a preliminary codebook (Miles et al., 2014; Saldaña, 2013). The coders then met to compare independent coding and clarify and revise codes until they reached a consensus on the final codebook. A subset of coders (E.W., E.M., V.W. and I.B.) engaged in a second cycle coding, using pattern coding or grouping similarly coded data to develop meta codes, to summarise emerging categories and themes (Miles et al., 2014; Saldana, 2013). Initial transcripts were then recoded by the same subset of coders using dedoose, a web-based application for excerpting, coding and analysis of qualitative research (dedoose, 2019). The subset of coders used constant comparison to compare responses across all participants and between participants of separate groups (client versus case manager; Glaser & Strauss, 1967).

The Institutional Review Board of Northwestern University approved this study. Written informed consent was obtained from all individual participants before the start of the focus group.

3 | RESULTS

Five themes emerged from the analysis: stressors, signs of stress, coping, lack of access and acceptability of care, and motivation and trust in care engagement. All themes were present in all focus groups, although there was some variation in the content of these themes across client and enhanced case manager focus groups. Codes of the respective themes are italicized throughout the results. Table 2 depicts a summary of the themes and representative quotes.

3.1 | Stressors

The theme of stressors predominated in focus groups of clients and case managers. The sources of stress were varied, but competing *responsibilities* of work, home care, school and childcare predominated all focus groups. *Finances* also emerged in both client and case manager focus groups, with several citing financial insecurity or struggling to pay bills each month as a source of stress. Many clients and case managers noted how obtaining and managing childcare in order to work was a significant source of stress for the clients. Similarly, *pregnancy and parenting*-related stressors outside of work-related childcare demands came up frequently in the groups. Respondents cited stress from raising multiple children, putting children's needs before the mother's own to the detriment of her health and well-being, the physical strain caused by pregnancy, and tending to children's health conditions, especially for those children born with HIV. Prevalent among these stressors was feeling as if the mothers did not have enough *interpersonal support* in raising their children, feeling isolated and stretched thin in terms of time and financial resources. However, some clients and case managers noted that conflict between the clients and their families, feeling overwhelmed by family members' attention, or needing to ask for support when they would prefer to remain independent also caused stress in the clients' lives. Dealing with a *history of trauma and mental illness* emerged in client and case manager focus groups, such as coping with past trauma, particularly sexual and physical abuse, and depression, including postpartum depression. A few clients mentioned that managing mental illness, such as taking psychotropic medication for conditions like bipolar disorder, was stressful.

Some of the stressors that emerged in the focus groups were specific to people living with HIV and pregnant and postpartum WLWH. Stress related to the *disclosure of HIV status*, especially unintentional or by others without the client's consent, frequently emerged in client and case manager focus groups. The fear of inadvertent disclosure led some clients to go to extra lengths to hide their status, such as making up reasons why they cannot breastfeed their infants or why they must go to medical appointments alone. A few clients mentioned the stress of feeling betrayed and ostracised when friends or family revealed their HIV status to others without the clients' consent. This was closely related to stress related to *HIV-related stigma*. Clients mentioned feeling as if others did or would treat them differently if they knew their status, like they were sick or to be avoided. Case managers highlighted the self-stigma of their clients, feeling ashamed of this status. Further, clients and case managers stated that many dealt with the stress of isolation brought on by hiding their status due to this stigma or fear of discrimination. Stress related to the potential for the *transmission of HIV* also emerged with clients saying they experienced fear during pregnancy and even for a few months after giving birth that their child would be HIV-positive. Some clients described the stress of having a child be born HIV-positive and needing to pursue medical treatment for that child. In both cases, clients endorsed feeling pressure to manage their and their baby's antiretroviral medications.

TABLE 2 Themes and representative quotes

Identified theme	Representative quotes
Stressors	
Responsibilities	Client 5: Sometimes we get so busy the day to day-whatever activities, whatever responsibilities we need to do, we never sit down or we feel we don't have time to just think about the simple things that can help us
	Case Manager 2: They're just looking for a way to be able to manage all the stuff that's going on in their life at any moment.
HIV-related Stigma	Client 4: You know people do look at you differently, whether it's a friend or family. It could be a stranger. They're gonna look at you like, really, you? Because you can't look at a person and say oh you got, you know we're not labeled on our foreheads. It's just you feel different once it's out there. Like you're walking down the street and everyone just know I'm positive
	Case Manager 5: The father of the baby could have been the one that gave them the virus. They still don't go home and confront the father of the baby due to their status.
Disclosure	Client 3: Because it's like 2 years, 2 years I've been positive and I've kept it to myself for 2 years, and it's been successful. Taking pills, going to appointments, pregnant, going through labor, having everyone there. It's been successful so far, so it's like how long can it be successful before it be that one time that it slips up.
	Case Manager 6: One lady told me last week her sister had the virus, but they only two know and they know if someone tells, 'if you're telling on me, I'm telling on you.' She just said, "I'm gonna die with this lie."
Transmission of HIV	Client 2: My set of twins, god forbid, they was born without it, but every day I wake up, when they gotta go to the doctor like is it gonna be triggered? Are they gonna tell me their lab work, you know what I mean? Now to bring another baby in and I sit here and I look at [the father of the baby] like you brought all this on me and just because I don't want you to pass it to nobody else, I'm fussing myself to be here with you.
	Case Manager 4: I notice a lot of stress and depression around my clients whose culture is to breastfeed. Primarily African clients and usually their families. They'll come to Chicago to help with the baby the first few weeks, so it's a lot of concern about what are they gonna say about this medication I'm giving the baby.
Pregnancy/ Parenting	Client 12: So it's like me not knowing if I'm not giving her enough milk or don't have enough for the next month or stuff like that. That's very stressful because I'm not running out of food, so why should she run out of food? You get what I'm saying? It's just so much
	Case Manager 5: She's [client] very, very depressed. She also is thinking about adoption. She's like 31 weeks pregnant right now, and you know it's hard to say you're gonna be okay
History of trauma or mental illness	Client 12: So basically when I had her I call it postpartum depression. That was something I didn't need on top of what I've already got
	Client 4: And it's like I was given it [HIV] by force. I was raped so when I found out, it was like an oh my gosh, like now when I tell my boyfriend, he's gonna wonder how I got it. So now I have to sit here and now tell my boyfriend something that I didn't want to tell him, and now it's too late
	Case Manager 5: Some of the clients I have are in a study right now, which goes through like a really extensive life history and, in some of those intakes, it came up that some of my clients had experienced like multiple sexual assaults.
Finances	Client 8: You know just the thought of how am I gonna work, who is gonna take care of them [my daughters] while I work, how I'm gonna pay bills, and apart from that you know you have your situation: HIV
	Case Manager 5: The idea that economically they're like stuck where they are because now they have a baby and they can't get a job and they don't have child care and kind of like this hopeless situation where they have the motivation to do something, but every other, all the other circumstances are stopping them
Interpersonal support	Client 13: It's a lot for one person. Like they said it's a village. In reality I don't have a village, so it's very, very stressful
	Case Manager 6: They have so much on their mind besides HIV. Not just finances, relationships with family. That's another issue of my clients because not most of my clients live in their own apartment. They live with family members, so the dynamics of what's going on in the home is playing a part too
Signs of stress	
Physical	Client 3: Like if I feel like I become too stressed out, there will be times like I don't go to sleep or anything. I don't. I cannot sleep
	Case Manager 3: If I'm there in an appointment for example and one of the physicians says something that the client wasn't too happy with and so she got tense and I could see it
Cognitive	Client 12: I beat myself up. Like I will beat myself up before I let someone else do it, and I really told it like 'okay, I don't need a bash party, okay?' Like I do it all by myself
	Case Manager 4: I see denial. They'll go into denial and won't take the medication at all. [Deny] their diagnosis

(Continues)

TABLE 2 (Continued)

Identified theme	Representative quotes
Emotional	Client 4: Sometimes it just, I just break down out of nowhere because it's like, it just builds up and builds up and then you just snap
	Case Manager 5: I have a client whose like depression presents as anger and I have another client whose depression presents as 'I'm crying all the time.'
Behavioural	Client 14: They're like, ""you're doing good." I'm like I sure don't feel like it, but they say she's [the baby] doing great but I'm neglecting myself … So when they ask me, I say, "Well, she's fine." I'm neglecting myself. Like, as in my meds, and so I know I wanna do this for her, but I don't have the umph to do it for me
	Case Manager 4: Their house might not be clean or they're not really managing with the other children well. Lack of motivation to take their medication or even to come to all of their appointments, as important as they know the appointments are
Coping	
Mindfulness	Client 11: Just isolate myself in the bathroom and just listen to the water. Not thinking I'm crazy but I actually just lay in the tub and turn on the sink water and just listen to it
	Client 5: [I] do the yoga for the baby, and it was relaxing because I know the instructor was like you know you gotta have your mind focused and stuff like that
	Case Manager 6: And I say [to my client], "When you get those feelings, take those deep breaths because deep breaths normally relieve you from the anxiety of what you're feeling."
Substance use	Client 1: My brother and father had passed, and I drank so heavily for a year before I got pregnant … I literally had like three, four, five fifths a day. Like I was drinking a lot, and I don't like make margaritas or nothing like that. I'm drinking shots, nice and cold
Traditional mental health care	Client 7: When I was pregnant with my son, I went to the psych ward. It just got me mellow like thinking like that was time for me to think and just you know what I'm saying get my mind straight. I was talking to people. The depression medication it helped
	Case Manager 3: We do- I guess you want to say- talk therapy. We talk it out. I started actually playing softer music in the car while the clients are in the car, so we can kinda talk
Relationships	Client 4: When I'm about to go off, I'll call [my case manager] … If I could call [my case manager, he] would be like Breathe…Where are you? Here I come
	Case Manager 4: I have clients who say to me, I'm depressed I want to talk and so we get to the home visit and from the moment I get there, they're like unleashing and discussing very personal stuff from like … relationship stuff, disclosure issues, finances, kids, being pregnant again, so repeat pregnancies
Self-care	Client 13: Just put my headphones in my ear and I would walk around, whether it be downtown, whether it be shopping.
	Case Manager 2: The way you feel after you have actually taken a minute to 5 min for yourself makes a world of difference. And I don't think a lot of our moms are there or have ever been told that before in their lives or even been given permission per se because some people feel like, 'I need permission to take care of myself or take a moment for myself.'
Lack of access and acceptability of care	
Childcare	Client 10: He's [the baby] been coming down with fevers. He has appointments so he can be tested also, and it's like nothing but barriers, and it's like hard. I can't be like can someone take him to this appointment for me because my situation, our situation, and then his father can't do it because his father has to work twice as hard as I do.
	Case Manager 6: [The clients] may not always have a babysitter
HIV specific barrier	Client 7: They was like, so is it AIDS? I'm like no, it's HIV. So it's not AIDS? No, it's HIV. I'm telling you what it is. Do you know the difference? People like automatically just think like oh so you got that. It's hard. Like for me it's hard for me to tell anybody
	Case Manager 3: Because they have their own set of secrets when they're walking into a group anyway. 'I'm the only one going through this. No one understands. I haven't even told the father of my baby, and he may be the one that gave me the virus.'
Mental health stigma	Case Manager 1: Because immediately for the [clients] that I have, they're like, "Therapy? I'm not crazy."
Provider characteristics	Case Manager 1: Certain agencies or just agencies in general have like turnover rates and so like I had a couple clients who connected very well with a counselor who ended up leaving within a couple of months and so then that's also kind of difficult because then you spew your life out to someone and then they're gone.
	Case Manager 5: I know that the clients that I've had have been very explicit like, "I'm not gonna talk to a white person." Like very up front, but I've also had encounters where like I've told them that, "You know you have every right that if you're not feeling this counselor, you can switch out," and a lot of them didn't know that or didn't think that that was a possibility

TABLE 2 (Continued)

Identified theme	Representative quotes
Motivation and trust in care engagement	
Relationships/Social support	Client 9: Me and my sister used to be rocky, but when she found out, she didn't tell nobody and it was just like our relationship became stronger, you know what I mean? Because she wanted to make sure I'm taking my medicine. Like now she just texted me, like you good?
	Case Manager 2: They're willing to come in, engage and participate as long as they feel like it's a safe space. You have to have the environment so that they know … that there's a nonjudgmental tone to the space that they're in
Traditional mental health care	Client 14: Groups, for me to sit and listen to everybody's stories, it helped me open up a lot more. I know I'm not by myself anymore
	Case Manager 1: With your patient/client, there are situations where environment is key, and you try to do brief intervention but you also in cases that I've had in the past, we try to reach out for resources of who is available, you can you talk to properly that we can set up either short term or long term, depending on your needs, and kind of out branching to groups and/or you know one-on-one therapy
Logistics	Client 16: You know if you give people transportation, they'll get there. It's not always about stipends. Because they want to be around people
	Case Manager 2: [In reference to support groups] You need to have a timeframe. You can't have like this continuous thing like we're gonna meet every week for a whole year, and then you're wondering why your numbers fall off because just like when you need to take a little break from something, so do the clients who you're working with
Disclosure	Client 5: You know we have HIV and it's really nice to be around people that you don't have to pretend or have to worry about if it slips out
Provider characteristics	Case Manager 5: I think for the facilitators it really, really has to be someone … Relatable … I think that it's more about relatability than anything with our clients, being able to talk to them

3.2 | Signs of stress

Another theme that emerged in the focus groups was clients' physical, cognitive, emotional and behavioural signs of stress. In terms of *physical* signs of stress, some clients noted that they felt sluggish or weak. Others reported increases in blood pressure, veins protruding from their foreheads, tunnel vision, panic attacks and sleep disturbance. Case managers reported seeing their clients appear physically tensed when stressed. Clients discussed noticing *cognitive* signs of stress, including negative self-talk such as self-directed criticism and thoughts of giving up, feeling like they are "going crazy," racing thoughts, and concentration difficulties. Case managers noted they see a denial of HIV status and current difficulties in clients when under stress. Clients noted that *emotionally*, they experience sadness, depression, irritability, frustration, fear and anxiety while stressed. Several clients stated that they feel the effects of stress build up until they shut down emotionally or release their anger. Case managers also noticed sadness, anxiety and anger and added that they see an emotional withdrawal in their clients while stressed. Both case managers and clients noted ***behavioural*** signs of stress, especially the neglect of day-to-day responsibilities and personal needs, including antiretroviral medication adherence and following regular eating patterns. Clients also discussed changes in how they interact with others, such as reducing how much they communicate or increases in yelling at and fighting with others.

3.3 | Coping

Coping, or ways that the clients managed the effects of psychosocial stress, came up frequently in the three focus groups. Clients described how they employed different *self-care* or soothing techniques. These included listening to music, taking a hot shower or bath, reading inspirational quotes and physical activities like walking and dancing. Prominent among this discussion was clients describing techniques for sorting through their thoughts and feelings with techniques like journaling and self-talk (e.g., "I just talk to myself, and like if I'm, especially when I'm stressed and I gotta stop and think and talk to myself.").

In response to participants being asked their knowledge of and thoughts on mind–body practices such as breathing, meditation and yoga, both case managers and clients discussed how they used some *mindfulness* techniques to cope with stress, although it was not often labelled directly as such. Most case managers stated that they practiced brief informal mindfulness practices with clients when they observed that clients appeared stressed or reported being stressed. Specifically, they would pause to notice thoughts, emotions, breathing or other sensory experiences. Several clients described focusing on their breathing and slowing down to notice thoughts and feelings. Some clients mentioned pausing to listen to the sound of rain or running water. While many clients stated that they were naive to formal mind–body practices, a few said that they had tried yoga and many clients expressed openness to learning and practicing mind–body practices like meditation and yoga as a way to cope with stress. Case managers shared that they believed learning and practicing mind–body skills, such as was described in the potential intervention, would be beneficial for their clients.

Case managers and clients discussed the importance of positive *relationships* in coping with stress. They noted that opening up to and spending time with trusted friends and case managers seemed to reduce stress and improve emotional well-being. Clients also described

support from partners, children and maternal figures as instrumental in reducing stress. A few case managers and clients mentioned utilising traditional mental health care to manage stress and mental illness symptoms like individual and group talk therapy, psychiatric medication and inpatient psychiatric hospitalisation. Clients also described *using substances* to cope with stress like cannabis and alcohol and using nighttime cold medicine to induce sleep in themselves.

3.4 | Lack of access and acceptability of care

Clients and case managers discussed the barriers they face in accessing mental health care and HIV-specific support. Many clients described not being able to access care for themselves outside the home due to the difficulty of obtaining *childcare* and finding a childcare provider they could trust. There were some cognitive and emotional issues with accessing care for the clients too. Both clients and case managers reported *HIV-specific barriers* to care, specifically the fear of disclosure. Respondents reported that many clients did not want to disclose their status in group settings or worried that others would deduce their HIV-positive status in the process of the clients' seeking care. Case managers also stated that they believed some clients did not pursue care due to denial or avoidance of thinking about their status. Case managers discussed *mental health stigma* as a barrier to care. They noted that their clients were less likely to engage in psychosocial interventions if they seemed like traditional psychotherapy (e.g. a "behavioural health" session might be acceptable, but "group therapy" was not). Case managers felt that clients might not engage in treatment due to the concern of being perceived as "crazy." Case managers also listed *provider characteristics* as a barrier to care, including difficulty trusting certain providers, particularly when there was discordance between the client's and provider's race or ethnicity. Case managers also mentioned that provider characteristics could be a barrier to maintaining or re-engaging in care when clients were uncomfortable with certain providers but did not feel they had the power or ability to request a new provider.

3.5 | Motivation and trust in care engagement

While clients and case managers discussed concerns and difficulties they had with mental health and HIV-supportive care, they also shared what motivates them to engage in care despite these barriers, and how trust in the service providers and settings enables them to initiate and remain in care. *Social support or relationships* was a dominant motivation for care engagement. Some clients shared how close family members or friends who were aware of their status helped them with their care, including making sure they were attending appointments. Other clients noted how their children were their motivation to seek care and promote their own health and well-being. Both case managers and clients emphasised the importance of the case manager-client relationship in promoting care. This included case managers encouraging clients to engage in care, vouching for other providers to promote trust, and navigating the different medical and behavioural healthcare systems. Several clients noted that their case managers' encouragement was the primary reason they engaged in psychosocial services.

When asked their preferences for a modality for a potential mindfulness intervention, both case managers and clients noted perceived benefits of groups. Clients noted that connecting with women with similar backgrounds, particularly with respect to HIV status, was a strong motivation for engagement. They stated that having these groups feel like a "safe space" or a nonjudgmental environment where clients could trust each other and their providers was crucial for their sustained engagement. Clients also discussed their desire for psychosocial groups specifically for WLWH so that they could *disclose* their status and speak openly in a trusting environment. While most clients preferred discreet groups with other WLWH, a couple of clients noted that opening up to large groups, even among those with HIV-concordant status could be emotionally difficult. Within the case manager focus group, participants emphasised how *provider characteristics* were crucial in promoting trust and, subsequently, engagement in care. These included the providers' ability to foster a nonjudgmental care environment and relate to and connect with clients, particularly through shared lived experience.

Both groups of participants discussed the *logistics* of psychosocial support and other HIV-specific services that facilitate their ability to seek out and attend care. When asked what would enable clients to attend a potential mindfulness intervention, clients and case managers mentioned that assistance with transportation and childcare would be necessary. They also discussed incentives that increased the likelihood of attending psychosocial groups and services for WLWH groups, such as refreshments and other monetary or material incentives. Concerning the location for a potential mindfulness intervention for mothers and WLWH, clients and case managers reported that clients would be more likely to go to a discreet location where it was not obvious that services for HIV were being provided. Clients and case managers also discussed ways that a psychosocial support group could be scheduled to facilitate clients' engagement. Some participants stated that weekly sessions would be best to foster a sense of cohesion, while others endorsed twice monthly since attending more frequently might feel burdensome. Clients mentioned that offering groups at various times of day could accommodate different work and childcare schedules. Case managers stressed the importance of making a mindfulness group time-limited so that interest and attendance do not diminish as they might with an ongoing group.

4 | DISCUSSION

Pregnant and parenting WLWH face multiple psychosocial stressors. They cope with role overload and the biological changes of pregnancy while simultaneously managing their own chronic health conditions and preventing perinatal transmission of HIV. This study

builds upon research on the psychological strain of experiencing these stressors with limited economic and social resources, showing the cumulative effect of this burden in the women's own words. This study also sets the stage for the adaptation of a mindfulness intervention to ameliorate the psychological effects of that burden.

Prevalent in the focus groups was the contributing role of isolation in clients' distress and as a barrier to care. It is common for pregnant women and new mothers to report feeling alone as they struggle to find the time and interpersonal support crucial to care for their children and themselves (O'Mahen et al., 2012; Paris & Dubus, 2005). This sense of isolation is often coupled with shame as they experience mood and anxiety symptoms amid pressure to match societal expectations of happy, nurturing mothers (Beck & Indman, 2005; Dunford & Granger, 2017). The participants in our focus groups echoed these observations. They added how fear of discrimination following disclosure of their HIV status and HIV-related stigma kept them from sharing their difficulties with loved ones or attending services where friends, family and acquaintances might see them and deduce their HIV status. As a case manager recounted her client telling her, "I'm gonna die with this lie," many of the clients in these focus groups hid their HIV status, even if it prevented them from getting the support they needed.

The toll of this isolation and intersectional hardships led to sleep difficulties, emotional lability and relationship discord among the clients. Perhaps most significantly, stress affected how the clients cared for themselves, with several women stating that after meeting their families' needs, their time, energy and motivation were depleted. For women managing a chronic medical condition that requires a daily medication regimen and additional medication regimens to manage for those mothers with newborns, this struggle with self-care can have negative consequences for their mental and physical health (Mellins et al., 2003; Tyer-Viola et al., 2014).

These focus groups' content points to the promise of a mindfulness group intervention specifically adapted for pregnant and parenting WLWH to decrease isolation and manage psychosocial stress. When the key components of M-Body, the mindfulness intervention on which this intervention would be based, were described to participants, they endorsed that a group that would help women learn and practice mindfulness skills seemed helpful and appealing. For example, one client stated, "Sometimes we get so busy with the day-to-day activities, whatever responsibilities we need to do, we never sit down or we feel we don't have time to just think about the simple things that can help us." Further, focus group participants expressed openness to mindfulness skills through the coping skills they employed. Some clients reported trying and liking formal mindfulness skills like yoga. Many participants discussed utilising informal mindfulness practices that fostered awareness of the present moment and their thoughts and feelings.

Considering adaptations to M-Body for pregnant and parenting WLWH, these focus groups revealed that trust was a requirement for engagement in any sort of intervention. Participants needed interventions in settings where they felt safe, without the stigma of mental health treatment or the risk of unintentional disclosure of their HIV status. In line with focus groups' content involving fear of disclosure and HIV-related stigma, it was crucial to participants that any mindfulness group intervention occur in a discreet setting where non-participants could not infer group members' HIV status. Focus group participants felt it was important that the mindfulness intervention be led or co-led by someone trustworthy and relatable who could understand the stress that participants face, ideally a person with shared lived experience such as another mother living with HIV. This preference maps onto the focus group themes of coping and motivation and trust in care engagement: the ability to form a relationship and trust with a provider was considered crucial for engagement in care. Clients' stressors, including caretaking and financial responsibilities, isolation, fear of involuntary disclosure of their HIV status, and HIV-related stigma, will be important topics to target in an adapted mindfulness intervention's didactic components. Highlighting sources and responses of stress specific to pregnant and parenting WLWH should increase the intervention's relevance.

This study had some limitations that should be discussed. It was of the utmost importance to the research team that the participants felt comfortable sharing their experiences living with HIV and stress. We chose not to collect any identifying demographic data to protect the anonymity of participants. For this reason, we could not compare codes or themes by sociodemographic characteristics, including parity and number and age of children. While individual interviews may have afforded greater privacy for the participants, we opted to conduct focus groups for the collaborative generation of ideas and potential interpersonal support among these new mothers. We countered issues of privacy and confidentiality through several measures: (a) keeping the size of the focus groups small, (b) establishing confidentiality as a guideline at the start of the focus groups and in the informed consent forms, (c) using self-chosen colours instead of names (e.g. Jane Doe wore a nametag that read "green" and was referred to as such during the focus group) and (d) requesting that participants did not state their names during the focus groups. Finally, three research team members who were present at the focus groups identify as white women. The code of provider characteristics, including race, emerged as a barrier to care in the case manager focus group but not in the client focus groups. Although all focus groups were led by the senior author who identifies as an African American woman, it is possible that the presence of the white researchers may have affected clients' openness to discussing provider characteristics as a barrier to care.

While this study added valuable information on pregnant and parenting WLWH's stress and coping, future studies could advance the understanding and treatment of their mental health. Firstly, individual interviews with pregnant and parenting WLWH may reveal themes that our study's participants were hesitant to discuss in a group setting. Although all participants in our study were either pregnant or raising a child under the age of 2 years, immediate stressors and coping may be different for pregnant and non-pregnant women. As such, future research could examine nulliparous and pregnant WLWH separately from parenting WLWH. Next, feasibility studies of mindfulness interventions for women of

this population will confirm the acceptability of mindfulness skills as discussed in this study. Finally, mindfulness intervention trials for pregnant and parenting WLWH would determine if an intervention of this kind effectively reduces the mental health concerns prevalent in this population, such as stress, depressive and trauma-related symptoms (Do et al., 2014; Machtinger et al., 2012).

With myriad sources of stress and its detrimental effects on the health and well-being of pregnant and parenting WLWH, acceptable psychosocial interventions to alleviate stress and mental health concerns are crucial. This study is the first step in developing a mindfulness intervention that could be an effective and non-stigmatising treatment to manage this stress and improve their mental health. We believe that a mindfulness intervention could tap into the present-focused awareness that the pregnant and parenting WLWH in our focus group already turn to during times of high psychosocial stress while cultivating formal mindfulness techniques to improve coping. Moreover, a group-based intervention implemented with respect for participants' desire for privacy surrounding their HIV status may create a community of mindfulness practitioners with shared lived experiences. Therefore, a group-based mindfulness intervention could lead to decreased isolation, validation of psychological and emotional experiences, and improved well-being of pregnant and parenting WLWH in the United States.

AUTHOR CONTRIBUTIONS

EM and IB devised the project. EW, EM, AS and IB contributed to study design and data collection. All authors contributed to data analysis. EW wrote the paper with support from all co-authors.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare that are relevant to the content of this article.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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