

Original Research Article

Using Patient Perspectives to Inform the Development of a Behavioral Intervention for Chronic Pain in Patients with HIV: A Qualitative Study

Jessica S. Merlin, MD, MBA,^{*†} Sarah R. Young, MSW,^{*} Mallory O. Johnson, PhD,[‡] Michael Saag, MD,^{*} William Demonte, PsyD,^{*} Riddhi Modi, MBBS, MPH,^{*} Sally Shurbaji, MSW, MPH,^{*} William A. Anderson, PhD, MPH, MPA,^{*} Robert Kerns, PhD,^{§,¶} Matthew J. Bair, MD, MS,^{||,|||,**} Stefan Kertesz, MD, MsC,^{††,‡‡} Susan Davies, PhD,^{§§} and Janet M. Turan, PhD, MPH^{¶¶}

^{*}Division of Infectious Diseases, Department of Medicine, University of Alabama at Birmingham, Birmingham, Alabama; [†]Division of Gerontology, Geriatrics, and Palliative Care, Department of Medicine, University of Alabama at Birmingham, Birmingham, Alabama; [‡]Department of Medicine, University of California San Francisco, San Francisco, California; [§]Pain Research, Informatics, Multimorbidities and Education (PRIME) Center, VA Connecticut Healthcare System, New Haven, Connecticut; [¶]Departments of Psychiatry, Neurology, and Psychology, Yale University, New Haven, Connecticut; ^{||}VA HSR&D Center for Health Information and Communication; ^{|||}Department of Medicine, Division of General Internal Medicine, Indiana University School of Medicine, Indianapolis, Indiana; ^{**}Regenstrief Institute, Indianapolis, Indiana; ^{††}Birmingham VA Medical Center, Birmingham, Alabama; ^{‡‡}Division of Preventive Medicine, Department of Medicine, University of Alabama at Birmingham, Birmingham, Alabama; ^{§§}Department of Health Behavior, School of Public Health, University of Alabama, Birmingham, Alabama; ^{¶¶}Department of Health Care Organization and Policy, School of Public Health, University of Alabama at Birmingham, Birmingham, Alabama, USA

Correspondence to: Jessica S. Merlin, MD, MBA, BBRB 222, 1530 3rd Ave. S, Birmingham, AL 35294-

2170. Tel: 215-806-1888; Fax: 205-934-5600; E-mail: jmerlin@uab.edu.

Funding sources: This work was supported by the National Institutes of Health (K23MH104073 [JSM], K24DA037034 [MOJ]); the University of Alabama at Birmingham (UAB) Center for AIDS Research, an NIH-funded program (P30 A1027767) that was made possible by the following institutes: NIAID, NCI, NICHD, NHLBI, NIDA, NIMH, NIA, FIC, and OAR; and the PRIME VA Health Services Research Center (CIN 13-047).

Conflicts of interest: None declared.

Abstract

Background. Chronic pain is a common and disabling comorbidity in individuals living with HIV. Behavioral interventions are among the most effective and safe nonpharmacologic treatments for chronic pain. However, the success of a behavioral intervention is influenced by how well it is tailored to the target population's biological, psychological, and social context. Given well-documented psychosocial vulnerabilities among persons with HIV, it is critical to develop a behavioral intervention for chronic pain tailored to this population.

Objective. To use qualitative methods to investigate patient preferences for the structure and delivery of a behavioral intervention for chronic pain in individuals with HIV.

Methods. Interviews and focus groups were used to elicit participant preferences. A thematic analysis approach, with an initial round of open coding, was used to develop the codebook and analyze the data.

Results. Qualitative data from 12 interviews and 3 focus groups with patients living with HIV and

chronic pain (total N = 24) were analyzed. Emergent themes fell into four major categories: perceived value of group sessions, incorporating peer leadership, and two key elements of how the intervention should be delivered: the HIV status of group participants and views on phone-delivered intervention content.

Discussion. This study provides a framework for the structure and delivery of a behavioral intervention for chronic pain in individuals with HIV based on patient preferences. We will use these results to design our intervention, and hope that our approach informs the work of investigators in other disciplines who seek to incorporate patient preferences during intervention development.

Key Words. HIV; Chronic Pain; Patient Preferences; Peer Interventions; Group Interventions

Introduction

Chronic pain—pain lasting longer than 3 months, beyond the period of normal tissue injury [1]—is a common comorbid condition in individuals living with HIV. Prevalence estimates vary widely, but range from 39% to 85% [2–10], higher than estimated in the general population [11]. In individuals living with HIV, chronic pain causes substantial disability; it is associated with mood and substance use disorders [9], and up to 10 times greater odds of functional impairment [12].

Nonpharmacologic, behavioral interventions to decrease pain and improve physical and emotional function in HIV-infected patients with chronic pain are needed. Commonly used pharmacologic therapies, including opioids, often do not result in substantial improvement in pain or physical and emotional function [13,14], and carry risks including misuse, addiction, and overdose [14]. For people living with HIV, opioids may actually be associated with worse pain [15], and may adversely interact with antiretroviral medications [16]. Behavioral interventions are among the most effective and safe nonpharmacologic treatments for chronic pain in the general population. These include Social Cognitive Theory (SCT)-based cognitive behavioral interventions that focus on self-management strategies to relieve pain and achieve functional goals [17–19].

The success of a behavioral intervention is heavily influenced by how well it is tailored to the target population's biological, psychological, and social context [20]. Given well-documented psychosocial vulnerabilities among persons with HIV [21], it is critical to develop a behavioral intervention specifically tailored to HIV-infected patients with chronic pain. We are aware of only two randomized controlled trials of SCT-based behavioral interventions (manualized cognitive behavioral therapy delivered by a psychologist) in HIV-infected individuals with chronic pain [22,23]. However, neither

intervention was systematically tailored to individuals with HIV; both suffered from poor attendance at intervention sessions and had only a small effect on patients' pain and function.

The current study proceeded from the view that a population's unique biopsychosocial context is likely to influence its preferences for intervention structure and delivery, which ultimately informs the best way to deliver the intervention and determines the intervention's success. Previously, we have described an adapted biopsychosocial framework for chronic pain in HIV [24], which can serve as a useful starting point for intervention development. To develop this framework, we identified biological, psychological, and social factors common to both HIV and chronic pain that are likely to contribute to pain and therefore important to consider in intervention development. For example, depression, stigma, and social isolation are associated with both HIV [21] and chronic pain [25], and these factors may be compounded in individuals who experience both conditions. Therefore, these factors may influence preferences for intervention structure and delivery in ways that cannot be assumed in advance; individuals may be socially isolated and therefore prefer group sessions to achieve social support; or they may be so depressed and stigmatized that they prefer individual sessions.

A critical first step in intervention tailoring is to broadly investigate participant preferences for the general structure and delivery of the intervention. Little has been written to guide investigators developing behavioral interventions on how such formative work might inform intervention design. We hope that this report will not only guide the design of our intervention, but will also inform other efforts to tailor interventions by incorporating patient preferences.

Methods

Individuals with HIV and chronic pain were recruited from an outpatient HIV clinic in the southeastern United States. This clinic serves a population that is made up of predominantly Black and White patients (59% and 36%, respectively). Twenty-five percent are female. Patients' primary insurers include private insurance (26%), Medicare (27%), and Medicaid (13%) [26]. Pre-Affordable Care Act, 34% were "uninsured" [26]; such patients are often covered under either the Federal Ryan White HIV/AIDS Program or by an Affordable Care Act-based insurance plan [26–28]. Most clinic patients are enrolled in the Center for AIDS Research Network of Integrated Clinical Systems (CNICS) cohort, which routinely collects electronic data on a variety of patient-reported outcome (PRO) measures at the point of care [29]. Study recruitment was based on identifying individuals who reported either moderate or severe pain on the EuroQOL quality of life measure [30] in the past 6 months. Additionally, participants were purposively sampled to include those who self-reported depression or anxiety symptoms (PHQ-9 \geq 10 [31], PHQ-Anxiety

module-anxiety symptoms, panic [31]) and/or current substance use (the Alcohol, Smoking, and Substance Involvement Screening Test [ASSIST] items pertaining to cocaine; amphetamines; hallucinogens; inhalants; opioids, stimulants, or sedatives purchased illicitly or taken for nonmedical purposes; does not include marijuana [32]). We used this recruitment strategy to represent individuals who may have had chronic pain that was more challenging to address due to these comorbid symptoms and behaviors. Potentially eligible participants were recruited by phone; further screening was conducted using the Brief Chronic Pain Questionnaire (BCPQ) [33,34]. Individuals who reported at least moderate pain for at least 3 months were invited to participate. When participants arrived for their study visit, the BCPQ was repeated to confirm at least moderate pain severity.

We also administered the Brief Pain Inventory (BPI) [35], which asks about pain severity at its worst, least, “on average,” and right now, and how that pain interferes with a variety of functional domains (general activity, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life). Both pain severity and interference are measured on a scale ranging from 0–10, with a score of 4–6 considered moderate pain or interference and 7–10 severe pain or interference [35].

Qualitative Data Collection

Qualitative data from these participants were collected in two stages. First, we conducted one-on-one in-depth interviews with 12 participants using a semistructured interview guide. In order to build rapport, participants were initially asked to give a general overview of their experiences with chronic pain. Then, they were broadly asked to describe their vision for a chronic pain program for patients with HIV. Participants were subsequently probed as to the format of the sessions (e.g., individual, group), who should deliver the sessions (e.g., doctor, nurse, social worker, peer), and the HIV status of group participants; open-ended questioning was used to allow participants to expand on their thoughts. After providing their overview, participants were also shown sample sections from a previously published chronic pain intervention manual for their impressions [36]. After initial qualitative data analysis of the individual interview data, we conducted three focus groups ($n = 20$ participants; six to eight participants per group). One focus group included eight participants drawn from those who had already participated in interviews; the remaining focus group participants were recruited in the same fashion described above.

The interview and focus group guides were piloted with patient volunteers in the clinic by a trained interviewer and refined prior to use with participants. Interviews and focus groups were conducted by a member of the study team experienced in qualitative data collection (WA). All interviews and focus groups were audio recorded and transcribed by a professional transcription

service. Transcriptions were uploaded into NVivo software for analysis. For each of the interview rounds, a similar analysis processes was used, which is described in detail here.

Analysis

Three study investigators (SRY, JSM, WA) coded the data independently using open coding and thematic analysis [37]. The first cycle of coding was deemed “open” because the researchers assigned first-impression meanings and codes to the data, but were open to the meanings changing as analysis became richer and deeper over time. Thematic analysis, or assigning meaning and/or themes and patterns to the data, was used because of its flexibility in helping to narrow down the data into meaningful key ideas [38,39]. All three independently coded data sets were examined together by one study investigator (SRY) who made comparisons between the three coders and highlighted areas of overlap and disagreement. The three investigators then met to discuss the comparisons and reach consensus on a reconciled code book. One investigator (SRY) then recoded data from this round using the reconciled code book, and the two others offered feedback, which was discussed by the team and reconciled to produce a final coded set of data.

Interim results were presented to the larger study team after four interviews to confirm that the data being collected would be helpful in informing intervention development. After 12 interviews were completed, the entire study team again reviewed interim results, this time to determine the appropriate next step. At that point, the team agreed that patient focus groups would potentially provide more varied perspectives and further clarification of major themes. Focus groups were presented with an outline of the intervention as developed by the study team based on input received during interviews. Participants were invited to provide feedback on this outline, as well as on other areas requiring clarification. Three focus groups were conducted and analyzed using the same approach described above. The study team reviewed focus group results and determined that theme saturation had been reached. The results presented here are combined from interviews and focus groups.

This study was approved by the Institutional Review Board of the University of Alabama at Birmingham.

Results

Of the 24 interview and focus group participants, 17 were male, 19 were African-American, 5 were white, and the mean age was 48 years (range 33–68). Median CD4+ T-cell count was 569 cells/mm³ (IQR 430–901), and 23 of 24 participants had an undetectable viral load. Mean pain severity “on average” on the BPI was 6.6 (SD 3, scale 0–10). Mean pain interference ranged from 6.1 (SD 2.8) for interference with relations with

other people to 7.8 (SD 2.0) for interference with sleep. Twelve participants reported symptoms of depression (PHQ-9 ≥ 10) or anxiety (PHQ-Anxiety module, anxiety symptoms or panic), and eight reported current substance use within the past 6 months on the ASSIST; of those, four reported both depression/anxiety and substance use. Pain was reported in a variety of locations, including numbness and tingling in hands and feet [11]; headache [10]; and pain in the knee [16], shoulder [13], lower back [12], and hip [10]. The median number of locations of pain reported was 3 (IQR 2–5).

Emergent themes fell into four major categories: perceived value of group sessions, incorporating peer leadership, and two key elements of how the intervention should be delivered: the HIV status of group participants and views on phone-delivered intervention content.

Quotes presented below are accompanied by age, race, and sex for interview participants; individual-level demographics are not available for focus group participants, who are identified via transcription only by their gender.

Perceived Value of Group Sessions

While participants embraced one-on-one sessions to individualize content, many participants viewed group sessions as an additional critical component of the intervention. Various reasons were discussed.

Learning from each other: Some participants said that groups would offer a setting where one could learn strategies for managing chronic pain not only from group leaders, but also from other participants:

You get to the point where you start to care about people in your group. And so you go home yourself and you put up some stuff and I mean you talked to this person when you all come back to the group and say, "Hey I read this, that and the other," and I tried it and it worked. And it might be something that the peer counselor or the care manager didn't see. So everybody has a part. (Female focus group participant)

Having other people that have, that started with chronic pain and people that have already had it and have dealt with it and have found things that have made it easier or made it a little lighter on them can then suggest to us things that will help make our load a little bit lighter. (53-year-old African-American female)

Social/emotional support: Participants also described the groups as places where people could draw support from a community of people who have similar struggles. One participant talked about how just attending the group could provide a participant with support:

A lot of times when I've noticed that we, say if I'm, when I'm hurting. If I'm feeling alone or lonesome,

it makes me hurt worse. It makes me feel even worse, bad. So if a person is going through pain, especially if a person is going through pain and they live by themselves, I mean that's a lot to deal with. Then you have nobody there to comfort you. You have nobody there to tell you it's going to get better, whether it's really going to get better or not. Just them telling you that simply could give relief to your mind I mean. (53-year-old African-American female)

Another participant elaborated on how group members might influence each other to improve their level of physical and social activity:

I think it will alleviate some depression, you know people feel connected to other groups or other people that are like them ... You know a lot of people in chronic pain tend to feel very isolated, very lonely ... sometimes they don't know how to reach out for help or what help to reach out for. Or they get so used to being in the house, all the activity stops, stop going places, you know. They have to get back to living. I think that's a part of it. Start introducing little things, take a chance, go to a concert. Go hear some live music you know, hey invite some friends over for a movie night. I mean just you know, something—there's so many different things. And when you find that you actually living and you're accomplishing things it makes you get out of yourself and you know the depression isn't as bad and you feel connected to people. And of course I feel like it's going to help you deal with your pain. (45-year-old African-American female)

Groups could also be a place where participants encourage each other to push forward and meet their goals:

I'm going to help you when you fall. I'm going to pick you up when you fall. But we're going to do it again. And we're going to do it again. And we're going to keep on doing it until you know. I got this. Let's go to the next step. (65-year-old White male)

Accountability: Another participant raised the role of accountability to others in the group, and that this might be especially important for those with poor social support:

When you don't have family or a group like this would become your family a lot of times you—and you're accountable to somebody and it feels like somebody cares like you're doing something good for the benefit of the people whereas if you don't have a family and then you're going through what you're going through ... So to have somebody that you always committed to, for different people some people it may not mean that much but to others it may mean more. You don't know what people's

family or personal life is like, you know they may not have that particular thing and they may need much more than somebody that does have that support. (Male focus group participant)

Confidentiality concerns: However, some participants did express concerns about group sessions. A few participants noted that not everyone may like participating in group sessions. For example, one participant reflected:

A group session might not be for everybody, you might have some people that need that one on one. But nobody is going to be 100% satisfied. (Female focus group participant)

Concerns about confidentiality were also identified; this is discussed further in our later discussion of HIV status. For example, one participant commented:

I'm a people person but ... even though everybody is probably there for the same thing but I still ain't comfortable because you know I just keep that part [HIV status] a secret in my life. (43-year-old African-American female)

Incorporating Peer Leadership

Participants voiced the importance of involving a trained staff interventionist in both individual and group sessions. However, there was also a strong desire to involve peer leaders, specifically a person living with HIV and chronic pain who is trained to colead the intervention sessions. Emergent subthemes were coleadership of the intervention by a peer and having sponsors or mentors.

Coleadership by a Peer

Peer involvement was seen as essential to success, with well-trained peers providing a dual perspective. As one participant explained when asked who would lead the intervention sessions:

It would be two different types of individuals. It would have to be a person that has an educational background, [and] a person that has "experience of it" background. You have to have two perspectives. (48-year-old African-American male)

While knowledge of the intervention content was essential (educational background), being a peer (experience of it) loaned both legitimacy and authenticity to the intervention. Rather than providing a dry, academic presentation, peers were viewed as being in a better position to speak the participants' "language." One participant explained the role of the peer leader as bridging the knowledge or education gap between medical staff and the participant:

Then as far as getting the leader of the sessions, I think that you do need chronic pain care manager ... Whereas the doctor may come in on one level

and then your peer can come in and sort of put it into laymen's terms. (Male focus group participant)
The need for the peer component goes beyond simple translation, however. The "experience of it" gives the peer authority that comes from having lived it—an aspect that our participants thought would be essential to the success of any intervention.

I wouldn't want to hear how to bake a cake from you if you've never baked one ... I need somebody who has been dealing with it for a while and is still here. Sometimes my pain gets to the point where you just want to go lay down somewhere and not get up. I need to hear from somebody to tell you ... You can make it. (Male focus group participant)
Or, another participant succinctly put it:

Then it is not just somebody you are all paying to get a check to come in to speak about it. It would be somebody that really knows what they are talking about. (Female focus group participant)
Further, one participant described the special knowledge a peer would possess to play the role of interventionist:

If you bring somebody in that number one does not know anything about how pain is managed and how pain comes on people who have HIV, I'm not going to be interested because you can't tell me and you haven't gone through what I've gone through, or you were not educated enough to participate enough to be able to tell me anything; so that's what I see. And I'm quite sure any one of us would be able to do something like that because we've been there.

In addition to the legitimacy the intervention derives from peer involvement, participants felt that peers are better positioned to empathize with and understand participants.

Female focus group participant 1: It would be good because the peer person they probably have some of the same pain and something that you have. They can relate to what you are saying.
Female focus group participant 2: That would help because we know that he or she are on the same level.
As another focus group participant explained:

To lead the session it should be someone dealing with chronic pain themselves, who is sympathetic with what we're going through. I can never take the medication the way the doctors prescribe it. I have to take at least double the dose and then suffer the other half of the month in the darkness and under the covers. That's just the way it has to be until I get something else happening ... And now I'm just addicted to the pain medicine and everything else. But it would be best if they had someone who you know, is dealing with it themselves. (Male focus group participant)

Overall, study participants expressed a strong belief that the intervention should not involve just a group of experts who deliver lectures. While limited “expert” content delivery was acceptable, the clear preference was for a peer, someone who had lived or is living what they live in terms of chronic pain and HIV. They wanted someone who could listen and empathize, but who had been well-trained and educated to provide solutions—solutions that the peers had learned and applied themselves.

Sponsors or Mentors

The need for peer support was a strong theme throughout the interviews and focus groups. Four participants voiced the specific idea of one-on-one peer support; two independently used the word “sponsor” and invoked the analogy to 12-step meetings [40]. For example, one participant talked about the importance of a sponsor in helping them stay on track and for support generally:

Because you know in AA and NA, they give you sponsors that so they help you stay in the middle of the road, keep you from falling off the, off the wagon. So in the pain situation, I would try to do that same thing. Give it, create it wherein they would have a support system, not just the pain, I mean the medicine, but you also have someone you can talk to as well. (49-year-old African-American male)

The same participant explained in further detail how the sponsor role might work, and how they might help participants implement what is learned during the intervention:

Well, the sponsor works in that, would work in that situation, say if they were, they were at home. It's evening time and all of a sudden, I have a major migraine headache. I can't stand for the lights to be on. I've got to turn the, unplug the telephone. I can't. So, so therefore, that sponsor, he or she that was at that meeting and someone had talked about that situation at the meeting and talked about what they done to make that situation better, then perhaps that sponsor can say, “Hey, remember at the last meeting when John Doe said that he did such and such and such. Why don't you try doing such and such and such? If it worked for John Doe, it might work for you, too.” (49-year-old African-American male)

Another participant reinforced the importance of a sponsor in troubleshooting when difficult situations arise:

Same way like with NA, you have your buddy system set up and you know you collect your phone numbers—when you're in heat—in a hot spot you have somebody you can call, you know? Just to talk or just to get you out of that mental mood that you're in, you know where you can see a light at the end of the tunnel, maybe get something done.

(45-year-old African-American female)

Preferences for Intervention Delivery

Participants also provided substantial input on how the intervention should be delivered. Here, we present the two themes that participants expressed most clearly and that would have a significant impact on our intervention design: HIV status of group participants and phone-delivered intervention content.

HIV Status of Group Participants

Participants were asked whether the intervention program should be limited to those living with HIV or if it could be open to anyone living with chronic pain. While several participants voiced that they would feel comfortable participating in a chronic pain intervention with a mixed group of individuals, with and without HIV, others had important reservations about mixed groups.

Most participants were open to participation by anyone with chronic pain.

It can help anybody, the HIV victims and other patients as well, some of them with obesity probably need help with their chronic pain. So it's for everybody and not just [those living with HIV]. (43-year-old African-American female)

Still, some participants thought that although it might benefit anyone, if the group were mixed, HIV should not be a topic of discussion—the group is about pain only:

We're going to talk about pain. We're not talking about HIV. We're just talking about pain. So both with or without HIV can be there ... the group would decide on what they'll talk about. But if you have someone without HIV in it, we're only going to talk about the pains that you're having. (68-year-old African-American male)

However, other participants noted some reservations about having a group with mixed HIV status. Stigma was discussed as being a particular concern. For example, one participant noted that having an all-HIV+ group might minimize the need to worry about potential stigma from HIV- participants:

If you got a mixed group, like I said, you're going to always have a person that's negative, uneducated about HIV and just got this just ignorant stigma that if they come in contact with you they're going to catch it ... If you're in a group with just your kind [HIV positive] you don't have to worry about it. (54-year-old African-American female)

Another participant noted that HIV stigma might prevent individuals without HIV from learning from their HIV+ peers:

People with HIV, if it's going to be an all-HIV group then they're going to have a commonness. If it's going to be some people with HIV and some people with not, the people that are uncomfortable

with that are not going to be able to receive any good information from that HIV-infected person unless the normal person is not—doesn't have that stigma ... I would think it would be better in the beginning maybe to have all the same [status]. (65-year-old White male)

Beyond questions of comfort and commonality, however, there were also concerns about privacy and confidentiality. For example, one participant stated:

And you've got your confidentiality ... even me, myself, I've been diagnosed over 16 years. You still have uneducated people that do not understand that just by sitting by me you will not get HIV. So like I said, it could be okay to have just one or it could be okay to just have it separate because some people just have no other way to put it but are just ignorant. So me personally, I would rather be with my own kind and not have to answer any questions to anybody else ... I actually wish they just had a hospital just for people with HIV so every time you go in you ain't got to give your diagnosis every time you go in ... That's why I said if there was a program it would have to be strictly for just the HIV positive people because like I said a lot of people still are not educated and stigma is alive. It's bad. (54-year-old African-American female)

Phone-Delivered Intervention Content

In individual interviews, lack of transportation was viewed as a major barrier to participation in chronic pain intervention sessions. Therefore, we asked focus group participants the potential role of phone calls in the intervention. In one focus group, a participant echoed our interview findings about using the phone to circumvent common transportation challenges:

I think some people it would be easier over the phone if they can't get here. It would be—it would be more easier than you might have some that have a disability that makes it really can't come and be interested and it would be more easier on them. And even for those that might not get transportation you know what I'm saying? It would be neat to do it over the phone. (Female focus group participant)

In another focus group, participants spoke positively about participating in a home-based intervention, which might allow people to speak more freely:

Male focus group participant: I mean sometimes, I would like to sometimes talk to a person on the phone. I am in the comfort of my house. Then come over to their home. We are comfortable enough that we can communicate things.

Female focus group participant: We do not have to talk secretly.

Male focus group participant: Yeah in code.

However, later in the same focus group, participants agreed that phone sessions would be less valuable than

group sessions, and should not be used to deliver intervention content. However, phone sessions could be used to check in with participants:

Moderator: What would be covered over the phone?

Female focus group participant: Appointments.

Female focus group participant: Appointments, who would be able to come. That is it.

Male focus group participant: I mean I think the group is outstanding, but there should still be a liberty there if I want to call you.

Female focus group participant: A phone call every now and then just to check.

Male focus group participant: It should not be like mandatory to say listen, this here, if anybody wants to be on the list, you want to communicate with somebody on the phone, just put it on this list. If you do not, then do not.

Participants in this focus group also expressed concerns about phone confidentiality:

Male focus group participant: In a group session, you are open and you are discussing everything. On the phone, you do not know what is there.

Female focus group participant: Right.

Female focus group participant: Yeah, that is true.

Male focus group participant: Yeah, that is why it is important to know the person. I mean you do not want to call just anybody. I mean you have got to have that relationship. I am just not going to call just because you are in the group. We may not agree or have the same form of thinking.

Discussion

This study presents formative qualitative work that will guide development of a behavioral intervention for chronic pain tailored to individuals with HIV. While other behavioral interventions for chronic pain have been tested in individuals with HIV [22,41], they have not been developed or tailored specifically for this population, and perhaps as a result, have had limited efficacy and session attendance. To our knowledge, this will be the first chronic pain intervention for this population developed using formative qualitative investigation to assess patient preferences for intervention structure and delivery. We believe that such formative work will be critical to our intervention's efficacy and effectiveness.

Our results suggest that the intervention should include group sessions; have substantial involvement from peer leaders, potentially including a role for sponsors or mentors; include only individuals with HIV; and avoid delivering content via phone. We believe that these preferences are influenced by the unique psychosocial milieu experienced by HIV-infected individuals with chronic pain; this study provides evidence to support this belief. Our previously published biopsychosocial framework for chronic pain in individuals with HIV [24]

can guide our understanding of some of the most important psychological and social factors involved. Specifically, we assert that three psychosocial factors identified in the framework—psychological distress, challenges with close personal relationships, and stigma—are likely to have contributed to our key findings.

In addition to one-on-one sessions to deliver intervention content, participants strongly advocated for a group component. Our biopsychosocial framework highlights the psychological distress caused by stigma and higher rates of psychiatric illness such as depression and anxiety in individuals with both HIV and chronic pain. Additionally, we discuss the importance of close personal relationships in improving HIV outcomes such as antiretroviral adherence and virologic outcomes, and the challenges faced by individuals with chronic pain in having close personal relationships. In this study, participants specifically highlighted the importance of feeling connected to others, less lonely, and less depressed as a rationale for group sessions. Therefore, this psychological distress and challenges encountered with close personal relationships potentially explain why participants preferred group sessions. It is reassuring that a recent pilot study of a group-based mindfulness intervention for chronic pain in individuals with HIV was found to be feasible and acceptable [42]. Also, our findings underscore the importance of training interventionists to foster an environment of support and respect that would allow participants to realize these benefits.

Participants also expressed a reluctance to use phone sessions to deliver substantive intervention content, and a preference for having HIV-only groups. Stigma and confidentiality concerns were used to justify these preferences. While not universal, we assert that if even a substantial minority of participants expressed these viewpoints, others may be concerned about them, even if to a lesser degree. These issues might prevent the most vulnerable patients from participating in an intervention that involves mixed HIV status groups or attempts to deliver potentially sensitive intervention content over the phone. Therefore, delivering substantive content by phone and conducting mixed groups could represent important barriers to intervention uptake if not considered and incorporated into the intervention. These findings also suggest that content related to HIV stigma and chronic pain stigma should be considered and incorporated.

Additionally, participants' comments on the potential role of phone sessions paint a mixed picture. On the one hand, phone sessions could be a good way to overcome barriers such as transportation or privacy concerns. On the other hand, phone sessions would fail to provide the kind of face-to-face and group interaction that participants seemed to find valuable. Participants suggested that a middle ground would be phone calls used as check-ins or reminders, not necessarily to deliver content.

Peers were frequently mentioned as an important part of the intervention. Two forms of peer involvement were mentioned: 1) co-leadership of the intervention by a peer with a deep understanding of the participants' struggles, and 2) a sponsor or mentor, who could provide support and troubleshoot in times of crisis. There is a strong evidence base for peer interventions for individuals with HIV targeted at a variety of outcomes. In general, peer interventions have shown promise in terms of feasibility and efficacy [43]. Notably, the clinic in which this study was conducted has been the site for prior peer interventions, and participants may have been familiar with this approach. Participants may have stressed the role of a peer for similar reasons that they stressed the role of a group: building close personal relationships with other individuals with chronic pain for support. Peers were also seen as having a first-person viewpoint, meaning that they hold unique expertise and can empathize with participants effectively. Participants' viewpoints on why peer involvement is so important will guide us in selecting and training someone who can optimally meet these needs.

This study has certain limitations. We purposively selected individuals with depression/anxiety and recent substance use, as this represents a population of individuals with HIV and chronic pain; thus we may have under-represented the views of those who do not have these comorbidities. Like other qualitative studies, our study is not designed to be broadly generalizable, but rather to inform the development of an intervention in a specific population. This study was conducted at one comprehensive HIV clinic in a city in the southeastern United States. Due to logistical and financial constraints, it was not possible to conduct a much larger qualitative study at sites across the United States. It is possible that the results obtained would have differed in other settings with better public transportation (and therefore perhaps less social isolation) or less HIV stigma [44–46]. Once the intervention is developed, we plan to obtain feedback from HIV clinics around the United States that are part of the Center for AIDS Research Network of Integrated Clinical Systems, of which our clinic is the lead site, prior to testing. Finally, we note that this study relied on persons willing and able to appear in person for focus groups and interviews. In this way, it may not capture special concerns or priorities of persons with geographic, time-related, or other contextual barriers to attending in-person programs.

In sum, this study presents formative qualitative work that provides a framework for the structure and delivery of a behavioral intervention for chronic pain in individuals with HIV. We will use these results as the basis for designing our intervention. In addition, we hope that our approach will inform the work of investigators in other disciplines who seek to incorporate formative qualitative work on patient preferences during intervention development.

References

- 1 Turk DC, Rudy TE. IASP taxonomy of chronic pain syndromes: Preliminary assessment of reliability. *Pain* 1987;30(2):177–89.
- 2 Merlin JS, Cen L, Praestgaard A, et al. Pain and physical and psychological symptoms in ambulatory HIV patients in the current treatment era. *J Pain Symptom Manage* 2012;43(3):638–45.
- 3 Newshan G, Bennett J, Holman S. Pain and other symptoms in ambulatory HIV patients in the age of highly active antiretroviral therapy. *J Assoc Nurses AIDS Care* 2002;13(4):78–83.
- 4 Harding R, Lampe FC, Norwood S, et al. Symptoms are highly prevalent among HIV outpatients and associated with poor adherence and unprotected sexual intercourse. *Sex Transm Infect* 2010;86(7):520–4.
- 5 Silverberg MJ, Jacobson LP, French AL, Witt MD, Gange SJ. Age and racial/ethnic differences in the prevalence of reported symptoms in human immunodeficiency virus-infected persons on antiretroviral therapy. *J Pain Symptom Manage* 2009;38(2):197–207.
- 6 Silverberg MJ, Gore ME, French AL, et al. Prevalence of clinical symptoms associated with highly active antiretroviral therapy in the Women's Interagency HIV Study. *Clin Infect Dis* 2004;39(5):717–24.
- 7 Cervia LD, McGowan JP, Weseley AJ. Clinical and demographic variables related to pain in HIV-infected individuals treated with effective, combination antiretroviral therapy (cART). *Pain Med* 2010;11(4):498–503.
- 8 Lee KA, Gay C, Portillo CJ, et al. Symptom experience in HIV-infected adults: A function of demographic and clinical characteristics. *J Pain Symptom Manage* 2009;38(6):882–93.
- 9 Merlin JS, Westfall AO, Raper JL, et al. Pain, mood, and substance abuse in HIV: Implications for clinic visit utilization, ART adherence, and virologic failure. *J Acquir Immune Defic Syndr* 2012;61(2):164–70.
- 10 Miaskowski C, Penko JM, Guzman D, et al. Occurrence and characteristics of chronic pain in a community-based cohort of indigent adults living with HIV infection. *J Pain* 2011;12(9):1004–16.
- 11 Institute of Medicine. *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington, DC: The National Academies Press; 2011.
- 12 Merlin JS, Westfall AO, Chamot E, et al. Pain is independently associated with impaired physical function in HIV-infected patients. *Pain Med* 2013;14(12):1985–93.
- 13 Noble M, Treadwell JR, Tregear SJ, et al. Long-term opioid management for chronic noncancer pain. *Cochrane Database Syst Rev* 2010;(1):CD006605.
- 14 Chou R, Fanciullo GJ, Fine PG, et al. Clinical guidelines for the use of chronic opioid therapy in chronic noncancer pain. *J Pain* 2009;10(2):113–30.
- 15 Koeppel J, Armon C, Lyda K, Nielsen C, Johnson S. Ongoing pain despite aggressive opioid pain management among persons with HIV. *Clin J Pain* 2010;26(3):190–8.
- 16 Gudin J. Opioid therapies and cytochrome p450 interactions. *J Pain Symptom Manage* 2012;44(suppl 6):S4–14.
- 17 Brady TJ. Measures of self-efficacy: Arthritis Self-Efficacy Scale (ASES), Arthritis Self-Efficacy Scale-8 Item (ASES-8), Children's Arthritis Self-Efficacy Scale (CASE), Chronic Disease Self-Efficacy Scale (CDSSES), Parent's Arthritis Self-Efficacy Scale (PASE), and Rheumatoid Arthritis Self-Efficacy Scale (RASE). *Arthritis Care Res (Hoboken)* 2011;63(suppl 1):S473–85.
- 18 Somers TJ, Shelby RA, Keefe FJ, et al. Disease severity and domain-specific arthritis self-efficacy: Relationships to pain and functioning in patients with rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2010;62(6):848–56.
- 19 Knittle KP, De Gucht V, Hurkmans EJ, et al. Effect of self-efficacy and physical activity goal achievement on arthritis pain and quality of life in patients with rheumatoid arthritis. *Arthritis Care Res (Hoboken)* 2011;63(11):1613–9.
- 20 Bartholomew LK, Parcel GS, Kok G, Gottlieb NH, Fernandez ME. *Planning Health Promotion Programs: An Intervention Mapping Approach*. San Francisco, CA: Jossey-Bass; 2011.
- 21 Pellowski JA, Kalichman SC, Matthews KA, Adler N. A pandemic of the poor: Social disadvantage and the U.S. HIV epidemic. *Am Psychol* 2013;68(4):197–209.
- 22 Trafton JA, Sorrell JT, Holodniy M, et al. Outcomes associated with a cognitive-behavioral chronic pain management program implemented in three public HIV primary care clinics. *J Behav Health Serv Res* 2012;39(2):158–73.

- 23 Evans S, Fishman B, Spielman L, Haley A. Randomized trial of cognitive behavior therapy versus supportive psychotherapy for HIV-related peripheral neuropathic pain. *Psychosomatics* 2003;44(1): 44–50.
- 24 Merlin JS, Zinski A, Norton WE, et al. A conceptual framework for understanding chronic pain in patients with HIV. *Pain Pract* 2014;14(3):207–16.
- 25 Holloway I, Sofaer-Bennett B, Walker J. The stigmatisation of people with chronic back pain. *Disabil Rehabil* 2007;29(18):1456–64.
- 26 Eaton EF, Kulczycki A, Saag M, Mugavero M, Raper JL. Immunization costs and programmatic barriers at an urban HIV clinic. *Clin Infect Dis* 2015;61(11): 1726–31.
- 27 Eaton EF, Mugavero MJ. Affordable Care Act, Medicaid expansion...or not: Ryan White Care Act remains essential towards access and equity. *Clin Infect Dis* 2016. pii: ciw280. [Epub ahead of print].
- 28 Policy. HAB. Clarifications regarding clients eligible for private health insurance and coverage of services by Ryan White HIV/AIDS Program. 2013. Available at: <http://hab.hrsa.gov/manageyourgrant/pinspals/pcn1304privateinsurance.pdf> (accessed September 13, 2013).
- 29 Crane HM, Lober W, Webster E, et al. Routine collection of patient-reported outcomes in an HIV clinic setting: the first 100 patients. *Curr HIV Res* 2007;5(1): 109–18.
- 30 Tran BX, Ohinmaa A, Nguyen LT. Quality of life profile and psychometric properties of the EQ-5D-5L in HIV/AIDS patients. *Health Qual Life Outcomes* 2012;10:132.
- 31 Kroenke K, Spitzer RL, Williams JB. The PHQ-9: Validity of a brief depression severity measure. *J Gen Intern Med* 2001;16(9):606–13.
- 32 Newcombe DA, Humeniuk RE, Ali R. Validation of the world health organization alcohol, smoking and substance involvement screening test (ASSIST): Report of results from the Australian site. *Drug Alcohol Rev* 2005;24(3):217–26.
- 33 Merlin JS, Walcott MM, Herbey I, et al. Qualitative investigation of a brief chronic pain screening tool in HIV-infected patients. *AIDS Patient Care STDS* 2014;28(4):176–82.
- 34 Merlin JS, Westfall AO, Chamot E, et al. Quantitative evaluation of an instrument to identify chronic pain in HIV-infected individuals. *AIDS Res Hum Retroviruses* 2015;31(6):623–7.
- 35 Cleeland CS, Ryan KM. Pain assessment: Global use of the brief pain inventory. *Ann Acad Med Singapore* 1994;23(2):129–38.
- 36 Bair MJ, Ang D, Wu J, et al. Evaluation of Stepped Care for Chronic Pain (ESCAPE) in veterans of the Iraq and Afghanistan conflicts: A randomized clinical trial. *JAMA Intern Med* 2015;175(5):682–9.
- 37 Creswell JW. Research design: qualitative, quantitative, and mixed methods approaches. 4th ed. Thousand Oaks: SAGE Publications; 2014.
- 38 Attride-Stirling J. Thematic networks: An analytic tool for qualitative research. *Qualitative Res* 2001;1(3): 385–405.
- 39 Braun V, Clarke V. Using thematic analysis in Psychology. *Qualitative Res Psych* 2006;3(2): 77–101.
- 40 Krentzman AR, Robinson EA, Moore BC, et al. How alcoholics anonymous (AA) and narcotics anonymous (NA) work: Cross-disciplinary perspectives. *Alcohol Treat Q* 2010;29(1):75–84.
- 41 Cucciare MA, Sorrell JT, Trafton JA. Predicting response to cognitive-behavioral therapy in a sample of HIV-positive patients with chronic pain. *J Behav Med* 2009;32(4):340–8.
- 42 George MC, Wongmek A, Kaku M, Nmashie A, Robinson-Papp J. A mixed-methods pilot study of mindfulness based stress reduction for HIV-associated chronic pain. *Behav Med* 2015:1–12. [Epub ahead of print].
- 43 Simoni JM, Nelson KM, Franks JC, Yard SS, Lehavot K. Are peer interventions for HIV efficacious? A systematic review. *AIDS Behav* 2011;15(8):1589–95.
- 44 Lichtenstein B. Stigma as a barrier to treatment of sexually transmitted infection in the American deep south: Issues of race, gender and poverty. *Soc Sci Med* 2003;57(12):2435–45.
- 45 Miles MS, Isler MR, Banks BB, Sengupta S, Corbie-Smith G. Silent endurance and profound loneliness: Socioemotional suffering in African Americans living with HIV in the rural south. *Qual Health Res* 2011; 21(4):489–501.
- 46 Kerr JC, Valois RF, Diclemente RJ, et al. HIV-related stigma among African-American youth in the Northeast and Southeast US. *AIDS Behav* 2014;18(6): 1063–7.