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## Pain Self-Management in HIV-infected Individuals with Chronic Pain: A Qualitative Study

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### Abstract

**Objective**—Chronic pain in individuals with HIV is a common, impairing condition. Behavioral interventions for chronic pain specifically tailored to this population have yet to be developed. We assert that understanding self-management strategies already used by persons living with these conditions is an essential first step, and is the objective of this investigation.

**Design**—We conducted a thematic analysis of qualitative data from 25 in-depth interviews with individuals with HIV and chronic pain.

**Results**—The primary pain self-management strategies articulated by participants were: physical activity; cognitive and spiritual strategies; spending time with family and friends and social support; avoidance of physical/social activity; medication-centric pain management; and substance use.

**Conclusions**—Some of these strategies may be viewed as beneficial and overlap with known HIV self-management strategies (cognitive strategies), whereas others may have negative health consequences (substance use). Interventions that incorporate healthy self-management strategies may be particularly effective in improving both HIV and pain outcomes.

### Keywords

HIV; chronic pain; self-management; pain psychology

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### Introduction

Chronic pain is a common condition, occurring in 30% of the general US population.(1) Due to its unique neurobiologic basis and impact on physical function, quality of life, and health outcomes, chronic pain has been conceptualized as a chronic disease.(1)

Chronic pain occurs in 39%-85% of HIV-infected individuals.(2-10) Additionally, evidence is emerging about the complex relationship between chronic pain and health outcomes for persons living with HIV. For example, our prior work has shown among HIV-infected individuals, chronic pain is associated with as much as 10 times greater odds of functional impairment.(11) Further, chronic pain in HIV-infected individuals is also associated with suboptimal retention in HIV primary care, which has important implications for HIV-related health outcomes.(9) Therefore, chronic pain in individuals with HIV is an important comorbidity with serious health implications.

Traditionally, chronic illnesses like chronic pain and HIV have been described mainly in terms of their biomedical persistence over time.(12) More recently, the importance of behavioral factors has been recognized, including daily self-management behaviors adopted by patients to cope with pain.(1, 12-14) Lorig et al have described core self-management behaviors common across chronic illnesses.(12) These behaviors include problem solving (e.g., clarifying the problem, coming up with solutions, following through, and evaluation); decision-making (which requires knowledge of common situations that may arise); finding and utilizing resources (e.g., community agencies, internet-based support groups); partnering with health care providers; and taking action (setting short-term goals and following through).

Effective self-management interventions have been developed for an array of chronic conditions and have been found to increase individuals' self-efficacy to perform these behaviors.(15) In addition, self-management programs aimed at improving HIV health outcomes have been developed and tested. Such self-management programs for HIV-infected individuals have resulted in improved adherence to antiretroviral therapy(16), retention in HIV primary care,(17) and physical and emotional health.(13) Similarly, pain self-management interventions have been shown to be effective for improving pain and physical and emotional function in individuals with chronic pain.(18-23) Self-management is an evidence-based approach in individuals with chronic pain, and the available evidence suggests that HIV-infected individuals are amenable to such interventions. However, no interventions exist specifically to address the challenges of living with both HIV and chronic pain.

Lorig et al have suggested that to develop effective self-management programs, one must first develop an in-depth understanding of the target chronic condition in the target patient population.(12) The current study used qualitative methods to better understand the chronic pain experience in HIV-infected individuals. This study was guided by the Biopsychosocial Framework for chronic pain in individuals with HIV(24) and included open-ended questions on strategies participants used to manage their pain. We assert that understanding the self-management strategies already used by persons living with chronic pain and HIV is an essential first step toward developing an effective intervention. The fact that patients already use these strategies suggests that they may be feasible and acceptable in this patient population, and could be used as a starting point for intervention development. Therefore, our objective was to identify pain self-management strategies used by persons living with comorbid HIV and chronic pain.

## Methods

The analyses presented here are part of a larger study designed to explore the chronic pain experience in individuals with HIV. This study was conducted within the 1917 Clinic Cohort, a prospective cohort of HIV-infected individuals who seek care at the University of Alabama at Birmingham (UAB). The majority of participants in this cohort are also enrolled in the Center for AIDS Research Network of Integrated Clinical Systems (CNICS), which routinely collects detailed medical record, clinical, and Patient Reported Outcome (PRO) data on its participants. A detailed description of our study design and recruitment has been published previously.(25)

For the overall study, we conducted in-depth interviews with CNICS participants at UAB, and included only individuals who had at least mild chronic pain based on the Brief Chronic Pain Screening tool.(26, 27) To represent the viewpoints of individuals who have chronic pain and are expected to be the target population for future interventions, we purposively sampled individuals with moderate depressive symptoms based on the PHQ-9 ( 10)(28) and anxiety symptoms/panic based on the PHQ-Anxiety module. (28) We also purposively sampled for current substance use based on the Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST).(29) As there is some evidence as to marijuana's efficacy for chronic pain, and few people develop true marijuana addiction, we assert that marijuana is in a separate category from other illicit substances. As we are interested in including perspectives from individuals with use of more addictive illicit drugs when we develop our intervention, we purposively sampled for those other substances, excluding marijuana. We oversampled individuals who met these thresholds but also included those who did not.

Our interview guide was structured using the Biopsychosocial Framework for chronic pain in individuals with HIV.(24) The interviewer (MW) was trained in qualitative research and had conducted similar qualitative interviews for several prior studies. She was also trained specifically on the interview guide for this study by the principal investigator in order to promote standardized delivery of open-ended probing across participants, which included numerous mock interviews. We probed on a wide array of topics, and have previously reported results related to psychosocial aspects of chronic pain in this sample.(25) Among

those topics, we included broad, open-ended probes to learn more about how individuals with chronic pain coped with or managed their pain (see Table for relevant probes). Responses to these probes and relevant data on pain self-management strategies that arose during any part of the interview were included in the analyses presented here.

We used a thematic analysis approach in our qualitative coding and analysis.<sup>(30)</sup> We used a thematic analysis approach in our qualitative coding and analysis.<sup>(31)</sup> This involved a process of familiarizing ourselves with the data, generating initial codes using an inductive process, collating codes into potential themes, reviewing those themes and generating a thematic map of the analysis, defining and naming our themes, and then producing the report. Our initial coding procedure involved inductive coding by the interviewer (MW), an experienced qualitative analyst (IH), and the principal investigator (JM) using NVivo 10.0.<sup>(32)</sup> During initial coding, numerous codes relating to how individuals attempted to self-manage their pain emerged. Two study authors (MW and JM) reviewed these codes and independently identified new sub-themes and higher order themes. The preliminary report generated from this process was sent to another investigator (JT) for initial review. A second review session followed and involved the investigative team (MW, JM and JT) to finalize themes. During that meeting, we discussed the emerging themes, identified those that needed to be merged due to content overlap, and decided on the final broad themes and subthemes to be used in the analysis.

## Results

As described in a prior publication,<sup>(25)</sup> of the 25 individuals included in this study, 6 had mild pain, 4 had moderate pain, 14 had severe pain, and 1 did not report pain severity but was determined to have chronic pain based on the rest of the interview. Most of the participants were male (20), 10 were age 50 years or greater, and 15 were African-American. The median CD4+ T-cell count was 571 cells/mm<sup>3</sup> (IQR 421-792), and 20 had a VL<200 copies/mL (the primary treatment endpoint for antiretroviral therapy). The majority (16) had symptoms of moderate depression or anxiety, and approximately half (12) reported actively using illicit substances. A wide range of body sites were affected by pain, the most common were: back (8), feet (8), leg (10) and shoulder (6). Fourteen participants (11 of whom had moderate or severe pain) reported that they were on government disability.

Regardless of pain severity, finding ways to manage one's pain was nearly universal among participants. Participants used a wide range of strategies and often reported combining strategies. Participants also acknowledged that some strategies worked well, and others did not. The primary strategies participants articulated were physical activity, cognitive and spiritual strategies; spending time with family and friends and social support; avoidance of physical/social activity; medication-centric pain management; and substance use.

### Physical Activity

Participation in physical activity, typically walking between 20-45 minutes at a time, was the most common strategy participants described using to manage their pain. Other forms of physical activity included housework and formal exercises (e.g., “crunches”). Most

participants expressed that although physical activities may be difficult and prove challenging at times, the net effect on their pain and overall health was beneficial.

One participant specifically mentioned exercise as a way of addressing his pain and suggested the following mechanism of action for the effects of physical activity in improving pain:

*I started some exercise...I need to get back on it. I haven't [laughter] in about a week. But I think when I was doin' that exercise I guess it was allowin' my joints to work and not get sedentary.* 42-year-old African-American male

Participants acknowledged that engaging in physical activity in the setting of chronic pain can be a struggle. One participant described engaging in daily physical activity despite substantial pain:

*When I first get up in the morning, I hurt. Oh my God! I hurt! I have to move around. I have to keep moving around, just to, to try, and get it to ease off.* 33-year-old Caucasian male

One participant noted that physical activity can even cause more pain in the short term; the benefits are more often seen long-term:

*A lot of times, even though it may hurt, yeah, movement and, and physical activity will help my pain overall... in the long run but you know, at the, at the exact moment, it may, it may hurt to do it but it, it does ease up.* 31-year-old Caucasian male

In addition, participants noted helpful adjustments to their activity level due to their pain. This was most commonly described in terms of pacing themselves, including resting when needed, and adjusting one's daily routine. For example, one participant described her struggle to exercise despite pain. She tried a few different types of exercise until she discovered that pacing herself by walking slowly was an achievable goal:

*I can do the walking pretty good, a couple blocks. Say a radius of three and a half, four blocks. Taking it slow...I can make it but that's all I got in me.... It don't do anything, you know, to, to cure the pain. It's just, just... It, it kind of bring on the pain.... And that's why I be reluctant to do it, you know, because it brings the pain on...But now I got a neighbor, she'll walk with me and sometimes we'll walk slow and we'll talk about the houses and the this and the that...and the other. It kind of moves it away from my mind. You know, we just going slow, just drifting along, I can make it alright. And in my earlier life, I was a fast walker ...Now, the slower I go, the better I do.* 66-year-old African-American female

Another participant described his effort to be physically active and the flexibility he has to adjust his daily routine to meet that goal as needed:

*I don't sit in a chair and get all down about issues and just waste away that way... I try to be as active as I possibly can and not let it [pain] affect me...Just being aware of what causes it and make sure I try to prevent that from happening, you know....That's, you know, that's the big issue, you know. Take my medication three*

*times a day for that. ... And the fact that I'm in a situation to where I control my activities ... I mean, if I had to get up in the morning and go to work every day, that would be terrible ... because there's no tolerance to I gotta go to that or I gotta go lay down or I gotta, can't do this. ... You know, I gotta go do this now....So I can control that now and, uh, it helps a great deal.... I wish I could go... I would like to go back to work and deal with that issue and stuff, but I have so many, uh... don't think they'll give me that much flexibility, you know....But, at this point in my life, I deal with it day to day and I manage it, you know, and if I want to walk, if I want to go somewhere to go walk to Wal-Mart with somebody, I'm going to do it....Got handicap parking, I'll park close to the front. 64-year-old Caucasian male*

### **Cognitive and Spiritual Strategies**

In the context of this study, we defined cognitive strategies as mental processes that individuals used to address their pain. These included positive thinking, relaxation, and distraction. Participants also described spiritual strategies they used for pain self-management, such as prayer.

**Positive Thinking**—Language used to describe positive thinking included “being positive,” “dealing,” “ignoring,” “fighting,” “adjusting to,” “learning to live with,” “accepting,” and “coping” with pain. For example, one participant described adopting a positive attitude and pushing himself to be active:

*Like today, I mean, I-I can't imagine sitting inside, saying oh, I hurt, I hurt, I hurt, wh-when it's a beautiful sunny day. I mean, that's to me, that's a waste. I guess, it's just my own psyche. I don't know. I don't you know, sleep-sleep, and stay in bed all day is to me, is a waste. 53-year-old Caucasian male*

Another participant expanded on exactly how she thinks positively about her pain:

*I'm telling myself just try to not to feel as bad as you feel, try to not to hurt as bad as you're hurting..... I get on a positive level with what I'm telling myself. 66-year-old African American female*

In general, participants tended to view chronic pain as a challenge to be overcome, and the desire to be “normal” (ability to care for self, work, enjoy social activities, etc) seemed to be an important motivator. While some participants described the importance of social support in staying positive (see below), one participant without strong social support emphasized self-reliance:

*But I try to alleviate it – I try to ignore it and – and just, you know, do what I have to do 'cause I'm not codependent on nobody. I mean, I'm not codependent on nobody.... I just try to ignore it 'cause I know I can't – can't just – just stop. .. 52-year-old African-American male*

**Relaxation**—A common cognitive strategy described by several participants was relaxation. No participant described a structured program of relaxation or meditation. Rather, participants described several informal ways to relax. As an example:

*I have to sit down and pray or meditate and take some deep breaths. I think they call that biofeedback, basically. You just have to make yourself. It's almost like a meditation thing. I just inhale and exhale until it goes away. Then before I know it, it's gone. 53-year-old African-American male*

**Distraction**—Another less commonly mentioned cognitive strategy was distraction. Some participants kept busy with activities to distract themselves from their pain:

*I do... try to keep myself busy with work. Just try to keep myself distracted from it...on a good day, whether I'm in pain or no , I'm busy....The more I have to do, the less time I have to think about the pain. If I'm really busy and, and focused and, and driven, then, then that's really has been the best way for me to, to manage and deal with pain. It's when I'm slow and bored and, and don't really have anything to occupy my mind...is when I really start feeling the pain. 31-year-old Caucasian male*

**Prayer**—A few participants also mentioned the role of spirituality and prayer in helping to alleviate their pain. One participant described in detail how she uses prayer and focuses on God while at church to reduce her pain:

*I be hurting so bad. And when I pray...I be like ooh, that'd do it for a while but the n [stammer] ease down, I'd be saying thank you, Jesus, uh huh, because especially those cramps... Oh, girl, those things hurt so bad. I be working, I be calling the Lord, I'd be just praying that he... everything. And after a while, you know, they kind of, kind of smooth out. And I'm sitting there just saying I dare you to move, you know. [Laugh] But at least it be going away. ...For some reason when I go to church on Sunday, I can get up on Sunday morning, be feeling ever so bad. Because I got other problems, too, you know, and well, something gonna mess with me. And I just tell the devil to get because I'm going to church. And it seems like when I go to church, whatever is bothering me, I get better.....You know, I think having to focus on God and the rest of it, he just push it away. 66-year-old African-American female*

### **Spending Time with Family and Friends and Social Support**

Some participants described spending time with family and friends as something that they genuinely enjoy. These participants described this as providing meaningful, fulfilling support that helped them deal with their chronic pain. For example, one participant described how his family provides social support:

*I have a very nice support system. So that's another thing that I have in my corner, you know? My family is supportive. You know, they know my status and the whole nine. They are behind me. That's another thing that gets me through. 49 year old African-American male*

### **Avoiding Physical/Social Activity**

A few participants described avoidance of physical and social activity as a strategy to manage pain. Concerns about exacerbating the pain and projecting an image of being in pain

(announces sickness/disease) were important factors influencing decisions to avoid or reduce physical and social activities.

*I'm trying to walk around and saying ooh, ouch and stuff like that because of the pain hits me. That's not good. I don't want to project that type of image. 55 year old African American male*

Common measures utilized to avoid pain included “staying off my feet”, not exercising or limiting exercise time, avoiding long trips, sleeping and staying at home:

*I stay in the bed and – I mean that's – that's my thing. The only time I get out is when I know I'm coming here to the doctor or to a class or I do some volunteer work. You know I try to the night before or during the day to take my meds so I – I won't – when I get home I won't be you know in so much pain. 49-year-old African-American male*

This participant went on to describe a more pervasive pattern of avoidance that included avoiding social contact, as well as escape from awareness through sleep:

*I pretty much stay to myself and watch my TV, or go to sleep.... I'm chillin. I'm in my own little world...I can't hurt myself in my own little world....I can only deal with the pain that I'm having and deal with it.... I get up screaming and hollering....Then I'm on the floor and on my knees begging the Lord. And then I can get to the pain meds. I put me some pain meds in me and just walk around until they kick in. when they kick in then the pain – I relax. I'm relaxed then. Then I go back and get into bed and go back to sleep. 49-year old African American male*

### Medication-Centric Pain Management

Several participants described managing their pain primarily with medications. One participant described how “the first thing I do in the morning is take a pain pill and the last thing I do at the end of the day before I go to sleep is take a pain pill.” When asked how she copes with pain on a typical day, she went on to focus on how she takes her pain medication:

*I just take my medicine...As I said, when I wake up in the morning, the first thing I grab is my pain medicine. I take a pill, I lay there for 30 minutes, then I'm able to get up and start about my day....Umm, approximately maybe four or five hours later I have to take another hydrocodone. Umm, I'm okay for another maybe four or five hours then I have to take another one....And this is, goes continuously. I take the Morphine twice a day....Nine o'clock in the morning, nine o'clock at night. So usually at nine, between nine and ten, mornings and nights, the Morphine has wore off and it's kind of I can feel the body pain a little bit more, but once it sets back in, because it's time released, I don't go on that roller coaster throughout the day. 47-year-old African-American female*

Going a step further, one participant described the elaborate schedule he developed for taking his pain medications and making them last long enough for him to sleep well:

*Some nights I ask, “Why Lord. My twelve hours is not up?” So I lay on here and just you know, chill with the part [of the pain pill] that I took, and let the other part*



*of twelve hours kick in. And some nights ... I took a Seroquel [antipsychotic] and I'm falling asleep. But then the Opana [opioid pain medication] and the Lortab is not in my system all the way in and I took it earlier and then I slept them many hours, and when the pain do hit, boom. I wake up. Like something – Like I had a car accident....And I'm like, "Oh I can't do that." So my thing is I try to at least take the Opana so when I'm asleep, it'll still be that twelve-hour release thing that still be kicking in. If some pain come, it's not as severe as it used to be. It's just out of nowhere there's some pain there. And I might have to get up and say well – I go and take a little tab before it start really kicking in. And then that's what I do. 49-year-old African American male*

Often, participants stressed the importance of taking pain medicine, while downplaying or not realizing that they are using other management strategies simultaneously. For example, when asked what helps their pain, one participant pointed to medications primarily, and then acknowledged other strategies (e.g. distraction, physical activity):

*I have to say it's the – its medicine. And like I said, that and combination with trying to take my mind off of it by either reading or – or you know I do walk on days that aren't freezing.... because we have a parking deck behind the facility. And a roof it's a nice area to walk because there are flowerbeds and everything. And I will go up there. I'll put my headphones in. I'll get lost in some music....And that helps, you know? Try to – try to take the soreness out of it. Or you know if it's sitting on that nerve sometimes that helps me to get it off that nerve. 53-year-old Caucasian female*

Another participant described using both physical and cognitive strategies (relaxation), and then stated that the only strategy she knows is medication:

*On a typical day, I manage it. I know I'm going to eat breakfast or something. Then I take my pill and stuff. Then I would rub something on my arms or something like that, and try to breathe and relax my body some and stuff like that. You know, just try to manage it. The only management that I know is taking medication and stuff for it. 54-year-old African-American male*

### **Substance Use**

In addition to using prescribed medications, uncommonly, participants mentioned using alcohol and illicit substances to alleviate their pain. No participant described this as a preferred or effective strategy. Rather, substance use was noted to be a short-lived solution with other potentially negative consequences, as one participant described:

*I've got drunk before, to get rid of the pain. I've taken cocaine before, to get rid of the pain. It didn't get rid of it long, but as soon as you hit it, for 30 or 40 seconds, no pain. I've done everything to try, and get out of the pain, and you taking pain medicine drinking, that's gonna depress you. Alcohol's a depressant, as you know, and uh, the Hydrocodone's a depressant. 56-year-old Caucasian male*

## Discussion

This is one of the first studies to qualitatively investigate pain self-management strategies used by HIV-infected individuals with chronic pain. In our sample, participants highlighted numerous strategies that they use to self-manage their pain. It is noteworthy that some of these strategies are, at face value, healthy (e.g., cognitive coping skills, seeking support from family or friends, physical activity), while others may have negative consequences. For example, avoiding physical activity or “fear avoidance” has been found to be associated with worse outcomes in individuals with chronic pain(33). However, while taking pain medication could help facilitate ability to participate in beneficial social and physical activity, medication-centric pain management as described here may become the focus of the patient's attention and could potentially eclipse other important strategies. Notably, to our knowledge, individuals in our cohort did not receive any formal instruction on pain self-management strategies (e.g., a formal pain self-management intervention as previously described). Rather, they engaged on their own.

Our study is consistent with existing literature on pain self-management. Prior studies of individuals with chronic pain in the general population highlight self-management strategies such as maintaining physical activity, taking medications, and massage.(34-36) Additionally, pain self-management programs often include modules on these strategies, in addition to other strategies highlighted in our study, for example, pain education including education about pain medications, cognitive symptom management including positive self-talk, and communication with providers. Importantly, these overlap almost completely with self-management strategies recommended for individuals with HIV and other chronic illnesses to address HIV disease outcomes.(13, 37) Several quantitative studies of a cohort of individuals in San Francisco with painful HIV neuropathy have highlighted the use of self-management strategies, including medications, exercise, and rest, as well as “unhealthy” behaviors such as smoking, alcohol use, and illicit substance use.(38-40) Our study is the first to investigate pain self-management strategies in individuals with HIV and diverse chronic pain syndromes, and to do so qualitatively. Additionally, we are among the first to describe not just medication use but specifically “medication-centric management” as a pain self-management approach.(41)

Use of unhealthy pain self-management strategies may have important implications for the health of persons living with HIV. For example, avoiding social situations due to pain may lead to social isolation, which is known to be associated with worse health outcomes.(42) Similarly, use of illicit substances to address chronic pain can lead to addiction, overdose, injuries, and accidents, which are known to be associated with worse HIV outcomes such as adherence to antiretroviral therapy and retention in care.(43) These effects may be especially pronounced when social isolation and illicit substance use are combined with other biopsychosocial factors at play in individuals with HIV, such as HIV-related stigma.

However, we note that participants in this study did not talk about these unhealthy strategies as their preferred means of managing pain. Rather, participants pointed out the limitations of such strategies. For example, they recognized that the effects of substance use on pain are often short lived. In contrast, participants spoke positively of healthier strategies and

emphasized their importance. This may have important implications for patient-provider communication about chronic pain, which can be a challenge for both parties.(44, 45) First, it is important for providers to recognize that patients are likely already employing one if not several pain self-management strategies when they seek care for their pain. Furthermore, our findings suggest that HIV providers and patients may share core beliefs about the usefulness of healthy strategies such as physical activity. For example, a patient and his physician would likely agree that being sedentary may help in the moment but can actually cause deconditioning, atrophy, and increased stiffness. While participating in physical activity can be difficult, it has ongoing benefits in terms of pain and overall health. Finding this common ground may provide a starting point for discussion between the patient and provider about healthy, effective approaches to managing chronic pain.

Despite a tremendous burden of chronic pain, a tailored intervention for individuals with HIV and chronic pain has not been developed. Such programs may be developed with the self-management strategies described in our analysis in mind. Inclusion of strategies that seem familiar, and for which patients already have self-efficacy based on prior experience, may improve intervention uptake. This could be particularly powerful when combined with deliberate intervention tailoring. For example, allowing individuals to pick from a menu of self-management strategies may be as effective as the clinician picking which strategies are used,(46) but has the potential to be more feasible and acceptable to patients. Further investigation into such interventions among HIV-infected individuals with chronic pain is needed. Additionally, existing pain self-management interventions already address unhealthy strategies such as fear avoidance (47); addressing others such as substance use may be key in individuals with HIV, for whom addiction is more common than in the general population. Finally, the overlap between previously described HIV self-management strategies and our participants' pain self-management strategies suggest that interventions could be developed that improve both HIV and pain outcomes simultaneously.

Our study has limitations. As is typical in qualitative studies, our results are not intended to generalize to all individuals with HIV and chronic pain, but rather those who we think are likely to be targets of future interventions. Similarly, given the lack of anonymity in qualitative interviews, participants may not have fully disclosed all relevant self-management strategies. However, our interviews were conducted by an experienced qualitative interviewer who developed good rapport with the participants and made clear the confidentiality of the information that was shared by the participants. Further, we did not set out to specifically to ask participants about self-management strategies, but rather, strategies for improving their pain more generally. Self-management strategies emerged as a strong theme, and therefore, we proceeded with a separate in-depth analysis as described here. Had we known to probe for this at the outset, we might have asked participants to compare various self-management strategies, including comparisons between healthy and unhealthy strategies. For similar reasons, we did not collect data on how they learned the strategies they reported. Pain self-management programs were not available in the clinic during the study period, and are not widely available in our area. However, we did not specifically ask participants about participation in such pain programs. Finally, our study was conducted in a patient-centered medical home, which provides HIV primary care, specialty medical care, case management, and a variety of mental health services including psychiatric medical

management and counseling. We did not ask participants if they learned about self-management strategies from one of our clinicians (e.g., from their primary care physician, our clinic's addiction counselor, social workers, etc). Participants' responses may differ in HIV clinics with a less robust array of such services.

In sum, we describe a variety of both healthy and unhealthy pain self-management strategies used by HIV-infected individuals with chronic pain and HIV. Some of these strategies overlap with HIV-specific self-management strategies. As the first study to qualitatively investigate pain self-management strategies in this patient population, our results will form the foundation on which interventions for chronic pain in individuals with HIV will be built. Additional intervention development work to investigate these potential approaches suggested by our findings, including interventions that target not only chronic pain, but overall HIV-related health, will be an important next step.

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## References

1. Institute of Medicine. *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Washington, DC: The National Academies Press; 2011.
2. Merlin JS, Cen L, Praestgaard A, Turner M, Obando A, Alpert C, 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. [PubMed: 22115794]
3. Newsham 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. [PubMed: 12149887]
4. Harding R, Lampe FC, Norwood S, Date HL, Clucas C, Fisher M, 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. [PubMed: 20551235]
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. [PubMed: 19329274]
6. Silverberg MJ, Gore ME, French AL, Gandhi M, Glesby MJ, Kovacs A, 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. [PubMed: 15356788]
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. [PubMed: 20210870]
8. Lee KA, Gay C, Portillo CJ, Coggins T, Davis H, Pullinger CR, et al. Symptom experience in HIV-infected adults: a function of demographic and clinical characteristics. *J Pain Symptom Manage*. 2009; 38(6):882–93. [PubMed: 19811886]
9. Merlin JS, Westfall AO, Raper JL, Zinski A, Norton WE, Willig JH, 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. [PubMed: 22766967]

10. Miaskowski C, Penko JM, Guzman D, Mattson JE, Bangsberg DR, Kushel MB. 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. [PubMed: 21684218]
11. Merlin JS, Westfall AO, Chamot E, Overton ET, Willig JH, Ritchie C, et al. Pain is Independently Associated with Impaired Physical Function in HIV-Infected Patients. *Pain Med*. 2013
12. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003; 26(1):1–7. [PubMed: 12867348]
13. Swendeman D, Ingram BL, Rotheram-Borus MJ. Common elements in self-management of HIV and other chronic illnesses: an integrative framework. *AIDS Care*. 2009; 21(10):1321–34. [PubMed: 20024709]
14. Carnes D, Homer KE, Miles CL, Pincus T, Underwood M, Rahman A, et al. Effective delivery styles and content for self-management interventions for chronic musculoskeletal pain: a systematic literature review. *Clin J Pain*. 2012; 28(4):344–54. [PubMed: 22001667]
15. Programs. SS-M. <http://patienteducation.stanford.edu/programs/>
16. Côté J, Godin G, Garcia PR, Gagnon M, Rouleau G. Program development for enhancing adherence to antiretroviral therapy among persons living with HIV. *AIDS Patient Care STDS*. 2008; 22(12):965–75. [PubMed: 19072103]
17. Brennan A, Browne JP, Horgan M. A systematic review of health service interventions to improve linkage with or retention in HIV care. *AIDS Care*. 2014; 26(7):804–12. [PubMed: 24354712]
18. Turk, D.; Meichenbaum, D.; Genest, M. *Pain and Behavioral Medicine: A Cognitive Behavioral Perspective*. New York: The Guilford Press; 1983.
19. Oliveira VC, Ferreira PH, Maher CG, Pinto RZ, Refshauge KM, Ferreira ML. Effectiveness of self-management of low back pain: systematic review with meta-analysis. *Arthritis Care Res (Hoboken)*. 2012; 64(11):1739–48. [PubMed: 22623349]
20. Du S, Yuan C, Xiao X, Chu J, Qiu Y, Qian H. Self-management programs for chronic musculoskeletal pain conditions: a systematic review and meta-analysis. *Patient Educ Couns*. 2011; 85(3):e299–310. [PubMed: 21458196]
21. Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. *Lancet*. 2004; 364(9444):1523–37. [PubMed: 15500899]
22. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns*. 2002; 48(2):177–87. [PubMed: 12401421]
23. Chodosh J, Morton SC, Mojica W, Maglione M, Suttrop MJ, Hilton L, et al. Meta-analysis: chronic disease self-management programs for older adults. *Ann Intern Med*. 2005; 143(6):427–38. [PubMed: 16172441]
24. Merlin JS, Zinski A, Norton WE, Ritchie CS, Saag MS, Mugavero MJ, et al. A Conceptual Framework for Understanding Chronic Pain in Patients with HIV. *Pain Pract*. 2013
25. M JS, W M, R C, H I, K SG, C E, et al. ‘Two Pains Together’: Patient Perspectives on Psychological Aspects of Chronic Pain while Living with HIV. *PLOS One*. in press.
26. Merlin JS, Walcott MM, Herbey I, Chamot E, Ritchie C, Saag MS, et al. Qualitative Investigation of a Brief Chronic Pain Screening Tool in HIV-Infected Patients. *AIDS Patient Care STDS*. 2014
27. Landmark T, Romundstad P, Dale O, Borchgrevink PC, Kaasa S. Estimating the prevalence of chronic pain: Validation of recall against longitudinal reporting (the HUNT pain study). *Pain*. 2012; 153(7):1368–73. [PubMed: 22575226]
28. 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. [PubMed: 11556941]
29. 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. [PubMed: 16096125]
30. Attridge-Stirling J. Thematic networks: an analytic tool for qualitative research. *Qualitative research*. 2001; 1(3):385–405.
31. B V, C V. *Qualitative Research in Psychology*. 2006:77–101.
32. Denzin, NK.; Lincoln, YS. *Handbook of Qualitative Reserch*. Thousand Oaks, CA: Sage; 2000.

33. Vlaeyen JW, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain*. 2000; 85(3):317–32. [PubMed: 10781906]
34. Kawi J. Chronic low back pain patients' perceptions on self-management, self-management support, and functional ability. *Pain Manag Nurs*. 2014; 15(1):258–64. [PubMed: 23232149]
35. Gong G, Li J, Li X, Mao J. Pain experiences and self-management strategies among middle-aged and older adults with arthritis. *J Clin Nurs*. 2013; 22(13-14):1857–69. [PubMed: 23534697]
36. Crowe M, Whitehead L, Jo Gagan M, Baxter D, Panckhurst A. Self-management and chronic low back pain: a qualitative study. *J Adv Nurs*. 2010; 66(7):1478–86. [PubMed: 20492018]
37. Webel AR, Dolansky MA, Henry AG, Salata RA. A qualitative description of women's HIV self-management techniques: context, strategies, and considerations. *J Assoc Nurses AIDS Care*. 2012; 23(4):281–93. [PubMed: 22079674]
38. Nicholas PK, Kempainen JK, Canaval GE, Corless IB, Sefcik EF, Nokes KM, et al. Symptom management and self-care for peripheral neuropathy in HIV/AIDS. *AIDS Care*. 2007; 19(2):179–89. [PubMed: 17364396]
39. Nicholas PK, Voss J, Wantland D, Lindgren T, Huang E, Holzemer WL, et al. Prevalence, self-care behaviors, and self-care activities for peripheral neuropathy symptoms of HIV/AIDS. *Nurs Health Sci*. 2010; 12(1):119–26. [PubMed: 20487335]
40. Nicholas PK, Voss JG, Corless IB, Lindgren TG, Wantland DJ, Kempainen JK, et al. Unhealthy behaviours for self-management of HIV-related peripheral neuropathy. *AIDS Care*. 2007; 19(10):1266–73. [PubMed: 18071970]
41. Matthias MS, Krebs EE, Collins LA, Bergman AA, Coffing J, Bair MJ. “I'm not abusing or anything”: patient-physician communication about opioid treatment in chronic pain. *Patient Educ Couns*. 2013; 93(2):197–202. [PubMed: 23916677]
42. Yang YC, McClintock MK, Kozloski M, Li T. Social isolation and adult mortality: the role of chronic inflammation and sex differences. *J Health Soc Behav*. 2013; 54(2):183–203. [PubMed: 23653312]
43. Celentano DD, Lucas G. Optimizing treatment outcomes in HIV-infected patients with substance abuse issues. *Clin Infect Dis*. 2007; 45(Suppl 4):S318–23. [PubMed: 18190306]
44. Frantsve LM, Kerns RD. Patient-provider interactions in the management of chronic pain: current findings within the context of shared medical decision making. *Pain Med*. 2007; 8(1):25–35. [PubMed: 17244101]
45. Vijayaraghavan M, Penko J, Guzman D, Miaskowski C, Kushel MB. Primary care providers' judgments of opioid analgesic misuse in a community-based cohort of HIV-infected indigent adults. *J Gen Intern Med*. 2011; 26(4):412–8. [PubMed: 21061084]
46. Kerns RD, Burns JW, Shulman M, Jensen MP, Nielson WR, Czlapiński R, et al. Can We Improve Cognitive-Behavioral Therapy for Chronic Back Pain Treatment Engagement and Adherence? A Controlled Trial of Tailored Versus Standard Therapy. *Health Psychol*. 2013
47. Kroenke K, Bair M, Damush T, Hoke S, Nicholas G, Kempf C, et al. Stepped Care for Affective Disorders and Musculoskeletal Pain (SCAMP) study: design and practical implications of an intervention for comorbid pain and depression. *Gen Hosp Psychiatry*. 2007; 29(6):506–17. [PubMed: 18022044]

**Table**  
**Interview Guide Questions and Probes Most Relevant to Pain Self-Management Behaviors**

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- Tell me about your pain? (Probes: Where do you have pain? When you have pain, what do you do to try to deal with it? How do you cope with your pain? How does pain affect your life? When was the last time you can remember being without pain? Does pain affect the people around you? Does your pain affect your relationships with people around you? Do you have pain all the time or does it come and go? What do you think causes your pain? What makes it better? What makes it worse? How does the pain feel? For example, sharp, dull, stabbing, burning, crushing?)
  
  - What things do you do to help treat your pain? (Probes: So, when you have pain, what do you do to try to make it go away? Are there any other therapies you use for your pain? Do you take any prescription medications for your pain? If so what are they? What are your reasons for taking pain medications? What are your reasons for not taking pain medications? Do you take any over the counter medications for your pain? If so, what are they? Like physical therapy, massage therapy, exercise, etc?)
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