CHALLENGES TO PATIENT-PROVIDER RELATIONSHIPS AND MANAGING CHRONIC PAIN OF AFRICAN AMERICANS WITH HIV AND A HISTORY OF DRUG USE IN BALTIMORE

by
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ABSTRACT

Chronic pain in people with HIV (PWH) is common and often undertreated, and likely compounds pain-related distress, stress of discrimination in healthcare, and substance use for self-medicating, which negatively impact PWH's interactions with healthcare providers and vice versa. Substance use- and race-associated stigma and bias in pain care also contribute to disparities in pain and its treatment. Challenges in managing chronic pain in the context of the current opioid epidemic present further threats to PWH's patient-provider relationships.

This mixed-methods dissertation explored the role of social discrimination and patient-provider engagement in PWH's quality-of-life in the context of chronic pain. The objective was to identify individual-level, interpersonal (patient-provider) and structural factors predictive of pain self-medicating and quality-of-life among African Americans with HIV and a history of drug use.

Structural equation modeling using longitudinal survey data from 331 PWH in Baltimore, Maryland, USA found that patient-centered patient-provider engagement with primary-care providers (PCE-PCP) mediated the effects of healthcare discrimination and pain treatment denial on later substance use for pain; and the effects of depression and healthcare discrimination on later mental health-related quality-of-life. In-depth interview and focus group discussions revealed PWH's experiences of tension, conflict, and distress in discussing pain and pain treatment with PCPs. Some reported feeling unfairly judged and prejudicially treated based on their history of drug use. Prior experiences of discrimination in healthcare settings also contributed to participants' mistrust in the healthcare system.

Participants expressed the need for providers interacting with them respectfully and empathically, and considering their opinions and preferences in treatment decision making.

Our findings suggest that interpersonal skills for PCE are important for addressing discriminatory treatment in healthcare, substance use, and mental health challenges of this marginalized population. Interventions should target people with intersecting vulnerabilities to discrimination and healthcare professionals interacting with them to foster mutual, collaborative patient-provider relationships. An integrated approach to treating pain and substance use concurrently with HIV and other comorbidities is much needed. A framework of compassion and joint patient-provider decision making with a goal of reducing social harms, pain and distress should be adopted for quality care and well-being of African American PWH.

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CHAPTER 1 – INTRODUCTION

Chronic pain is estimated to impact over 100 million adults (around one-third of the overall population) in the US, and is especially prevalent among persons who have behavioral health (i.e. substance use or other mental health) disorders.[1] People with HIV (PWH) are at high risk of developing chronic pain due to high levels of comorbidities including nerve damage associated with HIV infection and its treatment, as well as other common comorbid conditions.[2,3] In the United States, research shows that 39%-85% of PWH report chronic pain, depending on the study population.[2,4] Moreover, chronic pain in PWH is vastly undertreated.[2–4] As HIV shifts from a terminal illness to a chronic condition with the advances in modern medicine, managing pain and optimizing function are increasingly important to PWH's mental health and quality of life.[2,4]

Socioeconomically marginalized African Americans with HIV experience structural barriers to quality healthcare and treatments, contributing to their disparities in health outcomes and well-being. Those with illicit drug use histories have particular challenges with chronic pain and its management, which may affect or be affected by interactions with their healthcare providers. Understanding structural and behavioral factors for improving long-term care quality and well-being of African American PWH may have implications for health disparities. The current study sought to investigate the role of chronic pain and perceived discrimination in healthcare settings in quality patient-provider relationships and well-being among African American PWH with a history of drug use in Baltimore.

Research has found that patient-centered, active patient-provider engagement is associated with PWH's increased adherence to medical appointments, higher rates of ART initiation and adherence, greater viral suppression, and higher odds of long survivorship.[5–7] Collaborative communication and shared treatment decision making between patient and provider is particularly important for chronic pain management as chronic pain is a complex phenomenon that often results from multifaceted biological, psychosocial and social structural factors. Additionally, the experience of chronic pain is subjective and its assessment depends on patients' self-report.[8] The quality of patient-provider relationships plays an important role in patients' disclosure of pain-related information, as well as provider evaluations of patients' pain symptoms and corresponding care plan.[8]

Managing chronic pain is challenging due to the lack of safe, effective long-term treatments. Opioid analgesics provide quick, short-term relief of acute pain and cancer pain, and their use for chronic nonmalignant pain has been aggressively promoted by the pharmaceutical industry in recent decades.[9–11] Long-term use of opioids, however, can cause opioid tolerance, opioid induced hyperalgesia (hyper sensitivity to pain) and opioid dependence, and jeopardize recovery from drug use disorders among persons with drug use histories.[12–15] The drastic increase in opioid prescribing for chronic pain in past decades has generated the current epidemic of opioid use disorder in the US.[16] Policies to address this national crisis focus on restricting opioid analgesic dispensing.[17–20] Yet there is limited access to well-established alternatives for pain management among socio-economically marginalized populations, who comprise the vast majority of PWH.

Because of the subjective nature of chronic pain experiences and provider concerns about treatment risks among persons with drug use histories, affecting an estimated half of PWH,[21] it is not uncommon for HIV patients and providers to have disagreement about chronic pain severity and its management. Patients often place a high value on pain relief; indeed, chronic pain can have major adverse impact on function and well-being. Healthcare providers tend to prioritize treatment safety and are cautious about potential adverse biological consequences of treatments. Based on concerns about abetting patients' drug dependence or misuse (i.e. taking medications in a way other than prescribed, or sharing or selling them), providers might question patients' motivations and discredit or minimize their reports of pain.[13,14] However, these suspicions are not always founded on evidence.[22] In one study, medical providers perceived higher misuse of prescription opioids among younger patients, racial/ethnic minorities, and persons reported recent illicit drug use; however, there were no differences found in patient reports of opioid misuse status by patient age or race/ethnicity.[22] African Americans, in particular, face structural racism and disparities in treatment access. They are less likely to be prescribed opioid analgesics compared to non-Hispanic whites with similar health conditions.[23,24] Indeed, research suggests that PWH with low socioeconomic status (SES), drug use histories, and of minority race or ethnicity are especially vulnerable to stigma and discriminatory behavior of healthcare providers and others.[25–27]

In the context of African Americans' historic experiences of discrimination and trauma, and prescribing policies intended to control the opioid epidemic, patient-provider discussions about pain and its treatment and risks for analgesic misuse may create relationship tension and frustration to both parties. Providers might find it difficult to adequately treat such patients' chronic pain with available resources while addressing their concerns over patients' potential misuse of analgesics. On the other hand, patients may interact with their providers in ways to legitimize their suffering and maintain their credibility as they struggle with chronic pain.[28–30] Healthcare providers' attempts to address patients' potential opioid-related harms could cause unintended negative consequences, including patients' maladaptive coping with inadequately managed pain, such as self-medicating to alleviate pain, leaving their doctor or disengaging in healthcare and treatments altogether. Such behaviors could exacerbate pain hypersensitivity and threats to the patient-provider relationship, compromising patients' long-term HIV care, health outcomes and well-being.[4,14,31,32]

This study utilized a mixed-methods approach to assess the role of social discrimination and patient-provider engagement in PWH's chronic pain and its adequate management. The overall objective was to identify individual-level, interpersonal (patient-provider) and other structural factors predictive of self-medicating for pain and quality of life among marginalized persons with PWH. The specific aims are to:

Aim 1: *Examine the associations among African American patient reports of pain symptoms, healthcare discrimination, being denied pain medication requested, and later patient-provider engagement and substance use for pain.*

Aim 2: *Assess whether patient-centered patient-provider engagement (PCE) with primary care providers (PCP) mediates the effects of the patients' high depressive symptoms and perceived discrimination in healthcare settings on their later mental health-related quality of life (MHRQOL).*

Aim 3: *Explore qualitatively patients' perceptions of barriers and facilitators to chronic pain management in their encounters with their providers and the healthcare system.*

This study is a part of a larger research project, AFFIRM Care (2013-2019), which examined shared decision making on end-of-life care among socio-economically disadvantaged PWH in HIV care and their providers and informal caregivers. Longitudinal survey data collected from 331 PWH enrolled in AFFIRM Care were analyzed using structural equation modeling to examine the potential direct and indirect effects of baseline pain symptoms, healthcare discrimination, and being denied pain medication request on 12-month substance use for pain, through patient-centered patient-provider engagement with primary care providers (PCE-PCP) at 6 months follow-up (Aim 1). We also examined whether 6-month PCE-PCP mediates the effects of PWH's baseline high depressive symptoms and perceived discrimination in healthcare encounters on their 12-month MHRQOL, using structural equation modeling (Aim 2). In-depth interview and focus group data collected with a subset of 27 study participants were analyzed to further explore the barriers and facilitators to chronic pain management in their encounters with the healthcare system (Aim 3).

This study has the strength of integrating quantitative and qualitative data strands to better understand the challenges to healthcare relationships and their role in managing chronic pain and promoting quality of life among PWH. The study findings have potential implications for structural approaches to improving quality care and reducing health disparities among marginalized persons as well as alleviating healthcare providers' burden related to tense relationships with chronic pain patients and improving quality care and health outcomes of vulnerable PWH. Findings of the study will inform healthcare providers and policy makers on multi-level approaches to improving healthcare quality and health benefits of healthcare, and avoid unintended consequences of opioid policies on the patient-provider relationship in ways that abet structural racism and discrimination and its adverse impact on African Americans' quality of life. The results could also inform future policy and guidelines in training on chronic pain and management outcomes. In addition, findings will add to current literature and theories for better understanding on how bias and discrimination contribute to healthcare disparities.

ORGANIZATION OF THE DISSERTATION

The dissertation is organized into eight chapters. Chapter 1 provides a brief overview of the dissertation background, aims, and significance. Chapter 2 presents a literature review on chronic pain and MHRQOL among PWH, and healthcare relationships in treating chronic pain. Chapter 3 discusses the theoretical underpinnings of the dissertation. It also presents a conceptual framework that guides the research questions and analyses, the specific aims and hypotheses of the dissertation, as well as its public health significance and implications. Chapter 4 describes the research methodology, including the study setting, the mixed-methods design, and the quantitative and qualitative data collection and analysis plans.

Chapter 5, 6, 7 are written as individual manuscripts. Chapter 5 describes the association between mistreatment in healthcare and substance use for pain among African Americans with HIV and a history of drug use, and the role of PCE-PCP in this association. Chapter 6 discusses PCE-PCP as a mediator on the paths from PWH's depression and healthcare discrimination to their later MHRQOL. Chapter 7 delineates PWH's perceived challenges as well as positive attributes in their encounters with the healthcare system when seeking pain treatment, focusing on the relational aspects of care.

Chapter 8 concludes the dissertation by integrating the findings of the three manuscripts, discussing the rigor of the research, presenting overall interpretation and conclusions, and suggesting directions for future research and intervention.

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CHAPTER 2 – LITERATURE REVIEW

Chronic pain among people with HIV and a history of drug use

Chronic pain, variously defined as persistent or recurrent pain lasting longer than 3 (or 6) months,[1,2] is common among PWH. Although the source of pain is not often clear, long-term HIV infection and perhaps some antiretroviral therapies (ART) can lead to significant neuropathic pain and pain-related inflammatory conditions.[3] In addition, compromised immune system function makes them more vulnerable to various diseases including cancer and age-related health conditions that could cause other types of pain.[4,5] As in the general population, musculoskeletal pain is among the most common pain reports of PWH.[3]

Chronic pain is estimated to affect 39%-85% of US PWH, and is particularly prevalent and severe among PWH with a history of substance use or mental health disorders. [3,5–10] In a prospective cohort study, a path model showed that HIV status was associated with pain, which was predictive of illicit drug use and more depressive symptoms.[9] Other studies point out relationships between chronic pain and psychological distress, depressive symptoms, and feelings of hopelessness, even when controlling for disease severity.[5,9,10] Chronic pain significantly impacts the physical functioning and quality of life of its sufferers. In one study with PWH in the US, chronic pain was independently associated with 10 times greater odds of impairment in functional ability.[11] Moreover, increased pain severity could lead to decreased mobility, distress and challenges accessing healthcare and HIV treatments.[4,12] Similarly with the general population, national studies found that pain is associated with higher outpatient service use, inpatient admissions and average length of stay, as well as emergency room visits among PWH.[13,14]

Challenges in treating chronic pain

Chronic pain among PWH is complicated to treat because of their high rates of comorbid psychiatric and substance use disorders and related chronic conditions such as liver and kidney diseases.[15,16] In a nationally representative sample of PWH in the US, nearly 40% of respondents reported using an illicit drug other than marijuana.[17] PWH with a history of drug use face increased challenges in pain management, including potential drug-drug interactions with complex ART regimens and treatment for other chronic conditions, as well as high risks of adverse side effects with long-term analgesic use.[15]

Treating pain and substance use disorders at the same time is challenging. While opioid replacement therapies such as methadone and buprenorphine could also be used to treat pain, the duration of their analgesic effects is much shorter than their effects on opioid withdrawal and craving.[15,18] Therefore, providers must strike a careful balance between maintaining treatment efficacy and minimizing adverse effects from excessive dosing.[15,18]

Long-term opioid use, including prescription opioid analgesics and opioid substitution therapy (e.g. methadone), could itself lead to opioid-induced hyperalgesia (hypersensitivity to pain) as well as serious negative consequences such as increased opioid tolerance, potential physiological dependence, misuse, withdrawal symptoms, and accidental overdose.[19] There are also significant potential risks for concurrent use of opioids and other sedative medicines, such as benzodiazepines.[20] Other potential side effects of long-term opioid use include constipation, abdominal pain, possible cardiovascular events, and hormonal dysregulation.[19]

Among the potential harms of long-term opioid use, opioid tolerance could impede effective pain treatment.[21] It is estimated that nearly 28% of individuals receiving chronic opioid therapy required increased doses for reasons other than progression of the underlying condition, suggesting the possibility of a physiologic adaptation to opioid therapy.[19] Although increased medication dosage may help overcome opioid tolerance, many doctors are reluctant to prescribe, based on fear of initiating or supporting patients' hyperalgesia, opioid dependence and potential misuse of prescription analgesics.[5,7,18]

An analysis of insurance claim data of over a half million enrollees in five commercial health plans found a dose-response association between long-term opioid therapy and increased risks for opioid use disorder (i.e., opioid misuse or dependence).[22] Individuals who received long-term (>90 days) high dose (120+mg per day) opioids had more than 100 times greater odds of developing an opioid use disorder than those who did not receive opioids for similar conditions.[22] Overall, though, patients prescribed opioid analgesics report low risks. In a 2010 Cochrane review, signs of opioid dependence were reported among 0.27% of participants receiving long-term opioid therapy across studies.[23]

Opioid-induced hypersensitivity to pain, however, makes individuals with a history of drug use more vulnerable to pain and further complicates their pain treatment.[21] Hyperalgesia is associated with long-term exposure to a range of opioids, including heroin and prescription opioids, and is improved only by long-term abstinence from opioids.[21] Hence, there is a concern that opioid substitution therapy for opioid misuse/dependence and opioid pain medication could aggravate chronic pain in the long term, and result in a vicious cycle of escalating chronic pain and addiction severity.[8] The complications of addiction and biochemical effects of opioid analgesics create challenges for doctors to weigh the balance between potential benefits of available pain treatments and their potential for misuse or adverse consequences of long-term use.[10,24]

Another potential harm of opioid analgesics is related to overdose risk. A retrospective cohort study with 9940 patients who received three or more opioid prescriptions within 90 days for chronic non-cancer pain found dose-dependent associations between recent opioid prescription and risk of overdose.[25] Patients receiving 100mg or more opioids per day had a 1.8% annual overdose rate, an 8.9 fold increase in risk compared with those receiving 1-20 mg per day (0.2% annual overdose rate).[25] The risk of overdose is further increased when opioids are combined with other sedatives, such as alcohol, benzodiazepines, muscle relaxants, or sedative-hypnotics.[19] Moreover, resuming opioid therapy after a period of abstinence is also associated with high risk of overdose, due to the interim loss of opioid tolerance.[19] Data released by the Centers for Disease Control and Prevention (CDC) suggest that overdose deaths related to prescription opioids increased 5-fold from 1999 to 2016.[26] During the year of 2016, there were 17,086 prescription opioids overdose deaths, accounting for 40% of all opioid-related overdose deaths.[27]

As a result of the challenges in managing chronic pain within the context of substance use, many PWH with a history of drug use suffer from undertreated pain.[18] They are less likely to report pain relief compared with those without a drug use history.[5] Despite widely reported chronic pain in this patient population, only a small percentage is prescribed with long-acting opioid analgesic.[10] In particular, women, people with low socioeconomic status (SES), and racial/ethnic minorities might be especially vulnerable as these groups report the highest rates of pain and lowest rates of pain relief through treatment.[3,10,28,29]

Current practices and policy

Opioid analgesics are effective for short-term pain relief and have been increasingly prescribed for chronic pain in recent years.[19] Based on the National Health and Nutritional Examination Survey (NHANES), the prevalence of long-term use of prescription opioids for 90 days or longer increased from 1.8% of US adults in 1999-2000 to 5.4% in 2013-2014, compared with an increase in prevalence of overall prescription opioid use from 4.1% to 6.8% of US adults during the same time period.[30] In 2014, U.S. pharmacies dispensed 245 million prescriptions of opioids, with 35% being therapies for at least 3 weeks.[31]

Although opioid analgesics rapidly relieve acute pain and improve function, treating chronic pain with opioids has multiple risks while the benefits are not well understood.[31] There is limited evidence supporting the long-term effects of opioid analgesics.[19,32] Meanwhile the drastic elevation in opioid analgesics dispensed over the past two decades has been associated with a national epidemic of prescription opioid disorder and overdose deaths.[31] To reduce opioid-related harms, CDC released the Guideline for Prescribing Opioids for Chronic Pain in 2016, which recommends minimum exposure to opioids when treating chronic pain, with the exception of cancer pain and end-of-life care. Nonpharmacological therapies (such as cognitive behavioral, exercise and multidisciplinary therapies) and nonopioid pharmacologic therapies (such as acetaminophen, nonsteroidal anti-inflammatory drugs [NSAIDs], and selected antidepressants and anticonvulsants) are deemed safer options and are recommended by the Guideline as preferred treatments. In addition, the Guideline suggests that when an opioid is prescribed, it should be combined with nonpharmacological therapy and nonopioid pharmacologic therapy as appropriate.[1] However, evidence is lacking on their sustained effectiveness in treating chronic pain.[1]

The CDC Guideline also includes recommendations for clinicians to evaluate and address opioid-related harm, such as building risk mitigation strategies (e.g. offering naloxone for overdose prevention) into patients' treatment plan, reviewing a patient's history of controlled substance prescriptions in the state prescription drug monitoring program (PDMP), conducting urine drug tests, and directly offering treatment for opioid use disorders when needed.[1]

In line with the CDC Guideline, local policy changes have taken place to address harms related to prescription opioids. In Maryland, a state PDMP became available in 2013, providing information regarding patients' prescription and treatment histories related to controlled substances.[33] It contains data on two important predictors for overdose deaths: multiple prescribers and high total daily opioid dosage.[1] However, providers did not fully utilize this information, as the registration and use rates of the Maryland PDMP was low.[33] Required by a new law, prescribers and dispensers were mandated for PDMP registration by July 1, 2017, and mandated PDMP usage beginning in July 1, 2018, with the goal of assisting their informed decision making regarding prescription opioids.[34] In addition, Maryland passed the Prescriber Limits Act in 2017, which requires providers to prescribe the lowest effective dose of an opioid, and a quantity that is no greater than needed for the expected duration of pain.[35] Informed by the CDC Guideline, Maryland State Medicaid also revised its prescription opioids policy, mandating prior authorization for dispensing high dose, high quantity, or long acting opioids, effective on July 1, 2017.[36] The prior authorization requires providers to check PDMP, use urine drug screens, offer naloxone, sign an opioid treatment agreement with patients, and attest to benefit outweighing risk.[36]

Current recommendations for chronic pain management

Around the same time as the CDC Guideline, the US Department of Health and Human Services (HHS) released the National Strategy for Pain, outlining the federal government's first coordinated plan for a comprehensive population-health level strategy to reduce the burden of chronic pain.[37] Based on an earlier report of the Institute of Medicine (IOM), the Strategy recognizes that chronic pain, as a significant public health problem, "can be a disease in itself that requires adequate treatment and research commitment".[37] Given the multifaceted nature of chronic pain, the Strategy calls for integrated, multimodal, and interdisciplinary strategies for chronic pain treatment, addressing biopsychosocial factors contributing to pain and its alleviation. Indeed, a combination of various therapies including medical, surgical, psychological, behavioral, and complementary approaches are recommended, necessitating coordinated care of health professionals from diverse fields.[37]

Access to chronic pain therapies

While extensive efforts have been directed to reducing opioid harms, the lack of safe and effective treatment for chronic pain remains a problem. Chronic pain therapies recommended by CDC and by HHS as outlined in the National Strategy for Pain are not necessarily available or suitable for every patient group. For example, NSAIDs are not effective for neuropathic pain, and while they could be used to treat non-neuropathic low back pain, long term use of NSAIDs is associated with gastrointestinal (e.g. bleeding), renal, and other systemic adverse effects that could be exacerbated by pharmacological interactions with HIV medications (e.g. tenofovir).[29,38] Acetaminophen prescription also requires closer hepatotoxicity monitoring in populations with a higher prevalence of advanced liver disease, including persons with HIV and hepatitis C virus coinfection which is highly prevalent in PWH with a history of drug use.[29]

To address considerations specific to treating PWH, in September 2017 the HIV Medicine Association (HIVMA) of the Infectious Disease Society of America (IDSA) issued the first comprehensive guidelines for managing chronic pain in this population, focusing on nonpharmacological therapies.[29] However as recognized in the CDC Guideline, nonpharmacological therapies for chronic pain are not always or fully covered by insurance, presenting financial barriers to patients' access to pain care.[1] For example, cognitive behavioral therapies range from $20 to $50 per visit, as compared with $10-$15 out-of-pocket costs for a 30-day supply of generic prescription opioids.[37] These economic implications play a big role in treatment choices. In a statement in response to the CDC's Guideline, the American Society of Anesthesiologists wrote that "a major challenge in incorporating the Guideline in daily practice is that some of these recommendations may not be covered by the patient's insurance, which inhibits physicians' ability to treat patients using non-opioid approaches."[39] Similarly, the American Pain Society noted that "unfortunately, many non-pharmacological therapies are not reimbursed by Medicaid, Medicare, or third-party payers."[39] As at least 40% of HIV-infected adults in medical care received health insurance through Medicaid and/or Medicare, lack of insurance coverage likely hinders access to comprehensive, multidisciplinary strategies for pain management among this population.[40]

Healthcare relationships in treating chronic pain

Patient-centered patient provider engagement

Patient-centered care is characterized by the emphasis of "treating the individual as a whole person" in contrast with the traditional biomedical model that focuses on "treating the disease". It has been increasingly advocated since the term was coined in 1969 by Balint.[41] The IOM's 2001 report *Crossing the Quality Chasm* envisioned patient-centeredness as a cornerstone of a better US health care system for the 21st century, with patient-centeredness recommended as a fundamental orientation for improved care quality, and by extension patient outcomes of healthcare.[42] The IOM defined patient-centered care as care that is "respectful of and responsive to individual patient preferences, needs, and values" and ensures that "patient values guide all clinical decisions".

Patients' active engagement in interactions with healthcare providers are critical to creating a *mutual (deliberative) relation* with the providers and is essential to achieving optimal quality of care across myriad health conditions and patient populations.[43–45] Among the core tenets of patient-centeredness is the establishment of therapeutic alliance and trust.[42] Collaborative communication between patient and provider, mutual understanding and shared decision making are related to increased access and adherence to treatment, retention in care, and improved health outcomes.[43,46–48] Studies with PWH found that patient-centered, active patient-provider engagement was associated with increased adherence to medical appointments, higher rates of ART initiation and adherence, greater viral suppression, and higher chances of long survivorship.[46,49,50]

Patient-provider collaboration relies on mutual respect and providers' willingness to invest time and effort to share information and engage patients in decision making processes.[43,51] Reciprocal communication between patient and provider is especially important for chronic pain management because pain is a complex phenomenon that is shaped by a myriad of physiological, psychosocial, and behavioral factors. Additionally, the experience of pain is subjective and assessment of chronic pain depends on patients' self-report.[51,52] Evaluating chronic pain requires providers to elicit information from patients regarding their mental and behavioral health, social lives, and physical and social functioning, which itself may affect the quality of patient-provider relationships.[53] Establishing patient-provider rapport and trust is critical for patients' disclosure of pain-related information, including pain symptoms and coping strategies, with implications for shared decision making on goals of care and treatment choices collaborative care planning and patient adherence.[51,53]

Patient-provider disagreement about pain diagnosis and treatment

The invisibility of chronic pain due to lack of objective biomarkers create room for healthcare providers to question and raise doubts about the intensity or even validity of patients' pain experiences.[54] In contexts of healthcare encounters, doctors often underestimate the pain severity reported by individuals with HIV and/or a history of drug use, leading to under-treatment of pain in these populations.[18,55] An early study with ambulatory HIV patients in New York City found that nearly 85% of the patients who met the criteria for AIDS were undertreated for pain.[28] Similarly, a multi-center study of 34 HIV treatment facilities in France found that doctors underestimated pain severity in 52% of patients.[55] Among those who reported moderate-to-severe pain, 57% did not receive any treatment and 22% received weak opioids. [55] More recently, a systematic review documented under-treatment of pain among PWH internationally.[56]

Discrepancies between doctor's judgement and patient's pain perceptions are based on the continuing predominance of biogenic models of chronic pain, rooted in Cartesian mind-body dualism of modern medicine. Accordingly, providers tend to attribute the origin of pain to biomedical causes and discredit patient reports of pain symptoms in the absence of biomedical evidence.[54,57,58] Despite increasing neurobiological evidence on mutual effects of biological and psychological mechanism of pain perception, and consensus of the pain research community on a biopsychosocial paradigm for treatment, the biomedical perspective of pain etiology and treatment prevails.[54] As a result, when pain is lacking physiological explanations it might not be seen as "real".[54] A qualitative study found that primary care providers often felt the need to search for "objective evidence" that validates patients' pain complaints.[59] In another study, physicians specializing in pain treatment were found to discredit patients' pain complaints that had no physical roots; believed that they knew better than the patients; and considered assertive patients to be hard to educate.[57] Pain symptoms in the absence of physiological evidence of injury were considered by physicians as only existing in patients' mind and not deserving medical attention.[57] Research also shows that patients with medically unexplained pain might feel the need to acknowledge or search for a biological etiology in order for doctors to legitimate their pain concerns and offer treatments to alleviate their suffering.[51,57,60]

Consistent with a biopsychosocial paradigm of chronic pain, psychogenic and sociogenic models are also useful for understanding chronic pain. Supported by recent neuroscience evidence, the psychogenic models of pain postulate that pain is a perception rather than a sensation, suggesting that pain is perceived uniquely by each individual.[61] In this sense, psychological factors could interact with environmental and biological factors to affect somatic complaints, such that pain is a complex condition in its own right and could be a symptom of (mental, bodily or social) distress.[61] Despite strong evidence that psychological treatments can ameliorate chronic pain for many, psychologic explanations of pain might be subject to providers' interpretation and have stigmatizing effects on patients.[58] In a narrative review, patients from multiple studies reported worry that their pain experiences would be discredited if it were determined to be psychogenic.[58] Patients expressed concern about the stigma attached to mental illness if they received a psychologic diagnosis.[58]

The sociogenic models of pain, on the other hand, emphasizes social reactions or consequences of pain behavior, which result from pain experiences and can be reinforced by interpersonal interactions.[54,61,62] Providers' questioning or doubting of the legitimacy of a patient's reported pain symptoms and other negative interpersonal interactions may lead to patients' renewed efforts at legitimation, along with feelings of alienation, depression and anxiety, which are found to exacerbate pain symptoms.[57,61] Moreover, such negative interpersonal interactions in healthcare settings could further perpetuate the historical trauma and medical mistrust in African American communities that are deeply rooted in the intergenerational harms of medical mistreatment.[63,64] Based on the sociogenic models, cognitive behavioral therapy could be used to modify negative patterns of social interactions and social cognitions and to develop additional strategies (cognitive, behavioral, mindfulness) for coping with pain.[5,65] Similarly, healthcare providers can use a patient-centered approach to facilitate pain management through cognitive and behavioral processes, by encouraging active patient participation in decisions about health, including goals of care and treatment decision making.[1,5] One criticism of the sociogenic models, though, is that the focus on addressing pain related behavior shifts attention away from pain experiences and patient's suffering.[54]

The uncertainty about pain diagnosis and the persistence of chronic pain due to lack of effective treatment could lead to feelings of ambiguity or failure among both patients and providers.[54] Moreover, it is not uncommon for patients and their providers to have conflicting attitudes regarding pain management, which could threaten potential patient-provider collaboration and patient outcomes.[51,57] Patients often place a high value on pain relief whereas providers prioritize treatment safety and are cautious against potential adverse consequences. This discord is exemplified in an analysis of patient-provider communication over opioid treatment for chronic pain, in which researchers observed that patients and physicians "wrestled with uncertainty" regarding opioid-related harms and misuse in the negotiation about pain treatment.[66] Patients attempted to reduce their providers' uncertainty by assuring their medication compliance, and to prove their worthiness of prescription opioids to prevent providers from discontinuing their prescription due to concerns about misuse. However, providers may lose trust in their patients if they perceive such attempts by their patients as inadequate or failed. In addition, given the power divide, negotiation about pain treatment could engender an adversarial attitude between patient and provider, further damaging patient-provider relationships, threatening their viability and patients' access to care.[67]

Discussions about treatment inadequacies and misuse potential could create tension between patient and provider, as well as substantial frustration to both parties. Providers might find it difficult to effectively address their concerns over analgesic misuse. Merlin and colleagues reviewed medical records from a chronic pain clinic as part of an HIV healthcare unit and identified stigmatizing labeling and emotional languages by providers when they described patients' behaviors associated with prescription medication misuse.[68] The term "drug-seeking behavior" was used to imply patients' underlying intention to obtain medication for non-medical purposes. Providers also expressed their frustration related to those behaviors and their worries about possible negative implications and consequences.[68] In such contexts, patients were compelled to strive to demonstrate their credibility as they struggle with unrelieved pain.[66,69,70]

Healthcare policies and practices to prevent opioid-related harms could cause unintended negative consequences on healthcare relationships and quality care among marginalized persons with pain. Patients might develop maladaptive coping when they fail to obtain adequate pain relief. There is documentation of problematic behaviors among pain sufferers that transgress opioid prescription policies to control unrelieved pain, such as doctor shopping (i.e. multiple prescriber episodes) or running out of medications early by over-use or drug sharing. These behaviors are often interpreted by healthcare providers as indicators of (escalating or relapsing to) drug dependence and thus alert them to reduce or stop prescribing pain medication.[18] The term "pseudoaddiction" is used to refer to such behaviors that seem to be driven by addiction, though in fact they may reflect unrelieved pain.[71] Unfortunately, doctors are often unable to discern pseudoaddiction from addiction, as the two present similar behaviors and could both be temporarily relieved by increased opioid analgesic dosage.[71,72] In addition to efforts for accessing prescription opioids, some undertreated patients turn (or relapse) to use of alcohol or illicit substances to alleviate their pain.[6,18,60,73,74] These problematic coping behaviors and self-medication further compromise patients' long-term care and health outcomes by exacerbating their exposure and sensitivity to trauma and pain, damaging patient-provider relationships, interfering with their adherence to therapies, and undermining continuity and quality of care.[6,68]

Biases and discrimination in healthcare relationships

National studies have revealed that African Americans, among other racial/ ethnic minorities, are consistently less likely to be prescribed opioid analgesics in ambulatory care settings for chronic non-cancer pain and in emergency departments, compared with non-Hispanic whites who have similar health conditions and pain severity.[75,76] One possible historical root for the racial bias in pain assessment and treatment might be the misbelief that the black body is more resistant to pain. The idea was used for centuries to justify slavery, rape and medical experimentation on African American bodies, inhumane procedures which were performed without anesthesia.[77,78]

Besides African Americans and PWH, biases regarding chronic pain treatment exist for other patient groups and conditions, such as women experiencing pain from chronic fatigue syndrome, fibromyalgia, and other conditions; people who are on prescription opioids for intractable pain; older adults; and people with behavioral (drug use and mental) health disorders.[37] These biases contribute to disparities in pain care and increased vulnerabilities to high healthcare costs and poor health outcomes among these groups.[37] Biased attitudes by providers is disempowerment of disadvantaged patient populations, and may perpetuate disparities in health and well-being by decreasing patient-provider collaboration and patients' adherence and retention in care.[79,80]

Providers' explicit and implicit biases create further challenges in healthcare relationships and quality care. While explicit biases manifest at the conscious level and are more easily detectable, implicit biases are based on unconscious attitudes and stereotypes, and are processed outside of awareness.[81] A 2017 systematic review on 42 empirical studies found consistent evidence that implicit biases existed among healthcare professionals at a similar degree as the general population.[82] Healthcare providers' implicit biases could impact their interaction with patients, clinical diagnoses, and treatment decisions.[83] Such biases are predictive of discriminatory actions and often operate against those who are already vulnerable and socioeconomically disadvantaged, thus further perpetuating health care disparities.[82]

There are numerous examples of biases and discrimination in patient-provider relationships. Mistrust between patients with chronic pain and their providers is not uncommon and could in part be a result of stereotyping. Doctors' judgments might not always be based on facts about individuals' behaviors but rather may be biased by imputed statuses of social categories (e.g. race/ethnicity, sex, gender) to which the patient belongs. A systematic review found healthcare professionals generally held negative attitudes toward patients with substance use disorders, were unable or unwilling to empathize with them, and perceived them as violent, manipulative, or poorly motivated.[79] Such biases could result in providers' misjudgments about the patients' pain reports and lead to non-collaborative, misinformed treatment decision making.

Many pain patients with a history of drug use known to their providers are under persistent suspicion by their providers of prescription opioid misuse and related behaviors (such as taking the opioid for non-medical purposes) or opioid diversion (i.e. transferring legally prescribed controlled substance from the individual for whom it was prescribed to another person, such as by selling it).[84] Doctors might think that their patients are deceptive or exaggerative about their symptoms in order to obtain pain medications for reasons other than pain relief.[5,18] However, such suspicion is not always fact-based. In a study, researchers observed discordance between healthcare providers' presumptions about opioid analgesic misuse among HIV chronic pain patients and patients' self-reports.[85] Providers were found to incorrectly predict higher misuse of prescription opioids among HIV patients who were younger, African Americans, and persons with recent illicit drug use, whereas there was no difference in reported misuse status by age or by race/ethnicity.[85]

Mental health related quality of life among people with HIV

Advancement in ART has transitioned HIV care toward a chronic disease management paradigm that emphasizes improving patient's long-term well-being.[86] Mental health-related quality of life (MHRQOL) is an important clinical objective for PWH, as they are more likely to experience significant psychological distress and increased mental health challenges.[87,88] A review of 49 studies identified socio-demographic, clinical, psychological and behavioral factors associated with dimensions of quality of life among PWH found that unemployment, lower income and lower education were all correlated with poorer MHRQOL.[87] Smoking and current drug use, but not former use, were also negatively associated with MHRQOL. While most studies reviewed showed no correlation between virological status and MHRQOL, lower CD4-cell counts were found to be associated with lower levels of MHRQOL, both cross-sectionally and prospectively. It is suggested that faster disease progression in PWH with low CD4-counts might lead to distress and decline in mental health. In addition, presence of HIV-related symptoms was also linked to reduced MHRQOL.[87]

Depression, stigma and discrimination are among the major contributors to poor MHRQOL among PWH.[87] Both ongoing depression and history of depression were found to be strongly associated with reduced MHRQOL.[87,89] Intervention studies showed that improvements in depression could lead to increases in psychosocial functioning and dimensions of quality of life, including MHRQOL.[90,91] In addition, PWH are vulnerable to multiple and often intersecting sources of stigma and discrimination, which could have detrimental effects on their MHRQOL.[92–94] HIV, substance use, chronic pain-related stigma, and racial and gender discrimination have all been linked to worse mental health and quality of life in PWH.[92–94]

Supportive relationships with friends, family, and healthcare providers play an important role in PWH's psychological well-being. Social support has direct effects on individuals' mental health, especially in high-stress contexts and could serve as a buffer to reduce the negative impacts of stressors.[87] Studies found higher levels of positive social support and greater numbers of people one can talk to (size of emotional support network) were associated with better MHRQOL.[87] PWH's trust, perceived affection and respect in patient-provider relationships were also related to higher MHRQOL, whereas dissatisfaction with the amount of information received from healthcare providers, and difficulties in patient-provider communication were linked to worse MHRQOL.[95–97]

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CHAPTER 3 – THEORETICAL FOUNDATIONS

THEORETICAL ORIENTATION

This research applied a social constructionist perspective to understanding interpersonal processes of healthcare that impact well-being among marginalized persons experiencing HIV, chronic pain and other stigmatizing, complex conditions. The study examined how legacies of oppression based on race, class, health conditions and other social constructs remain in healthcare settings and adversely impact African Americans' marginalization and disparities in health and well-being. Social constructionism postulates that meaning is constructed through social processes rather than inherent in the nature of things. Conrad and Barker discussed the social construction of illness and summarized key findings regarding cultural meanings of illness as well as socially constructed illness experience and medical knowledge.[1] They suggested that "all illnesses are not the same", in the sense that certain illnesses are particularly embedded with cultural meanings. For example, contested illnesses such as chronic fatigue syndrome and irritable bowel syndrome, which are rule-out illnesses that cannot be determined biomedically and are only recognizable through otherwise unexplained common symptoms, are often subject to provider suspicions.[1,2]

Chronic pain overlaps with contested illness categories in that it is not objectively measurable, often lacks a clearly defined underlying cause and is seldom curable.[3] Similar to other contested illness sufferers, individuals with chronic pain are burdened with "the cultural meaning of a medically invisible condition", which is reflected in the social response to their condition, including how they are treated by healthcare providers within the healthcare system.[1] When pain has no organic root or is presumed to be psychogenic, the sufferer might be considered as not having a "real" illness or even being mentally unstable.[3] To make their pain more visible, some patients express their symptoms through pain behaviors. However this communication strategy may raise providers' doubt and lead to frustration at the lack of treatment effectiveness and continued patient complaints. As a result, the social response to chronic pain and its manifestations leads to stigmatization of the condition of chronic pain and the person so afflicted.

The social construction of medical knowledge contributes to the varying cultural meanings of specific illnesses. Medicalization, a process through which a condition is determined to be a "medical" problem and should be treated medically, illustrates how medical knowledge is socially constructed and used in healthcare encounters in ways that promote a patient's health and well-being or potentially malign them and perpetuate their suffering.[1,2] This process is social context-dependent and shaped by many factors, including the society's intent for social control (e.g., by defining what constitutes normal); the existence of an intervention; and the relative influence of the main stakeholders, such as the pharmaceutical and insurance industries, medical institutional authority, drug control/enforcement authorities, and the people who suffer from the condition and the extent to which they are organized as a lobbying force.[1,2]

The recent medicalization of chronic pain was largely driven by the commercial interests of the pharmaceutical industry as well as the desire of the afflicted individuals for medical solutions to their problem, in the context of inadequate attention to pain treatment prior to the 1990's.[2,4] When the sustained-release opioid analgesic OxyContin (generic name: oxycodone) was introduced to the market in 1996, its manufacturer Purdue Pharma aggressively promoted it along with the use of opioid analgesics in general, especially for chronic non-cancer pain.[5] The limited post-approval oversight of controlled drugs (such as monitoring industry marketing and promotion) by regulatory authorities failed to prevent Purdue Pharma from employing a number of controversial campaign strategies to mislead the public about the risks and benefits of prescription opioids.[4–6] Inspirational videos featuring patient testimonials were used to shape a public perception that chronic pain is a medical condition which can be effectively relieved by opioids and thus does not need to be tolerated, and that it requires active and intensive pharmaceutical treatment. [4,5] Free samples (e.g. a "patient starter" program providing free 7- to 30-day supply) and branded promotional items (such as hats and stuffed animals) were widely distributed.[4,5] Purdue Pharma also invested extensively in influencing opinion leaders in the medical community by holding all-expenses-paid pain-management and speaker-training conferences.[4,5] Prescriber profile databases were used to identify physicians with large numbers of chronic pain patients, who were then targeted by sales representatives through the encouragement of a bonus reward system.[4,5] These marketing tactics greatly influenced prescribers' behaviors and public expectations regarding proper pain treatment and pain relief, resulting in a huge increase in the use of prescription opioids for non-cancer pain, along with enhanced consumer expectations for confirmation and empathy for their suffering through medical processes of pain diagnosis and treatment.

Medicalization has various social consequences, regardless of the effectiveness of the medical treatment.[7] Framing a condition as a medical problem leads to attempts to develop medical causes and solutions, and a failure in addressing nonmedical aspects of the problem such as social (e.g. stigmatization of chronic pain sufferers) and structural factors (e.g. limitations in healthcare and insurance systems, and in the regulatory infrastructure).

Through medicalization, collective social structural problems are individualized, resulting in dislocation of responsibility, which might have social justice implications.[7] In the medicalization of chronic pain, the misrepresented risks and benefits of opioid analgesics and vested political and economic interests further contributed to the opioid epidemic, in which the healthcare system plays an important role.[4] The medicalization process of chronic pain, while lacking appropriate medical solution, along with the punitive oriented healthcare policies that vastly attribute the responsibility to individual actors (patients and providers) for addressing the epidemic of prescription opioid use disorder, potentially further impeding disparity populations' engagement with their providers and thus access to quality healthcare.

The concept of "liminality" was employed by Jackson for analyzing the complexity of chronic pain and is useful in understanding the problems of medicalizing chronic pain.[3] A liminal state is "betwixt and between" categories; it is neither one thing nor another.[3] The ambiguity of liminal beings causes confusions of "category mixing" and challenges the social order system that follows the hegemonic dualistic classification logic.[3] Therefore liminal entities do not have a proper position or place in the social cultural space, which is regulated by law, custom and convention.[3] Chronic pain sufferers are assigned liminal statuses because their condition transgresses the mind (mental) and body (physical) territories and is often an ongoing and incurable condition. Thus, chronic pain sufferers are often considered neither "properly ill" nor "properly sick" as the cause and symptoms of the condition cannot be determined biomedically.[3]

Jackson has argued that the liminal qualities of chronic pain create ambiguity, uncertainty, frustration and other negative emotions among persons with whom the pain sufferer engages, including their healthcare providers.[3] Chronic pain framed as a biomedical problem implies an expectation for “cure”, given biomedicine’s emphasis on acute conditions and curative care. While the medicalization of chronic pain gives its sufferers a “sick role”, the sick role is only valid for a bounded time period. From the social control standpoint, the social disruption associated with the often unending or recurring quality of chronic pain, together with its “uncertain ontological status”, elicits stigmatizing social responses to pain complaints and pain behaviors, concerning who is entitled to the sick role and who deserves the “secondary gain” from it, such as receiving sympathy, welfare benefits, and medical services including prescription opioids.[3] These responses, hallmarked by doubt or disbelief in chronic pain complaints, have serious interpersonal, emotional, and health consequences.[8]

Drawing from social constructionism, the present research is interested in the reality around pain treatment from patients’ perspectives; in particular, how chronic pain patients conceptualize pain causes, experiences, and behaviors. In the study of social construction of illness, Conrad and Barker postulate that “all illnesses are constructed at the experiential level”.[1] This research aims to explore lived experiences of managing chronic pain, with a focus on patient-provider interactions in the clinical context, and its impacts on patients’ health and well-being outcomes.

Finally, this research examines the intersecting systems of multiple sources/statuses of stigmatization and discrimination to further examine the sociogenic aspects of chronic pain and its effects on the well-being of marginalized persons. The theoretical framework of intersectionality posits that multiple social statuses intersect to yield health disparities and advantages, and problematizes the unidimensional analyses of single social characteristic categories that individualizes and minimizes health impacts of structural discrimination on communities experiencing health disparities.[9] In *Conceptualizing stigma*, Link and Phelan point out that individuals could be labeled with multiple stereotypes; therefore, some groups are more stigmatized than others.[10] They also emphasize the existence of multiple mechanisms for stigmatizing, and that researchers must consider a host of stigmatizing circumstances when studying disparities in the distribution of life opportunities, including health and well-being.[10] Through the lens of intersectionality, this research focuses on a population at the intersection of multiple stigmatized labels: illicit drug use, HIV infection, minority race/ethnicity and poverty.

CONCEPTUAL FRAMEWORK

The conceptual framework (Figure 3.1) is informed by the Interaction Model of Client Health Behavior (IMCHB).[11] The IMCHB is a patient-centered model that captures the dynamics by which individuals' unique physiological, psychosocial, and environmental factors combine with their interaction with healthcare providers to produce health outcomes. The model delineates the interrelationships between three main components: individual patient characteristics (client singularities), interpersonal process between patient and provider during a healthcare encounter (client-professional interaction), and resulting patient health outcomes. The IMCHB was first developed in the field of nursing research and has been applied to various healthcare settings.[12,13] Benefiting from the philosophy of nursing practice, the IMCHB has a strong emphasis on the relational aspects of health care and the process through which patient and provider together determine a health decision and a health action.[11,14]

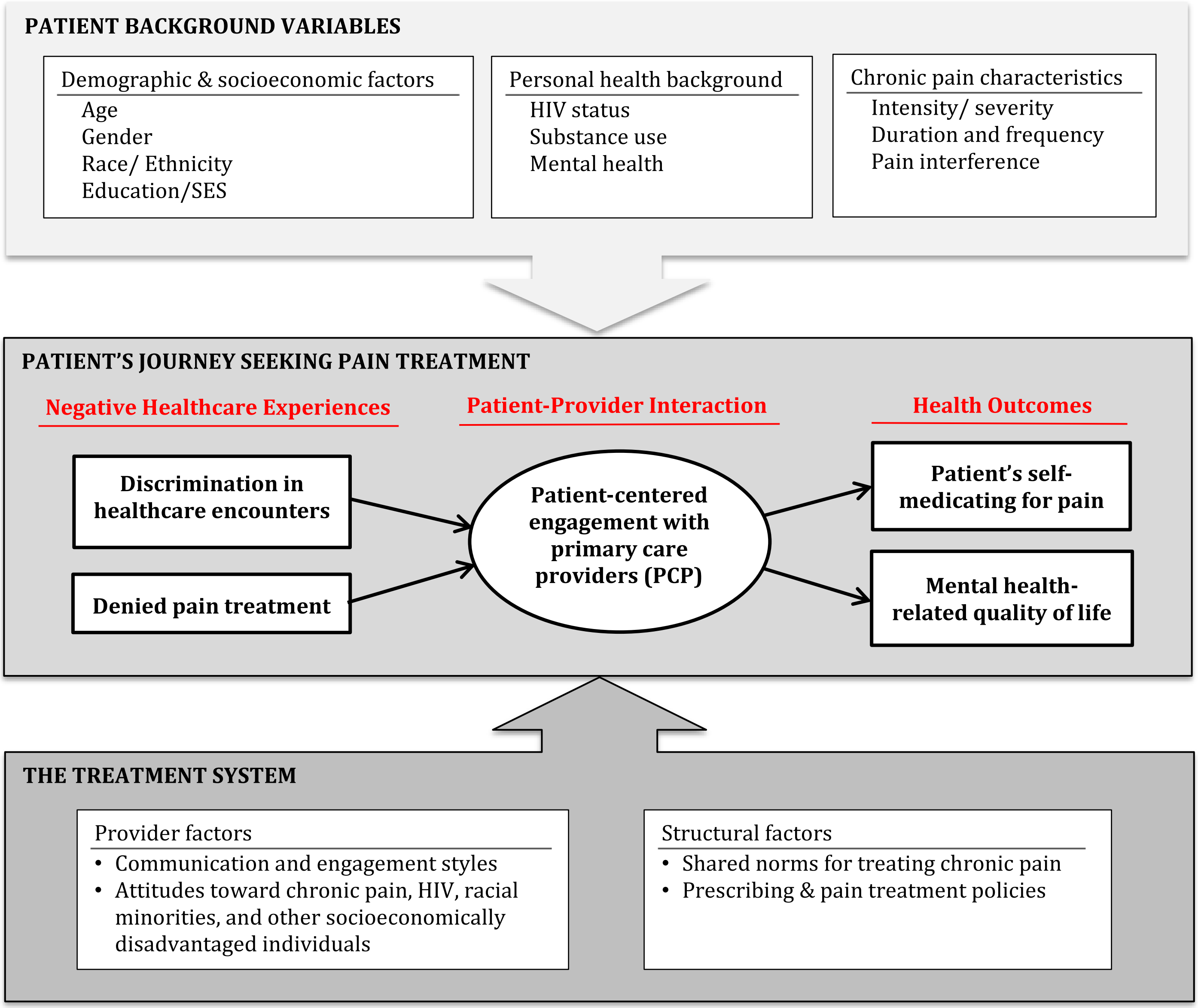
The IMCHB posits that patient background variables—including demographic characteristics, social and environmental support and constraints, and previous health care experiences—have important effects on the subsequent patient behaviors and treatment outcomes. By shaping patient motivations, cognitions, and emotions, patient background variables influence their responses to health problems and impact how they behave during patient-provider interactions, which in turn affect their health outcomes. In addition, the fit of providers' reactions to the patients' responses to their health problems may also contribute to patients' health seeking behavior (such as self-medicating for pain) and its impact on well-being.

Adapted from the IMCHB, the conceptual framework of the present research (Figure 3.1) depicts how various individual-level, interpersonal (patient-provider) and structural factors work in conjunction to impact patient's journey adapting to and negotiating treatment for chronic pain. Patient individual factors including demographics, SES, HIV status, substance use, mental health, and pain symptoms are known to be associated with biases and discrimination in health care and with treatment access.[15] Negative healthcare experiences such as discriminatory treatment, dismissed pain complaints, and being denied access to pain medication or other treatments could undermine patients' ability, motivations, and willingness to optimally engage with healthcare providers in subsequent encounters, and lead to undesired health outcomes. Health outcomes of focus in the present study comprised: 1) patients' self-medicating for pain, which could be a result of insufficient access to pain treatment and might lead to more adverse consequences; and 2) patients' mental health-related quality of life (MHRQOL), an important objective for PWH that might reflect the psychological impacts of negative healthcare experiences and suboptimal patient-provider interactions.

The IMCHB posits various aspects of patient-provider interaction, including provider's provision of health information that is appropriate in amount, and is meaningful and comprehensible by the patient; provider affective support and attention to patient's level of emotional arousal; maximized patient decisional control within the appropriate range based on patient individual factors; and the match between patient needs and provider skills and competencies. In the current research, patient-provider interaction is operationalized as patient-centered engagement with primary care providers (PCP), which highlights characteristics that largely overlap with elements described in the IMCHB: patient-provider shared decision making, provider's provision of sufficient and comprehensible information on treatment options, side effects, and risks, as well as provider's support for patient decisions and knowing the patient as a person.

In addition to patient individual factors, provider and structural factors that may impact patients' healthcare experiences are also included in the conceptual framework. Provider attitudes and communication styles play important roles in the quality of patient-provider engagement, and in healthcare biases and discrimination. Structural factors such as organizational climate in healthcare settings including shared norms for treating chronic pain, and the federal, local, and institutional policies relevant to pain treatment also have important influences on patient access to pain treatment, and on how providers interact with patients.

Figure 3.1 Conceptual framework



RESEARCH OBJECTIVES & AIMS

The objective of this research is to identify individual-level, interpersonal (patient-provider) and structural factors predictive of self-medicating for pain and quality of life among marginalized PWH. The specific aims are to:

Aim 1: *Examine the associations among patient reports of pain symptoms, healthcare discrimination, being denied pain medication requested, and later patient-provider engagement and substance use for pain.*

In this quantitative aim, it is hypothesized that adjusting for patient factors,

1) Patients' bodily pain and prior experiences of discrimination in healthcare encounters and being denied pain medication would be related to worse engagement with their primary care providers (PCP) at a later time;
2) Higher patient-centered patient-provider engagement (PCE) with PCP (PCE-PCP) is prospectively associated with lower likelihood of substance use for pain; and
3) There are indirect paths from pain and each type of negative healthcare experience to the substance use for pain outcome, mediated by PCE-PCP.

Aim 2: *Assess whether PCE-PCP mediates the effects of the patients' high depressive symptoms and perceived discrimination in healthcare encounters on their later mental health-related quality of life (MHRQOL).*

In this quantitative aim, it is hypothesized that adjusting for patient factors,

1) Depression and prior experience of discrimination in healthcare encounters are associated with reduced PCE-PCP and poor MHRQOL at a later time;
2) PCE-PCP is prospectively associated with MHRQOL;
3) PCE-PCP mediates the effects of patients' depression and perceived discrimination in healthcare encounters on their mental health related quality-of-life.

Aim 3: *Explore patients' perceptions of barriers and facilitators to chronic pain management in their encounters with the healthcare system.*

In this qualitative aim, in-depth interview and focus group discussions with patients are used to:

1) Explore participants' lived experiences with chronic pain, HIV, and drug use histories to provide a context for understanding their challenges in seeking treatment for and managing chronic pain;
2) Explore participants' experiences and expectations in seeking and obtaining chronic pain treatment;
3) Identify challenges and opportunities in healthcare relationships regarding chronic pain management;
4) Understand how quality of patient-provider engagement plays a role in the management of chronic pain and potential risks for relapse to drug use among a marginalized population that experiences intersectional health and social disparities.

PUBLIC HEALTH SIGNIFICANCE

The proposed study addresses an important health problem of chronic pain among African Americans with HIV and a history of drug use. While past research has examined the disparate chronic pain burden among various populations, including racial/ ethnic minorities and people with a history of drug use or with HIV, very little research has focused on the intersection of drug use, HIV infection, and minority race/ethnicity. Considering the high HIV and drug use risks among African Americans, and the high rate of drug use among PWH,[16] this research will fill gaps in the literature by focusing on this uniquely vulnerable population with regard to discrimination and chronic pain.

The study utilizes an innovative mixed-methods approach that incorporates different data sources to better understand from patients' perspectives the challenges to healthcare relationships and patient-provider collaborative management of chronic pain among PWH. Particularly, the study examines the barriers to pain treatment among individuals at the intersection of multiple vulnerabilities, i.e. drug use, HIV infection, and minority race/ethnicity. Findings of the study will add to current literature and theories for better understandings of how discrimination in healthcare encounters contributes to pain and disparities in access to and outcomes of quality care.

The study has potential implications for improving the quality of long-term care for PWH, and alleviating healthcare providers' burden related to relationship tension with chronic pain patients. Findings of the study could help healthcare providers gain important insight into improving patient-provider collaboration, and help medical education and training address biases and increase empathy in providing health care. The results will inform provider and patient interventions and programs on patient-centered care and chronic pain management. Findings could also inform future policy and guidelines in treating vulnerable chronic pain patients.

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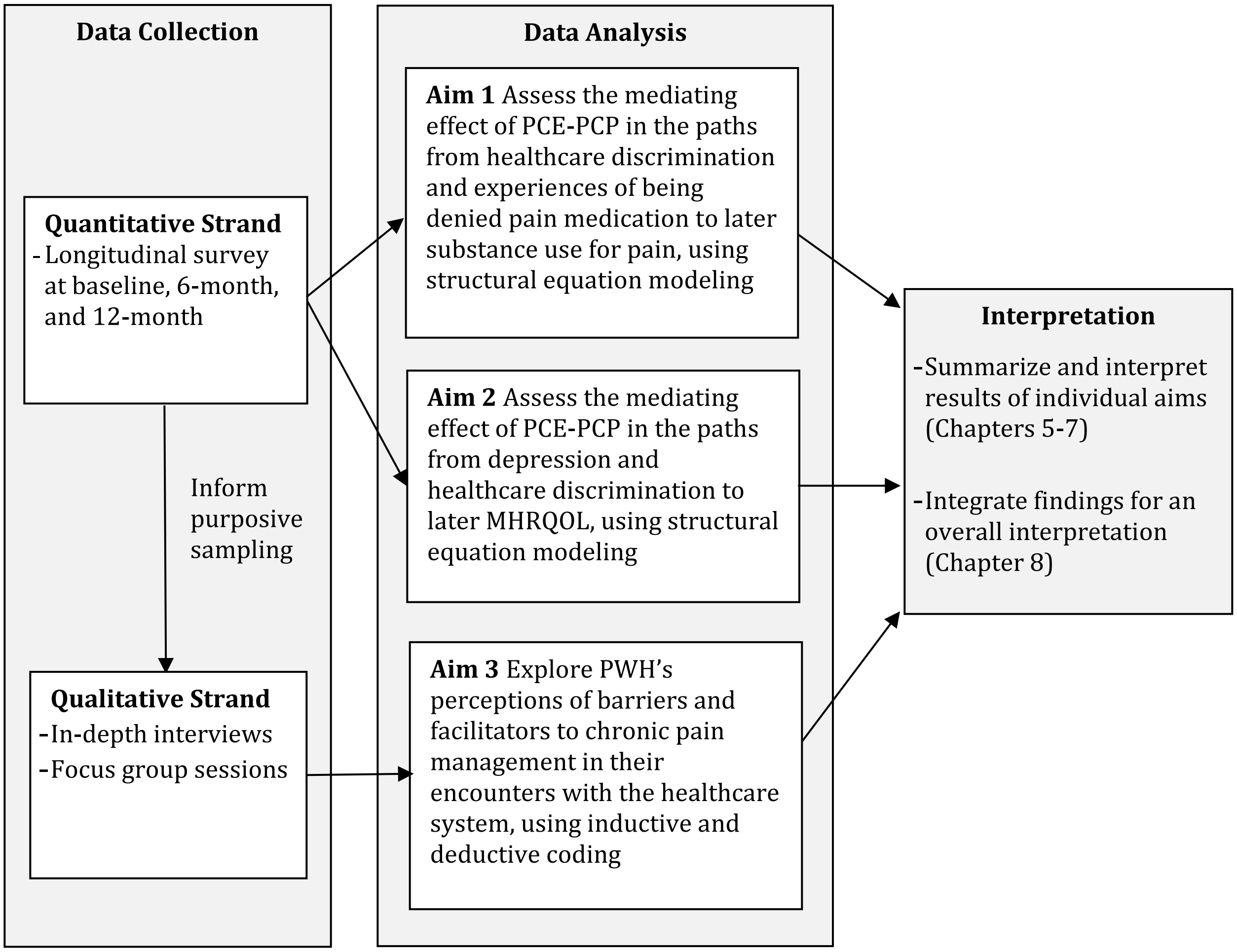
CHAPTER 4 – METHODS

RESEARCH DESIGN

This research is a part of a larger study AFFIRM Care (2013-2019), which examines social environmental factors associated with health outcomes and well-being among socio-economically disadvantaged PWH and their informal caregivers. A mixed-methods approach was employed utilizing a convergent parallel design, in which concurrently collected quantitative and qualitative data were analyzed independently for an overall interpretation.[1] Data collected in the quantitative strand were used to assist purposive sampling to select information-rich cases for the qualitative strand. At the interpretation stage, findings from different data strands were integrated to facilitate a more comprehensive understanding of PWH's challenges to patient-provider relationships and managing chronic pain. Figure 4.1 provides a diagram showing the flow of the research design, and an overview of the methods used to address each research aim.

Figure 4.1 Convergent parallel mixed-methods study design



RECRUITMENT & RETENTION

The AFFIRM Care Study recruited participants from the Johns Hopkins adult HIV clinic and community venues in Baltimore, Maryland, USA. The recruitment criteria included being an adult (ages 18 years or over), HIV seropositive, and reporting current or former use of heroin, crack, or cocaine. A total number of 372 PWH were enrolled in the AFFIRM Care Study. Among them, 370 filled out the baseline survey, and 331 completed all three semiannual surveys. No statistically significant difference was found in the demographic characteristics and other background variables between participants retained in the study and those lost to follow-up (Table 4.1).

Table 4.1 Comparisons between participants retained in the study and those lost to follow-up

	Participants retained in the study (n=331)	**Participants lost to follow-up (n=39)**	
	Mean (SD) or % (n)	*Mean (SD) or % (n)*	*p-value**
Demographics			
Age	52.31 (*SD*=6.67)	53.33 (*SD*=6.60)	.37
Male gender	56.5% (*n*=187)	46.2% (*n*=18)	.22
African American race	95.8% (*n*=317)	92.3% (*n*=36)	.33
Education			.40
8th grade or less	9.1% (*n*=30)	15.4% (*n*=6)	
Some high school, no diploma	39.3% (*n*=130)	28.2% (*n*=11)	
High school diploma or GED	31.1% (*n*=103)	38.5% (*n*=15)	
Some college or technical training	16.9% (*n*=56)	15.4% (*n*=6)	
College degree	2.7% (*n*=9)	0% (*n*=0)	
Any graduate training	0.9% (*n*=3)	2.6% (*n*=1)	
Monthly income			.18
No income	0.9% (*n*=3)	0% (*n*=0)	
Less than $250	5.4% (*n*=18)	5.1% (*n*=2)	
$250-$499	9.4% (*n*=31)	12.8% (*n*=5)	
$500-$999	55.6% (*n*=184)	74.4% (*n*=29)	
$1000-$1499	19.0% (*n*=63)	5.1% (*n*=2)	
$1500-$1999	4.8% (*n*=16)	0% (*n*=0)	
$2000 or more	4.2% (*n*=14)	2.6% (*n*=1)	
Average level of pain (0-10) at baseline	5.16 (*SD*=3.49)	5.62 (*SD*=3.58)	.44
Substance use assessed at baseline			
Last time injected drugs			.15
Never	48.9% (*n*=162)	42.1% (*n*=16)	
More than 5 years ago	30.5% (*n*=101)	31.6% (*n*=12)	
1-5 years ago	5.1% (*n*=17)	10.5% (*n*=4)	
6-12 months ago	3.9% (*n*=13)	10.5% (*n*=4)	
1-6 months ago	4.2% (*n*=14)	5.3% (*n*=2)	
In the past month	7.3% (*n*=24)	0% (*n*=0)	
Alcohol consumption			.87
Less than once a week or never	60.1% (*n*=199)	66.7% (*n*=26)	
1-2 times per week	10.6% (*n*=35)	10.3% (*n*=4)	
Several times a week	10.6% (*n*=35)	10.3% (*n*=4)	
Once a day	8.5% (*n*=28)	7.7% (*n*=3)	
More than once a day	10.3% (*n*=34)	5.1% (*n*=2)	

*ANOVA tests were conducted for continuous variables and Chi-square tests were conducted for categorical variables.

A subsample of 33 PWH participated in in-depth interviews or focus group sessions. Between August 2014 and July 2019, we conducted 27 in-depth interviews and 1 focus group (consisted of 3 sessions). We chose to collect data through both in-depth interviews and focus group sessions because while one-on-one conversations work best for sensitive topics such as drug use and misuse, interactions among group participants allow exchange of ideas and provide an opportunity to generate rich discussions around less sensitive topics, such as strategies and resources for pain management.

After the first 12 in-depth interviews, we reviewed the interview transcripts and invited three participants who had more experiences interacting with the healthcare system in relation to their chronic pain for a follow-up interview. We also reviewed surveys that participants filled out for the AFFIRM Care Study, and identified those who consistently reported pain symptoms at all three survey time points, and those experienced tension in healthcare encounters (such as experiences of discrimination or being denied pain medication) to invite for interviews. In addition, participants reporting moderate to severe pain in the surveys, as defined by a rating of 5-7 on the Brief Pain Inventory Scale[2] (0 = no pain, 10 = worse pain possible), were invited to join a focus group because they might be more likely to experience ambiguity and uncertainty in pain treatment, which could lead to tense care relationships. We adjusted the recruitment for the qualitative strand to balance the gender composition in the sample. Figure 4.2 presents a consort diagram of the study. Details about the quantitative and qualitative data collection procedures and instruments are described in Chapters 5-7.

Figure 4.2 Consort diagram

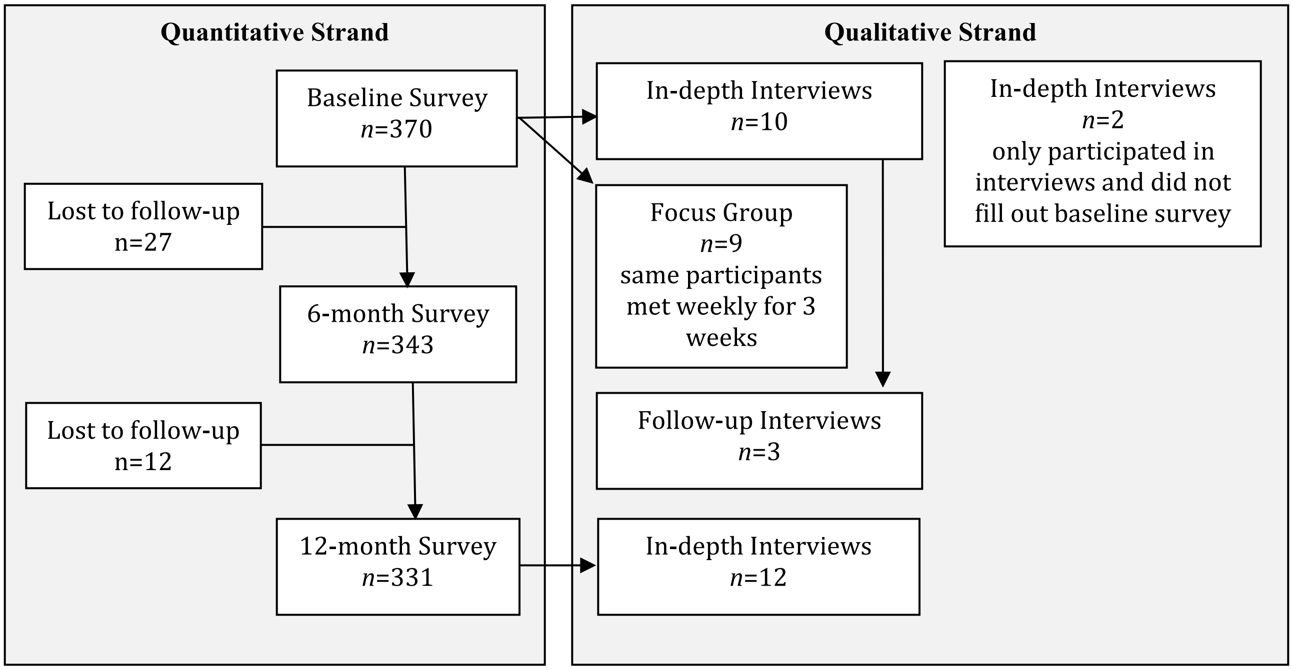
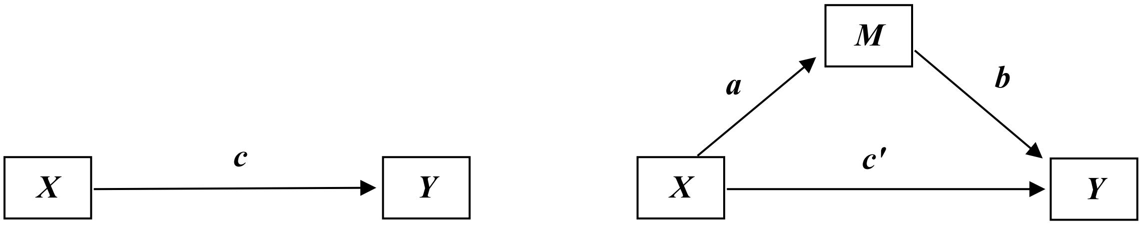


Table 4.2 Indicator variables for the PCE-PCP factor

Survey Questions	Measurement Scale
My main healthcare provider –	
Knows me as a person	yes / no
Involves me in decisions about my treatment as much as I would like	0 – 3 (never – always)
Explains the pros and cons of different treatment options	0 – 3 (never – always)
Supports my decisions	0 – 3 (never – always)
Provides me enough information about treatment side effects or risks	0 – 3 (never – always)
Involves my partner or close family members in my care as much as I would like	0 – 3 (never – always)

Figure 4.3 Path models illustrating total effect (left) and mediated effect (right) of X on Y



DATA ANALYSIS

Quantitative strand

To address *Aim 1* and *Aim 2*—both of which examined PCE-PCP in relation to PWH's health and quality-of-life outcomes—we conceptualized PCE-PCP as a latent variable measured by 6 items (Table 4.2). First, we conducted an exploratory factor analysis with the six items measuring PCE-PCP at baseline and at 6-month in Mplus 8.4.[3] Next, we used structural equation modeling with weighted least square mean and variance adjusted (WLSMV) estimation[4] to examine the mediating effects of PCE-PCP in the following paths:

1) From healthcare discrimination and experiences of being denied pain medication to later substance use for pain *(Aim1); and*
2) From depression and healthcare discrimination to later mental health-related quality of life *(Aim 2).*

Mediation occurs when the association between an independent variable X and a dependent variable Y can be explained by an intervening (mediating) variable M (Figure 4.3). We used a one-step approach to demonstrate mediation by examining the indirect effect of X on Y through M.[5] Previously, Baron and Kenny outlined three steps for determining a mediation effect in their classic paper published in 1986:[6]

1) Establish the association between X and Y (path c in Figure 4.3);
2) Establish the association between X and M (path a in Figure 4.3);
3) Examine the association between M and Y, controlling for X (path b in Figure 4.3).

When a mediation effect exists, c' should be smaller than the total effect (c) in absolute value. Baron and Kenny suggested that a non-detectable c' would indicate complete mediation, meaning that the association between X and Y can be fully explained by M.

In addition, Baron and Kenny recommended using the Sobel z-test to assess the indirect effect a x b in Figure 4.3.

Baron and Kenny's work has laid important foundations for further development in the field of mediation analysis and since then, many researchers have made recommended adjustments to their approach, including relaxing the requirement to first establish the association between X and Y (path c in Figure 4.3).[5,7,8]

As Shrout and Bolger explained, when the effects of X on M (path a in Figure 4.3) and M on Y (path b in Figure 4.3) are both medium in size, such as in causal processes where X and Y are temporally distal, the bivariate association between X and Y will be small in size.[7] As a result, there could exist scenarios where the available study sample size have enough power to detect the X-M and M-Y associations, but not the X-Y association (path c in Figure 4.3). In such case, our understanding of the relationship between X and Y could be improved by taking the mediation process into consideration. Therefore, the establishment of X-Y association should not be a prerequisite for perusing mediation analysis.

Moreover, suppressor processes could exist and make the X-Y bivariate association appear weak.[7,8] If the indirect effect $a \times b$ and the direct effect c' are similar in magnitude but have opposite signs, they might cancel each other out and result in a total effect (c) that is close to zero. In this scenario, the mediation effect exists despite the lack of a significant X-Y bivariate association.

In this research, we applied MacKinnon's recommended one-step approach to demonstrate mediation by estimating the indirect effects (*a x b*), instead of following Baron and Kenny's three steps.[5] Bootstrap tests were used to examine the indirect effects because bootstrap confidence intervals take into account potential non-normal distribution of the mediated effects and are more accurate than symmetric confidence intervals in Sobel's test.[5] Therefore, bootstrap tests have superior statistical power to detect mediation in comparison with Sobel's test, and are particularly recommended for small to moderate sized samples.[7] Using this one-step approach, a significant indirect effect with a confidence interval that does not include zero would suggest mediation, without the need to establish prior bivariate association between the independent and the outcome variables.[5,7,8]

In the model building for both *Aim 1* and *Aim 2*, exposures measured at baseline were entered as independent variables and outcomes assessed at 12-month were used as dependent variables. The mediating effect of 6-month PCE-PCP on each *X*-*Y* path was examined. The use of longitudinal data to establish temporality between independent, mediating, and dependent variables prevented reverse causality. We also identified potential confounders for each pair of *X*-*X*, *X*-*M*, *X*-*Y*, and *M*-*Y* based on literature review, and included them as covariates in each model. In addition, baseline measurements of the mediator and the outcome were adjusted for in the models, to strengthen the plausibility of the no unmeasured confounding assumptions.[9] Figures 4.4 and 4.5 show the mediation models tested in *Aim 1* and *Aim 2*, respectively.

Figure 4.4 Mediation models tested for *Aim 1*

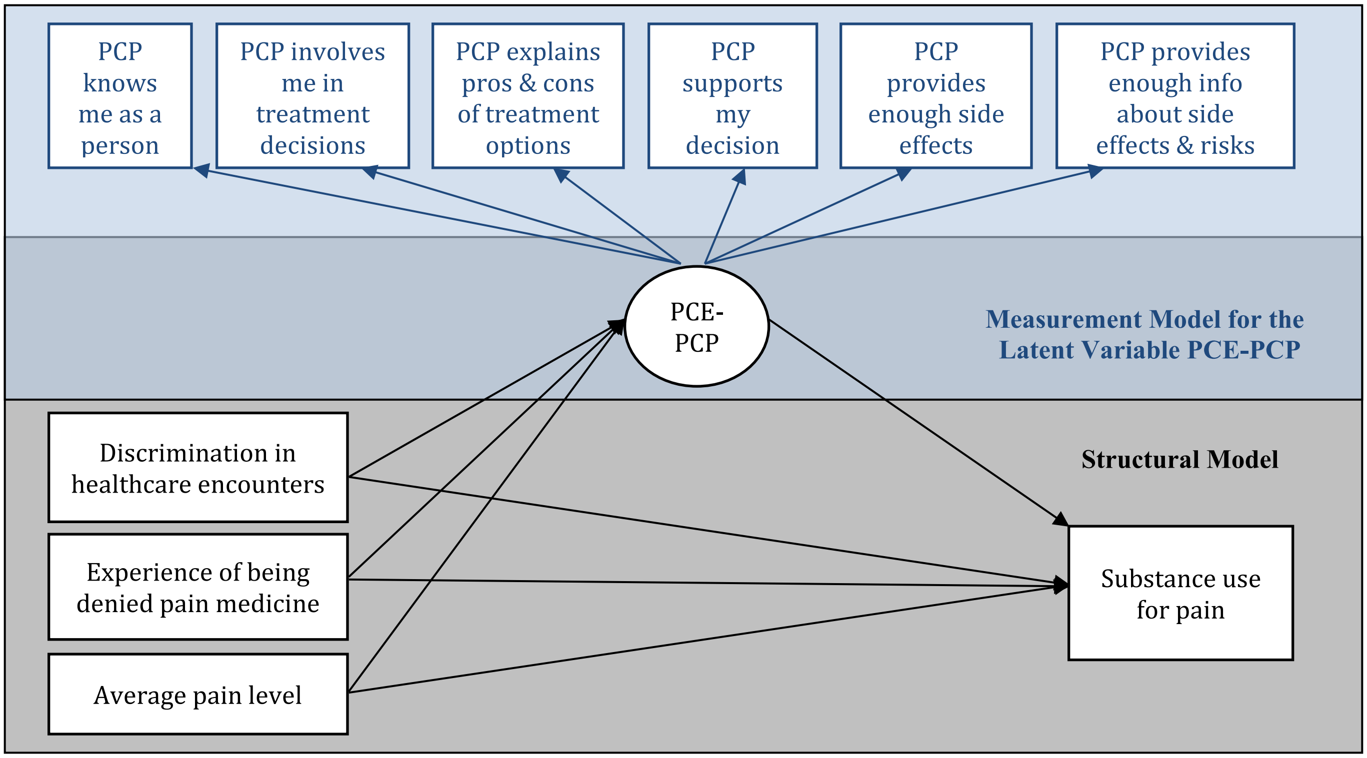
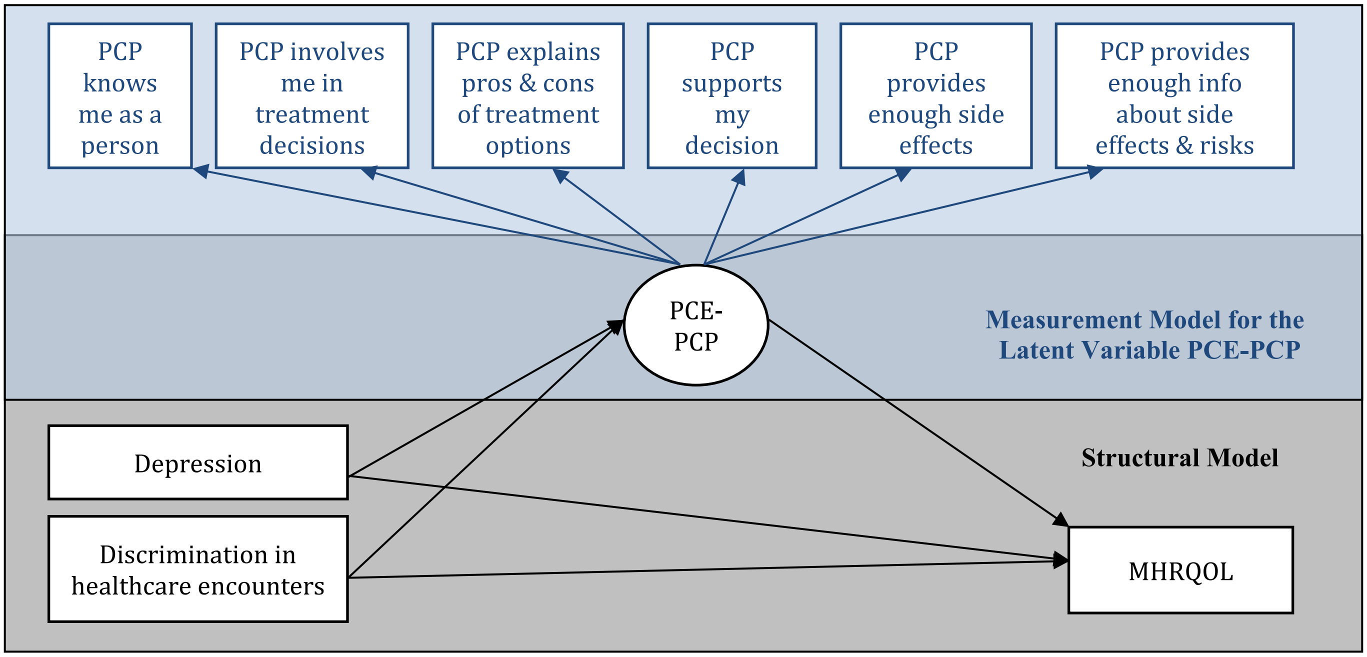


Figure 4.5 Mediation models tested for *Aim 2*



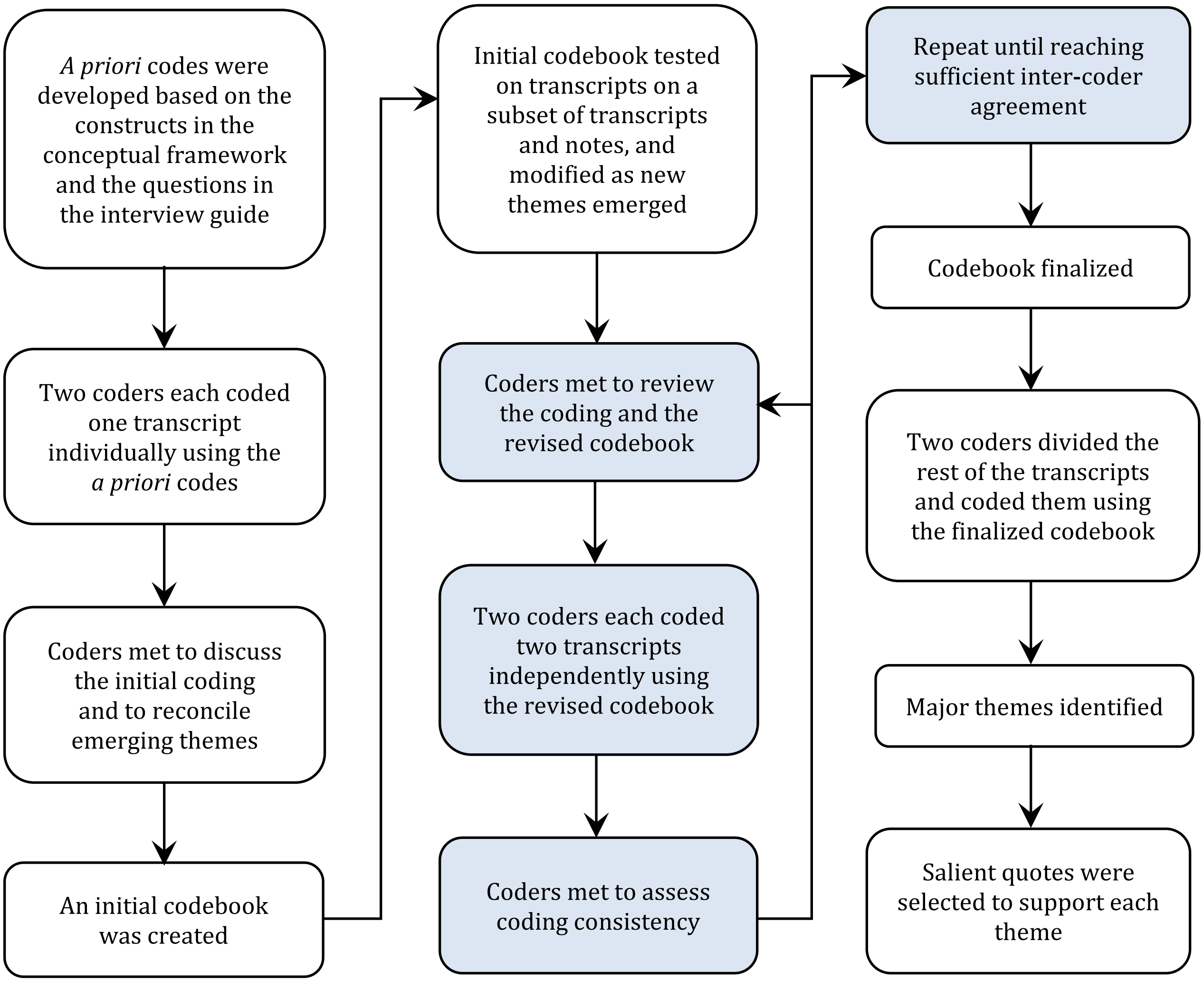
Qualitative strand

To address *Aim 3*, a qualitative approach was used to explore PWH's perceptions of barriers and facilitators to chronic pain management in their encounters with the healthcare system. In-depth interviews and focus group sessions were audio-recorded and professionally transcribed verbatim. A combination of inductive and deductive coding was used for data analysis. Figure 4.6 shows the coding iterations.

I first developed *a priori* codes based on questions in the interview guide and research constructs of interest. A second coder and I each read one transcript and its associated field notes individually, and applied the *a priori* codes while writing memos on emerging themes, personal reflections, and analytic notes. The two coders then met and discussed the initial coding and reconciled emerging themes noted by each. Based on these discussions, I created an initial codebook with definitions and examples, tested it on a subset of the transcripts and notes, and revised the codebook as any new theme emerged. At the end of this process, the team reconvened to review the coding and the revised codebook.

Next, both coders independently coded two transcripts using the revised codebook and met to assess coding consistency and modified the codebook as needed. This process was repeated until sufficient inter-coder agreement was reached. Finally, the two coders divided the rest of the transcripts and coded them using the finalized codebook. Major themes were identified, and salient quotes were selected to support each theme. Throughout this iterative process, the principal investigator (PI) of the study served as an auditor to review and monitor the development of the codebook and the analysis.

Figure 4.6 Qualitative data coding iterations for *Aim 3*



Ensuring data quality

Field notes and analytic memos were taken to assist reflexivity. Recruitment and data collection were conducted through a community-based research facility that has established long, positive relationships with this study population. This rapport facilitated participants' open disclosure and strengthened the credibility of the data. To improve confirmability, we presented our results using context-rich descriptions. In addition, we interviewed 15 clinicians of various healthcare professions and specialties who treated PWH with chronic pain problems in the hospital system where the majority of our participants received care. Although clinician data were not included in the analysis of this dissertation, their views on patient-provider dynamics in managing chronic pain for this patient population helped shape our interpretation of the participants' accounts. The final interpretations of the findings were made in collaboration with a clinician faculty co-investigator specialized in HIV care.

ETHICAL CONSIDERATIONS

The study protocol and materials were approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board prior to the start of the recruitment. Given the sensitive information such as HIV status and illicit drug use collected in this research, potential risks include breaches of confidentiality or any information that participants share in this research. We followed a series of procedures to protect human research subjects and to ensure data safety.

Informed consent and voluntary participation

Participants' informed consent was obtained prior to their enrollment in the study. The consent form detailed the procedures and associated risks of the research participation, and will be explained by research staff. The consent process took place in a private space and in the form of conversation to make sure that participants fully understand everything explained, with all their questions answered. Participants obtained a copy of the consent for their records, along with contact information of the study staff, principal investigator (PI), and Johns Hopkins Bloomberg School of Public Health Institutional Review Board (JHSPH IRB) in case any additional questions or issues arise later during the research process. Participants were ensured the voluntary aspects of research participation, meaning that they can refuse or withdrawal their participation at any point during the study. Before each focus group session or in-depth interview, verbal consent was obtained from the participants. Participants did not need to agree to take part in every component of the research in order to remain a participant in the study.

Protection against breaches of confidentiality

Participants were given a unique study code number. A location sheet and the signed consent form are the only documents that have participant personal information, and are stored separately from any research data. A master list that links code number and identifiable information is maintained in a separate safe area, and accessible only by selected members of the research team. All research staff members were required to complete the JHSPH human subjects training and education program, and signed a pledge of confidentiality prior to interactions with participants. In addition, the principal investigator (PI) of the AFFIRM Care project has obtained a protective order from the Attorney General of the United States under the Comprehensive Drug Abuse Prevention and Control Act of 1970 (i.e., Certificate of Confidentiality) to protect participants from potential subpoena.

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CHAPTER 5 – PATIENT-CENTERED ENGAGEMENT AS A MEDIATOR IN THE ASSOCIATIONS OF HEALTHCARE DISCRIMINATION, PAIN CARE DENIAL, AND LATER SUBSTANCE USE AMONG A SAMPLE OF PREDOMINATELY AFRICAN AMERICANS WITH HIV

ABSTRACT

Background Chronic pain is a prevalent, under-addressed condition among people with HIV (PWH) or using drugs, and likely compounds stress of discrimination in healthcare and self-medicating or other problematic coping. Because of the challenges in treating pain in the context of substance use, collaborative, patient-centered patient-provider engagement (PCE) may be particularly important for mitigating the impact of pain on illicit drug use and promoting sustained recovery. We examined whether PCE with primary care provider (PCE-PCP) mediated the effects of pain, healthcare discrimination, and being denied pain medication on later substance use for pain among African Americans with HIV and a drug use history, a population at the intersection of multiple vulnerabilities.

Methods 331 PWH who reported current or former drug use were recruited from HIV clinics and community venues in Baltimore, Maryland, USA and completed 3 semi-annual surveys. We estimated the direct and indirect paths of baseline levels of pain, healthcare discrimination, and experience of being denied for pain medication, through PCE-PCP at 6-month follow-up (a latent mediator), to substance use for pain at 12-month, using structural equation modeling with weighted least square mean and variance adjusted (WLSMV) estimation. Bootstrap confidence intervals were obtained for indirect effects. Analysis adjusted for baseline assessment of the mediator and the outcome, demographic covariates, depressive symptoms, and substance use.

Results Baseline pain level was directly associated with a higher chance of substance use for pain at 12-month (Standardized Coefficient =0.26, *p*<.01), but not with PCE-PCP. There were significant indirect paths from baseline discrimination (Standardized Coefficient =0.05, 95% *CI* = [0.01, 0.13]) and from baseline report of being denied pain medicine (Standardized Coefficient =0.06, 95% *CI* = [0.01, 0.14]) to higher chance of substance use for pain at 12-month, mediated through worse PCE-PCP at 6-month.

Conclusions PCE interpersonal skills and integrative care models are important for addressing discrimination and rejection in healthcare and substance use of this vulnerable population. An integrated approach for treating pain and substance use disorders concurrently with HIV and other comorbidities is much needed. Interventions should target people with intersecting vulnerabilities to discrimination and healthcare professionals to promote patient-centered patient-provider engagement.

INTRODUCTION

The quality of patient-provider relationships plays a critical role in HIV care, and is especially important for treating pain, a prevalent comorbid condition among people with HIV or a history of substance use disorder.[1–4] Patient-centered patient-provider engagement (PCE)—an interaction style characterized by mutual respect, collaborative communication, mutual understanding, and shared decision making—is related to increased access and adherence to treatments, retention in care, and improved health outcomes.[5–8] Previous research has found positive associations of PCE with antiretroviral therapy (ART) initiation and adherence, viral suppression, and substance use treatment utilization.[5,9–11] In pain management, PCE may facilitate patient-provider discussion of patients' pain experiences, mutual collaboration on a care plan, and patient trust and adherence.[12]

Chronic pain and substance use disorders often co-occur and impede effective management of either condition alone.[13] A history of substance use disorder is associated with more prevalent and severe chronic pain, while pain itself is a driver for opioid or nonopioid substance use, further perpetuating substance dependence.[14–16] This complex, bi-directional relationship makes managing pain within the context of substance use particularly challenging.

Opioids are powerful analgesics; however, long term use of opioids is associated with worse, harder-to-treat pain through increased opioid tolerance and opioid induced hyperalgesia (hypersensitivity to noxious stimuli).[4,16–18] Opioids or prescription analgesics may abet patients' substance use problems and potential for drug misuse and overdose.[4,16,17] Furthermore, for PWH, high rates of liver and kidney diseases and toxicities of long-term analgesic use restrict their options for pain care. As a result, it is a delicate task for clinicians to balance potential risks and benefits of opioids or other analgesics and many PWH and persons in care for substance use disorders report long-term pain and inadequate treatment.[19,20] Thus, it is important that healthcare providers engage with patients collaboratively to ensure mutual understanding and agreement on treatment goals and care plans.

It is not uncommon for patients to place a higher value on pain relief and healthcare providers to emphasize treatment safety over pain relief.[12,21] Patient-provider discussions about treatment inadequacies and abuse potential can lead to relationship discord. Providers may feel frustrated by their inability to effectively address their concerns over opioid harms. On the other hand, providers' attempts to detect aberrant use or misuse of pain medication (i.e. taking the medication in a way other than prescribed) or drug diversion (i.e. transferring legally prescribed controlled substance from the individual for whom it was prescribed to another person, such as by trading it on the street), can impede patient trust in their providers and the healthcare system.[22] Indeed, in the context of the opioid epidemic and provider scrutiny in their opioid prescribing, many patients with pain report needing to authenticate their pain experiences and defend against providers' suspicions of "drug-seeking" behaviors (manipulative behaviors to obtain controlled medications that have abuse potential).[23–25] Patient-provider disagreement or conflict regarding pain management create significant challenges in healthcare relationships that can undermine communication and quality care and impede patients' pain management and recovery from drug misuse.[12]

Individuals with HIV and a history of injection drug use are more likely to receive inadequate pain treatment.[4] Despite widely reported chronic pain in this patient population, only a small proportion of PWH are prescribed a long-acting opioid analgesic.[19] When pain is not adequately managed, patients in prior studies have reported doctor shopping (i.e. seeking multiple prescribers), self-medicating to alleviate pain and other coping that expose them to higher risks for drug overdose and other long-term adverse health impacts.[17] Many pain patients whose access to prescription analgesics have been denied or restricted have a hard time finding a provider who can properly address their pain management needs to establish care with.[26] They might feel helpless with the healthcare system and transition to other pain relief sources such as alcohol, non-prescription opioids or illicit drugs.[1,17,27,28] These problematic coping behaviors and self-medication could cause severe harm to patients' health while compromising their long-term care by further damaging patient-provider relationships.[1,29]

Healthcare professionals' clinical judgements are susceptible to biases and stereotypes, giving rise to discrimination and disparities in healthcare and health outcomes.[30,31] Individuals in socially disadvantaged groups and those with disabilities and other traditionally stigmatized health conditions such as HIV, behavioral health (i.e. substance use or other mental health) disorders, and contested illnesses (e.g. unexplained pain) are particularly vulnerable to healthcare discrimination.[30–35] A systematic review found healthcare professionals had difficulty empathizing with patients with substance use disorders, and perceived them as violent, manipulative, or poorly motivated.[36]

Certain groups are disproportionately affected by chronic pain and pain undertreatment. In particular, women, people with low socioeconomic status, and racial/ethnic minorities report the highest rates of pain and lowest rates of pain relief through treatment.[2,19,37,38] Research analyzing nationwide samples in the US showed that African Americans and Latinxs were less likely to be prescribed opioid analgesics for chronic non-cancer pain.[39,40] People using prescription opioids for intractable pain, and those suffering from substance use disorder and mental illness also experience increased biases in health care, which compounds risks of discrimination based on race/ethnicity and socioeconomic status.[41] Such discriminatory treatment itself could intensify pain and contribute to healthcare inequity that further exacerbates disparities in pain and other health and wellbeing outcomes.[41]

Discrimination has been associated with a wide range of adverse health outcomes from psychological distress, substance use, poor adherence to treatment, compromised mental and physical health, to increased mortality.[34,35,42] Experiences of discrimination in healthcare settings could lead to mistrust and dissatisfaction with healthcare providers and the healthcare system and further reduce their healthcare utilization and engagement with their providers, jeopardizing their access to and retention in care and health outcomes.[34,35] The current research examined experiences of discrimination in healthcare settings among African Americans with HIV and a history of drug use, a population that is at the intersection of multiple vulnerabilities

We analyzed pain symptoms and two negative healthcare experiences—discrimination and being denied pain medication—in association with later PCE and substance use for pain. We hypothesized that patients' bodily pain and prior experiences of discrimination in healthcare encounters and being denied needed pain treatment would be prospectively related to less respectful, collaborative engagement with their primary care provider (PCP), which would predict substance use for relieving pain. In addition, we tested the potential mediating effect of PCE with PCP (PCE-PCP) on the path from pain and each type of negative healthcare experience to the substance use for pain outcome. The objective was to better understand how pain, healthcare discrimination, and denied pain medication requests contribute to the dependence or relapse to substance use, and the role of PCE-PCP in these relationships.

METHODS

Procedure

This research is part of the AFFIRM Care study, which examines social environmental factors associated with health outcomes and well-being among socio-economically disadvantaged people with HIV and their informal caregivers. Study participants (n=331) were recruited from HIV clinics and community venues in Baltimore, Maryland, USA and completed 3 semi-annual surveys between 2014 and 2018. The inclusion criteria comprised being an adult (18 or over), HIV seropositive, and reporting current or former use of heroin, crack, or cocaine. The surveys were administered by computer assisted personal interview (CAPI), with sensitive information elicited by audio computer assisted self-interview (ACASI). The AFFIRM Care study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Measures

Outcome

The outcome of interest was substance use for pain. At baseline, participants were asked whether they ever used alcohol or illicit drugs to relieve pain (yes/no). At follow-ups, the same question was asked regarding self-medicating behavior in the past 6 months.

Mediator

PCE-PCP was operationalized as a latent variable and measured with 6 items. A yes-no question, “My doctor knows me as a person”, was used to assess patient-centeredness.[10] Questions based on the Engagement with Healthcare Provider Scale were used to assess collaborative aspects of patient-provider engagement, including: my doctor explains treatment pros and cons and provides enough information about side effects or risks, shows support for my decision making around treatment options, and sufficiently involves my close family or friend in my healthcare. Response options were from 0 (never) to 3 (always).[43] Participants were asked to report on their main healthcare provider when answering these questions.

Independent variables

Discrimination in healthcare encounters based on race/ethnicity, language, HIV status, and drug use history were assessed using four items modified from the Health Care Quality Survey.[44] Participants were asked: “In the last two years, have you ever felt that the doctor or medical staff you saw [at a healthcare visit] judged you unfairly or treated you with disrespect because of: 1) your race or ethnicity; 2) how you speak; 3) your having HIV; or 4) using or having used drugs.” Participants answered yes or no for each item. A binary variable was then generated to summarize if participants experienced any discrimination by healthcare providers in the past two years.

Experiences of being denied pain medication was assessed by a yes-no question, ”Have doctors ever refused to give you the pain medications you felt you needed?”

Self-reported pain symptoms were measured using the Brief Pain Inventory.[45] Participants rated their average level of pain during the past 30 days on a 0-10 scale, from no pain (0) to worst possible pain (10). Pain frequency, severity, and interferences with activities and social relationships in the past 30 days were also assessed but not included in the statistical model.[45]

Other covariates

Depressive symptoms were measured by the Center for Epidemiologic Studies Depression Scale 10-item version (CESD-10) and dichotomized using the established cut point of 10 to indicate probable depression.[46] To assess injection drug use history, participants were asked about the last time they injected drugs, including illicit drugs and medications that were not prescribed to them, with response options from 0 (never) to 5 (in the past month). Daily alcohol consumption was determined by self-reported frequency of drinking any kind of alcoholic beverage in the past 6 months.

Items adapted from the Prescription Drug Use Questionnaire were used to assess aberrant drug use as well as use of alcohol or illicit drugs to relieve pain.[47] Aberrant use of prescription pain medication was measured by three types: ever had to take more pain medications than prescribed, ever obtained pain medications from family or friends, and ever had to buy pain medications on the street. Participants answered yes or no to each item; responses were combined into one binary variable for any versus no aberrant use of pain medication. Demographic information was also collected.

Data analysis

Descriptive analyses were conducted in SPSS v.27,[48] and the PCE-PCP factor was fit in Mplus 8.4.[49] We then examined the direct and indirect effects of baseline pain, healthcare discrimination, and being denied pain medication, through 6-month PCE-PCP, to 12-month substance use for pain, using structural equation modeling with weighted least square mean and variance adjusted (WLSMV) estimation.[50]

Bootstrap tests of the indirect effects were used to establish mediation. Bootstrap confidence intervals are more accurate than symmetric confidence intervals because they account for potential non-normal distribution of the mediated effects.[51] Therefore, bootstrap tests are powerful and are particularly recommended for small to moderate sized samples.[52] A significant indirect effect with a confidence interval that does not include zero would suggest mediation, without the need to establish prior bivariate association between the independent and the outcome variables.[51–53]

Baseline measurements of the outcome (substance use for pain) and the mediator (PCE-PCP) were adjusted for in the model. Other baseline covariates included in the model were: gender (male vs. female or other), African American race/ethnicity, education (less than high school/GED vs. higher), depression, injection drug use history, daily alcohol consumption in the past 6 months, and aberrant use of pain medication.

RESULTS

Table 5.1 shows baseline sample characteristics. Participants were predominately African American (95.8%). The mean age of the sample was 52.31 years (*SD* = 6.67 years). Most participants (56.5%) were male, and 17.8% were non-heterosexual. Almost half of the participants had less than high school education (48.3%), and the majority (71.3%) reported an income less than $1000 per month. More than one-third (35.6%) of the participants had probable depression (CESD-10 ≥ 10). Around half (51.1%) of the sample reported ever injecting illicit drugs, and 18.7% reported daily alcohol consumption at baseline.

Among various types of healthcare discrimination experiences, those related to current or previous drug use were most reported (12.1%), followed by race/ethnicity-related (6.0%), HIV-related (5.7%), and linguistic (4.2%) discrimination. In combination, 15.4% of the sample reported experiences of any discrimination in healthcare encounters during the previous 2 years, and 6.3% (*n*=21, data not shown) reported experiencing more than one type of discrimination.

On average, participants rated their pain level during the past 30 days as 5.16 points (*SD* = 3.49) on a scale of 0-10. The majority of the participants (62.5%) experienced moderate to very severe pain, 39.8% had frequent or constant pain, and 36.3% and 26.6% said their pain moderately to extremely interfered with their normal activities and with their social relationships, respectively. Over one-fifth (21.5%) of the participants reported experiencing their doctor deny them pain medication they needed, and 32.6% reported having used alcohol or other drugs to relieve pain. Aberrant use of pain medication was common; 42.6% of the participants reported any aberrant use of pain medication at a point in their lives, 27.8% of the sample reported taking more pain medication than prescribed, 29.0% had obtained pain medications from family or friends, and 18.7% had bought them on the street.

Participants reported high PCE-PCP at baseline and 6-month follow-up (Table 2). The vast majority (93.7% at baseline and 95.8% at 6-month follow-up) felt that their PCP knew them “as a person”, involved them in treatment decisions (89.7% answered “usually” or “always” at baseline, and 90.0% at 6-month), explained pros and cons of treatment options (92.1% answered “usually” or “always” at baseline, and 88.2% at 6-month), supported their decisions (87.3% answered “usually” or “always” at baseline, and 81.9% at 6-month), and provided enough information about side effects or risks (92.1% answered “usually” or “always” at baseline, and 89.7% at 6-month). Most participants also felt that their PCP involved their partner or close family members in their care as much as they would like (60.7% answered “usually” or “always” at baseline, and 67.7% at 6-month).

Separate exploratory factor analyses with the six items measuring PCE-PCP at baseline and at 6-month indicated an underlying single dimension with good model fit (for baseline measurements: Comparative Fit Index [CFI]=1.00, Tucker-Lewis Index [TLI]=1.00, Root Mean Square Error of Approximation [RMSEA]=0.02, 90% *CI*=0.00, 0.07]; for 6-month measurements: CFI= 1.00, TLI= 1.00, RMSEA= 0.04, 90% *CI*=0.00, 0.08).[54] Factor loadings ranged from 0.63 to 0.94 for baseline measurements and from 0.54 to 0.90 for 6-month measurements.

Figure 5.1 shows the statistically significant direct and indirect paths from baseline pain level and experiences of discrimination in healthcare encounters and being denied pain medication to substance use for pain at 12-month, via PCE-PCP at 6-month. The structural equation model indicated that both baseline discrimination (Standardized Coefficient =-0.17, *p*<.01) and denied pain medication (Standardized Coefficient =-0.19, *p*<.01) were related to reduced PCE-PCP at 6-month, and that 6-month PCE-PCP was negatively associated with substance use for pain at 12-month (Standardized Coefficient =-0.30, *p*<.01). There was a significant indirect path from baseline discrimination to higher odds of substance use for pain at 12-month (Standardized Coefficient =0.05, 95% *CI* = [0.01, 0.13]), mediated through reduced PCE-PCP at 6-month. Similarly, we also found a significant indirect effect from baseline experience of being denied pain medicine through reduced PCE-PCP at 6-month to higher chances of substance use for pain at 12-month (Standardized Coefficient =0.06, 95% *CI* = [0.01, 0.14]).

On the other hand, baseline pain level was directly associated with higher chances of substance use for pain at 12-month (Standardized Coefficient =0.26, *p*<.01). There was no significant indirect effect between these two variables, suggesting that the effect from pain to substance use for pain was not mediated by PCE-PCP. The model achieved good fit (CFI=0.96, TLI=0.95, RMSEA=0.04, 90% *CI*= 0.03, 0.05).[54] Overall, 30% of the variance in substance use for pain, and 42% of the variance in PCE-PCP was explained by the model.

Table 5.1 Baseline sample characteristics (*N*=331)

	Mean (*SD*) or % (*n*)
Demographics	
Age	52.31 (*SD*=6.67)
Male	56.5 % (*n*=187)
Sexual orientation	
Gay	12.7% (*n*=42)
Straight	82.2% (*n*=272)
Bisexual	3.9% (*n*=13)
Other	1.2% (*n*=4)
African American race	95.8% (*n*=317)
Education	
8th grade or less	9.1% (*n*=30)
Some high school, no diploma	39.3% (*n*=130)
High school diploma or GED	31.1% (*n*=103)
Some college or technical training	16.9% (*n*=56)
College degree	2.7% (*n*=9)
Any graduate training	0.9% (*n*=3)
Monthly income	
No income	0.9% (*n*=3)
Less than $250	5.4% (*n*=18)
$250-$499	9.4% (*n*=31)
$500-$999	55.6% (*n*=184)
$1000-$1499	19.0% (*n*=63)
$1500-$1999	4.8% (*n*=16)
$2000 or more	4.2% (*n*=14)
Depression (CESD-10 score ≥10)	35.6% (*n*=118)
Substance use	
Last time injected drugs	
Never	48.9% (*n*=162)
More than 5 years ago	30.5% (*n*=101)
1-5 years ago	5.1% (*n*=17)
6-12 months ago	3.9% (*n*=13)
1-6 months ago	4.2% (*n*=14)
In the past month	7.3% (*n*=24)
Alcohol consumption	
Less than once a week or never	60.1% (*n*=199)
1-2 times per week	10.6% (*n*=35)
Several times a week	10.6% (*n*=35)
Once a day	8.5% (*n*=28)
More than once a day	10.3% (*n*=34)
Substance use for pain	32.6% (*n*=108)
Aberrant use of pain medication	
Taken more pain medications than prescribed	27.8% (*n*=92)
Obtained pain medications from family or friends	29.0% (*n*=96)
Bought pain medications on the street	18.7% (*n*=62)
Discrimination in healthcare encounters related to	
Race or ethnicity	6.0% (*n*=20)
Use of language and characteristics of speech	4.2% (*n*=14)
HIV status	5.7% (*n*=19)
Current or pervious drug use	12.1% (*n*=40)

Experiences of being denied pain medication	21.5% (*n*=71)
Pain symptoms	
Average level of pain (0-10)	5.16 (*SD*=3.49)
Pain frequency	
None in past 30 days	23.0% (*n*=76)
Rarely	19.3% (*n*=64)
Occasionally	17.8% (*n*=59)
Frequently	19.6% (*n*=65)
Almost constantly	20.2% (*n*=67)
Pain severity	
None in past 30 days	23.0% (*n*=76)
Slight	14.5% (*n*=48)
Moderate	35.3% (*n*=117)
Severe	18.1% (*n*=60)
Very severe	9.1% (*n*=30)
Pain interference with normal activities	
Not at all	30.8% (*n*=102)
A little bit	32.9% (*n*=109)
Moderately	12.4% (*n*=41)
Quite a bit	19.3% (*n*=64)
Extremely	4.5% (*n*=15)
Pain interference with social relationships	
Not at all	45.0% (*n*=149)
A little bit	28.4% (*n*=94)
Moderately	12.1% (*n*=40)
Quite a bit	12.4% (*n*=41)
Extremely	2.1% (*n*=7)

Table 5.2 Factor loadings for PCE-PCP indicator variables at baseline and 6-month (*N*=331)

	Descriptive statistics		**Factor loadings**	
	baseline	**6-month**	**baseline**[a]	**6-month**[b]
	% (n) "yes"			
My doctor knows me as a person	93.7% (*n*=310)	95.8% (*n*=317)	0.76*	0.54*
	% (n) "usually" or "always"			
Involves me in decisions about my treatment as much as I would like	89.7% (*n*=297)	90.0% (*n*=298)	0.85*	0.87*
Explains the pros and cons of different treatment options	92.1% (*n*=305)	88.2% (*n*=292)	0.94*	0.90*
Supports my decisions	87.3% (*n*=289)	81.9% (*n*=271)	0.72*	0.85*
Provides me enough information about treatment side effects or risks	92.1% (*n*=305)	89.7% (*n*=297)	0.84*	0.87*
Involves my partner or close family members in my care as much as I would like	60.7% (*n*=201)	67.7% (*n*=224)	0.63*	0.67*

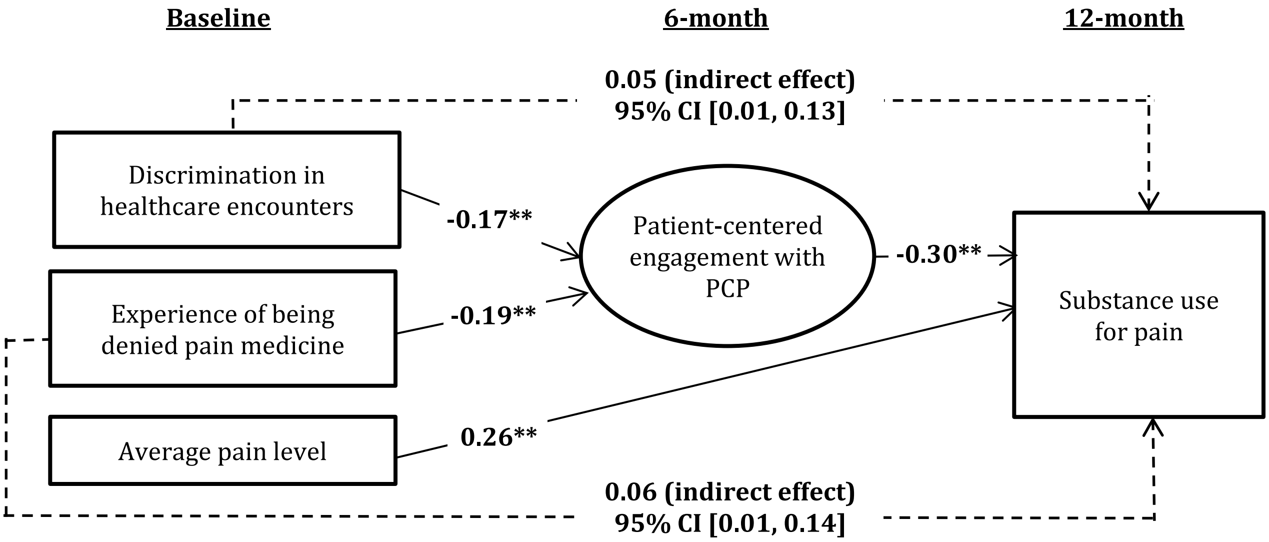
Geomin rotated loadings are reported (oblique rotation)

[a] Model-fit statistics: CFI= 1.00, TLI= 1.00, RMSEA= 0.02 (90% *CI*=0.00, 0.07)

[b] Model-fit statistics: CFI= 1.00, TLI= 1.00, RMSEA= 0.04 (90% *CI*=0.00, 0.08)

*Significant at 5% level

Figure 5.1 Structural equation model showing standardized coefficients of direct (solid lines) and indirect paths (dashed lines) from baseline pain level as well as experiences of discrimination in healthcare encounters and being denied pain medication to 12-month substance use for pain, via 6-month patient-centered engagement with primary care providers (PCE-PCP).



Notes: Path coefficients are standardized by both the dependent and independent variables in each path. Bootstrap-corrected confidence interval (*CI*) is included for the indirect effect. Covariates adjusted for in the model were baseline measurements of PCE-PCP and substance use for pain, male gender, African American race, high school education, depression, injection drug use history, daily alcohol consumption in past 6 months, and aberrant use of pain medication. Direct paths were included from all covariates to 6-month PCE-PCP and 12-month substance use for pain, but not shown in the graph. Only significant paths among the main variables of interest in the graph are shown for ease of readability (Affirm Care study; N=331). CFI=0.96, TLI=0.95, RMSEA=0.04 (0.03, 0.05); *$p<.05$, **$p<.01$

DISCUSSION

Our results demonstrated that, as hypothesized, among a sample of predominately African American persons with HIV and a history of drug use, suboptimal patient-provider engagement exacerbated the effects of prior negative healthcare experiences on later self-medicating behaviors. Experiences of discrimination in healthcare encounters and being denied pain medication were both associated with lower reported PCE- PCP, which was linked to later higher chances of using illicit drugs or alcohol to relieve pain. Contrary to our hypothesis, the association between baseline pain level and 12-month substance use for pain was not mediated by PCE-PCP.

Previous research found cross-sectional associations between pain symptoms and less patient-centered, collaborative patient-provider engagement.[55] In our structural equation model, baseline pain was not related to 6-month PCE-PCP. It is possible that patients' pain symptoms interfere with patient-provider dynamics only if they are experiencing pain. For example, patients could be actively engaged in their routine care, but less so when they experience pain, underscoring the challenges to patients and their clinicians in managing pain symptoms and its adverse impact on continued or relapse to drug use. Indeed, pain management is especially challenging for the study population, many of whom have a history of illicit opioid use and dependence. While experiencing elevated pain, they may feel frustrated or distressed by inadequate treatment options or engagement in their care planning or decision making. Indeed, a prior study shows when pain is not adequately acknowledged or treated, patients may perceive their providers as unempathetic.[55] However, findings of the present research might suggest that when patients' pain is alleviated, they return to a high level of engagement with their PCP.

Our data revealed a high burden of bodily pain among (primarily African American) people with HIV and a history of drug use. Moreover, baseline pain level was independently associated with substance use for pain relief at 12-month in structural equation modeling, controlling for baseline substance use for pain, injection drug use history, daily alcohol consumption and other potential confounding variables. This result is consistent with prior findings in the Multicenter AIDS Cohort Study, which showed that higher pain level was predictive of higher level of subsequent drug use.[13] To address substance use and relapse driven by poorly managed pain, and to prevent it from further perpetuating pain symptoms, an integrated approach is needed to treat chronic pain and addiction concurrently. In the US, addiction treatment services historically operate outside the general medical system.[56] This fragmented treatment model not only fails to meet patients' need to manage addiction and pain comprehensively, but also adds to the existing barrier to coordinated care that many people with HIV and multiple comorbidities are already struggling with. Our results support other researchers' call for integrating addiction services into general medicine.[56]

Our findings also highlighted the need for addressing discrimination and promoting social justice in healthcare. In a recent US national survey, about one fifth of the respondents reported having experienced healthcare discrimination in their lives, mostly more than once.[30] Our study found that around 15% of individuals in a highly stigmatized group had recent experiences of healthcare discrimination related to race/ethnicity, HIV status, drug use history, or the way they spoke. Over 6% of the sample experienced more than one type of discrimination. Healthcare professionals, like other people, are not immune from biases.[57] Intervention is much needed to reduce the harm.

Patients who are denied pain medications might feel that they are not treated fairly, even when their providers have valid reasons not to prescribe. In our analysis, the effects of denied pain medication requests were statistically significant after adjusting for patient-reported healthcare discrimination, suggesting that experiences of discrimination in healthcare encounters and being denied for pain medication both independently contributed to worse engagement with PCP and worse substance use outcome. These negative healthcare experiences might lead to feelings of rejection and undermine patients' empowerment to advocate for their healthcare needs and to actively involve in their care. In addition, prior experiences of non-supportive providers may result in patients' defensive attitudes and reluctance in disclosing pain-related behaviors, as well as mistrust in the healthcare system. In a qualitative study, patients with chronic non-cancer pain whose prescription opioids were reduced or discontinued described feelings of marginalization and fear of doctor's invalidation.[58] They also expressed resentment toward the medical system, including pharmaceutical companies and the physician-industry relationships, and doubts about the motivation behind the opioids tapering decisions.[58] Previous research also showed that patients' perceived healthcare discrimination negatively affected their subsequent communication with healthcare providers.[59] Patients might feel constrained by their past negative healthcare experiences, and thus have a more difficult time continually establishing positive relationships with care providers. Intervention with a goal to facilitate better patient-provider collaboration that specifically addresses the dynamics of pain should be designed to target individuals in the socially disadvantaged groups as well as healthcare professionals who provide care for the vulnerable populations.

There are important implications for intervening on PCE. Our results illustrated a potential mechanism through which experiences of healthcare discrimination impact maladaptive coping for pain through reduced PCE-PCP, suggesting an intervention opportunity to improve behavioral health for individuals who are vulnerable to discrimination and stigma, and to interrupt the vicious cycle of substance use and chronic pain, in which substance use driven by pain could further aggravate the pain.[14] Poor engagement with PCP might lead to lower healthcare utilization and higher chances of pain self-medication using illicit drugs or alcohol, which could further perpetuate the substance use stigma that this patient population is already experiencing, and their marginalization in the healthcare system. On the contrary, a collaborative, respectful healthcare relationship might help patients appreciate their providers' considerations more and therefore better adhere to provider instructions even when their pain cannot be fully alleviated, and at the same time help providers empathize more with their patients' suffering and factor that in their interaction with patients as well as their clinical decision making.

This study has several limitations. First, the modest sample size did not allow detection of the bivariate associations between baseline predictors and the 12-month outcome, although by introducing the mediator we were able to improve the statistical power for the indirect effects in spite of the sample size limitation.[52] Future research with larger sample sizes could help further advance our understandings of these associations. Second, all measures were self-reported and subject to social desirability and recall bias. Although self-administered survey through ACASI was used to collect information on sensitive topics, biases may still exit. In addition, recall bias may have led to underestimates of pain levels. Third, we likely underestimated the prevalence of healthcare discrimination experienced by this population as we only assessed four types of discrimination. Finally, the possibility of unmeasured confounders cannot be completely ruled out, even though we tried to minimize it by controlling for the baseline measurements of the mediator and the outcome along with other covariates in structural equation modeling.

CONCLUSIONS

Our research demonstrates different pathways through which physical pain and social pain, in the form of discrimination and rejection in healthcare, lead to substance use among a socioeconomically disadvantaged group of people with HIV and a history of drug use. By exploring the impacts of the lived experiences of dehumanizing interactions in the healthcare setting, this study exemplifies how systemic barriers and discrimination affect recovery, health, and well-being in a marginalized community. There is an urgent need for addressing discrimination in healthcare and for integrating pain and addiction treatment. Our findings suggest a potential for mitigating the impacts of negative past healthcare experiences on patients' substance use outcomes through improved patient-provider engagement, underlining the importance of promoting patient-centered care.

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APPENDIX

Table 5.3 Standardized (β) and unstandardized (B) path coefficients for direct and indirect effects in the structural equation model. Significance levels (p-values) for standardized path coefficients and standard errors (SE) for unstandardized path coefficients are included for the direct effects, and bootstrap confidence intervals (CI) are included for the indirect effects. Statistically significant effects, indicated by a p-value < .05 for direct effects and a 95% CI that does not include zero, are labeled in bold texts.

Independent variable	**Direct effect on 6-month PCE-PCP**		**Direct effect on 12-month substance use for pain**		**Indirect effect on 12-month substance use for pain, through 6-month PCE-PCP**	
	β (*p*)	**B (*SE*)**	**β (*p*)**	**B (*SE*)**	**β (95% *CI*)**	**B (95% *CI*)**
Discrimination in healthcare encounters, baseline	**-0.17 (.009)**	**-0.26 (0.11)**	-0.06 (.46)	-0.18 (0.25)	**0.05 (0.01, 0.13)**	**0.16 (0.02, 0.40)**
Experience of being denied for pain medicine, baseline	**-0.19 (.005)**	**-0.25 (0.10)**	-0.09 (.28)	-0.26 (0.27)	**0.06 (0.01, 0.14)**	**0.16 (0.01, 0.40)**
Average pain level, baseline	0.03 (.68)	0.00 (0.01)	**0.26 (.004)**	**0.09 (0.03)**	-0.01 -0.06, 0.03)	-0.003 (-0.02, 0.01)
PCE-PCP, baseline	**0.51 (<.001)**	**0.34 (0.07)**	0.18 (.07)	0.28 (0.15)		
PCE-PCP, 6-month	-	-	**-0.30 (.005)**	**-0.64 (0.24)**		
Substance use for pain, baseline	-0.09 (.24)	-0.11 (0.09)	**0.19 (.02)**	**0.46 (0.20)**		
Male gender, baseline	0.01 (.85)	0.01 (0.07)	0.04 (.66)	0.08 (0.18)		
African American race, baseline	0.07 (.29)	0.19 (0.17)	-0.08 (.25)	-0.45 (0.39)		
High school education, baseline	0.04 (.55)	0.04 (0.08)	**0.16 (.05)**	**0.37 (0.19)**		
Depression, baseline	-0.13 (.06)	-0.15 (0.08)	0.12 (.12)	0.30 (0.20)		
History of injection drug use, baseline	-0.02 (.74)	-0.01 (0.03)	-0.06 (.47)	-0.04 (0.06)		
Daily alcohol consumption, baseline	-0.00 (.98)	-0.00 (0.09)	0.03 (.72)	0.08 (0.72)		
Aberrant use of pain medication, baseline	-0.04 (.61)	-0.05 (0.09)	0.08 (.36)	0.18 (0.20)		

CHAPTER 6 – THE MEDIATING ROLE OF PATIENT-CENTERED, PATIENT-PROVIDER ENGAGEMENT IN LINKS BETWEEN DEPRESSION, HEALTHCARE DISCRIMINATION AND LATER MENTAL HEALTH-RELATED QUALITY OF LIFE AMONG AFRICAN AMERICANS WITH HIV AND A HISTORY OF DRUG USE

ABSTRACT

Background Enhancing mental health-related quality of life (MHRQOL) is an important clinical objective for people with HIV (PWH), as they are more likely to experience significant psychological distress and increased mental health challenges. Depression, pain, stigma, and discrimination are among the main contributors to poor MHRQOL in this population and can negatively impact PWH's interaction with their healthcare providers, and vice versa. The current study examined whether the quality of patient-provider engagement in HIV primary care mediated the effects of depression and prior experiences of discrimination in healthcare settings on later MHRQOL among African Americans with HIV and a history of drug use.

Methods 331 PWH who reported currently taking HIV medication and current or former drug use were recruited from HIV clinics and community venues in Baltimore, Maryland, USA and completed 3 semi-annual surveys. Structural equation modeling with weighted least square mean and variance adjusted (WLSMV) estimation was used to test the potential direct and indirect effects of baseline depression and healthcare discrimination on 12-month MHRQOL (measured by MCS-12; the SF-12 Mental Component Summary), through patient-centered patient-provider engagement with primary care providers (PCE-PCP) at 6 months follow-up. Bootstrap confidence intervals were obtained for indirect effects.

Results Baseline descriptive statistics showed a high percentage of probable depression (35.6%) and a low MCS-12 mean score (38.72, *SD*=6.88) compared with the US general population norm of 50 (*SD*=10). There were significant indirect paths from baseline depression (Standardized Coefficient =-0.04, 95% *CI* = [-0.10, -0.01]) and healthcare discrimination (Standardized Coefficient =-0.05, 95% *CI* = [-0.12, -0.01]) to lower MHRQOL at 12-month, mediated through reduced PCE-PCP at 6-month, after adjusting for baseline assessment of the mediator and the outcome, demographic covariates, substance use, average pain level, and time since HIV diagnosis.

Conclusions African Americans with HIV and a history of drug use face high levels of mental health challenges. Our findings suggest a potential for mitigating the impacts of depression and healthcare discrimination on MHRQOL through intervening on the quality of patient-provider engagement. Complementary clinician and patient training are needed to promote quality patient-provider engagement to improve the well-being and attenuate the health impacts of discrimination on this socioeconomically marginalized population.

INTRODUCTION

People with HIV (PWH) are at greater risk for mental health disorders that compromise their healthcare engagement and well-being.[1,2] Prevalent psychiatric comorbidities include depression, anxiety, and substance use disorders.[1–4] In an early study of a nationally representative sample of adults receiving HIV care in the US, 36% and 16% screened positive for major depression and generalized anxiety disorder, respectively, nearly 40% reported use of illicit drugs other than marijuana, and over 12% met the criteria for drug dependence.[2] More recently, Do and colleagues analyzed nationwide health surveillance data and reported a prevalence of 12% for a current major depressive episode among PWH receiving care in the US, which is three times higher than the general population.[5] Mental health problems have been linked to lower retention in HIV care and reduced adherence to antiretroviral therapy (ART), leading to poor health outcomes.[1,6,7]

With advances in ART and improved survival, HIV is now managed within a chronic disease paradigm that emphasizes improving patient's long-term well-being.[8] Mental health-related quality of life (MHRQOL) is an important clinical objective for PWH, as they are more likely to experience significant psychological distress and increased mental health challenges.[1,9] Depression, stigma, and discrimination are major contributors to poor MHRQOL in this population.[9] Both ongoing depression and history of depression were found to be strongly associated with reduced MHRQOL.[9,10] Intervention studies showed that improvements in depression could lead to increases in psychosocial functioning and dimensions of quality of life, including MHRQOL.[11,12] In addition, PWH are vulnerable to multiple and often intersecting sources of stigma and discrimination, which could have detrimental effects on their MHRQOL.[13–15] HIV, substance use, chronic pain-related stigma, and racial and gender discrimination have all been associated with worse mental health in PWH.[13–15]

The quality of patient-provider interactions in the care for PWH also plays a critical role in their psychological well-being.[16–18] Patient-centeredness, based on principles of dignity and autonomy, is a collaborative style of clinical care that respects each individual patient's unique needs and values.[19] Patient-centered care was featured as one of the six aims for high-quality care in the Institute of Medicine's vision for a better US health care system for the 21st century.[19] Patient-centered patient-provider engagement (PCE) involves clinicians offering comprehensible information including treatment options and inviting patients' active involvement in clinical decision making to establish mutual trust in the healthcare relationship.[20,21] PCE has been associated with increased adherence to medical appointments, higher rates of ART initiation and adherence, greater viral suppression, and higher chances of long-term survival among PWH.[22–24] Moreover, prior research showed that HIV patients' dissatisfaction with the amount of information received from healthcare providers, and difficulties in patient-provider communication were associated with worse MHRQOL, whereas trust, perceived affection and respect in patient-provider relationships were associated with higher MHRQOL.[16–18]

Patient stigmatization, discrimination, and other negative experiences in healthcare settings could have sustained negative impacts on their engagement with their healthcare providers. Research analyzing patients' self-reports along with audio-recordings of their medical visits has found that perceptions of discrimination by clinicians or staff during a previous healthcare encounter negatively impacted their subsequent communication with clinicians, especially regarding non-verbal, affective aspects of communication.[25] Experiences of discrimination have been associated with anticipation of continued discrimination and stigma, as well as the internalization of stigma.[26] Different forms of stigma can operate in conjunction and further damage an individual's interaction with others.[27] As a result, discrimination in healthcare might make patients feel rejected and disempowered, thus impeding their active engagement with providers at their following healthcare encounters.[28] In addition, past discrimination of the healthcare system and non-clinician could also result in medical mistrust, attenuating patients' building positive relationships with providers.[29]

Depression could also adversely impact patient-provider engagement. Depressive symptoms might distort patients' evaluation of their interactions with healthcare providers and cause them to feel less respected.[30] Because of the emotional distress and lack of energy experienced by depressive patients, they might demonstrate poor health behaviors and medical nonadherence that could lead to provider frustration and strain patient-provider relationships.[30,31] Moreover, patients with depression could pose a further burden on providers, as they often need more time and resources for their care.[31]

The current study focused on a population that is vulnerable to multiple sources of stigmas and discrimination and poor quality of life. We examined whether PCE with primary care providers (PCE-PCP) mediated the effects of depression and prior experiences of discrimination in healthcare settings on later MHRQOL among African Americans with HIV and a history of drug use.

METHODS

Procedure

This research is part of the AFFIRM Care project, which examined social network and main caregiving relationship factors associated with healthcare decision making and health outcomes among socio-economically disadvantaged PWH. Participants (n=331) were recruited from HIV clinics and community venues in Baltimore, Maryland, USA and completed 3 semi-annual surveys between 2014 and 2018. The inclusion criteria were being adult (18 or over), HIV seropositive, and currently or formerly using heroin, crack, or cocaine. The surveys were administered by computer assisted personal interview (CAPI). The AFFIRM Care study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Measures

Outcome

The outcome of interest was MHRQOL, measured by the Medical Outcomes Study 12-Item Short-Form Health Survey (SF-12), a shortened version of the 36-item physical and mental health-related quality of life scale.[32] Dimensions of MHRQOL assessed by SF-12 included vitality (energy/ fatigue), social functioning, role limitations due to emotional problems, as well as psychological distress and psychological well-being.[32] Following the scoring guideline, we calculated the SF-12 Mental Component Summary (MCS-12) score, which was a standardized sum of weighted survey responses.[33] The norm-based standardized scores have a mean of 50 and standard deviation of 10 in the US general population.[33] Example survey questions included "During the past 30 days, have you, as a result of emotional problems, accomplished less than you would like?" and "During the past 30 days, how much of the time have you felt calm and peaceful?"

Mediator

PCE-PCP was conceptualized as a latent variable, measured with 6 items. A yes-no question, "My doctor knows me as a person", was used to assess patient-centeredness.[24] Questions modified from the Engagement with Healthcare Provider Scale were used to assess other aspects of patient-provider engagement, including: doctor involves patient and their partner or close family as much as they would like, doctor explains treatment pros and cons and provides enough information about side effects or risks, and doctor shows support for patient decision, rated from 0 (never) to 3 (always).[34] Participants were asked to think about their main healthcare provider when answering these questions.

Independent variables

Depressive symptoms were measured by the Center for Epidemiologic Studies Depression Scale 10-item version (CESD-10), and dichotomized using the established cut point of 10 to indicate probable depression.[35]

Discrimination in healthcare encounters related to race, language, HIV status, and drug use history were assessed using four items modified from the Health Care Quality Survey.[36] Participants were asked: "In the last two years, have you ever felt that the doctor or medical staff you saw judged you unfairly or treated you with disrespect because of: 1) your race or ethnicity; 2) how you speak; 3) because you have HIV; 4) because you use or used to use drugs." Participants answered yes or no for each item. A binary variable was then generated to summarize if participants experienced any discrimination by healthcare providers in the past two years.

Other covariates

Demographic data included gender and age. To assess history of injection drug use, participants were asked about the last time they injected drugs, including illicit drugs and medications that weren't prescribed to them, with response options from 0 (never) to 5 (in the past month). Daily alcohol consumption was determined by self-reported frequency of drinking beer, wine, mixed drinks or any kind of alcoholic beverage in the past 6 months. Self-reported pain symptoms were measured using the Brief Pain Inventory.[37] Participants rated their average level of pain during the past 30 days on a 0-10 scale, from no pain (0) to worst possible pain (10). Length of time since HIV was diagnosed was categorized into three groups: less than 15 years, 15-24 years, and 25 years or more.

Data analysis

Descriptive analyses were conducted in SPSS v.27,[38] and the PCE-PCP factor was fit in Mplus 8.4.[39] We then examined the direct and indirect effects of baseline depression and healthcare discrimination, through 6-month PCE-PCP, to 12-month MHRQOL, using structural equation modeling with weighted least square mean and variance adjusted (WLSMV) estimation.[40] Bootstrap tests of the indirect effects were used to establish mediation. Bootstrap confidence intervals are more accurate than symmetric confidence intervals, because they account for potential non-normal distribution of the mediated effects.[41] Therefore, bootstrap tests are powerful and are particularly recommended for small to moderate sized samples.[42] Significant indirect effect with a confidence interval that does not include zero would suggest mediation, without the need to establish prior bivariate association between the independent and the outcome variables.[41–43] The model controlled for the following covariates measured at baseline: male gender, African American race, education (less than high school vs. high school diploma/GED or higher), history of injection drug use, daily alcohol consumption in the past 6 months, average pain level, and length of time since HIV was diagnosed. In addition, we adjusted for baseline measurements of the outcome (MHRQOL) and the mediator (PCE-PCP) to reduce the possibility for potential unmeasured confounders.

RESULTS

Table 6.1 shows baseline sample characteristics. Participants were predominately African American (95.8%); 3.3% White, 0.9% other race or multiracial). The mean age was 52.31 years (*SD* = 6.67 years) in the sample, over half (56.5%) were male, and 17.8% were non-heterosexual. Almost half of the participants had less than high school education (48.3%), and the majority earned less than $1000 per month (71.3%). Around half (51.1%) of the sample reported a history of injection drug use, and 18.7% reported daily alcohol consumption at baseline. On average, participants rated their pain level during the past 30 days as 5.16 points (*SD* = 3.49) on a scale of 0-10, with the majority (69.8%, data not shown) reporting moderate to severe pain rated 4 points or higher. The majority of the participants had lived with HIV for 15 years or longer (73.1%). More than one-third of the participants had probable depression (35.6%), as determined by a CESD-10 score equal to or greater than 10. Among various types of healthcare discriminatory experiences, those related with current or previous drug use were most reported (12.1%), followed by race/ethnicity-related (6.0%), HIV-related (5.7%), and linguistic (4.2%) discrimination. In combination, 15.4% of the sample reported experiences of any discrimination in healthcare encounters, and 6.3% (*n*=21, data not shown) reported more than one type of discrimination during the previous 2 years. The mean MCS-12 score was 38.72 (*SD*=6.88) at baseline.

Participants reported high PCE-PCP at baseline and 6-month follow-up (Table 6.2). The vast majority (93.7% at baseline and 95.8% at 6-month follow-up) felt that their PCP knew them "as a person", involved them in treatment decisions (89.7% answered "usually" or "always" at baseline, and 90.0% at 6-month), explained pros and cons of treatment options (92.1% answered "usually" or "always" at baseline, and 88.2% at 6-month), supported their decisions (87.3% answered "usually" or "always" at baseline, and 81.9% at 6-month), and provided enough information about side effects or risks (92.1% answered "usually" or "always" at baseline, and 89.7% at 6-month). Most participants also felt that their PCP involved their partner or close family members in their care as much as they would like (60.7% answered "usually" or "always" at baseline, and 67.7% at 6-month). Separate exploratory factor analyses with the six items measuring PCE-PCP at baseline and at 6-month indicated an underlying single dimension with good model fit (for baseline measurements: Comparative Fit Index [CFI]=1.00, Tucker-Lewis Index [TLI]=1.00, Root Mean Square Error of Approximation [RMSEA]=0.02, 90% *CI*=0.00, 0.07]; for 6-month measurements: CFI= 1.00, TLI= 1.00, RMSEA= 0.04, 90% *CI*=0.00, 0.08).[44] Factor loadings ranged from 0.63 to 0.94 for baseline measurements and from 0.54 to 0.90 for 6-month measurements.

Figure 6.1 shows the statistically significant direct and indirect paths between baseline depression and healthcare discrimination, 6-month PCE-PCP, and 12-month

MHRQOL. The structural equation model indicated that both baseline depression (Standardized Coefficient =-0.16, *p*<.05) and baseline discrimination in healthcare encounters (Standardized Coefficient =-0.20, *p*<.01) were associated with reduced PCE-PCP at 6-month, and that 6-month PCE-PCP was associated with higher MHRQOL at 12-month (Standardized Coefficient =0.26, *p*<.01). There were significant indirect paths from baseline depression (Standardized Coefficient =-0.04, 95% *CI* = [-0.10, -0.01]) and healthcare discrimination (Standardized Coefficient =-0.05, 95% *CI* = [-0.12, -0.01]) to lower MHRQOL at 12-month, mediated through reduced PCE-PCP at 6-month. No direct effects were detected from the independent variables measured at baseline to 12-month MHRQOL, after adjusting for the mediated effects and all covariates in the model. The model achieved good fit (CFI=0.97, TLI=0.96, RMSEA=0.04, 90% *CI*= 0.03, 0.05).[44]

Table 6.1 Baseline sample characteristics (*N*=331)

	Mean (*SD*) or % (*n*)
Age	52.31 (*SD*=6.67)
Male	56.5 % (*n*=187)
Sexual orientation	
Gay	12.7% (*n*=42)
Straight	82.2% (*n*=272)
Bisexual	3.9% (*n*=13)
Other	1.2% (*n*=4)
African American race	95.8% (*n*=317)
Education	
8th grade or less	9.1% (*n*=30)
Some high school, no diploma	39.3% (*n*=130)
High school diploma or GED	31.1% (*n*=103)
Some college or technical training	16.9% (*n*=56)
College degree	2.7% (*n*=9)
Any graduate training	0.9% (*n*=3)
Monthly income	
No income	0.9% (*n*=3)
Less than $250	5.4% (*n*=18)
$250-$499	9.4% (*n*=31)
$500-$999	55.6% (*n*=184)
$1000-$1499	19.0% (*n*=63)
$1500-$1999	4.8% (*n*=16)
$2000 or more	4.2% (*n*=14)
Last time injected drugs	
Never	48.9% (*n*=162)
More than 5 years ago	30.5% (*n*=101)
1-5 years ago	5.1% (*n*=17)
6-12 months ago	3.9% (*n*=13)
In the past month	4.2% (*n*=14)
Alcohol consumption	
Less than once a week	60.1% (*n*=199)
1-2 times per week	10.6% (*n*=35)
Several times a week	10.6% (*n*=35)
Once a day	8.5% (*n*=28)
More than once a day	10.3% (*n*=34)
Average level of pain (0-10)	5.16 (*SD*=3.49)
Length of time since HIV was diagnosed	
Less than 15 years	26.9% (*n*=89)
15-24 years	42.9% (*n*=142)
25 years or more	30.2% (*n*=100)
Depression (CESD-10 score ≥10)	35.6% (*n*=118)
Discrimination in healthcare encounters related to	

Race or ethnicity	6.0% (*n*=20)
Use of language and characteristics of speech	4.2% (*n*=14)
HIV status	5.7% (*n*=19)
Current or pervious drug use	12.1% (*n*=40)
Mental health-related quality of life (MCS-12 score)	38.72 (*SD*=6.88)

Table 6.2 Factor loadings for PCE-PCP indicator variables at baseline and 6-month (*N*=331)

	Descriptive statistics		**Factor loadings**	
	baseline	**6-month**	**baseline**[a]	**6-month**[b]
	% (n) "yes"			
Knows me as a person	93.7% (*n*=310)	95.8% (*n*=317)	0.76*	0.54*
	% (n) "usually" or "always"			
Involves me in decisions about my treatment as much as I would like	89.7% (*n*=297)	90.0% (*n*=298)	0.85*	0.87*
Explains the pros and cons of different treatment options	92.1% (*n*=305)	88.2% (*n*=292)	0.94*	0.90*
Supports my decisions	87.3% (*n*=289)	81.9% (*n*=271)	0.72*	0.85*
Provides me enough information about treatment side effects or risks	92.1% (*n*=305)	89.7% (*n*=297)	0.84*	0.87*
Involves my partner or close family members in my care as much as I would like	60.7% (*n*=201)	67.7% (*n*=224)	0.63*	0.67*

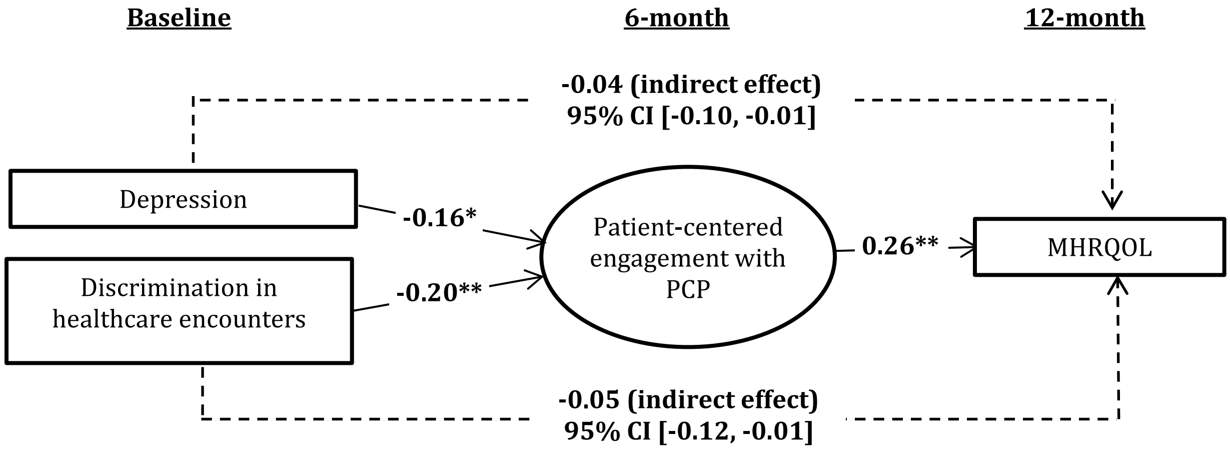
Geomin rotated loadings are reported (oblique rotation)

[a] Model-fit statistics: CFI= 1.00, TLI= 1.00, RMSEA= 0.02 (90% *CI*=0.00, 0.07)

[b] Model-fit statistics: CFI= 1.00, TLI= 1.00, RMSEA= 0.04 (90% *CI*=0.00, 0.08)

*Significant at 5% level

Figure 6.1 Structural equation model showing standardized coefficients of direct (solid lines) and indirect paths (dashed lines) from baseline depression and experiences of discrimination in healthcare encounters to 12-month MHRQOL, via 6-month patient-centered engagement with primary care providers (PCE-PCP).



Notes: Path coefficients are standardized by both the dependent and independent variables in each path. Bootstrap confidence intervals (*CI*) are included for the indirect effects. Covariates adjusted for in the model were baseline measurements of PCE-PCP and MHRQOL, male gender, African American race, high school education, history of injection drug use, daily alcohol consumption in past 6 months, average pain level, and length of time since HIV was diagnosed. Direct paths were included from all covariates to 6-month PCE-PCP and 12-month MHRQOL, but not shown in the graph. Only significant paths among the main variables of interest in the graph are shown for ease of readability (Affirm Care study; N=331). CFI=0.97, TLI=0.96, RMSEA=0.04 (0.03, 0.05); *$p<.05$, **$p<.01$

DISCUSSION

Among a sample of socioeconomically marginalized PWHs, we identified structural factors linked to later MHRQOL. Study participants reported a high level of probable depression and low MRQOL (38.72, *SD*=6.88) compared with the US general population norm of 50 (*SD*=10), which was standardized based on the distribution of scores in the general US population in the 1980s and confirmed in the more recent 2005-2015 United States Medical Expenditure Panel Survey.[33,45] This is consistent with prior studies suggesting that PWH might have lower MHRQOL than the general population. A multicenter, multi-country clinical trial reported a mean MCS-12 score of 47.4 (*SD*=11.3) among people with early-stage HIV in North America.[46] Several studies that included persons with more advanced HIV reported mean MCS-12 scores between 41.9 and 42.9, although no association was found between HIV viral load and MCS-12 scores.[47–49] The low MCS-12 scores in our study suggest that African Americans with HIV and a history of drug use are among the groups that face particularly high burden of mental health challenges, across different populations of PWH.

Structural equation modeling suggested a mediated path from PWH's prior experience of discrimination in healthcare settings to lower subsequent MHRQOL, mediated through reduced PCE-PCP. Experiences of discrimination could cause chronic stress and expectations of rejection and devaluation from others.[13,26] Healthcare discrimination might lead to medical mistrust and reluctance to engage with providers in healthcare out of interest in self-protection from further mistreatment.[29] In such circumstances, providers might mistake patients' non-involvement as indifference and consider them as unmotivated or uncooperative, perpetuating structural discrimination, distrust, and poor engagement. Suboptimal patient-provider interaction could further discourage patients' involvement and negatively impact their treatment and quality of life.[16–18] Thus, the negative impacts of healthcare discrimination on PWH's well-being are reinforced through harming their engagement with PCP.

Literature shows that many PWH have more than one stigmatized category or identity, including HIV status and other health conditions such as chronic pain, substance use and other mental disorders, race, ethnicity, gender, sexual orientation, socioeconomic status, and more.[13,14] Past research has linked various stigma and discrimination experienced by PWH with declined mental health.[13–15] The theoretical framework of intersectionality posits that individuals at the intersection of multiple stigmatized identities face interlocking systems of privilege and oppression, which result in compounded disparities.[13,50] Stigma processes include labeling, stereotyping, setting apart (separation of "us" from "them"), status loss, and discrimination within the context of power differential.[51] Individuals could be labeled with multiple stereotypes; therefore, some groups are more stigmatized than others.[51] In the current study, we examined different forms of discrimination in healthcare encounters and found overlaps among discrimination related to race or ethnicity, use of language or speech characteristics, HIV status, and drug use history. Future research should further investigate how intersecting stigma impact healthcare relationships and quality of life, by contrasting individuals experiencing different levels and combinations of discrimination. Research is also needed to understand whether and how PCE-PCP plays a role in the relationships between different forms of stigma, other than those enacted as discrimination, and MHRQOL.

Our results also indicate that the link between depression and reduced MHRQOL was mediated by decreased PCE-PCP. Prior studies have found associations between severity of depressive symptoms and reports of poor patient-provider communication by patients with type 2 diabetes and chronic coronary disease.[52,53] Patients with higher levels of depression were less likely to report that their providers explained their conditions clearly or involved them in joint decision-making.[52,53] One possible explanation is that clinicians might be affected by patients' interpersonal styles and engage differently with those who present depression because of misperceiving possible passive attitudes or flat expressions or affect with lack of interest in engagement.[52] It is possible that individuals' depression leads them to withdraw during interactions with healthcare providers, impeding providers' understanding of their needs and concerns and engagement with them in active exchange of information and shared decision making. Research analyzing audio-recorded clinical visits found that PWH with higher CES-D scores showed more negative affect and initiated less social chit-chat during visits, and were less likely to report that their providers knew or respected them in post-visit surveys.[31] Similarly, providers were less likely to engage PWH with higher CES-D scores in social chit-chat or report positive regard for them.[31] Patient behaviors affected by their depression, such as history of nonadherence to treatments and medical appointments, might contribute to providers' negative attitudes.[31] Providers might also find it difficult to amply address patients' multiple health issues under the pressure of time constraints during clinical visits.[52] They might not be able to identify patients' needs related to their depression, in addition to their HIV and other comorbid conditions. Thus, suboptimal patient-provider engagement could undermine care quality and further exacerbate patients' mental health.

The association between depression and poor MHRQOL has been well documented in literature.[9,10] A randomized trial evaluating the effects of depression treatment among PWH found that improvement in depressive symptom severity was related to increased MHRQOL.[11] An observational study using a representative, random sample of PWH in France also found an association between depression symptoms and lower MHRQOL.[54] In our structural equation model, individuals' baseline depression did not have a significant direct effect on their MHRQOL at 12-month. This indicated that after accounting for the mediation effect of PCE-PCP and all other variables in the model, the remaining association between depression and MHRQOL was small and not detectable with the statistical power available. There might exist other pathways between depression and MHRQOL that was not captured by our model. For example, several studies have shown that social support mediates the effects of depression on dimensions of quality of life including MHRQOL among various patient populations, such as PWH, community-dwelling elder adults, and post-stroke patients.[55–57]

Results of this study suggest a potential for improving PWHs' mental health outcomes through intervening on PCE. Integrative interventions are needed to improve quality of patient-clinician relationships. Medical education and clinician training should incorporate elements to promote PCE and develop providers' communication skills to better elicit and understand patients' needs and values, offer patients comprehensible information, respond to patients' emotions, and encourage patients' involvement in decision making.[58] Providers should identify and give special attention to patient groups that are more likely to experience challenges in patient-provider interactions, including those who are vulnerable to stigma, discrimination, and depression. Patient interventions should also target these groups to increase their empowerment and ability to better interact with providers and to actively involve them in their own care. Finally, efforts are needed to create a supportive healthcare environment, for instance, through policy and investments in supportive infrastructure to facilitate PCE.[59]

One strength of the study is the use of longitudinal data to establish a temporal order of associations among variables. However, it also has several limitations. Participants of the study were recruited from HIV clinics and other community venues. Therefore, the findings might not be generalizable to PWH who are not connected to care. Moreover, there might exist other paths from healthcare discrimination and depression to MHRQOL that were not detectable by our modest sample size. There were also limitations related to the measurements. The prevalence of healthcare discrimination experienced by this population might be underestimated, as additional types of discrimination are possible. In addition, although we measured different forms of discrimination, we were not able to examine the effects of intersectional discrimination due to the limited sample size. Future research should further investigate the interlocking systems of multiple stigmatization and discrimination to better understand their impacts on healthcare relationships and quality of life through the lens of intersectionality. Also, we did not assess the length of time participants had been seeing their PCP, nor did we examine their engagement with healthcare providers other than their PCP. Finally, the observed associations in our model might be due to factors not measured. For example, neurocognitive impairment, which is common though often mild among PWH, and may have contributed to depression, lower PCE-PCP, and poor MHRQOL.

Conclusions

This research underscores the important role of patient-centered care in the MHRQOL among socioeconomically disadvantaged persons with HIV and a history of drug use, who are vulnerable to multiple forms of stigma, chronic stress, and mental disorders. The negative impacts of depression and experiences of discrimination in healthcare settings on PWH's psychological well-being could be perpetuated by their suboptimal engagement with PCP. The results inform policies, programs, and clinical practices for reducing disparities in mental health outcomes through intervening on the quality of patient-provider engagement in primary care. Findings of the study suggest that PCP may have the ability to improve patient MHRQOL through their patient-provider interaction style. Further research is needed to better understand the potential for and the mechanism of enhanced PCE-PCP in mitigating the harmful effects of depression and healthcare discrimination. In particular, studies are merited on how different proximal outcomes of PCE-PCP—such as improved patient-provider relationships and care continuity, and changes in patients' health behaviors—contribute to patients' MHRQOL, and how efforts facilitating PCE could be tailored to meet the needs of individuals with depression and experiences of healthcare discrimination.

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APPENDIX

Table 6.3 Standardized (*β*) and unstandardized (*B*) path coefficients for direct and indirect effects in the structural equation model. Significance levels (*p*-values) for standardized path coefficients and standard errors (*SE*) for unstandardized path coefficients are included for the direct effects, and bootstrap confidence intervals (*CI*) are included for the indirect effects. Statistically significant effects, indicated by a *p*-value < .05 for direct effects and a 95% *CI* that does not include zero, are labeled in bold texts.

Independent variable	**Direct effect on 6-month PCE-PCP**		**Direct effect on 12-month MHRQOL**		**Indirect effect on 12-month MHRQOL, through 6-month PCE-PCP**	
	***β* (*p*)**	***B* (*SE*)**	***β* (*p*)**	***B* (*SE*)**	***β* (95% *CI*)**	***B* (95% *CI*)**
Depression, baseline	**-0.16 (.02)**	**-0.19 (0.09)**	-0.04 (.54)	-0.51 (0.82)	**-0.04 (-0.10, -0.01)**	**-0.58 (-1.46, -0.08)**
Discrimination in healthcare encounters, baseline	**-0.20 (.001)**	**-0.32 (0.11)**	0.08 (.12)	1.51 (0.97)	**-0.05 (-0.12, -0.01)**	**-0.99 (-2.26, -0.18)**
PCE-PCP, baseline	**0.53 (<.001)**	**0.42 (0.09)**	-0.03 (.68)	-0.30 (0.74)		
PCE-PCP, 6-month	**-**	**-**	**0.26 (.002)**	**3.09 (1.11)**		
MHRQOL, baseline	0.10 (.11)	0.01 (0.01)	**0.14 (.02)**	**0.14 (0.06)**		
Male gender, baseline	0.01 (.87)	0.01 (0.08)	0.11 (.05)	1.43 (0.74)		
African American race, baseline	0.06 (.39)	0.17 (0.20)	0.04 (.50)	1.48 (2.17)		
High school education, baseline	0.03 (.70)	0.03 (0.08)	0.03 (.61)	0.39 (0.76)		
History of injection drug use, baseline	-0.04 (.53)	-0.02 (0.03)	-0.03 (.58)	-0.15 (0.27)		
Daily alcohol consumption, baseline	-0.03 (.65)	-0.04 (0.09)	0.08 (.16)	1.38 (0.99)		
Average pain level, baseline	0.00 (.95)	0.00 (0.01)	**-0.11 (0.04)**	**-0.22 (0.11)**		
Length of time since HIV was diagnosed, baseline						
Less than 15 years	*ref*	*ref*	*ref*	*ref*		
15-24 years	-0.10 (.25)	-0.12 (0.11)	-0.00 (.96)	-0.05 (0.95)		
25 years or more	0.02 (.86)	0.02 (0.11)	-0.01 (.94)	-0.08 (0.94)		

CHAPTER 7 – PATIENT PERSPECTIVES ON THE CHALLENGES AND OPPORTUNITIES IN PATIENT-PROVIDER RELATIONSHIPS REGARDING CHRONIC PAIN MANAGEMENT AMONG AFRICAN AMERICANS WITH HIV WHO USE DRUGS: A QUALITATIVE STUDY

ABSTRACT

Background Chronic pain in people with HIV (PWH) is common and often undertreated; certain sub-groups are particularly vulnerable. Stigma and bias in pain care associated with substance use and minority race contribute to disparities in pain and its treatment. Challenges in treating chronic pain in the context of the current opioid epidemic present further threats to patient-provider relationships. This study explored patients' perceptions of barriers and facilitators to chronic pain management in their encounters with the healthcare system, among a population of African American PWH who use drugs.

Methods We conducted 27 in-depth interviews and 1 focus group with a total of 33 participants (16 female, 16 male, 1 other gender) between August 2014 and July 2019 in Baltimore, Maryland, United States. Data were analyzed using a combination of inductive and deductive coding through an iterative process, during which *a priori* codes were first developed based on questions in the interview guide then modified as new themes emerged.

Findings Many participants described conflicts with their providers regarding pain causes and treatment strategies, which created an added burden of psychological distress on top of their physical pain. Provider concerns about analgesic misuse and diversion were perceived as untrusting by several participants, who felt unfairly judged based on their history of drug use. Prior experiences of discrimination by healthcare providers or staff also contributed to participants' mistrust in the healthcare system. There were instances

where participants chose to hide information about unrelieved pain or skipped medical appointments in order to avoid dispute with their providers and the frustration that it could cause. When pain was not adequately addressed, some sought pain relief through self-medication. Participants emphasized the need for clinicians to know and treat them as whole persons instead of focusing on single health problems or behaviors. They wanted their providers to interact with them with respect and empathy, and to incorporate their opinions in treatment decisions.

Conclusions Our findings revealed tension, conflict, and distress among African American PWH with a history of drug use when discussing pain and pain treatment with their healthcare providers. Managing chronic pain for individuals with active or history of substance use disorders can be complicated. A framework of compassion and joint problem solving with a goal of reducing social harms, pain and distress should be adopted. Interventions and clinician trainings are needed to cultivate provider empathy and to foster positive, collaborative patient-provider relationships.

INTRODUCTION

Chronic pain is a prominent health problem among people with HIV (PWH). PWH are at higher risk of developing chronic pain due to nerve damage associated with HIV infection and its treatment, as well as other factors related to common comorbid conditions.[1,2] In the United States, research shows that 39%-85% of PWH report chronic pain, depending on the study population.[1,3] Moreover, chronic pain in PWH is vastly undertreated.[1–3] Certain groups experience an increased burden of chronic pain and pain undertreatment, including women, racial/ethnic minorities, individuals with low socioeconomic status (SES), and those with substance use and other mental disorders.[1,4–6] Stigmatization and bias in pain care contribute to these health and treatment disparities.[7] National studies suggest that African Americans, among other racial/ethnic minorities, are consistently less likely to be prescribed opioid analgesics in emergency departments and in ambulatory care settings for chronic non-cancer pain, compared with non-Hispanic whites who have similar health conditions and pain severity.[8,9] In addition, women experiencing pain from chronic fatigue syndrome, fibromyalgia, and other conditions, people who are on prescription opioids for intractable pain, older adults, and people with substance use and other mental disorders are also more likely to receive inadequate pain treatment.[7]

PWH of minority race or ethnicity with low socioeconomic status and a history of drug use are vulnerable to multiple layers of stigma.[10–12] HIV/AIDS related stigma has been recognized as one of the major barriers to HIV prevention, treatment and care.[13–16] In addition, research shows that race-related prejudice plays a role in patient-provider communication in HIV care.[17,18] Compared to conversations with white patients, HIV care providers were found to be more verbally dominant and less likely to engage in discussions of beliefs, values, aspirations or preferences with black patients.[17,18] PWH with a history of drug use face further prejudice and discrimination against addiction.[19] A systematic review found health professionals generally held negative attitudes toward patients with substance use disorders, were unable or unwilling to empathize with them, and perceived them as violent, manipulative, or poorly motivated.[20] Such biases could result in providers' misjudgments about the genuineness of patients' pain complaints and lead to misinformed treatment decisions.

Chronic pain is also associated with stigma, especially when the cause of pain cannot be confirmed. Because there is no objective biomarker for chronic pain, questions and doubts might arise during healthcare encounters regarding pain severity, or even the validity of patient's pain experiences.[21] Physicians specializing in pain treatment were found to discredit patients' pain symptoms that were lacking physiological explanations, and consider them as only existing in patients' mind and therefore not deserving medical attention.[22] The invisibility and subjective nature of chronic pain, coupled with provider concerns over analgesic misuse and stigmatizing attitudes toward substance use, create further challenges in chronic pain management. Patient reports of unrelieved pain could be considered as indicators of addiction, leading to reduced treatment access, suboptimal care, and compromised patient-provider relationships.[19,23]

Developing and sustaining collaborative patient-provider relationships is essential in the care of chronic disorders, including HIV, substance use, and chronic pain.[24–29] Challenges in treating chronic pain, especially in the context of the current opioid epidemic, present significant threats to care relationships. The uncertainty of pain diagnosis and the lasting quality of chronic pain due to lack of safe and effective long-term treatment could generate feelings of failure and ambiguity among both patients and providers.[21] Moreover, it is not uncommon for chronic pain patients to hold conflicting attitudes, goals and expectations with their providers regarding pain management.[22,29] Disagreements about treatment inadequacies and risk for analgesic misuse often create tension between patient and provider, as well as substantial frustration to both parties.[30–33]

In this study, we explored patients' perceptions of barriers and facilitators to chronic pain management in their encounters with the healthcare system, among a uniquely vulnerable population of African American PWH who use drugs. The objective was to understand the challenges and opportunities in the healthcare relationships of this patient group that is disproportionately affected by chronic pain as well as stigma and bias in health care.

METHODS

Recruitment

The present research was part of the AFFIRM Care Study, which examined quality of life and advance care planning with medical providers among socio-economically disadvantaged PWH and their informal caregivers in Baltimore, Maryland, United States. The AFFIRM Care Study recruited participants from the Johns Hopkins adult HIV clinic and community venues through flyers. The inclusion criteria for the AFFIRM Care Study were being adult (18 or over), HIV seropositive, and reporting current or former use of heroin, crack, or cocaine.

We conducted 27 in-depth interviews and 1 focus group (consisted of 3 sessions) between August 2014 and July 2019. After the first 12 in-depth interviews, we reviewed the interview transcripts and invited three participants who had more experiences interacting with the healthcare system in relation to their chronic pain for a follow-up interview. We also reviewed surveys that participants filled out for the AFFIRM Care Study, and identified those who consistently reported pain symptoms at all three survey time points, and those experienced tension in healthcare encounters (such as experiences of discrimination or being denied pain medication) to invite for interviews. In addition, participants reporting moderate to severe pain in the surveys, as defined by a rating of 5-7 on the Brief Pain Inventory Scale[34] (0 = no pain, 10 = worse pain possible), were invited to join a focus group because they might be more likely to experience ambiguity and uncertainty in pain treatment, which could lead to tense care relationships. We adjusted the recruitment to balance the gender composition in the sample.

Data collection

Interviews and focus group sessions were conducted in a private room at a community-based research facility. In-depth interviews were conducted one-on-one by the study principal investigator (PI) and trained research team members. The interviews followed a semi-structured guide, and generally lasted for 1-1 ½ hours each. During the early stages of the data collection, the interview guide was modified to emphasize participants' lived experiences with chronic pain and to examine their interactions with healthcare providers regarding pain management. Later the guide was revised again to expand the discussion around participants' overall relationship with the healthcare system in relation to pain management, and to explore in more depth various aspects of their engagement with their main care providers. The focus group was led by the PI, also following a semi-structural guide, and included 9 participants who met weekly for three weeks to cover various topics related to chronic pain and its management, approximately 1 ½ hours each time. Field notes were taken by the interviewers and focus group observers during data collection.

Written consent was obtained from all participants prior to data collection. Individuals did not need to agree to take part in every component of the research in order to remain participants in the AFFIRM Care Study. Participants received $25 for each in-depth interview or focus group session in compensation for their time. The study was approved by the Johns Hopkins School of Public Health Institutional Review Board.

Data analysis

The in-depth interviews and focus groups were audio-recorded and professionally transcribed verbatim. A combination of inductive and deductive coding was used for data analysis.

First, *a priori* codes were developed based on questions in the interview guide and research constructs of interest. Both the first author of the paper and a second coder individually read one transcript and its associated notes, applying these codes while writing memos on emerging themes, personal reflections, and analytic notes. The two coders then met and discussed the initial coding and reconciled emerging themes noted by each. Based on these discussions, the first author created an initial codebook with definitions and examples, tested it on a subset of the transcripts and notes, and revised the codebook as any new theme emerged. At the end of this process, the team reconvened to review the coding and the revised codebook.

Next, both coders independently coded two transcripts using the revised codebook and met to assess coding consistency and modified the codebook as needed. This process was repeated until sufficient inter-coder agreement was reached. Finally, the two coders divided the rest of the transcripts and coded them using the finalized codebook. Major themes were identified, and salient quotes were selected to support each theme. Throughout this iterative process, the PI served as an auditor to review and monitor the development of the codebook and the analysis.

RESULTS

A total number of 33 African Americans with HIV (16 female, 16 male, 1 other gender) contributed to 27 in-depth interviews and 1 focus group (4 female, 5 male). There was no overlap between in-depth interview and focus group participants. The median age was 55 (range 45-71). Table 7.1 shows sample characteristics.

Table 7.1 Participant characteristics (*N*=33)

	Median (Range) or % (*n*)
Age	55 (45-71)
Gender	
Female	48.5% (*n*=16)
Male	48.5% (*n*=16)
Other	3.0% (*n*=1)
African American race[a]	100% (*n*=31)
Education[a]	
Less than high school	25.8% (*n*=8)
High school diploma or GED	41.9% (*n*=13)
Some college or more	32.3% (*n*=10)
Monthly income[a]	
$0 - $999	83.9% (*n*=26)
$1000 or more	5% (*n*=16.1)
Years since HIV diagnosis[a]	21 (5-35)
Comorbid health condition[a]	
Diabetes	12.9% (*n*=4)
Cardiovascular disease	32.3% (*n*=10)
Mental health disorder	35.3% (*n*=11)
Other medical condition	19.4% (*n*=6)

[a] Two participants did not provide this information (N=31).

To contextualize themes identified across transcripts and to illustrate how these themes are integrated within individuals' healthcare experiences in an intertwined manner, below we present three case narratives that are representative of varied healthcare relationships and pain management experiences, followed by more detailed description and examples for each theme. The three cases are chosen because they represent three distinct paradigms of patient-provider dynamics that contrast one another. Pseudonyms are used in the case narratives to protect participants' identity.

Michael's narrative

Michael was first diagnosed with HIV in his early thirties. About a decade later, he was diagnosed with a kidney disease, which he believed was caused by his HIV medication. The steroids used to treat his kidney then damaged his bones, and led to avascular necrosis. By the time he was in his early fifties, he was in constant pain from a urinary catheter, and avascular necrosis in his shoulders, knees, hips, and everywhere.

Navigating among multiple healthcare specialists was a real challenge for Michael, as poor care coordination produced much confusion and chaos.

> "I have my primary care, I have an orthopedic surgeon, I have a nephrologist, and somebody else. I have a bunch of doctors, and they always don't coordinate with each other as far as medications and things [...] It's a pain to get them coordinated. They don't know – they don't talk to each other. I mean, they're all in the same building but they believe in email instead of just getting the hell up and going to a damn desk and talking to somebody. So I was in – I was in an emergency room once for five days because they couldn't get a hold of my doctor who was just upstairs."

One time Michael was prescribed two different medications by two doctors for the same health condition. To avoid this type of oversight, Michael tried to keep all his medical records in one system, by only seeking care with the same provider group.

> "I mean, that's why I stick to one hospital [...] because at least here they could look on the same database and you can see – all the doctors can see the same medical chart. But, I mean, if I were going here for my kidneys and I was going to [Hospital Name] for my bones, and – I don't know how they would – I mean, you could probably wind up dead."

Michael also faced financial barriers to needed treatment. He said his providers refused to prescribe him analgesics and insisted his pain being addressed by surgical procedures, while he could not afford the recommended surgery.

> "They [clinicians] were like, 'Well, we're not going to give you any opioids because what you need is surgery.' And I was telling them I have to – I said – this is before I got my dialysis stuff put in. I was like, 'I can't afford to fix everything that's wrong

> with me with surgery. So I need something to hold me up, you know.' But they wouldn't do it."

Unable to obtain prescription analgesics, Michael sought pain relief through alcohol, which led to more tension between him and his providers.

> "Sometimes the best thing for me to do is I'll drink a beer or I'll drink – but then they [the providers] consider me self-medicating, but they won't give me painkillers. And then one of my doctors is telling me that [...] they tried to put me down as a substance abuser, so I couldn't get a kidney [transplant] because I drink."

When communicating his pain symptoms with the providers, Michael sensed their untrusting attitudes.

> "You can't just tell them [healthcare providers] you're in pain, they have to validate it [...] they start doing so many procedures on you that are unnecessary instead of just listening to you."

Sometimes he felt the need to defend himself, which was especially frustrating while he was in pain.

> "[Communication with providers] turns into a pissing contest. And it's kind of hard – it's difficult when you're in pain, or you're sick, and you have to defend yourself. So, I mean, it's just like, ugh."

Michael was extremely dissatisfied with his care. He disapproved of his providers' clinical judgments and communication styles, and criticized their condescending attitudes: "I mean, sometimes they talk to you like you're a child, and I'm like 50 years old, you know." He continued, "[...] what doctors fail to realize is that they're in the service industry. They're not above anyone, they're there to serve us."

Michael was particularly frustrated that the medication side effects which ended up causing him more health problems were never explained to him in the first place, and was considering taking legal actions against his providers.

> "[...] they [the providers] don't tell you about the side-effects of all the medications when they give it to you. You know. So that's why I'm consulting a lawyer."

In addition, Michael did not feel that the healthcare system overall was serving patients well.

> "I don't agree with the medical community on a bunch of things. I mean, they just – I don't know. I don't know who they're trying to please. Basically they're just trying to rape your insurance."

Michael concluded that he had to actively advocate for himself in healthcare and take responsibility for his own treatment, because doctors are not reliable.

> "I realized one thing. This is just from watching my doctors. And I was like, 'Why do they spend so much money going to medical school?' Because all they do after you tell them what's wrong with you is go on WebMD. I'm serious. That's all they do."

Brenda's narrative

Brenda's skeletal muscular disorder, compounded with her obesity, has caused a lot of limitations in her daily life. While obesity restricted her mobility and exacerbated her skeletal muscular pain, the pain impeded her ability to take effective steps to lose weight. She has also experienced increased difficulty performing her work.

> "I'm not working as an LPN [licensed practical nurse] anymore. As a matter of fact, I'm not even licensed anymore. I had to let my license lapse. I couldn't do it. I can't stand on my feet that long. So I'm doing private duty. Going to people's homes. Trying to help take care of them. It's hard. It is hard because sometimes it require you to stand on your feet and that's hard. I can only stand for so long [...] I have seriously considered quitting my job and filing for disability again [...] But who wants to live on a once a month income?"

Brenda's primary care provider (PCP) wanted her to lose weight instead of relying on pain medicine, but it was a catch-22 situation for her since she needed some pain relief in order to start exercising.

> "So that's the issue I have with her [PCP] as far as giving me what I need. I'm in this body. I know how it feels. And she says, 'Well, just lose the weight. Just lose the weight.' Well, that's easier said than done. Like I explained to her. To lose the weight, I have to exercise but to exercise, I'm in pain so it's hard to exercise. But if she would

> give me the medicine that I need to at least make the pain a lot more tolerable, I could do more exercise. I would lose the weight quicker but I need to exercise and lose the weight and I can't exercise because I'm in pain. But I'm in pain because I need to lose the weight."

The analgesic class that Brenda's PCP prescribed her was not powerful enough to alleviate her pain. She understood her PCP's concerns around prescription drug misuse, but felt that the risk was unfairly evaluated as she had been abstinent from substance use for a long time.

> "But if she [PCP] would prescribe me Oxycodone or Tylenol 3s or Tylenol 4, that along with what else I take, it helps. It'll take the pain away but she will not give me the other medicine because I was a previous drug user. But I only had one drug of choice. I was a crack cocaine smoker. I didn't shoot drugs, I didn't take pills, I didn't liquor, I didn't smoke marijuana. I did one drug and like I tried to explain to her, if I want to get high, I want to go get high, I'm not going to play with it. But she won't give me anything stronger [...] I think she's stuck on 'No, because you were an addict,' and that's her whole thing. I was an addict, she doesn't want me to fall. I get it. Okay. But that [opioid] was never my drug of choice. [And] I have been clean over 20 years."

Brenda's PCP tried to further reduce her already-insufficient pain medicine, which led to severe pain flare and Brenda's admission to the emergency department.

> "So [I was taking] the combination of the Tramadol and the Celebrex, and she [PCP] wanted to take one of them away. Okay. So, [she said,] 'You only need one,' and I ended up back and forth to the emergency room because I was in too much pain. So she let me take the two of those together."

Despite such discord around pain treatment, Brenda had a long, positive rapport with her PCP. She had been seeing the same PCP for over 10 years and said "everything else is wonderful." She just wished her PCP would show more understanding and empathy when it comes to managing her pain. "You're not in my body. You don't feel what I feel," Brenda said. "I think that she [PCP] should consider my feelings a little more and trust me and my knowledge of my body."

> **Brenda:** “She’s been my primary care doctor for quite some time. I wouldn’t change. Even though with her battle about the medicine, I would not change primary care doctors. I like her. I think she has my best interest at heart. I really do. If there’s something like a medicine that’s been pulled or recalled or something, she’s on it. She lets me know. If something comes back abnormal in blood work or any type of labs, she’s on it. She pays attention. She’s on it. She knows me well. She really pays attention. She’s on it. She knows when I’m feeling good and when I’m not feeling good [...]”
>
> **Interviewer:** “How well do you feel that she listens to your need in terms of managing your pain?”
>
> **Brenda:** “I think she listen. I’m going to be honest. I think she listens but I don’t think she considers how I feel about it a lot of times [...] I’m not trying to get high. I’m trying to stop this pain. But I do understand why she feels the way she feels. I totally get it but I need her to get it from me. I need her to see my side.“
>
> Brenda said she would just continue working on the disagreements with her PCP.
>
> “I really love my doctor. I do. I wouldn’t trade her for nothing in the world. I could shake her sometime. But I wouldn’t trade her.”

Sharon’s narrative

Sharon developed chronic pain in her knees, feet, and back after gaining a significant amount of weight, on top of the multiple comorbid conditions she was already living with. She mainly used over-the-counter pain medicine to manage her pain. She let all her doctors know that she did not want any prescription opioids, due to fear that it would trigger relapse to substance use. To minimize the chance of an accidental exposure, she requested false documentation in her medical chart stating that she was allergic to opioid analgesics and cold medicine containing codeine.

Sharon’s chronic pain severely limited her mobility. She had to pause and catch her breath multiple times, just walking from one end of a room to the other. She also had problems going up and down stairs, standing, or staying seated for a long time.

> "I didn't want to do nothing. It made me like—[I asked] everybody in my house, 'Can you get me this? Can you bring me that? Can you go to the store? Could you get this for mommy? Can you go over here? Can you go downstairs and look at [something for me]?' I got real lazy."

Sharon's PCP, whom she had been seeing for more than 20 years, worried that her obesity would lead to diabetes. However, Sharon did not believe in her own ability to lose weight: "Because I was like, this is ridiculous. Look how big I am." She also resisted her doctor's diagnosis that her obesity was causing the pain. She said, "I'm not even listening to that, I just want the pain to go away." Sharon's PCP, on the other hand, continued to reassure Sharon that she could make the behavior change to lose weight, and was very encouraging the whole time. The PCP maintained a gentle yet firm attitude, even when Sharon screamed out of frustration or cried out of despair.

> "When I be in pain I just get so…'I don't want to hear nothing you're talking about. Just figure out why my knees hurt because this is it.' I would scream at her [PCP] [...] Then I'd start crying [...] I was like, 'How do you do that stuff [exercise and diet control for weight loss]?' And I would scream. She's like, 'Just do it.' I was like, 'I can't.' She was like, 'Yes you can.' We had that argument twice."

When Sharon disputed with her PCP and raised other probable causes of her weight-gain and pain, the doctor did not dismiss them. She took Sharon's concerns seriously by examining her thoroughly, referring her to a range of specialists, and reiterating that she must lose weight.

> "I'm like, 'What is wrong? In one week I had gained like seven pounds.' I was like, 'What is wrong with me. It's got to be fluids.' She [PCP] test me fluids. She test me for everything. Nothing. I love her. Dr. [Name] is the best. She's like, 'You are driving me crazy. We're going to try this one more test and then we're going to know that it's you need to lose weight.' [...] She does good. I'm sorry, she is the best. If you've got her as a doctor, you've got it. She's like, 'Let's try this. Go and do this. If this don't work, you know what it means, you've got to lose weight.' She always adds, 'You know you've got to lose weight.'"

When asked how well her PCP explained things to her, Sharon said:

> "Very good. I mean, step by step to do everything. You know, 'If you don't do this, this, and this.' Very thorough. And she know me like a book. She know everything. My breathing. I have exercise induced asthma because of the weight. She's good."

Sharon did not take action to lose weight until she experienced blurry vision from uncontrolled diabetes, followed by 5 days of hospitalization. The diabetic diagnosis triggered her to start a diet change, and eventually lost 44 pounds of weight and all her pain. She was so happy with all the things she could do after losing weight: dancing, walking down stairs smoothly without having to do one step at a time, and running.

> "I haven't ran in years. And like maybe like February, the bus was coming and I got off of one bus and I ran. I was so amazed with myself. I was like, 'Oh my god, you can run.' So I can run now."

Themes overview

Narratives from Michael, Sharon and Brenda exemplified various patient-provider relationships and interaction styles, and how they contributed to the quality of participants' overall healthcare experiences in pain management. Below, we organize key themes that emerged across all transcripts into two categories: participants' relationship with the healthcare system, and patient-provider communication in the context of pain management. Table 7.2 shows an overview of the themes in each category.

Table 7.2 Themes overview

Participants' relationships with the healthcare system ● Loyalty to and connectedness with the care team ● Trust and mistrust in healthcare ● Discrimination in healthcare ● Quality of patient-provider relationships
Patient-provider communication in the context of pain management ● Quality of patient-provider communication regarding pain management ● Patient-provider conflicts or disagreement about pain management ● Provider empathy

Key themes on participants' relationships with the healthcare system

Loyalty to and connectedness with the care team

Similar to Brenda and Sharon, many participants had been receiving care from the same HIV care practice or provider for a long time, and had developed strong loyalty and a sense of connectedness:

> "I'm not leaving there [my clinic], you know what I mean? I've been positive since [...] It probably was '84. But I've been with them since the beginning and they've been keeping me alive and they've been doing really well and I've never been sick [...] So I've been there and I'm just not going anywhere. They've been too helpful for me." -Male, 54 years old

Several participants indicated their healthcare providers as an important source of support, especially since they did not have a lot of support from other aspects of their lives. A 51-year-old male participant said his real support is his doctor, more than his family and friends. Another participant described her care team as her "medical family" and stressed the significant role they played in her life.

> "Most of my support comes from the clinic, my therapist and my GYN, medical, my Suboxone counselor, my Suboxone doctor, my primary care doctor [...] I do have some support. I don't have it from my family members like I should, but-- well, I would like for them to be involved in my life, but they're not, so I do have a hospital family, medical family." –Female, 51 years old

Because of the multimorbidity many PWH experience, it is critical to have care continuity and good coordination of care, as emphasized in Michael's account. Similar to Michael, a participant explained that in order to manage her complex treatment regimen and to avoid potential risks for drug-drug interaction, she went to the same provider group for all her medical needs to ensure all treatment history being documented in one place and easily accessible to any clinician that sees her.

> "I'm not running around to different other doctors, because that doctor might want to give you something too that may not go with your medicine. Everything I'm taking [Provider Group] can see it." –Other gender, 71 years old

Trust and mistrust in healthcare

Several participants demonstrated trust in their providers, or in the place where they seek care. A 58-year-old PWH explained it was the positive experience of his friends and family who shared the same doctor with him made him trust his doctor. Another participant (female, 51 years old) suggested it takes time to build trust. She has been delaying the discussion about her hip pain with her new primary care provider as she needed more time to open up to the doctor. A few participants mentioned that they defended their hospital when others questioned its reputation:

> "Most people say, 'Do you know they experiment on people at [Hospital Name]?' I hear that so much. I say, 'Yeah, but I like them. I like [Hospital Name]. If they didn't experiment and find out what's wrong, they wouldn't know about anything. You have to experiment on something in order to fix something. To correct it or whatever.'" –Female, 63 years old

However, participants also questioned the motivation behind some treatment decisions, thinking they could be driven by financial interest. The 63-year-old woman who defended her hospital said she really disliked some of her medicines, and suspected that the reason her doctor insisted prescribing them was because that is "the way doctors make their money." There were also notions of patients being utilized as research subjects or education materials. One participant believed his doctor's surgery suggestion was an excuse to open up his leg, just so that the doctor could investigate and learn how a procedure was previously done by a more experienced clinician:

> "Medical field is really nothing but experimentation and you come up with something. But I won't be experimented on [...] I have been through enough in my lifetime." –Male, 55 years old

Discrimination in healthcare

Many participants reported experiencing discrimination related to their HIV status, drug use, sexuality or race during healthcare encounters, which negatively impacted their trust in the healthcare system. A 55-year-old PWH recalled she had to explain to a phlebotomist, who was very rude to her after learning her HIV status, that she was not infected through drug injections. When she showed her veins proving no sign of intravenous drug use, the phlebotomist breathed a sigh of relief and thanked her: "I really needed to hear this".

Several participants revealed they left a healthcare provider or a practice after facing such stigmatizing and judgmental attitudes. A bisexual man stopped seeing a therapist at an HIV clinic due to sexuality-related discrimination.

> "Because I told him I was a pastor and a counselor and began to explain to him the kinds of things that I was doing, and he told me I was a liar [...] He said I wasn't a counselor. I was not worth anything. He said the judgment of my situation was because I was going to die and go to hell, I'm lying on God [...] I remember when I first got in there and started talking to him, very comfortable the whole nine yards and then all of a sudden it became a whole different story. He became, when he found out I was clergy and that I was still being intimate with people, he seemed to have turned a whole different disposition." –Male, 58 years old

One participant cried on her way out of a clinic, stating “people are cruel as hell”. The discriminatory treatment she experienced when seeking care made her avoid medical visits as much as she could:

> “And you know what, even if I get sick or a cold or whatever, I don’t even like going to the doctors [...] by me having that HIV, it turns me off from going to the doctors because people don’t know how to look at you or take you. So I don’t deal with all that negativity. To hell with it. If I’m bad enough, if I’m sick enough, then I go to the emergency room at [Hospital Name]. That’s the way I am because I always have been at [Hospital Name]. They the one that told me I had the HIV. So I’m not worried about nobody” –Female, 63 years old

It was not only health workers, but also other actors within healthcare settings that could lead to discriminatory treatment within these settings. For example, a confrontation between one participant and the police in an emergency room exemplified how discrimination in healthcare settings could hinder timely treatment. In this case, the consequence of the police asking a person with emergency medical need to leave the emergency room could have been fatal:

> “He [the police] came over. I must have fell asleep and he came over and woke me up and said the lady called my name so I said, ‘I didn’t hear it’. You know, and I guess he was like, ‘You have to go’. And I’m like, ‘I have to go? What do you mean I have to go?’ [The police,] ‘She called your name. You’re just trying to stay in here.’ [I said,] ‘No, I’m not trying to stay in there.’ And at that time, I actually had endocarditis. I actually had endocarditis that time. So I left. I came back the next morning, I was admitted to the hospital [...] I really do have a pain and I go to the emergency room, the first thing they think is I’m trying to find a place to sleep at night. Because a lot of people do use emergency room for places to sleep but somebody coming and of course I am not dressed the best.”–Male, 55 years old

Quality of patient-provider relationships

Participants also commented on the quality of the relationships they had with their main healthcare providers. Several participants felt their providers understood them well. For example, a 55-year-old participant said her doctor could tell whether she was doing well by her facial expressions and how much she talked.

Providers' communication styles played a key role in building rapport. One participant articulated that he trusts his provider's decisions not only because she is the doctor, but because she listens to him:

> "Because I trust her [my doctor] so much, I usually agree with the process of what she's doing. Because she's the doctor [... and] the fact that she listens to me in that whole process. Because my father-in-law [who is a cardiologist] told me, said, 'Listen, a doctor's job is not just to tell you what to do. His first job is to listen to what you're saying and how you feel about what he is recommending. And when they don't do that, then you need to stand up.' And so I don't have to stand up so much when it comes to her." –Male, 58 years old

He also loved that his provider took his questions seriously and would make the effort to search for answers and get back to him at a later time when she did not have an immediate response.

In addition, participants appreciated when their providers engaged them in discussion and respected their decisions. A 64-year-old participant indicated she had a good relationship with her primary care provider "because she doesn't just do stuff; she discuss stuff with me", and that they communicated with each other openly "so there's nothing hidden". Another participant described her collaborative relationship with her provider:

> "If I'm not satisfied with something, I let him [my doctor] know and we work it out with what he think is best for me [...] He works with me. He listens to me when I tell him what I want to do with my body. He accepts it. Sometimes even learns from me." –Female, 56 years old

Key themes on patient-provider communication in the context of pain management

Quality of patient-provider communication regarding pain management

Participants discussed the communication they had with their providers regarding pain management. One prevailing theme was that open, honest two-way communication helps facilitate mutual understanding between patients and providers, even when the patient's pain cannot be effectively addressed. A participant with painful sciatica appreciated his orthopedic surgeon for examining and explaining the cause of his pain thoroughly, stating that he "got a problem with the sciatica" but not with the doctor. He also described the ongoing conversation his primary care provider had with him around opioid harms, which made him respect her effort to taper him off prescription pain medicine:

> "She discussed the fact that sometimes these medications could be addictive. And we discussed that every time I got them. You know, how you control them, how it's making you feel, and everything. So I'm good with that. I respect her for that [...] And she would be saying like, you know, by the federal government being so hard on it, it's, you know, they try to wean people off of it, you know, so – I can understand that. Because there is a lot of abuse with it. You know. And she keeps it real and I like that. You know, we have a nice communication as far as my medical history." –Male, 63 years old

Another participant with unrelieved pain acknowledged that although he was not satisfied with the treatment, he understood his provider's concerns with prescription opioids:

> "I didn't like it, but I understood, but I did understand. And like because of course we all want to be comfortable. But at no point did I think that he was being cruel or mean or anything like that. And he didn't – he was the kind of person who wanted you to communicate with him from an honest perspective." –Male, 58 years old

On the other hand, providers' extreme caution when prescribing opioids could be perceived as distrust by patients. A 58-year-old man said when it comes to prescribing pain medicine, "they [doctors] just question you really hard".

A few participants pointed out that their providers appreciated their honesty regarding their pain symptoms and treatment (non)adherence. A 71-year-old transgender woman stated, "You have to be up front with your doctor, and most doctors love it when somebody tells them the truth and don't be sitting up there lying [about their symptoms]."

One participant whose doctor trusted her with prescription pain medicine attributed that trust to her candid self-disclosure about substance use:

> "I always told him [my doctor] I was a drug user-- and not pills street drugs [...] I only take [opioid analgesics] if the doctor prescribe them to me. I'm not going to take no pills. So he was all right with that. And he understood because I'm open with him. I don't hide from my doctors. I tell them. If I'm back getting high again I let them know." –Female, 52 years old

However, participants were not always able to have an open dialogue with their providers, due to worries that their history of drug use or misuse might impact pain treatment access.

> "I basically have to get to know the doctor first, know what they'll tolerate and what they won't tolerate, because, see, some doctors won't-- if somebody was on drugs before, some of them don't like giving them certain things [prescription pain medication]." –Male, 51 years old

There were also concerns that medical charts could contain information about patients' pasts that might label them in an undesired way, and bias providers' judgements about their present. A participant who just started seeing a new pain management specialist wanted his doctor to get to know him by talking to him rather than through his medical records.

> "What my goal is to be doing is taking her [the doctor's] mind away from what the paper's saying about me [...] 'You try to know me from somebody else's judgment of me, not what you see or what you're learning. You're going by what somebody said. You're not going by what I said.'" –Male, 60 years old

Some participants felt that when seeking pain treatment, they were unfairly judged or penalized based on their past records of substance use. A participant with chronic pain felt helpless that his current medical needs were obscured by his past drug use:

> "But I mean what can we say? What can we do? If you [the doctor] got all of the power and you just look at me in terms of I'm a drug addict and I'm just trying to get and use, then what good is me telling you [that the pain medicine is not working] because you're going to do what you're going to do anyway. You're dealing with me

> on account of my past behavior, not the person that's sitting here saying his leg hurting and he need more strength [in pain medication]." –Male, 54 years old

As a result, he was without pain medicine for about two weeks every month. He contrasted his current struggle with the positive experiences he had with his previous primary care provider, who always acted upon his reported pain symptoms without doubting the authenticity of the pain complaints based on his history of substance use disorders. Meanwhile, the doctor kept close monitoring of his substance use. The doctor's insistence in not prescribing opioid analgesics for someone with active drug use or misuse, on top of a focus on the participant's current behaviors in separation from his past records, further facilitated his recovery from substance use.

> "If I mention it [the pain medicine] ain't working he [my doctor] would immediately change it. That's why I love him, you know what I mean, not that I was saying it [that the pain medicine is not working] for the wrong reasons. He knew I wasn't going to tell him no lie [...] Now, don't get me wrong, when I messed up [the doctor] didn't fucking play. He didn't play. He even got to the point and say, 'If you're going to do that shit, I'm not writing [you the prescription] no more-- then die.' And I said, 'Alright, I'm sorry.' And I stopped fucking playing and I start taking my medicine like I was supposed to and I stopped doing certain things and I think it was around the time I got clean because of that." –Male, 54 years old

Several participants reported that their history of substance use disorders continued to alarm their providers, even long after their abstinence. One participant was planning to enter a methadone program not for substance use treatment but for pain management, as her main healthcare providers repeatedly declined to prescribe pain medication: "I have 14 years clean, I haven't used a drink or drug in 14 years and I got to get on this [methadone] program, I got to get on it, if it's going to help [with my pain] then I'm going for it." She expressed feelings of powerlessness and lack of control over her own health care, as her main care providers only treated her HIV and ignored her other needs.

She also started skipping medical appointments to avoid the frustration of being denied pain treatment.

> " They [the doctors] don't want to give me nothing because I'm a recovering addict and that don't make sense [...] They're not meeting me at all my needs, they're not. I'm very upset with them, you know, because it's a lot more that they can do that they aren't doing. 'And so what if I don't come to my appointment, you know why, because you're [the doctor] not doing anything for me anyway, so why waste your time and my time? Why show up, so you can slam the door in my face again and tell me there's nothing else you can do?' [...] so I can stay humble and don't be nasty to nobody else, to avoid all that, I don't go, I won't go." –Female, 45 years old

Conversely, participants felt trusted when their recovery from substance use was recognized by healthcare providers. One participant talked about an experience of using an implantable drug delivery device that signifies his provider's acknowledgement of his abstinence:

> "They sent me home [from the hospital] with something, with a thing on my arm that went directly to my heart [...] But when I was out there using [drugs] and stuff, they didn't do that down in Baltimore City. I had to stay in a treatment center for a month and a half [...] Because if you take [the device] and do drugs in that tube that they give you, and die from it, the hospital would... So that's why they couldn't do that. But [this time] they entrusted me." –Male, 60 years old

Other positive patient-provider engagement reported by participants included instances of joint decision making in pain treatment. A 56-year-old PWH said his provider involved him in care decisions and tried to accommodate his input as much as possible when addressing his pain.

Participants also emphasized the importance for providers to respect their decisions, as conveyed by a participant declining a recommended surgery:

> "I told her [the orthopedic surgeon], I didn't want to have surgery right now [...] I'm not ready for that. And she, she went along with it. Because it's my last say so, it's my decision, period. You know, you can recommend me, I appreciate everything you keeping it real and being honest with me. But the last say so is me. And I do not choose to have surgery now. So you know, she respects that." – Male, 63 years old

However, providers did not always engage in reciprocal communications. A participant with chronic pain depicted his doctor's authoritative attitude:

> "The only options that he [the doctor] gave me was, 'I'm going to take this [pain medicine] away, and you're going to have that.'" –Male, 60 years old

Participants expressed the need for providers to get to know them as a person. A 58-year-old male complained that his doctor spent most time reading his medical records and little effort engaging him in conversation. Another participant felt disrespected when during his first visit with a doctor, the doctor appeared only interested in his lab results.

> "When I came in the room, when I sat down, the first thing she [the doctor] took out was her lab scores. I got up and walked out. She said, 'What's wrong with you?' I said, 'Miss, the first thing you done was pull the lab scores.' She said, 'No, this is how I get to know you.' I said, 'Through my blood?" I said, 'Then you won't get to know me,' and I left." –Male, 55 years old

A participant with unrelieved pain after a hip replacement surgery spoke of her provider's narrow focus on one health problem at a time, and failure to treat her as a whole person:

> "Well, he's the one [doctor] that did the hip replacement. I mean, he'll say, 'Well, how is your hip?' [I'll say,] 'It's not too good.' [He'll then say,] 'Yeah, well.' That's because I'm there for the knees. So he's not even really going to address the hip [...] because his time with the hip is up." –Female, 51 years old

Although most participants desired a more equal patient-provider relationship in which their opinions were valued, a few preferred a paternalistic interaction style from their providers.

> "I need a strong person [doctor] who knows what they're talking about, because I'm a strong person, and I need you to tell me if what I'm deciding to do is going to hurt me." -Male, 58 years old

A focus group participant said it takes a doctor with a firm attitude and resistance to his manipulation to deter him from obtaining prescription opioids through deception.

> "The doctor I have now he is a no-nonsense type of doctor and for me that's what I need [...] if I find a doctor and I feel as though he's soft or I could do anything I want with him I'll do him just like anybody on the street. I will use him [to get drugs]." – Male, 57 years old

Patient-provider conflicts or disagreement about pain management

Many participants disagreed with their providers on how much medication was enough for alleviating their pain. One participant opposed his primary care provider's tapering plan, due to fear of pain undertreatment that would impede his physical functioning. He contrasted himself with those misusing drugs, emphasizing that his demand for analgesics was based on the need to maintain productivity, therefore well justified.

> "He [the primary care provider] cut down the doses. And then he cut down how many he was given me [...] He said, 'Well, we want to get you to the point where we are.' [I said,] 'That's okay. If you can get me off of it, and you can give me something else that will ease the pain, meditation or something. You can't just take people off pain management, and just nothing. Like I said, if I was out here like a junkie or something robbing stuff or something like that, yeah. You get me off of it. But if I'm in pain, I done worked all my life. I've got a few years left, and I'm just sitting around doing nothing to nobody. I'm still trying to work. You'd be productive, and you want to take that away from me? All right. Come on man.' So me and him, that's the kind of argument we would have." –Male, 60 years old

When participants' pain could not be adequately addressed by their providers, some sought alternative sources for obtaining prescription analgesics, or turned to other substance use for pain relief. These self-medicating behaviors often resulted in more tension with providers, besides their negative impacts on patients' health. A participant argued with pain clinic providers after her prescription was replaced with a less powerful analgesic class, blaming them for pushing her to the black market.

> "They [pain clinic providers] had me on pain pills and they took me off and put me on a mild, something mild called Tramadol that don't work [...] so I have to go and buy pills from somebody I know [...] Like I told them, 'I'm going to do what I'm going to do; I'm not going to hurt. If you don't want to give it to me then I got to buy it off

> the street. You all suggest I don't buy it off the street but you all don't want to give it to me. Make your mind up.' Yeah, I tell them, 'Make your mind up.'" –Female, 45 years old

Another commonly reported self-medicating approach was medication sharing. Participants gave and received prescription pain medication from friends and family out of compassion, because they did not want to see each other suffer. One participant spoke of an overdose experience from medication sharing, recognizing the danger of this practice:

> "I had a friend who gave me a couple of them [oxycodone] for pain. Well, see, the ones that he gave me, he was on 80 milligrams. It put me to sleep for four days. And he gave me two of them. But he told me, he said, 'Fool, I didn't give them to you to take whole like that. I meant for you to break them in half.' I said, 'But you didn't tell me that like that. You told me after the fact. You know?' So you know, but I came through it. But like he said, I could have OD'd [died from overdose]." –Male, 63 years old

Some participants were reluctant to request stronger analgesics or disclose their aberrant use of prescription medicine for unrelieved pain, due to fear of losing treatment access. A participant said he had to take more than the prescribed dose in order to alleviate his pain. As a result, he constantly ran out of medication early, which he believed led his main HIV care provider to suspect him for prescription drug diversion and to terminate their patient-provider relationship.

> "They [the clinic staff] called me-- well, it was getting near time to go back and I hadn't heard nothing. So it was like two weeks without hearing anything and I'm still remembering. So I called the clinical supervisor and I said nobody called me and they told [me] they were going to do something about it-- and I remember [Doctor Name] says she doesn't want to be my doctor no more [...] They think everybody sell their pills because she even said that to me. I was like, 'Sell them? Sell what? I don't even have nothing to sell because I take them all. Shit, I ain't even got enough for me how the hell am I going to sell some?'" –Male, 54 years old

The participant was later assigned to another physician at the same clinic. Nevertheless, this experience made him even more hesitant to inform providers about his unrelieved pain, fearing that they might mistake his motivation and stop prescribing or even remove him from the clinic. Instead, he used heroin to supplement the prescription pain medicine he received. He acknowledged what he did was wrong, but said the only alternative was to endure the pain: "I'm not justifying the wrong, you know what I mean. I did what I thought [was the best option under the circumstances]-- it was stupid and it cost me more than I'm willing to pay. I won't do it again. I'll just fucking hurt, you know. I mean like now." He further explained that he is willing to tolerate undermanaged pain and address it in his own way, if that is what it takes to stay in care for his HIV, which he prioritizes over pain treatment.

> "It's more important for me to stay there for my HIV as opposed to pain. If they took the medicine for pain, alright, fuck it, I'll just do what I need to do. When I hurt to the point I can't stand it I'll have to try to find a way, but I wouldn't leave." –Male, 54 years old

Provider empathy

Many participants conveyed the need for providers to be empathetic with their suffering and try to understand their feelings.

> "The pain that I'm in — And he was cutting down on the medicines and stuff like that. I'd be like, "You cut that down?" I said, "You can cut that down, because you're not in pain. You don't had to deal with it." "I felt as though when you first cut my medicine that was unfair to me right there and then. I've got to get through the course of the day. Not you. You get through the course of the day your way." –Male, 60 years old

> "Nobody ain't got my pain, nobody don't know what I go through, so you can't tell me jack about it, you don't have this body, I'm stuck with this body, not you. And I just want a way out; I just want to be normal, that's not asking for too much." – Female, 45 years old

Participants needed their providers to show that they care. One participant talked about a quarrel he had with his provider when the provider discovered his entering of a detox program while on opioid analgesics, which was a violation of his pain management contract. The provider's cold reaction when he explained it was a necessary step for him to obtain assisted housing for his son deeply eroded his trust in the provider and harmed their patient-provider relationship.

> "And I'm like 'Doc, I lied. I'm lying because I'm trying to get in there and get detoxed and trying to get housing and so I can get me and my son [a place to live together].' And man that shit don't mean nothing. It didn't mean nothing. So when I realized it didn't mean shit to her, I was like fuck her and I'm sorry to say it like that but that's the way I took it, because if you don't care about me then I don't need to care about you. I understand that's her job and up until that point we were fine. We were really fine. But what it did to me, it made me real reluctant about what I say to you when one time I thought I could tell you all anything. Now, I'm real like you'll see me right here moving because I'm assessing what you say to me and how I need to respond to that, when one time I would just tell the truth." –Male, 54 years old

Since then, he switched to a separate health practice for substance use treatment. He made sure it was not connected in any way with the hospital system where he was receiving care for HIV and chronic pain, saying "because if they are [affiliated] then all they're going to do is punch a button and my name is going to come up and they're going to [know] everything I'm in there for and what it's done [...]"

One focus group participant articulated that physicians' empathetic attitude helps, even when they decline to prescribe analgesics.

> "I'm just saying there's better doctors that that understand what you going through. I'm not saying that these doctors gonna prescribe you what you want, but they better understand what you going through [...]" –Male, age unknown

DISCUSSION

Our findings revealed tension between PWH with a history of drug use and their healthcare providers in discussing pain and pain treatment. Tension was usually rooted in disagreement regarding pain management approaches—oftentimes around prescription opioids in relation to patients' substance use history, or the feasibility of nonpharmaceutical approaches (such as weight loss)—and causes of pain, which have implications on how the pain should be addressed. This tension was heightened while patients were experiencing the pain, regardless of their overall relationships with their providers, as illustrated in Michael, Brenda, and Sharron's narratives.

Michael had a general distrust in the medical system and countless disagreements with his numerous providers, many of which were about his pain. On the other hand, Brenda's disputes with her PCP were specific to the prescribing of opioid analgesics, despite her long, positive relationship with the provider and satisfaction with other aspects of her care. Similarly, Sharon, who had also established an excellent rapport with her PCP for a long time, had heated arguments with her provider about the causes of her pain and treatment strategies before her pain was successfully addressed.

Patient-provider conflicts in managing chronic pain create added burden to patients, on top of the physical discomfort of their bodily pain and its impact on psychological distress. Longitudinal studies have found that pain can contribute to the development of depression, which might further exacerbate pain severity.[35–37] In the present research, many participants were distressed that they could not effectively communicate their need and reach a mutual agreement on treatment plan with their providers. They also voiced feelings of powerlessness during these interactions. Similar to our findings, prior research has documented power struggles between patients and providers, as well as their diverging goals and attitudes regarding chronic pain management.[23,29–31,33,38,39] Strained care relationships due to tension in pain management could be particularly detrimental to PWH, for its implications on retention in care.

Many participants in our study highly valued their continued relationships with their care team. Nevertheless, conflicts with providers and distress associated with pain undermanagement could lead to their non-adherence to medical appointments, and potentially dropping out of care. There were also worries that disputes with providers regarding pain treatment might jeopardize their overall access to care. To avoid patient-provider conflicts and the potential consequences on care access, one participant chose to withhold information about his unrelieved pain and prioritize his HIV care when interacting with his provider.

On the other hand, existing patient-provider trust and rapport enabled patients' open dialogues with providers and continued engagement in care even when they were dissatisfied with the pain management strategy, as illustrated in Brenda's account. Patients might be more willing to work together with providers on disagreements regarding pain management when they feel a genuine connection with their providers. Participants in our study who were involved by their providers in reciprocal communication, during which providers explained things in detail and listened to them with respectful and non-judgmental attitudes, believed it facilitated patient-provider trust and rapport. They appreciated their providers' open and genuine conversation around opioid harms, and accepted the fact that their pain could not be effectively addressed. They were able to separate their disappointment in pain treatment (or the lack of it) from their overall satisfaction in their engagement with the providers.

Our findings underscore the importance of patient-centered patient-provider engagement in managing chronic pain. Patient-centered care requires understanding and treating patients holistically, and is characterized by patient-provider collaborative communication, mutual understanding and shared decision making.[40–42] Patient-centeredness is crucial for establishing therapeutic alliance in healthcare, and has been linked to improved compliance with medical appointments, retention in care, and health outcomes.[24,40,43,44] Given the lasting and difficult-to-treat nature of chronic pain and the common patient-provider diverging attitudes toward potential harms of prescription opioids, how providers approach disagreements with patients is important, especially when the desired pain relief cannot be achieved.[29]

Participants in our study emphasized the need for clinicians to know and treat them as whole persons, and rejected clinicians' isolated attention on their individual health problems or behaviors. They wanted their providers to respect their decisions and feelings, as one man articulated that it is healthcare providers' obligation to incorporate patient opinions in clinical decisions. Participants also wished to be engaged in a caring and empathetic manner.

Similar to our study, prior research showed that patients with chronic pain who perceived their providers exhibiting genuine concerns for them were more accepting of denied or restricted opioid prescription.[33] They were also more likely to attribute their providers' prescribing decisions to external factors such as opioid associated harms and risks, instead of their providers' mistrust in them or indifference to their suffering.[33] Researchers also support affective communication in chronic pain management, which requires clinicians' attentive listening, taking enough time, building patient trust in their competence, and giving patients the feeling that they are doing all they can.[45]

Besides disagreements on pain treatment, there exit other threats to patient-provider relationships in the management of chronic pain. Participants in our study acknowledged their prescription drug diversion and misuse, such as medication sharing among friends and family or taking it in a way other than prescribed. One participant admitted his urge to obtain prescription opioids from his provider through manipulation. These patients' accounts highlight the challenges clinicians face when prescribing opioid analgesics. While health professionals are committed to prevent opioid associated risks, the means of prevention through scrutinizing patients' behaviors and restricting prescription opioids could result in damaged care relationships, inadequately managed pain, and increased substance use for pain. Providers should weigh these different consequences and strive for a balance that would minimize the overall harm.

Consistent with our findings, chronic pain patients with coexisting substance use disorders interviewed in a previous study acknowledged their problematic drug behaviors, and rejected their providers' derogatory languages in describing those behaviors.[30] They also voiced their desire for safe and effective pain management that would not induce relapse.[30] Addressing opioid risks including potential drug misuse and diversion while providing pain relief is a delicate task. Providers need to carefully approach these sensitive topics with understanding and empathy, recognizing that substance use disorders are chronic conditions and that recovery is an ongoing process. As Bailey and colleagues pointed out, a framework of compassion is much needed in managing chronic pain in the context of substance use disorder.[46]

Of particular concern are the dire consequences of inadequate pain management. Similar to our findings, literature has documented alternative strategies used by undertreated patients to alleviate their pain, including alcohol, non-prescription opioids, or other illicit substance.[3,30,46–48] Relapse triggered by undertreated pain not only impedes patients' recovery from substance use disorders, but further exacerbates substance use stigma. Besides the harmful impacts on health, participant's self-medicating behaviors also led to more tension and eroded trust in healthcare relationships.

One major theme that emerged from this study was mistrust in healthcare. Clinicians' attempts to detect potential prescription drug misuse and diversion through close inspection of patients' pain symptoms and drug use behaviors were interpreted by some participants as skepticism. As a result, these risk assessment and mitigation strategies for opioid analgesics further perpetuated mistrust between patients and providers. Many participants felt that their integrity was questioned when seeking pain treatment. These feelings resonate with accounts of chronic pain patients in previous qualitative studies, where participants reported being accused of drug seeking and lying about pain experiences by their providers.[23,30] The perceived untrusting attitudes of providers led to increased frustration on patients' side, and hampered open communication between patients and providers.

There is a lack of evidence supporting the effectiveness of commonly used mechanisms in reducing problematic opioid use behaviors, such as opioid treatment agreements (pain contracts) and urine drug tests.[49,50] Moreover, these surveillance efforts often lead to stigmatizing results, patient-provider mistrust, and destabilized therapeutic relationships.[49,51] In our study, a participant entered a detox program while receiving opioid analgesics. Instead of incorporating the participant's concurrent need for substance use and chronic pain treatment, his provider focused on his violation of the pain contract and was convinced that his report of unrelieved pain was an indication of addiction. The provider's failure in addressing patient needs not only compromised his care comprehensiveness by driving him away to seek substance use treatment somewhere else, but also caused lasting harms and deep mistrust in the patient-provider relationship.

Participants in this study reported discrimination and stigmatizing experiences in healthcare settings. These experiences could also result in patients' mistrust in the healthcare system in general, and hinder their ability to actively engage with providers in subsequent healthcare encounters. In particular, because of the prevalence of substance use stigma in healthcare and its impacts on care quality and access to treatment,[20] participants were concerned about how their health information was recorded and used, as well as who had access to those records. Although a few participants recognized the important role of medical records in keeping track of their treatment history and preventing adverse medication events such as drug-drug interaction and excessive dose, there were worries that documentation in medical charts could be labeling. Furthermore, several participants felt that they were unfairly judged based on their history of drug use in the past. The concerns of our study participants are supported by prior research that found clinicians' use of labeling and discrediting language in medical records, that could perpetuate stereotypes and further disfranchise and alienate patients in marginalized groups.[32,52] These concerns might discourage patients from disclosing information related to their history of substance use.

Our study has several limitations. The first few in-depth interviews did not focus intentionally on healthcare experiences regarding chronic pain, as it was not the major objective of the original study. While the interview was initially designed to assess palliative care interests and indications, including intractable pain and other distressing symptoms, participants spent a substantial amount of time discussing pain management.

We thus modified the interview guide to deliberately capture these discussions, and continued to revise our questions as new themes emerged. However, we may have missed exploring these topics extensively in the early interviews. To compensate for the missed opportunities, we invited selected participants for follow-up interviews. We also continued our recruitment until reaching thematic saturation.

It is also worth noticing that participants in this study were PWH who had access to care, and mostly been in care for a long time. The findings might not be transferable to other populations. In addition, the majority of the participants were receiving care from the hospital that our research facility is affiliated with. Although confidentiality and anonymity were assured, there is a chance that participants might have reservations when speaking negatively about their providers. However, this study also benefited from a long-term, positive relationship that our community-based research facility has established with the study participants, a population of African Americans who use drugs and have historically demonstrated prevailing mistrust toward institutions.[53,54] Owing to this rapport, we were able to obtain rich data through participants' open disclosures of their personal accounts, including sensitive topics such as their self-medicating behaviors. In addition to the in-depth conversations with individual participants during one-on-one interviews, the focus group allowed lively discussions of less sensitive topics, such as strategies and resources for pain management, and preferences for providers' engagement style.

Finally, we acknowledge that providers' views and interpretations of patient-provider engagement may differ from those presented in this study. We sought to incorporate provider perspectives through interviews with 15 clinicians of various healthcare professions and specialties, who treated PWH with chronic pain problems in the hospital system where the majority of our participants received care. Although clinician data were not presented in the current research, their views on patient-provider dynamics in managing chronic pain for this patient population helped shape our interpretation of the findings. One of the co-authors, GC, who is a practicing clinician specialized in HIV care, also contributed clinical perspectives to the final interpretations and conclusions of the study.

Conclusions

The present research delineated patients' perceived challenges as well as positive attributes in their encounters with the healthcare system when seeking pain treatment. We contribute to the literature by exploring the relational aspects of health care for chronic pain among African Americans with HIV and a history of drug use, a vulnerable population that face multiple layers of stigma and health disparities.

Our findings have important implications for fostering a positive, collaborative care relationship in managing chronic pain for this marginalized population, among which exist widespread and significant levels of medical mistrust that is deeply rooted in the historical trauma of medical mistreatment as well as individuals' experiences of discrimination in health care.[53,54] Interventions should target clinicians who provide care for this population to promote and enhance their skills for attentive listening, respecting patients' knowledge and their various needs, maintaining a nonjudgmental attitude, offering comprehensible information for disease and treatment options, actively involving patients in decision making, and approaching disagreement more empathetically.

Managing chronic pain for individuals with active or historic substance use disorders is complicated. A framework of compassion with a goal of reducing social harms, pain and distress should be adopted, rather than a punitive model. Instead of penalizing patients with chronic pain who relapse to substance use by removing their treatment access, healthcare providers should recognize their concurrent needs for pain and substance use treatment and incorporate both in their care, especially since poorly managed pain could further trigger relapse. Future research should investigate effective ways to build capacity for and streamline the integration of substance use treatment into general medical care.

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CHAPTER 8 – CONCLUSION

The overall objective of this dissertation was to identify individual-level, interpersonal (patient-provider) and structural factors predictive of self-medicating for pain and quality of life among marginalized PWH. This objective was addressed using a mixed-methods approach with a convergent parallel design, in which longitudinal surveys, focus group sessions and in-depth interviews with African Americans with HIV and a history of drug use in Baltimore were conducted concurrently and analyzed independently for an overall interpretation. This chapter summarizes and integrates the findings of the three manuscripts presented in Chapters 5-7, and discusses the overall strengths and limitations, implications for policy, practices, interventions and programs, and opportunities for future research.

SUMMARY & INTEGRATION OF RESULTS

Structural equation modeling presented in Chapters 5 and 6 suggested that PCE-PCP mediated the effects of prior experiences of discrimination in healthcare settings on later substance use for pain and reduced MHRQOL among African Americans with HIV and a history of drug use. During in-depth interviews and focus group discussions, participants reported experiencing discrimination related to their HIV status, drug use, sexuality or race in previous healthcare encounters, as described in Chapter 7. They shared instances of discriminatory treatment from healthcare providers, clinical staff, and other actors within the healthcare settings, such as police in the emergency department. These experiences caused them significant distress, damaged their trust in the healthcare system, and had profound impacts on their future care seeking behaviors. One participant explicated that she avoided medical visits as much as possible to protect herself from potential healthcare discrimination.

It is possible that PWH's reduced trust in the healthcare system due to prior experiences of discrimination in healthcare settings led to their guarded attitudes and difficulties establishing mutual, collaborative relationships in their subsequent engagement with healthcare providers. Many in-depth interview and focus group participants worried that documentation in their medical records could be stigmatizing. Some felt that they were unfairly judged or penalized based on their past records of substance use. A participant walked out of a doctor's office the first time he saw the doctor, as soon as the doctor sat down and started reviewing his records instead of having a conversation with him. The suboptimal patient-provider engagement could negatively impact care quality and lead to PWH's worse health and quality of life outcomes.

A mediated path was also found from patients' experiences of being denied pain medication to later substance use for pain through reduced PCE-PCP, as discussed in Chapter 5. This mechanism might be explained by the account of an in-depth interview participant, whose conflict with his provider around pain management led to the termination of his care relationship. When the participant was later assigned to a new provider, he started hiding information about his unrelieved pain, due to fear that patient-provider conflicts might further harm his access to HIV care. Instead of discussing pain undertreatment with his provider, he modified the prescribed analgesic dose on his own and used heroin to supplement the prescription pain medicine.

Results from Chapter 6 also suggested an indirect path from PWH's depression to lower MHRQOL, mediated through decreased PCE-PCP. Indeed, as illustrated in Chapter 7, patients’ psychological distress negatively impacted the quality of their interactions with healthcare providers. A participant described that she screamed and cried in front of her provider when in pain, and refused to listen to the provider’s recommendations for addressing her pain. In addition, findings from in-depth interviews and focus groups indicated that patient-provider conflicts regarding pain causes and its treatment could create an added burden of psychological distress, on top of patients' physical pain.

The quantitative results showing that the association between PWH’s depression and worse MHRQOL could be explained by reduced PCE-PCP might suggest that health care plays a substantial role in the lives of this patient population with chronic disease and multimorbidity. The notion that health care is an integral part of these patients’ lives is supported by the in-depth interview and focus group findings described in Chapter 7. Several participants indicated their healthcare providers as an important source of support, especially since they did not have much support from other aspects of their lives. One participant said even though her family was not involved in her life, she had her care team as her “medical family”. It is possible that health care and care relationships play such an important role in supporting PWH’s emotional and behavioral health, as well as the social aspects of their quality of life, that when the quality of patient-provider interaction is reduced due to patients’ depressive symptoms, their overall MHRQOL is also diminished.

Qualitative results discussed in Chapter 7 also revealed PWH’s desire for patient-centered engagement with their providers. In-depth interview and focus group participants emphasized the need for clinicians to know and treat them as whole persons, and rejected clinicians’ isolated attention on their individual health problems or behaviors. They wanted their providers to elicit and consider their opinions and preferences in treatment decision making, including for pain care. Participants appreciated when their providers engaged them in discussions about treatment options and respected their decisions. They also wanted their providers to interact with them in a caring and empathetic way. The ideal patient-provider engagement styles described by in-depth interview and focus group participants aligned with the characteristics of PCE-PCP measured in the longitudinal survey analyzed in Chapters 5 and 6.

Altogether, findings from Chapters 5, 6, and 7 underscore the important role of PCE-PCP in providing care for African Americans with HIV and a history of drug use. The results suggest that interpersonal skills for patient-centered engagement are important for addressing discriminatory treatment in healthcare, substance use, and mental health challenges of this marginalized population. Our findings can inform policy to address structural factors contributing to stigma and discrimination, and the practices of health professionals, clinical staff, and other individuals involved in the healthcare system. Findings also have implications for interventions and programs for both patients and providers, and as well as for areas of future research.

STRENGHTS & LIMITATIONS

This research has the strength of utilizing longitudinal data to establish temporal sequences between the independent variables, the mediator, and the outcome variables in the structural equation models presented in Chapters 5 and 6. Because the outcome of interest in these analyses could feed back to impact the independent variables or the mediator—for example, self-medicating for pain might perpetuate substance use related stigma and discrimination, or might directly impact patient-provider engagement—temporal sequence is critical for understanding the observed associations. Additionally, the mixed-methods approach allowed the use of qualitative data to support and supplement quantitative findings, and facilitate a more in-depth understanding of the challenges to healthcare relationships and managing chronic pain among PWH with a history of drug use.

There are also several limitations. As the data collection relied completely on self-report, sensitive questions such as illicit drug use and misuse of prescription pain medicine might subject to social desirability biases. Similarly, it is possible that PWH might over-report positive engagement with primary care providers and under-report discriminated experiences in healthcare encounters. Although self-administered survey through ACASI was used to collect information on these sensitive topics, biases may still exit. Alternative strategies could include direct observations or recordings of clinical encounters. Another limitation associated with measurements is that types of discrimination other than those assessed by the survey (race, HIV, substance use, and linguistic) were not captured. Besides, although we measured different forms of discrimination, we were not able to examine the effects of intersectional discrimination due to the limited sample size.

The modest sample size in the quantitative strand also restricted our statistical power, and limited our capability in detecting other possible paths between the independent and outcome variables. Nevertheless, by introducing the mediator to the models we were able to improve the statistical power for detecting the indirect effects examined in Chapters 5 and 6, despite the sample size restriction.[1] Furthermore, unmeasured confounders cannot be completely ruled out, although by controlling for the baseline measurements of the mediator and the outcome along with other covariates in structural equation modeling we were able to reduce the possibility.

Participants in both the quantitative and qualitative strands were PWH who had access to care. As a result, the findings might not be generalized to other populations. Although qualitative findings brought insights to understanding the quantitative associations revealed by structural equation modeling, because qualitative data were collected before quantitative analysis was completed, in-depth interview and focus group questions were not designed to directly explain those associations.

Finally, we acknowledge that the patient perspectives presented in this study might differ from those of the healthcare providers. Our study team include a practicing clinician specialized in HIV care, who contributed clinical perspectives to the final interpretation and conclusions of the study. Moreover, we sought to incorporate provider perspectives through interviews with 15 clinicians of various healthcare professions and specialties, who treated PWH with chronic pain problems in the hospital system where the majority of our participants received care. Although clinician data were not presented in this dissertation, their views on patient-provider dynamics in managing chronic pain for this patient population helped shape how we interpreted the findings.

PUBLIC HEALTH IMPLICATIONS

Implications for policy

Our findings highlight the need for addressing structural factors such as structural racism and other systemic biases that contribute to stigma, discrimination, and disparities in quality of life, as well as for promoting social justice in health care. Policy could be implemented to prevent discrimination and to increase access to pain treatment among stigmatized groups, including African Americans, PWH, and people with a history of drug use. Funding and resources should be allocated for interventions and programming to address bias in health care, and to facilitate PCE and create a supportive healthcare environment for improving patient well-being. Medical payers could further increase the demand for patient-centered communication through reimbursement strategies,[2] and foster collaborative care relationships that could help reduce the harms caused by patients' past experiences of discrimination and rejection in health care.

The discriminatory treatment that individuals experienced during healthcare encounters might be perpetuated by the documentation in their medical records. Prior research analyzing clinical encounter notes found physicians' use of labeling, stigmatizing, disapproving, and discrediting languages that could perpetuate stereotypes and inequitable inequitable care.[3,4] Guidelines could be developed to help reduce biases in clinical documentations by improving clinicians' language use and its potential, lasting harms on patients' health care. Moreover, patients should be encouraged and provided assistance to access and read notes in their own medical records to promote the transparency of the documentation.

Results of our study suggest that inadequately treated pain might cause psychological distress and trigger substance use, along with other negative health consequences. To address substance use and relapse driven by poorly managed pain, and to prevent it from further perpetuating pain symptoms and stigma related to pain and substance use, an integrated approach to treating pain and substance use concurrently with HIV and other comorbidities is much needed for improving the well-being of PWH and Black Americans in particular. In the US, substance use treatment services historically operate outside the general medical system.[5] Although prescription opioids could be used both for treating pain and opioid use disorders, medication-assisted substance use treatment facilities generally lack the capacity to address patients' chronic pain management need. This fragmented treatment model not only fails to meet patients' need to manage substance use and pain comprehensively, but also adds to the existing barrier to coordinated care that many people with HIV and multiple comorbidities are already struggling with. Our findings support other researchers' call for integrating addiction services into general medicine.[5]

Implications for practices

Findings of this research have important implications for the practices of health professionals, clinical staff, and other members of the healthcare system to address stigma and biases in health care. In addition, findings suggest that PCP might have the ability to mitigate the negative impacts of depression, as well as discrimination and rejection in health care, and to improve patients' health and quality of life outcomes through patient-centered communication skills.

Healthcare providers should be aware of the patient groups that are more likely to experience challenges in patient-provider interactions, including those who are vulnerable to stigma, discrimination, and depression, and give them special attention. Furthermore, clinicians should utilize pre-visit screening or conversations during the health care visit to identify individuals who may be experiencing psychological distress and having difficulties optimizing their engagement with providers, and those who may have experienced healthcare discrimination in the past. Because patients' negative feelings from previous stigmatizing and discriminatory experiences in healthcare encounters might stay with them and transfer to other clinicians, further creating self-fulfilling prophecies and confirming stereotypes,[4] healthcare providers need to invest additional efforts to counteract any harms that may have already been caused when engaging with marginalized patient groups, in particular, African American PWH with a history of drug use.

Based on our study results, a framework of compassion with a goal of reducing social harms, pain and distress is recommended over a punitive model when navigating the complexity of managing chronic pain for individuals with active or historic substance use disorders. Instead of penalizing patients with chronic pain who relapse to substance use by reducing or removing their access to pain treatment, healthcare providers should recognize their coexisting needs for pain and substance use treatment and incorporate both in their care, especially since poorly managed pain could further trigger relapse to substance use for pain self-medication, which could further perpetuate the substance use stigma that this patient population is already experiencing, and their marginalization in the healthcare system.

Implications for interventions and programs

Integrative intervention and programming are needed to enhance quality of patient-clinician relationships. Results of this study suggest an opportunity through intervening on PCE to improve the behavioral and mental health of individuals who are vulnerable to stigma, discrimination, and psychological distress or other mental health challenges, and to interrupt the vicious cycle of substance use and chronic pain, in which substance use driven by pain could further aggravate the pain.[6] Interventions should target individuals with intersecting vulnerabilities to discrimination and those who might suffer from depression, as well as healthcare professionals interacting with them, to foster mutual, collaborative patient-provider relationships.

Patient education through groups, workshops or coaching sessions with formal practices could help increase their empowerment and ability to better interact with providers, advocate for their health care needs, and actively participate in health care decision making.[7] Educational materials delivered in waiting room could incorporate tips for improving patient-provider communication to better prepare patients for their visits.[7] In addition, treatment advocacy or patient counseling programs could be implemented to assist patients' self-advocacy and informed decision making, and serve as a bridge between patients and providers to facilitate collaborative communication.[8]

Medical education and clinician training should include modules promoting PCE and developing providers' communication skills to listen to patients attentively and better elicit, understand and respect their needs and values, offer patients comprehensible information for disease and treatment options, respond to patients' emotions, actively invite patients' involvement in clinical decisions and approach disagreement more empathetically.[2] Such modules could be built into the curriculum of medical schools and residence programs and continuing education courses and workshops.[2] Other training programs depending on practice settings or through medical groups could also be used to reinforce and update lessons over time.[2] Elements for communication skill building such as viewing videos that model desirable ways to interact with patients followed by role-play for different patient encounter scenarios and receiving feedback could be incorporated.[7] Check lists and question prompts could also be embedded in clinical workflow to assist patient-provider communication and enhance PCE.[9] There is also a need to train clinicians on providing integrated care for chronic pain and substance use, and to reduce their prejudice and bias related to substance use and other stigmatized conditions.

FUTURE RESEARCH

Further research is needed to better understand the potential mechanism of the mediated paths from denied pain treatment and healthcare discrimination to substance use for pain and from depression and healthcare discrimination to lower MHRQOL, both through reduced PCE-PCP as discussed in Chapters 5 and 6, and the mechanism through which enhanced PCE-PCP might mitigate the harmful effects of depression, and discrimination and rejection in health care. In particular, studies are merited on how different proximal outcomes of PCE-PCP—such as improved patient-provider relationships, treatment access, care quality and care continuity, as well as changes in patients' health behaviors—contribute to patients' health and quality of life outcomes, and how efforts facilitating PCE could be tailored to meet the needs of individuals with depression and experiences of discrimination and rejection in health care.

Future research should also investigate effective ways to build capacity for and streamline the integration of substance use treatment into general medical care, in order to address substance use and pain concurrently with HIV and other comorbidities for improving the health and quality of life outcomes of African American PWH with a history of drug use. In addition, more research is needed to identify other patient populations that are vulnerable to stigma and biases in health care, and are in need of policy, intervention and programming efforts to enhance the quality of their care and overall well-being.

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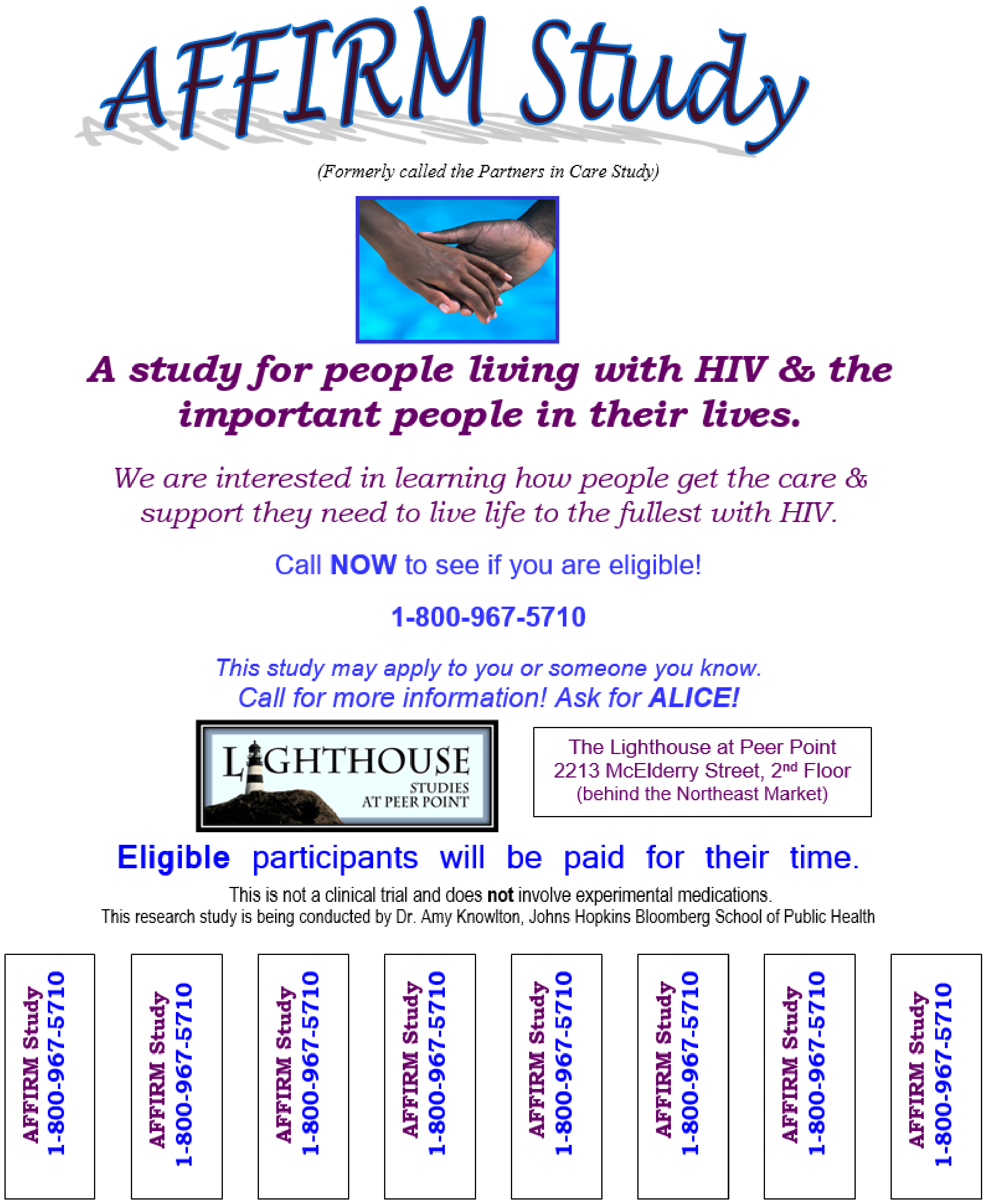
APPENDICES

APPENDIX A: RECRUITMENT FLYERS



AFFIRM Study

(Formerly called the Partners in Care Study)

A study for people living with HIV & the important people in their lives.

We are interested in learning how people get the care & support they need to live life to the fullest with HIV.

Call **NOW** to see if you are eligible!

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This study may apply to you or someone you know.
*Call for more information! Ask for **ALICE!***

LIGHTHOUSE
STUDIES
AT PEER POINT

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Eligible participants will be paid for their time.

This is not a clinical trial and does **not** involve experimental medications.
This research study is being conducted by Dr. Amy Knowlton, Johns Hopkins Bloomberg School of Public Health

AFFIRM Study
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APPENDIX B: SURVEY INSTRUMENT

AFFIRM CARE INDEX BASELINE (English)

VERSION = 12

YR1NUM = TODAY - 365

YR1AGO = ShortDate(YR1NUM)

MS6NUM = TODAY - 183

MS6AGO = ShortDate(MS6NUM)

DY90NM = TODAY - 90

DY90AG = ShortDate(DY90NM)

DY30NM = TODAY - 30

DY30AG = ShortDate(DY30NM)

FACE SHEET

READ: AFFIRM Care Index Baseline Survey

[INTERVIEWER: Please complete the following information]

FC1. Enter PID

— — — —

FC2. Re-enter PID

— — — —

If FC2 is not equal to FC1 then READ: "CHECK PID" and skip to FC1.

FC3. ENTER TODAY'S DATE

__ __ / __ __ / __ __ __ __ mm / dd / yyyy

If FC3 is not equal to TODAY then READ: "[INTERVIEWER: Please enter correct date]" and skip to FC3.

FC4. INTERVIEWER I.D. NUMBER

— — —

READ: Thank you for coming in today. The following survey will ask you about your background, lifestyle, healthcare, and the help you give and receive from the people in your life. For most of the survey, I will ask you questions. For one part of the survey, I will leave the room and you will enter your responses into the computer. I will help you get started with that portion.

Everything you tell me is completely confidential and will not be shared with your doctors or other healthcare providers and will not affect your healthcare at Johns Hopkins now or in the future. There are no right or wrong answers so be as honest as possible. Please let me know if you need a break to stretch or get coffee. Do you have any questions before we begin?

FC5. **Are you male or female?** (Choose one)

1	Male
2	Female
3	Other
8	Refuse to Answer

FC6. **How old are you?**

— — —

777	Don't Know
888	Refuse to Answer
999	Not Applicable

FC7. **What is the highest level of education you've had?** [PROBE FOR HIGHEST EDUCATION CLIENT HAD; if the client says some high school, ask if they got their GED.] (Choose one)

1	8th grade or less
2	Some high school, no diploma
3	High school diploma or G.E.D.
4	Some college or technical training
5	College degree like B.A. or B.S.
6	Any graduate training
77	Don't Know
88	Refuse to Answer
99	Not Applicable

HEALTH SERVICE USE

READ: This set of questions is about your health and healthcare.

A1. **What kind of medical insurance or assistance do you currently have?** [Read items A-E one at a time and check mark each insurance that client has; if client says "No" to all, probe to determine if client has medical coverage.] (Check all that apply)

__ Medicaid, Medical Assistance, or Medicare (this includes PAC or Priority Partners)
__ Private insurance through a job or employer
__ V.A. or CHAMPUS
__ Other
__ Client doesn't have any medical insurance or get assistance
__ Don't Know
__ Refuse to Answer
__ Not Applicable

If (A1A is equal to 1 or A1B is equal to 1 or A1C is equal to 1 or A1D is equal to 1) and A1E is equal to 1 then READ: "[INTERVIEWER: You may not check box E if any other boxes are checked]" and skip to A1.

If A1D is not equal to 1, then skip to instruction before A3.

A2. **What kind of medical insurance or assistance do you have?**

____
____
____
____
____
____
____

READ: The following questions are about your general healthcare service use.

A3. **In the past 6 months, how many times have you gone to an emergency room for your healthcare?**

__ __ __	# of times
777	Don't Know
888	Refuse to Answer
999	Not Applicable

A4. **When was the last time you were hospitalized -- I mean you were admitted and stayed there overnight?** (Choose one)

0	Never
1	More than 5 years ago
2	More than 1 year ago
3	7 - 12 months ago
4	1 - 6 months ago
5	Within the past month
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If not (A4 is equal to 2 or A4 is equal to 3 or A4 is equal to 4 or A4 is equal to 5), then skip to A15.

A5. **In the last few years, have you been hospitalized twice within a 4 week period?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If not (A4 is equal to 4 or A4 is equal to 5), then skip to instruction before A8.

A6. **In the past 6 months, how many times were you admitted to a hospital** (stayed overnight)?

— — —	# of times
777	Don't Know
888	Refuse to Answer
999	Not Applicable

A7. **Including for drug detox or mental healthcare, in the past 6 months, how many nights did you stay at a hospital?**

— — —	# of nights
777	Don't Know
888	Refuse to Answer
999	Not Applicable

READ: The followng questions are about your discharge from the hospital after your last hospital admission.

A8. **The last time you were discharged from the hospital, did you stay at:** [READ RESPONSES] (Choose one)

1	your home
2	someone else's home
3	some other place
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If not (A8 is equal to 1 or A8 is equal to 2), then skip to instruction before A10.

A9. **Did you receive professional home health services at that time -- did a paid person come to your house and help you?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If A8 is not equal to 3, then skip to A12.

A10. **What kind of place were you discharged to?** (Choose one)

1	Rehabilitation or assisted care facility without medical care
2	Nursing home
3	Shelter
4	Residential treatment program
5	Other
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If A10 is not equal to 5, then skip to A12.

A11. [INTERVIEWER: Enter client's response]

— —
— —
— —
— —
— —
— —
— —

A12. (When you were discharged), **did someone you know meet you at the hospital?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

A13. (When you were discharged) **did you have any difficulty caring for yourself, like moving around or shopping?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

A14. **When you went home, was there someone who stayed with you or helped you out while you were recovering?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

A15. **In the past 6 months, did you <u>use</u> any of the following services?** [INTERVIEWER: <u>Read</u> items A-D, <u>waiting</u> for a response after each item; if client says "Yes" check that item.] (Check all that apply)

__ Nursing home
__ Assisted living (doesn't offer nursing care)
__ Home health services
__ Dental health
__ None of the above
__ Don't Know
__ Refuse to Answer
__ Not Applicable

If (A15A is equal to 1 or A15B is equal to 1 or A15C is equal to 1 or A15D is equal to 1) and A15E is equal to 1 then READ: "[INTERVIEWER: You may not check the last box if any other boxes are checked]" and skip to A15.

A16. **In the past 6 months, did you <u>need but not get</u> any of the following services or assistance?** [INTERVIEWER: <u>Read</u> items A-O, <u>waiting</u> for a response after each item; if client says "Yes" check that item.] (Check all that apply)

__ Nursing home
__ Assisted living (doesn't offer nursing care)
__ Home health services
__ Dental health
__ Addictions treatment
__ Mental health care
__ Food (including nutritional supplements)
__ Housing
__ Emergency financial help
__ Transportation
__ Payment for medication
__ Appointment or medication reminders
__ Help getting medical services (medical case management)
__ Help getting other services (non-medical case management)
__ Legal assistance
__ None of the above
__ Don't Know
__ Refuse to Answer
__ Not Applicable

If (A16A is equal to 1 or A16B is equal to 1 or A16C is equal to 1 or A16D is equal to 1 or A16E is equal to 1 or A16F is equal to 1 or A16G is equal to 1 or A16H is equal to 1 or A16I is equal to 1 or A16J is equal to 1 or A16K is equal to 1 or A16L is equal to 1 or A16M is equal to 1 or A16N is equal to 1 or A16O is equal to 1) and A16P is equal to 1 then READ: "[INTERVIEWER: You may not check the last box if any other boxes are checked]" and skip to A16.

A17. **When did you first test positive for HIV? Please tell me the year.**

— — — — yyyy
7777 Don't Know (Year)
8888 Refuse to Answer (Year)
9999 Not Applicable (Year)

READ: Now, I would like to know about your HIV primary healthcare, meaning a visit to a doctor or nurse to have a checkup during which you may have discussed HIV medications, had your blood drawn, or talked about your blood test results.

A18. **When was the last time you had a primary healthcare visit for HIV or AIDS?** (Choose one)

1	Within the past month
2	1-6 months ago
3	More than 6 months ago
4	More than 1 year ago
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If A18 is not equal to 1 and A18 is not equal to 2, then skip to A20.

A19. **In the past 6 months, how many primary healthcare visits for HIV or AIDS have you had?** [USE 6MTH WORKSHEET IF NEEDED]

___ ___ ___	number of visits
777	Don't Know
888	Refuse to Answer
999	Not Applicable

A20. **For your last viral load blood test, was your viral load detectable or undetectable.**[INTERVIEWER: if the clients says s/he didn't get the result, ask about the last viral load result s/he got; if the clients says s/he never had a viral load blood test, click "Not Applicable."] (Choose one)

1	Detectable
2	Undetectable
7	Don't Know
8	Refuse to Answer
9	Not Applicable

A21. **In the past 2 years have you usually seen the same doctor, nurse or care provider for your HIV medical care?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EMS USE

B1. **How many times have you used emergency medical services in the past 5 years, meaning you or someone else called 9-1-1 and an ambulance came for you?**

— — — —	times
7777	Don't Know
8888	Refuse to Answer
9999	Not Applicable

If B1 is equal to 0, then skip to instruction before C1.

B2. **When was the last time you had ambulance or emergency medical service? Please tell me the year.**

— — — —	yyyy
7777	Don't Know (Year)
8888	Refuse to Answer (Year)
9999	Not Applicable (Year)

B3. **For that call, did the ambulance take you to a hospital emergency room?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If B3 is not equal to 1, then skip to instruction before C1.

B4. **For that call, were you admitted to the hospital, that is, stayed overnight?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

MENTAL HEALTH SERVICE USE

READ: Now I'm going to ask you about your mental health, service use, and medications. Remember, what you say will be kept confidential.

C1. **Not including drug or addiction treatment, in the past year, have you received any counseling, therapy, or medication for your nerves or any emotional problems?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If C1 is not equal to 1, then skip to instruction before D1.

C2. **Are you currently taking any medication for a mental health condition?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

DRUG TREATMENT SERVICE USE

READ: Now I am going to ask you some questions about your experiences with drug treatment services in the past 6 months.

D1. **In the past 6 months, have you been enrolled in a methadone program?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

D2. (In the past 6 months), **have you been in an outpatient drug treatment program where they gave you buprenorphine or suboxone?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

D3. (In the past 6 months), **have you been in an outpatient treatment program or seen a drug treatment counselor, where they did <u>not</u> give you medication?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

D4. **In the past 6 months, were you in medically monitored drug detox where you stayed overnight?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

D5. **In the past 6 months, how often have you gone to a self-help program, such as NA or AA? Would you say:** [READ RESPONSES] (Choose one)

0 Never
1 Once a month
2 Several times a month
3 Several times a week
4 Everyday
7 Don't Know
8 Refuse to Answer
9 Not Applicable

HEALTH RELATED QUALITY OF LIFE

READ:* *The following questions are about your health.

E1. **In general, would you say your health is:** [READ RESPONSES] (Choose one)

1 Excellent
2 Very good
3 Good
4 Fair
5 Poor
7 Don't Know
8 Refuse to Answer
9 Not Applicable

E2. **How much does your health now limit your <u>moderate activities</u> such as moving a table, pushing a vacuum cleaner, or playing a sport?** [SHOW CARD 1] (Choose one)

0 No, not limited at all
1 Yes, limited a little
2 Yes, limited a lot
7 Don't Know
8 Refuse to Answer
9 Not Applicable

E3. **How much does your health now limit your climbing <u>several</u> flights of stairs?** [SHOW CARD 1] (Choose one)

0 No, not limited at all
1 Yes, limited a little
2 Yes, limited a lot
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ:* *The next few questions are about the past 30 days.

E4. **During the past 30 days, have you, as a result of your <u>physical health</u>, accomplished <u>less</u> than you would like?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

E5. (During the past 30 days), **were you, as a result of your physical health, limited in the kind of work or other activities you did?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

E6. (During the past 30 days), **have you, as a result of emotional problems, accomplished less than you would like?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

E7. (During the past 30 days), **have you, as a result of emotional problems, not done work or other activities as carefully as usual?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

E8. (During the past 30 days), **how much did pain interfere with your normal work or activities, including both work outside the home and housework? Would you say:** [READ RESPONSES] (Choose one)

0	Not at all
1	A little bit
2	Moderately
3	Quite a bit
4	Extremely
7	Don't Know
8	Refuse to Answer
9	Not Applicable

E9. **During the past 30 days, how much of the time have you felt calm and peaceful?** [SHOW CARD 27~] (Choose one)

0	None of the time
1	A little of the time
2	Some of the time
3	Most of the time
4	All of the time
7	Don't Know
8	Refuse to Answer
9	Not Applicable

E10. (During the past 30 days), **how much of the time did you have a lot of energy?** [SHOW CARD 27~] (Choose one)

0 None of the time
1 A little of the time
2 Some of the time
3 Most of the time
4 All of the time
7 Don't Know
8 Refuse to Answer
9 Not Applicable

E11. (During the past 30 days), h**ow much of the time have you felt downhearted and depressed?** [SHOW CARD 27~] (Choose one)

0 None of the time
1 A little of the time
2 Some of the time
3 Most of the time
4 All of the time
7 Don't Know
8 Refuse to Answer
9 Not Applicable

E12. (During the past 30 days), **how much of the time has your physical health or emotional problems interfered with your social activities?** [SHOW CARD 27~] (Choose one)

0 None of the time
1 A little of the time
2 Some of the time
3 Most of the time
4 All of the time
7 Don't Know
8 Refuse to Answer
9 Not Applicable

E13. **How much time do you spend at home on an average weekday? Would you say:** [READ RESPONSES] (Choose one)

0 None of the day
1 Some of the day like a few hours
2 Most of the day
3 All day
7 Don't Know
8 Refuse to Answer
9 Not Applicable

COGNITIVE AND PHYSICAL FUNCTION

READ: The following questions are about your memory.

F1. **How would you rate your memory right now? Would you say it is:** [READ RESPONSES] (Choose one)

1	Excellent
2	Very good
3	Good
4	Fair
5	Poor
7	Don't Know
8	Refuse to Answer
9	Not Applicable

F2. **In the past few weeks, how often have you had to do things very slowly to make sure you were doing them right?** [SHOW CARD 16] (Choose one)

0	Never
1	Once in a while
2	Fairly often
3	Very often
77	Don't Know
88	Refuse to Answer
99	Not Applicable

F3. **In the past few weeks, how often have you had trouble remembering recent events?** [SHOW CARD 16] (Choose one)

0	Never
1	Once in a while
2	Fairly often
3	Very often
77	Don't Know
88	Refuse to Answer
99	Not Applicable

F4. (In the past few weeks), **how often have you had trouble following or keeping up in conversations?** [SHOW CARD 16] (Choose one)

0	Never
1	Once in a while
2	Fairly often
3	Very often
77	Don't Know
88	Refuse to Answer
99	Not Applicable

F5. (In the past few weeks), **how often have you had your mind go blank?** [SHOW CARD 16] (Choose one)

0	Never
1	Once in a while
2	Fairly often
3	Very often
77	Don't Know
88	Refuse to Answer
99	Not Applicable

F6. **In the past few weeks, how often have you gotten lost in a place you know well?** [SHOW CARD 16] (Choose one)

0	Never
1	Once in a while
2	Fairly often
3	Very often
77	Don't Know
88	Refuse to Answer
99	Not Applicable

F7. **In the last 30 days, how often did memory problems interfere with your daily activities? Would you say...** [READ RESPONSES~] (Choose one)

0	Never
1	Rarely (1 day a week or less)
2	Some days (2-4 days a week)
3	Most days (5-6 days a week)
4	Every day (7 days a week)
7	Don't Know
8	Refuse to Answer
9	Not Applicable

F8. **Has a doctor ever told you that you have dementia?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

HEALTH SYMPTOMS

READ: The next questions are about symptoms you might have had during the past 30 days.

G1. **During the past 30 days, have you had nausea or vomiting?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

G2. (During the past 30 days), **have you had shortness of breath or difficulty breathing?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

G3. (During the past 30 days), **have you had weight loss?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

G4. (During the past 30 days), **have you had a change in the way you look?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

G5. (During the past 30 days), **have you had any other symptoms that bothered you?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If G5 is not equal to 1, then skip to instruction before G9.

G6. **Name a symptom that bothered you during the past 30 days.**

— —
— —
— —
— —
— —
— —
— —

G7. **Please name another symptom that bothered you** (during the past 30 days). [INTERVIWER: If the client says none, click "Not applicable."]

— —
— —
— —
— —
— —
— —
— —

If G7 is equal to NOT APPLICABLE, then skip to instruction before G9.

G8. **Name another symptom that bothered you** (during the past 30 days). [INTERVIWER: If the client says none, click "Not applicable."]

— —
— —
— —
— —
— —
— —
— —

If G1 is not equal to 1, then skip to instruction before G11.

G9. **During the past 30 days, how often did you have nausea or vomiting?** [SHOW CARD 17] (Choose one)

1 Rarely
2 Occasionally
3 Frequently
4 Almost constantly
7 Don't Know
8 Refuse to Answer
9 Not Applicable

G10. **Usually, how severe was the nausea or vomiting?** [SHOW CARD 18] (Choose one)

1 Slight
2 Moderate
3 Severe
4 Very severe
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If G2 is not equal to 1, then skip to instruction before G13.

G11. (During the past 30 days), **how often did you have shortness of breath or difficulty breathing?** [SHOW CARD 17] (Choose one)

1 Rarely
2 Occasionally
3 Frequently
4 Almost constantly
7 Don't Know
8 Refuse to Answer
9 Not Applicable

G12. **Usually, how severe was the shortness of breath or difficulty breathing?** [SHOW CARD 18] (Choose one)

1 Slight
2 Moderate
3 Severe
4 Very severe
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If G3 is not equal to 1, then skip to instruction before G14.

G13. (During the past 30 days), **how severe was your weight loss?** [SHOW CARD 18] (Choose one)

1 Slight
2 Moderate
3 Severe
4 Very severe
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If G4 is not equal to 1, then skip to instruction before H1.

G14. (During the past 30 days), **how severe was the change in the way you looked?** [SHOW CARD 18] (Choose one)

1 Slight
2 Moderate
3 Severe
4 Very severe
7 Don't Know
8 Refuse to Answer
9 Not Applicable

PAIN SYMPTOMS AND ABERRANT PRESCRIPTION DRUG USE

READ:* *The following questions are about pain during the past 30 days.

H1. **On a scale of 0-10, how would you rate your average level of pain during the past 30 days, with 0 being no pain and 10 being the worst possible pain?**

00	No pain
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Worst possible pain
77	Don't Know
88	Refuse to Answer
99	Not Applicable

If H1 is equal to 0, then skip to instruction before H6.

H2. **During the past 30 days, how often did you have pain?** [SHOW CARD 17] (Choose one)

1	Rarely
2	Occasionally
3	Frequently
4	Almost constantly
7	Don't Know
8	Refuse to Answer
9	Not Applicable

H3. **Usually, how severe was the pain?** [SHOW CARD 18] (Choose one)

1	Slight
2	Moderate
3	Severe
4	Very severe
7	Don't Know
8	Refuse to Answer
9	Not Applicable

H4. **During the past 30 days, how much did pain interfere with your normal activities?** [SHOW CARD 10] (Choose one)

0 Not at all
1 A little bit
2 Moderately
3 Quite a bit
4 Extremely
7 Don't Know
8 Refuse to Answer
9 Not Applicable

H5. (During the past 30 days), **how much did pain interfere with your relations with other people?** [SHOW CARD 10] (Choose one)

0 Not at all
1 A little bit
2 Moderately
3 Quite a bit
4 Extremely
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ: Please answer Yes or No to the following statements.

H6. **If I had severe, chronic pain, I am afraid my doctor would not believe I am in pain.**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

H7. **Have you ever taken pain medications that were prescribed to you by a doctor?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If H7 is not equal to 1, then skip to H9.

H8. **During the past 30 days, have you taken pain medications that were prescribed to you by a doctor?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

H9. **Have doctors ever refused to give you the pain medications you felt you needed?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

H10. **Have you ever visited the emergency room because of your pain problems?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

H11. **Have you ever visited the Johns Hopkins Hospital pain clinic?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If H11 is not equal to 1, then skip to instruction before I1.

H12. **How helpful was the pain treatment you received at the Hopkins pain clinic? Would you say:** [READ RESPONSES~] (Choose one)

0 Not helpful
1 Somewhat helpful
2 Very helpful
7 Don't Know
8 Refuse to Answer
9 Not Applicable

HIV MEDICATIONS

READ: Now I will ask you questions about the medicines you are currently taking to treat the HIV virus directly.

I1. **Are you currently taking medications for your HIV, that is, you have taken them for at least one day in the past 30 days?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If I1 is equal to 1, then skip to instruction before I5.

I2. **Have you ever taken medications for your HIV?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

I3. **What is the main reason you are not taking medications for HIV?** (Choose one)

01 Had (or concerned about) serious side effects
02 Feeling good, don't need them
03 My doctor has not prescribed or has taken me off them
04 Ran out of pills
05 Cannot afford them/no insurance
06 Using drugs or alcohol
07 Taking a break from them
08 They remind me that I have HIV
09 I don't want others to know I have HIV
10 Incarcerated
11 Other
77 Don't Know
88 Refuse to Answer
99 Not Applicable

If I3 is not equal to 11, then skip to instruction before I5.

I4. [INTERVIEWER: Enter client's response]

— —
— —
— —
— —
— —
— —
— —

If I1 is not equal to 1 and I2 is not equal to 1, then skip to instruction before J1.

I5. **About how many years all together have you taken HIV medications? [**INTERVIEWER: If the client says less than 1 year, code 1 year.]

___ ___ ___	years
777	Don't Know
888	Refuse to Answer
999	Not Applicable

HIV STIGMA

READ: Even though people may know better, some people may have a lot of feelings about having HIV or AIDS. Please tell me how you feel.

J1. **Thinking about having HIV, how much do you feel that you need to hide it?** [SHOW CARD 11] (Choose one)

0 Not at all
1 Just a little
2 Somewhat
3 Very much
7 Don't Know
8 Refuse to Answer
9 Not Applicable

J2. (Thinking about having HIV), **how much do you feel blamed by others?** [SHOW CARD11] (Choose one)

0 Not at all
1 Just a little
2 Somewhat
3 Very much
7 Don't Know
8 Refuse to Answer
9 Not Applicable

J3. (Thinking about having HIV), **how much do you think HIV is a punishment for something?** [SHOW CARD11] (Choose one)

0 Not at all
1 Just a little
2 Somewhat
3 Very much
7 Don't Know
8 Refuse to Answer
9 Not Applicable

J4. **Thinking about having HIV, how much do you think other people are uncomfortable being around you?** [SHOW CARD11] (Choose one)

0 Not at all
1 Just a little
2 Somewhat
3 Very much
7 Don't Know
8 Refuse to Answer
9 Not Applicable

J5. (Thinking about having HIV), **how much do you fear you will lose your friends?** [SHOW CARD11] (Choose one)

0	Not at all
1	Just a little
2	Somewhat
3	Very much
7	Don't Know
8	Refuse to Answer
9	Not Applicable

J6. (Thinking about having HIV), **how much do you fear your family will reject you?** [SHOW CARD11] (Choose one)

0	Not at all
1	Just a little
2	Somewhat
3	Very much
7	Don't Know
8	Refuse to Answer
9	Not Applicable

RESILIENCY

READ: Please listen to the following statements about how your health challenges may have affected you. You may answer: Yes or No.

K1. **My health challenges have helped me grow as a person.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

K2. **My health challenges have changed my view on what is important in life.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

K3. (My health challenges) **have drawn me closer to someone.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

K4. (My health challenges) **have made me more sensitive to the needs of others.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

HEALTHCARE ENGAGEMENT (Medical Decision Making and Uncertainty Tolerance)

READ: People today are faced with many decisions about their healthcare -- for example: whether to start or change a medicine or other health treatment. We want to know how you prefer to make medical treatment decisions. Please tell me how much you agree or disagree with the following statements.

L1. **In making decisions about health treatments, I'm comfortable with my doctors making decisions for me.** [SHOW CARD 20] (Choose one)

1 Strongly disagree
2 Disagree
3 Neither agree nor disagree
4 Agree
5 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L2. **I prefer to get as much information as possible about treatment options.** [SHOW CARD 20] (Choose one)

1 Strongly disagree
2 Disagree
3 Neither agree nor disagree
4 Agree
5 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L3. **I usually discuss medical treatments and options with someone I am close to.** [SHOW CARD 20] (Choose one)

1 Strongly disagree
2 Disagree
3 Neither agree nor disagree
4 Agree
5 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L4. **Thinking about your doctors, do you prefer to:** [READ RESPONSES] (Choose one)

1 Make decisions without much advice from them
2 Get their advice and then make decisions
3 Make decisions together
4 Leave decisions up to them
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L5. **Thinking about your family and close friends, do you prefer to:** [READ RESPONSES] (Choose one)

1 Make medical treatment decisions without much advice from them
2 Get their advice and then make decisions
3 Make decisions together
4 Leave decisions up to them
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ: The following questions refer to the primary care doctor you usually see, or if you don't have someone you usually see, think about the last doctor you saw for healthcare.

L6. **My doctor knows me as a person.** (Please answer Yes or No.)

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L7. **My doctor involves me in decisions about my treatment as much as I would like.** [SHOW CARD 3~] (Choose one)

0 Never
1 Sometimes
2 Usually
3 Always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L8. **My doctor explains the pros and cons of different treatment options.** [SHOW CARD 3~] (Choose one)

0 Never
1 Sometimes
2 Usually
3 Always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L9. **My doctor supports my decisions.** [SHOW CARD 3~] (Choose one)

0 Never
1 Sometimes
2 Usually
3 Always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L10. **My doctor provides me enough information about treatment side effects or risks.** [SHOW CARD 3~] (Choose one)

0 Never
1 Sometimes
2 Usually
3 Always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

L11. **My doctor involves my partner or close family members in my care as much as I would like.** [SHOW CARD 3~] (Choose one)

0 Never
1 Sometimes
2 Usually
3 Always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ: The following questions are about your experiences with other doctors or other health providers.

L12. **In the last 12 months, how often did they explain things in a way you could understand?** [SHOW CARD 3~] (Choose one)

0	Never
1	Sometimes
2	Usually
3	Always
7	Don't Know
8	Refuse to Answer
9	Not Applicable

L13. (In the last 12 months, how often did they) **show respect for what you had to say?** [SHOW CARD 3~] (Choose one)

0	Never
1	Sometimes
2	Usually
3	Always
7	Don't Know
8	Refuse to Answer
9	Not Applicable

READ: Please tell me how much you agree or disagree with the following statements.

L14. **I am comfortable with the idea that some treatments may not work to improve my health.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

L15. **My health problems will be manageable if I take medications as prescribed.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

L16. **The future of my health is unknown even if I do everything I can.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

L. SOCIAL NETWORK INVENTORY

READ: INTERVIEWER: ***Administer the Social Network Inventory***

(Depress Flying Windows Key and Maximize Survey Folder to access link.)

HEALTH-RELATED SUPPORT

READ: Now I want to ask you about the kind of help you may have received from family or friends, or professional services, in the last year.

[INTERVIEWER: If the client states specifically that he or she does not need a kind of help, code "Not Applicable.]

N1. **In the last year, who has gone with you to a doctor's appointment or to the ER to get medical care?** [SHOW CARD 29] (Choose one)

0 Nobody
1 Family or friends
2 Professionals (paid workers)
3 Both
7 Don't Know
8 Refuse to Answer
9 Not Applicable

N2. (In the last year), **who has run errands, prepared food, or cleaned for you?** [SHOW CARD 29] (Choose one)

0 Nobody
1 Family or friends
2 Professionals (paid workers)
3 Both
7 Don't Know
8 Refuse to Answer
9 Not Applicable

N3. (In the last year), **who has helped you keep track of money or bills?** [SHOW CARD 29] (Choose one)

0 Nobody
1 Family or friends
2 Professionals (paid workers)
3 Both
7 Don't Know
8 Refuse to Answer
9 Not Applicable

N4. **In the last year, who has helped you get transportation to somewhere you needed to go?** [SHOW CARD 29] (Choose one)

0	Nobody
1	Family or friends
2	Professionals (paid workers)
3	Both
7	Don't Know
8	Refuse to Answer
9	Not Applicable

N5. (In the last year), **who has stayed with you while you were sick?** [SHOW CARD 29] (Choose one)

0	Nobody
1	Family or friends
2	Professionals (paid workers)
3	Both
7	Don't Know
8	Refuse to Answer
9	Not Applicable

N6. **In the last year, who has visited you while you were in the hospital?** [SHOW CARD 29] (Choose one)

0	Nobody
1	Family or friends
2	Professionals (paid workers)
3	Both
7	Don't Know
8	Refuse to Answer
9	Not Applicable

N7. (In the last year), **who has helped you with personal care, which includes eating, bathing, and dressing?** [SHOW CARD 29] (Choose one)

0	Nobody
1	Family or friends
2	Professionals (paid workers)
3	Both
7	Don't Know
8	Refuse to Answer
9	Not Applicable

N8. (In the last year), **who has helped you with your medication like reminded you to take it or gotten it for you?** [SHOW CARD29] (Choose one)

0	Nobody
1	Family or friends
2	Professionals (paid workers)
3	Both
7	Don't Know
8	Refuse to Answer
9	Not Applicable

CAREGIVING AVAILABILITY AND ACCEPTANCE

READ: Please tell me how much you agree or disagree with the following statements.

O1. **I have a family member or friend who would help care for me if I were sick in bed for several weeks.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

O2. **If I was sick and couldn't care for myself, I would want to have a professional like a doctor, nurse, or home health aide to assist me rather than family or friends.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

NORMS OF CARE ACCEPTANCE

P1. **Being helped by family or friends makes me feel dependent on them.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

P2. **Being helped by family or friends makes me feel like I'm a burden to them.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

P3. **Accepting care from others is a way to allow others to serve God.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

P4. **I often don't ask for help when I'm sick and need it because I don't want to owe favors to people.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

P5. **I often care for others' health more than I care for my own health.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

MAIN SUPPORTER INVOLVEMENT IN HEALTHCARE AND RECIPROCITY OF SUPPORT

Q1. [INTERVIEWER: Enter the first name of the most supportive person from the network survey; IF CLIENT DID NOT IDENTIFY ANY SUPORTIVE PERSON, CLICK "Don't Know", "Refused", or "Not Applicable"]

— —
— —
— —

If Q1 is equal to DON'T KNOW or Q1 is equal to REFUSE TO ANSWER or Q1 is equal to NOT APPLICABLE, then skip to instruction before R1.

READ: This section of the survey is about [Response to Q1], the person you named as most supportive. I am interested in the types of things you do for each other and how you are getting along.

Q2. **Would you say that [Response to Q1] helps you out <u>more</u>, <u>the same</u>, or <u>less than</u> the other people in your life?** (Choose one)

1 More
2 The same
3 Less than
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ: In the past year, how much of the following things did you do for [Response to Q1]?

Q3. **How much have you helped [Response to Q1] around the house in the past year?** [SHOW CARD 5] (Choose one)

0 None
1 Some
2 A lot
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Q4. **How much have you given or lent money or something valuable to [Response to Q1] in the past year?** [SHOW CARD 5] (Choose one)

0 None
1 Some
2 A lot
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Q5. **How much have you cared for [Response to Q1]'s children, family, or friends** (in the past year)? [SHOW CARD 5] (Choose one)

0	None
1	Some
2	A lot
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Q6. **How much have you spent time with [Response to Q1] in the past year?** [SHOW CARD 5] (Choose one)

0	None
1	Some
2	A lot
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Q7. **How much have you participated in [Response to Q1]'s family activities** (in the past year)? [SHOW CARD 5] (Choose one)

0	None
1	Some
2	A lot
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Q8. **How much have you shown affection and appreciation for [Response to Q1] in the past year?** [SHOW CARD 5] (Choose one)

0	None
1	Some
2	A lot
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Q9. **How much have you given things to [Response to Q1]** (in the past year)? [SHOW CARD 5] (Choose one)

0	None
1	Some
2	A lot
7	Don't Know
8	Refuse to Answer
9	Not Applicable

READ: The following questions are about [Response to Q1]'s help with your healthcare.

Q10. **Has [Response to Q1] ever talked with your doctor about your health symptoms or treatments?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Q11. **Has [Response to Q1] ever gone with you to an examination room at a clinic or hospital?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Q12. **How often do you talk to [Response to Q1] about your medical treatments and side effects? Would you say:** [READ RESPONSES] (Choose one)

0 Never
1 A few times
2 More than a few times but not often
3 Often
4 Very often
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Q13. **How often do you involve [Response to Q1] in decisions about your medical treatment? Would you say:** [READ RESPONSES~] (Choose one)

0 Never
1 Sometimes
2 Usually
3 Always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Q14. **How often does or could [Response to Q1] be helpful in helping you with decisions about your medical treatment? Would you say:** [READ RESPONSES~] (Choose one)

0 Never
1 Sometimes
2 Usually
3 Always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

NEGATIVE SUPPORT FROM SUPPORTER

If Q1 is equal to DON'T KNOW or Q1 is equal to REFUSE TO ANSWER or Q1 is equal to NOT APPLICABLE, then skip to instruction before S1.

READ: Please tell me how strongly you agree or disagree with the following statements.

R1. **[Response to Q1] is concerned about your health and well-being. Would you say:** [READ RESPONSES] (Choose one)

1 Strongly disagree
2 Disagree
3 Agree
4 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

R2. **[Response to Q1] helps you out as much as he or she can.** [READ RESPONSES] (Choose one)

1 Strongly disagree
2 Disagree
3 Agree
4 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ: Conflicts sometimes arise with people we're close to. Thinking about your relationship with [Response to Q1], please tell me how often the following occurred in the past 30 days

R3. **In the past 30 days, how often did you feel that [Response to Q1] wished he or she didn't have to help you so much?** [SHOW CARD 8] (Choose one)

0 Rarely or never
1 Sometimes
2 A lot
3 Most of the time or always
7 Don't Know
8 Refuse to Answer
9 Not Applicable

R4. **In the past 30 days, how often did [Response to Q1] complain about helping you out?** [SHOW CARD 8] (Choose one)

0	Rarely or never
1	Sometimes
2	A lot
3	Most of the time or always
7	Don't Know
8	Refuse to Answer
9	Not Applicable

R5. **In the past 30 days, how often did [Response to Q1] act hostile about helping you?** [SHOW CARD 8] (Choose one)

0	Rarely or never
1	Sometimes
2	A lot
3	Most of the time or always
7	Don't Know
8	Refuse to Answer
9	Not Applicable

R6. **In the past 30 days, how often have you felt you needed some time away from [Response to Q1]?** [SHOW CARD 8] (Choose one)

0	Rarely or never
1	Sometimes
2	A lot
3	Most of the time or always
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Self Administered Sections Start Here

CLIENT PRACTICE QUESTIONS

READ: For this next part of the survey you will be answering questions directly into the computer using a special pen. You will hear the questions from these speakers and you can adjust the volume with this knob. You will enter your responses without me knowing what you have answered. After I help you get started I will be just outside the door if you have any questions.

READ: [INTERVIEWER: Get the client ready for the practice questions; adjust speaker volume]

READ: The next few questions will be for practice. These will give you an idea of the different types of questions you will see during the interview. Using the blue pen, press the <u>Next Question</u> button on the screen to begin.

S1. Some of the questions will ask you to answer either YES or NO. For example:

Are you wearing blue today? Choose your answer by touching YES or NO with the pen.

1 Yes
0 No
8 Refuse to Answer

S2. Some of the questions will ask you to pick <u>one answer</u>. For example: How much do you agree with this statement? Blue is my favorite color. Select your answer by touching the button with the pen. (Choose one) (Choose one)

1 Strongly agree
2 Somewhat agree
3 Somewhat disagree
4 Strongly disagree
8 Refuse to Answer

S3. Some of the questions will ask you to pick <u>one or more answers</u> from a list of choices. For example: Which of the following colors do you like? Using the pen, choose all the colors you like. Then touch the <u>Next Question</u> button to move on. (Check all that apply) (Check all that apply)

__ Blue
__ Red
__ Green
__ Yellow
__ Purple
__ Refuse to Answer

READ: Do you remember how many colors you chose on the last question? Click the <u>Previous Question</u> button to see how many you chose. The question will be re-read to you. If you want, you may change your answers. Touch the <u>Next Question</u> button to move on.

READ: We are now ready to start. If you have any questions or need help, please ask your interviewer who will be right outside the door.

Remember that all of your answers are confidential. If you are not sure of an answer, please choose the answer that is most right. Please allow the question to be asked completely before giving your answer.

Touch the <u>Next Question</u> button to move on.

MEDICATION AND DRUG USE (Self-administered)

READ: In this section, I will ask you about the medications and drugs you are using.

All Medications

T1. **In the past 3 months, not including over-the-counter drugs, have you taken medications for any of the following medical conditions? Check all that apply.** (Check all that apply)

__ HIV/AIDS
__ Hepatitis C
__ Diabetes (sugar)
__ Blood pressure or heart disease
__ Mental health
__ Pain
__ Other
__ None
__ Refuse to Answer

If T1G is not equal to 1, then skip to instruction before T3.

T2. **Please enter the other medical conditions that you have taken medications for in the past 3 months.**

— —
— —
— —
— —
— —
— —
— —

If T1A is not equal to 1, then skip to instruction before T4.

T3. **Were the HIV/AIDS medications you took in the past 3 months prescribed to you by a doctor?**

1 Yes
0 No
8 Refuse to Answer

If T1B is not equal to 1, then skip to instruction before T5.

T4. **Were the hepatitis C medications you took in the past 3 months prescribed to you by a doctor?**

1 Yes
0 No
8 Refuse to Answer

If T1C is not equal to 1, then skip to instruction before T6.

T5. **Were the diabetes medications you took in the past 3 months prescribed to you by a doctor?**

1 Yes
0 No
8 Refuse to Answer

If T1D is not equal to 1, then skip to instruction before T7.

T6. **Were the blood pressure or heart disease medications you took in the past 3 months prescribed to you by a doctor?**

1 Yes
0 No
8 Refuse to Answer

If T1E is not equal to 1, then skip to instruction before T8.

T7. **Were the mental health medications you took in the past 3 months prescribed to you by a doctor?**

1 Yes
0 No
8 Refuse to Answer

If T1F is not equal to 1, then skip to instruction before T9.

T8. **Were the pain medications you took in the past 3 months prescribed to you by a doctor?**

1 Yes
0 No
8 Refuse to Answer

If T1G is not equal to 1, then skip to instruction before T10.

T9. **Were the other medications you took in the past 3 months prescribed to you by a doctor?**

1 Yes
0 No
8 Refuse to Answer

If T1A is not equal to 1 and T1B is not equal to 1 and T1C is not equal to 1 and T1D is not equal to 1 and T1E is not equal to 1 and T1F is not equal to 1 and T1G is not equal to 1, then skip to instruction before T11.

T10. **About how many pills do you take per day? Please enter the number.**

__ __ __ pills
888 Refuse to Answer

If T1A is not equal to 1, then skip to T13.

HIV Medications

T11. **In the past 30 days, on average, how would you rate your ability to take all of your HIV medications as your doctor prescribed?** (Choose one)

1	Very poor
2	Poor
3	Fair
4	Good
5	Very good
6	Excellent
88	Refuse to Answer

T12. **During the past 3 months, did you ever miss taking your HIV medication for two days or longer?**

1	Yes
0	No
8	Refuse to Answer

T13. **During the past 3 months, have you taken any tranquilizing medications such as Valium, Xanax, Ativan or Klonopin? These are usually for anxiety, but may also be used for sleep or blood pressure.**

1	Yes
0	No
8	Refuse to Answer

T14. **During the past 3 months, have you taken any other mental health medications such as Zoloft, Celexa, Wellbutrin, or Seroquel? These are usually for depression, manic depression or bipolar disorder, but may be used for smoking cessation, sleep or pain.**

1	Yes
0	No
8	Refuse to Answer

T15. **During the past 3 months, have you taken any medications such as Vicodin, Dilaudid, Percocet, or Oxycontin? These are usually used for pain.**

1	Yes
0	No
8	Refuse to Answer

T16. **During the past 3 months, have you taken any other medications for pain that I haven't mentioned**?

1	Yes
0	No
8	Refuse to Answer

T17. **Have you ever taken other drugs or alcohol to help relieve pain?**

1	Yes
0	No
8	Refuse to Answer

T18. **Have you ever had to take more pain medication than was prescribed for you?**

1 Yes
0 No
8 Refuse to Answer

T19. **Have you ever gotten pain medications from family or friends?**

1 Yes
0 No
8 Refuse to Answer

T20. **Have you ever had to buy pain medications on the street?**

1 Yes
0 No
8 Refuse to Answer

Smoking

READ: I'd like to ask you a few questions about cigarettes.

T21. **Have you smoked cigarettes in the last 30 days?**

1 Yes
0 No
8 Refuse to Answer

If T21 is not equal to 1, then skip to instruction before T23.

T22. **How soon after waking up do you usually have your first cigarette of the day?** (Choose one)

1 Within 5 minutes
2 6 - 30 minutes
3 31 - 60 minutes
4 After 60 minutes
8 Refuse to Answer

If Q1 is equal to DON'T KNOW or Q1 is equal to REFUSE TO ANSWER or Q1 is equal to NOT APPLICABLE, then skip to instruction before T24.

T23. **Does [Response to Q1] currently smoke cigarettes?**

1 Yes
0 No
8 Refuse to Answer

Drug/Substance Use

READ: Now I want to ask you some questions about drug use. Remember, information you give is confidential and your name will not be linked to any of the answers you provide. Please answer honestly. Touch the Next Question button to move on.

T24. **When was the last time you had a drink containing alcohol, that is, beer, wine, a mixed drink or any kind of alcoholic beverage?** (Choose one)

0 Never in your life
1 More than 5 years ago
2 1-5 years ago
3 Between 6 and 12 months ago
4 1 to 6 months ago
5 In the past month
8 Refuse to Answer

T25. **When was the last time you smoked marijuana?** (Choose one)

0 Never in your life
1 More than 5 years ago
2 1-5 years ago
3 Between 6 and 12 months ago
4 1 to 6 months ago
5 In the past month
8 Refuse to Answer

T26. **When was the last time you used heroin?** (Choose one)

0 Never in your life
1 More than 5 years ago
2 1-5 years ago
3 Between 6 and 12 months ago
4 1 to 6 months ago
5 In the past month
8 Refuse to Answer

T27. **When was the last time you used cocaine or crack?** (Choose one)

0 Never in your life
1 More than 5 years ago
2 1-5 years ago
3 Between 6 and 12 months ago
4 1 to 6 months ago
5 In the past month
8 Refuse to Answer

T28. **When was the last time you <u>took other stimulants, such as, speed, amphetamines, meth or methamphetamines?</u>** (Choose one)

0	Never in your life
1	More than 5 years ago
2	1-5 years ago
3	Between 6 and 12 months ago
4	1 to 6 months ago
5	In the past month
8	Refuse to Answer

If T24 is less than 4, then skip to T30.

T29. **How often, in the past 6 months, did you have a drink containing alcohol, that is, beer, wine, a mixed drink or any kind of alcoholic beverage?** (Choose one)

1	Less than once a week
2	1-2 times per week
3	Several times a week
4	Once a day
5	More than once a day
8	Refuse to Answer

T30. **When was the last time you injected drugs, including prescription drugs that weren't prescribed to you.** (Choose one)

0	Never in your life
1	More than 5 years ago
2	1-5 years ago
3	Between 6 and 12 months ago
4	1 to 6 months ago
5	In the past month
8	Refuse to Answer

MAIN PARTNER/SUPPORTER CONFLICT (Self-administered)

U1. **Do you currently have a main partner? A main partner is a partner that you would call your boyfriend or girlfriend, spouse, or significant other.**

1 Yes
0 No
8 Refuse to Answer

If U1 is not equal to 1, then skip to instruction before U8.

U2. **Is this partner male or female?**

1 Male
2 Female
8 Refuse to Answer

Conflict with Main Partner

READ: Next I am going to ask you some questions about your relationship with your main partner. No matter how well a couple gets along, there are times when they disagree or fight. Please answer whether you or your partner has done any of these things to each other in the last 12 months.

Touch the Next Question button to move on.

U3. **In the last year, has your main partner called you a name or put down your family or friends, or have you done this to your partner?**

1 Yes
0 No
8 Refuse to Answer

U4. **In the last year, has your main partner tried to keep you from doing something you wanted to do, like going out with friends or going to meetings, or have you done this to your partner?**

1 Yes
0 No
8 Refuse to Answer

U5. **In the last year, has your main partner slapped or hit you or have you slapped or hit your partner?**

1 Yes
0 No
8 Refuse to Answer

READ: I have just a couple more questions about your main partner. Touch the Next Question button to move on.

U6. **Have you told your main partner that you are HIV positive?**

1 Yes
0 No
8 Refuse to Answer

U7. **Has your main partner told you that he or she is HIV positive or HIV negative? If your main partner has <u>not</u> told you his or her HIV status, please click button C for Unsure.** (Choose one)

1	HIV positive
2	HIV negative
3	Unsure
8	Refuse to Answer

Conflict with Main Supporter

If U1 is equal to 1, then skip to instruction before V1.

If Q1 is equal to DON'T KNOW or Q1 is equal to REFUSE TO ANSWER or Q1 is equal to NOT APPLICABLE, then skip to instruction before V1.

READ: Next I am going to ask you some questions about your relationship with your main supporter [Response to Q1]. No matter how well people get along, there are times when they disagree or fight. Please answer whether you, or she or he has done any of these things to each other in the last 12 months.

U8. **In the last year, has your main supporter called you a name or put down your family or friends, or have you done this to him or her?**

1	Yes
0	No
8	Refuse to Answer

U9. **In the last year, has your main supporter tried to keep you from doing something you wanted to do, like going out with friends or going to meetings, or have you done this to him or her?**

1	Yes
0	No
8	Refuse to Answer

U10. **In the last year, has your main supporter slapped or hit you or have you slapped or hit him or her?**

1	Yes
0	No
8	Refuse to Answer

READ: I have just a couple more questions about your main supporter.

U11. **Have you told your main supporter that you are HIV positive?**

1	Yes
0	No
8	Refuse to Answer

U12. **Has your main supporter told you that he or she is HIV positive or HIV negative? If your main supporter has not told you his or her HIV status, please click button C for Unsure.** (Choose one)

1	HIV positive
2	HIV negative
3	Unsure
8	Refuse to Answer

TRUST IN HEALTHCARE SYSTEM (Self-administered)

READ: Please tell me how strongly you agree or disagree with the following statements about healthcare.

V1. **I completely trust doctors' decisions about which medical treatments are best for me.** (Choose one)

1 Strongly agree
2 Agree
3 Neither agree nor disagree
4 Disagree
5 Strongly disagree
8 Refuse to Answer

V2. **Health professionals care more about holding costs down than about doing what is best for my health.** (Choose one)

1 Strongly agree
2 Agree
3 Neither agree nor disagree
4 Disagree
5 Strongly disagree
8 Refuse to Answer

V3. **Health professionals are more interested in treating specific diseases than in caring for the whole person.** (Choose one)

1 Strongly agree
2 Agree
3 Neither agree nor disagree
4 Disagree
5 Strongly disagree
8 Refuse to Answer

READ: The following questions are about all of the experiences you have had with health care visits in the last 2 years. Please answer Yes or No.

V4. **In the last 2 years, have you ever felt that the doctor or medical staff you saw judged you unfairly or treated you with disrespect because of your race or ethnicity?**

1 Yes
0 No
8 Refuse to Answer

V5. **In the last 2 years, have you ever felt that the doctor or medical staff you saw judged you unfairly or treated you with disrespect because of how you speak?**

1 Yes
0 No
8 Refuse to Answer

V6. **In the last 2 years, have you ever felt that the doctor or medical staff you saw judged you unfairly or treated you with disrespect <u>because you have HIV</u>?**

1	Yes
0	No
8	Refuse to Answer

V7. **In the last 2 years, have you ever felt that the doctor or medical staff you saw judged you unfairly or treated you with disrespect <u>because you use or used to use drugs</u>?**

1	Yes
0	No
8	Refuse to Answer

READ: Please open the door and your interviewer will be with you shortly.

V8. INTERVIEWER: Enter password to continue survey.

— — — —

If V8 is not equal to 2213 then READ: "Please enter the correct password" and skip to V8.

Self Administered Sections End Here

FAMILY NORMS OF CAREGIVING

READ: The following questions are what might happen in your family when someone has a serious chronic illness and can't care for him or herself.

W1. **In my family, when someone has a serious chronic illness and can't care for themselves, we pull together and care for them.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

W2. (In my family, when someone has a serious chronic illness and can't care for themselves), **we prefer to care for them at home rather than have them at a nursing home.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

W3. (In my family, when someone has a serious chronic illness and can't care for themselves), **the women or girls are the ones to care for them.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

W4. (In my family, when someone has a serious chronic illness and can't care for themselves), **we often have disagreements about who should care for them.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

W5. (In my family, when someone has a serious chronic illness and can't care for themselves), **we feel it's our duty to care for family in need.** [SHOW CARD 7] (Choose one)

1 Strongly disagree
2 Disagree
3 Agree
4 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

W6. (In my family, when someone has a serious chronic illness and can't care for themselves), **we often have disagreements about what medical treatments and care they should have.** [SHOW CARD 7] (Choose one)

1 Strongly disagree
2 Disagree
3 Agree
4 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

EOL HEALTHCARE PREFERENCES AND DECISION MAKING

READ: There is a new Maryland law not many people know about that requires hospital patients to fill out a form which states what kind of life-saving care, such as CPR, they would want if they were in critical condition and couldn't tell their doctors what care they wanted. The document is called a MOLST form (Medical Orders for Life-Sustaining Treatment). It is similar to an advanced directive form. The questions I will ask have nothing to do with your current health or future care you will get at Johns Hopkins.

X1. **Have you heard of an advance directive or the MOLST form?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If X1 is not equal to 1, then skip to instruction before X3.

X2. **Have you ever signed a MOLST form or advance directive, perhaps when being discharged from a hospital or admitted to an assisted care facility?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Proxy Healthcare Decision Maker

READ: This new Maryland law also encourages patients to name someone who doctors can talk to about medical treatments if there is a critical situation where patients can't talk for themselves. Medical decision makers may be partners, family or friends.

X3. **Have you ever been asked to name a medical decision maker or signed a document naming such a person?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If X3 is equal to 1, then skip to X5.

X4. **Can you think of anyone who may be able to make medical decisions for you if you are not able to make decisions on your own?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If X4 is not equal to 1, then skip to instruction before X9.

X5. **What is this person's first name?**

— —
— —
— —

X6. **What is your relationship to this person? You are their . . . .** [RECORD RELATIONSHIP CODE FROM SHEET]

— —

77	Don't Know
88	Refuse to Answer
99	Not Applicable

If X6 is not equal to 75, then skip to X8.

X7. [INTERVIEWER: Record client's relationship to the person]

— —
— —
— —
— —
— —
— —
— —

X8. **Is this person** (the medical decision maker) **male or female?** (Choose one)

1	Male
2	Female
3	Other
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If X3 is equal to 1, then skip to instruction before X16.

Difficulty choosing a medical decision maker

READ: Now, we are going to ask your opinion about things that make it hard for you to choose a medical decision maker. Everything you tell me is completely confidential and will not be shared with your doctors or other healthcare providers. Please answer yes or no.

X9. **I want to be in control of my life. Does this make it hard for you to choose a medical decision maker?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X10. **I am afraid to talk about being really sick as it might bring bad luck. Does this make it hard for you to choose** (a medical decision maker)?

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X11. **I would rather leave my health to God and to prayer. Does this make it hard for you to choose** (a medical decision maker)?

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X12. **I do not want to burden my family or friends with such decisions. Does this make it hard for you to choose** (a medical decision maker)?

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X13. **There is no one I trust to make medical decisions for me. Does this make it hard for you to choose** (a medical decision maker)?

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X14. **Are there other reasons why it might be hard for you to choose a medical decision maker?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If X14 is not equal to 1, then skip to instruction before X16.

X15. **What are those reasons** (why it might be hard for you to choose a medical decision maker)?

— —
— —
— —
— —
— —
— —
— —

READ: Please tell me how much you agree or disagree with the following statements.

X16. **Family and doctors should follow a person's wishes for medical treatments as closely as possible.** [SHOW CARD 20] (Choose one)

1 Strongly disagree
2 Disagree
3 Neither agree nor disagree
4 Agree
5 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

X17. **Family and doctors can consider their own interests when making healthcare decisions for someone.** [SHOW CARD 20] (Choose one)

1 Strongly disagree
2 Disagree
3 Neither agree nor disagree
4 Agree
5 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

X18. **For family and doctors, following a person's wishes for medical treatment can provide comfort in knowing they're doing the right thing.** [SHOW CARD 20] (Choose one)

1 Strongly disagree
2 Disagree
3 Neither agree nor disagree
4 Agree
5 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ: For the next questions please answer yes or no

X19. **Have you been close to someone who got more medical care than she or he wanted at the end of their life, like surgery or chemotherapy?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Communication with medical provider and family

X20. **Has your family ever had major disagreements about medical treatment for a family member who was critically ill and not able to tell doctors about what treatment she or he wanted?** (Please answer Yes or No).

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X21. **Have you ever talked with your doctor about what medical treatments you would want if you were not able to make decisions for yourself?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If X21 is equal to 1, then skip to X23.

X22. **Do you think it would be, beneficial to you to talk about your critical care preferences with your doctor?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X23. **Have you ever talked with your family or friends about what medical treatments you would want if you were not able to make decisions for yourself?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If X23 is equal to 1, then skip to X25.

X24. **Do you think it would be beneficial to you, to talk about your critical care preferences with a close family member or partner?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X25. **When do you think is the best time to talk about critical care decisions? Would you say:** [READ RESPONSES] (Choose one)

1 Before getting sick, while healthy
2 When first diagnosed with a serious illness
3 When first sick from a serious illness
4 When first hospitalized with a serious illness
5 At the end stage of illness
7 Don't Know
8 Refuse to Answer
9 Not Applicable

X26. **Other than family members, friends or a partner, who do you think are the best people to talk with a person about critical care decisions? Would you say:** [INTERVIEWER: Read items A-F, waiting for a response after each item; if client says "Yes" check that item.] (Check all that apply)

__ Someone from your community
__ A social worker or case manager
__ A psychologist
__ A nurse
__ A physician
__ A religious advisor (e.g. pastor or imam)
__ Some other person (other than family, friends, partners)
__ Don't Know
__ Refuse to Answer
__ Not Applicable

If X26G is not equal to 1, then skip to X28.

X27. **Who do you think is the best person** (to talk to a person about critical care decisions)?

— —
— —
— —
— —
— —
— —
— —

X28. **Where do you think is the best place to have these discussions?** (Choose one)

1 At home
2 At a hospital or clinic
3 Doctor's office
4 Church
5 Any private place
6 Other
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If X28 is not equal to 6, then skip to instruction before X30.

X29. [INTERVIEWER: Enter client's other respons]

— —
— —
— —
— —
— —
— —
— —

If X2 is equal to 1, then skip to instruction before X31.

X30. **Would you be interested in learning more about the new Maryland law and getting assistance on deciding on medical care you'd want if something critical were to happen?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Care preferences -- place

READ: Please tell me how much you agree or disagree with the following statements. These questions have nothing to do with your current health status.

X31. **If I could not care for myself, I would prefer to live at home with assistance from a home health aide or other healthcare professional.** [SHOW CARD 7] (Choose one)

1 Strongly disagree
2 Disagree
3 Agree
4 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

X32. **If I could not care for myself, I would prefer to live at home with assistance from my partner, family, or friends.** [SHOW CARD 7] (Choose one)

1 Strongly disagree
2 Disagree
3 Agree
4 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

X33. **If I could not care for myself, I would prefer to live in a long term care facility such as a nursing home, rather than at home.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Care preferences -- values

READ: Now, I'm going to ask your opinion about what would matter most if you were faced with a critical health situation. Please tell me how much you agree or disagree with the following statements.

X34. **Being able to do the things I most enjoy would be more important to me than living as long as possible.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X35. **If my heart stopped beating or I was in a coma, I would not want CPR** (pressing on a person's chest and blowing into their mouth to help them breathe again). [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

X36. **Which of the following health problems, if any, do you think are worse than death for a person?** [INTERVIEWER: Read items A-F, waiting for a response after each item.] (Check all that apply)

__ Always having severe pain
__ Being totally dependent on others for care (like for eating, bathing, moving)
__ Being in a coma that he/she won't come out of
__ Living in a nursing home for the rest of his/her life
__ Having a breathing tube down his/her throat for the rest of your life
__ Having severe dementia, not being able to remember things or people
__ None are worse than death
__ Don't Know
__ Refuse to Answer
__ Not Applicable

If (X36A is equal to 1 or X36B is equal to 1 or X36C is equal to 1 or X36D is equal to 1 or X36E is equal to 1 or X36F is equal to 1) and X36G is equal to 1 then READ: "[INTERVIEWER: You may not check the last box if any other boxes are checked]" and skip to X36.

X37. **If you had to make a choice at this time, would you want medical care that:** [SHOW CARD 30] (Choose one)

1 Helps you live as long as possible, even if it means having more discomfort or disability OR
2 Relieves discomfort or disability as much as possible, even if that means not living as long OR
3 Both
7 Don't Know
8 Refuse to Answer
9 Not Applicable

PALLIATIVE CARE AND HOSPICE SERVICES

Palliative Care

READ: Palliative care is specialized medical care for persons with serious illness. The focus is to <u>improve quality of life</u> by reducing pain and other distressing symptoms. It includes support for patients and families. A team of specialists work with a person at any stage of illness.

Y1. **Have you ever heard of palliative care?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If Y1 is not equal to 1, then skip to instruction before Y5.

Y2. **Has anyone you've been close to ever used palliative care?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Y3. **To what extent do you think that palliative care might be helpful for you now? Would you say:** [READ RESPONSES] (Choose one)

0 Not at all
1 A bit
2 A lot
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Y4. **To what extent do you think that palliative care might be helpful for you in the future?** [READ RESPONSES] (Choose one)

0 Not at all
1 A bit
2 A lot
7 Don't Know
8 Refuse to Answer
9 Not Applicable

Hospice

READ: This next section is about hospice. Hospice is a program that provides care to people at the last stage of life. The goal is to keep them as comfortable as possible.

Y5. **Have you ever heard of hospice?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If Y5 is not equal to 1, then skip to instruction before Z1.

Y6. **Has anyone you've been close to ever used hospice services?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If Y6 is not equal to 1, then skip to instruction before Z1.

Y7. (Thinking of the person close to you who used hospice), **how would you rate his or her hospice experience? Was it:** [READ RESPONSES] (Excellent means the hospice team was very supportive and kept everyone informed and pain was controlled.) (Choose one)

1	Excellent
2	Good
3	Fair
4	Poor
7	Don't Know
8	Refuse to Answer
9	Not Applicable

SPIRITUALITY (General)

READ: This section is about your religious or spiritual beliefs.

Z1. **How important is spirituality or religion in your life right now? Would you say:** [READ RESPONSES] (Choose one)

1	Not at all important
2	Somewhat important
3	Important
4	Very important
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Z2. **How often do you go to religious services? Would you say:** [READ RESPONSES] (Choose one)

0	Never
1	Once or twice a year
2	Every month or so
3	Once or twice a month
4	Every week
5	More than once a week
7	Don't Know
8	Refuse to Answer
9	Not Applicable

READ: Please tell me how much you agree or disagree with the following two statements.

Z3. **I feel God's love for me, directly or through others.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

Z4. **I desire to be closer to or in union with God.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

SATISFACTION WITH NETWORK CONTACT

READ: I am now going to ask if you feel <u>satisfied</u> with the contact you have with loved ones. Please answer yes, no or somewhat.

AA1. **Are you satisfied with the contact you have with** (one of) **your children?** [SHOW CARD 21] (Choose one)

0	No
1	Somewhat
2	Yes
7	Don't Know
8	Refuse to Answer
9	Not Applicable

AA2. (Are you satisfied with the contact you have) **with your family?** [SHOW CARD 21] (Choose one)

0	No
1	Somewhat
2	Yes
7	Don't Know
8	Refuse to Answer
9	Not Applicable

AA3. (Are you satisfied with the contact you have) **with your friends?** [SHOW CARD 21] (Choose one)

0	No
1	Somewhat
2	Yes
7	Don't Know
8	Refuse to Answer
9	Not Applicable

DYADIC COPING

If Q1 is equal to DON'T KNOW or Q1 is equal to REFUSE TO ANSWER or Q1 is equal to NOT APPLICABLE, then skip to instruction before CC1.

READ: In everyday life people sometimes feel stressed about things. The following statements are about how [Response to Q1] and you deal with stress.

BB1. **When we are stressed, [Response to Q1] withdraws from me.** [SHOW CARD 24] (Choose one)

1 Very rarely
2 Rarely
3 Sometimes
4 Often
5 Very often
7 Don't Know
8 Refuse to Answer
9 Not Applicable

BB2. (When we are stressed), **[Response to Q1] tries to help but does so unwillingly and without motivation.** [SHOW CARD 24] (Choose one)

1 Very rarely
2 Rarely
3 Sometimes
4 Often
5 Very often
7 Don't Know
8 Refuse to Answer
9 Not Applicable

BB3. (When we are stressed), **we talk about the problem and how to deal with it together.** [SHOW CARD 24] (Choose one)

1 Very rarely
2 Rarely
3 Sometimes
4 Often
5 Very often
7 Don't Know
8 Refuse to Answer
9 Not Applicable

BB4. **I am satisfied with the way that [Response to Q1] and I deal with stress together.** [SHOW CARD 24] (Choose one)

1	Very rarely
2	Rarely
3	Sometimes
4	Often
5	Very often
7	Don't Know
8	Refuse to Answer
9	Not Applicable

FAMILY PROBLEM SOLVING

READ: The following questions are about your family.

CC1. **I am satisfied with the way my family helps me deal with problems that come up.** [SHOW CARD 28] (Choose one)

1 Almost always
2 Some of the time
3 Hardly ever
7 Don't Know
8 Refuse to Answer
9 Not Applicable

CC2. (I am satisfied) **with the way my family expresses love and affection.** [SHOW CARD 28] (Choose one)

1 Almost always
2 Some of the time
3 Hardly ever
7 Don't Know
8 Refuse to Answer
9 Not Applicable

CC3. (I am satisfied) **with the amount of time my family and I spend together.** [SHOW CARD 28] (Choose one)

1 Almost always
2 Some of the time
3 Hardly ever
7 Don't Know
8 Refuse to Answer
9 Not Applicable

READ: Please tell me how much you agree or disagree with each statement.

CC4. **In my family, we talk about our problems with each other.** [SHOW CARD 7] (Choose one)

1 Strongly disagree
2 Disagree
3 Agree
4 Strongly agree
7 Don't Know
8 Refuse to Answer
9 Not Applicable

CC5. (In my family), **if someone has a problem, we work together to deal with it.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

CC6. (In my family), **when we are angry or upset we don't talk to each other.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

CC7. (In my family), **we usually turn to one main family member when we have a problem.** [SHOW CARD 7] (Choose one)

1	Strongly disagree
2	Disagree
3	Agree
4	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

PSYCHOLOGICAL WELL-BEING

READ: Now I'm going to ask you some questions about how you have been feeling during the past week. Please tell me whether you would agree with any of the statements I read; and if so, how many days in the past week you have experienced each thing I mention.

[INTERVIEWER: If client says they don't know or can't answer a question, please ask them for their best guess or opinion and remind them that all of their answers are confidential.]

DD1. (During the past week), **I felt depressed.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD2. (During the past week), **I felt that everything I did was an effort.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD3. (During the past week), **my sleep was restless.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD4. **During the past week, I was happy.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD5. (During the past week), **I felt lonely.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD6. **During the past week, people were unfriendly.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD7. (During the past week), **I enjoyed life.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD8. (During the past week), **I felt that people disliked me.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD9. (During the past week), **I could not get going.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

DD10. (During the past week), **I felt sad.** [SHOW CARD 9] (Choose one)

0 Rarely or none of the time (<1 day a week)
1 Some or a little of the time (1-2 days a week)
2 Occasionally or a moderate amount of time (3-4 days a week)
3 Most or all of the time (5-7 days a week)
8 Refuse to Answer

READ: How much were you bothered by the following symptoms during the past week?

DD11. (During the past week), **how much were you bothered by nervousness or shakiness inside?** [SHOW CARD 10] (Choose one)

0	Not at all
1	A little bit
2	Moderately
3	Quite a bit
4	Extremely
7	Don't Know
8	Refuse to Answer
9	Not Applicable

DD12. (During the past week), **how much were you bothered by suddenly feeling scared for no reason?** [SHOW CARD 10] (Choose one)

0	Not at all
1	A little bit
2	Moderately
3	Quite a bit
4	Extremely
7	Don't Know
8	Refuse to Answer
9	Not Applicable

RESILIENCY AND MEANING MAKING

READ: This next section is about how you feel about changes in your life and health. Please answer yes or no to the following statements.

EE1. **Everything happens for a reason.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE2. **I could be a lot worse off than I am.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE3. **It is not my challenges; it is how I respond to them that counts.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE4. **I have a strong sense of purpose of my life.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE5. **I am able to adapt to changes in my body.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE6. **I worry about losing my dignity as my body ages.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE7. **I am inspired by someone I know who is or was able to age with grace and dignity.**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

READ: Please tell me how much you agree or disagree with the following statements.

EE8. **God determines whether you live or die.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE9. **Those who believe in God do not need to plan for medical care they'd want if they weren't able to speak for themselves.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

EE10. **Those who believe in God would want everything done to keep them alive in any condition they're in.** [SHOW CARD 20] (Choose one)

1	Strongly disagree
2	Disagree
3	Neither agree nor disagree
4	Agree
5	Strongly agree
7	Don't Know
8	Refuse to Answer
9	Not Applicable

SATISFACTION WITH LIFE AND SELF

READ: [SHOW CARD 22] I am now going to ask how satisfied you feel with your life, on a scale from 0 to 10: 0 means you feel completely dissatisfied and 10 means you feel completely satisfied. The middle of the scale is 5, which means you feel neutral -- neither satisfied nor dissatisfied.

FF1. **How satisfied are you with your ability to meet your basic needs, such as housing, food, and clothes?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF2. (How satisfied are you) **with your mental health?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF3. (How satisfied are you) **with your physical health?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF4. (How satisfied are you) **with what you are achieving or have achieved in life?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF5. (How satisfied are you) **with your relationships with friends?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF6. (How satisfied are you) **with how safe you feel outside your home?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF7. (How satisfied are you) **with feeling connection to your community?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF8. (How satisfied are you) **with your ability to do things that are important to you?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF9. (How satisfied are you) **with your ability to live or continue living a quality life?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF10. (How satisfied are you) **with your spirituality or religion** (your spirituality or relationship with God)**?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF11. **Thinking about your life and personal circumstances, how satisfied are you with your life as a whole?** [SHOW CARD 22]

00	Completely dissatisfied
01	
02	
03	
04	
05	
06	
07	
08	
09	
10	Completely satisfied
77	Don't Know
88	Refuse to Answer
99	Not Applicable

FF12. **Are there other things that I haven't mentioned that affect how you feel about your life right now?** [INTERVIEWER: If yes, please ask the client to specify.]

— —
— —
— —
— —
— —
— —
— —

DEMOGRAPHIC INFORMATION

READ: Now I'd like to change topics.

GG1. **Do you consider yourself straight, gay, bisexual, or other?** (Choose one)

1 Gay
2 Straight
3 Bisexual
4 Other
7 Don't Know
8 Refuse to Answer
9 Not Applicable

GG2. **What is your relationship status? Are you currently:** [READ RESPONSES] (Choose one)

1 Married
2 In a committed relationship
3 Separated
4 Divorced
5 Widowed
6 Single
77 Don't Know
88 Refuse to Answer
99 Not Applicable

GG3. **In the past year, that is from [YR1AGO] to today, have you slept for at least one week in any of the following places: a squatting place, an abandoned building, a car, a homeless shelter, a park or on the street?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

If GG3 is not equal to 1, then skip to GG5.

GG4. **In the past month, have you slept for at least one week in any of the following places: a squatting place, an abandoned building, a car, a homeless shelter, a park or on the street?**

1 Yes
0 No
7 Don't Know
8 Refuse to Answer
9 Not Applicable

GG5. **Do you currently have a place where you stay 5 to 7 nights a week?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG6. **What type of place do you currently live in?** [INTERVIEWER: if client says house or apartment, ask if they own it, rent it, or if it is someone else's.] (Choose one)

01	A squat, car, or on the street
02	Shelter or emergency housing
03	Transitional (time-limited) single-room hotel
04	Permanent single-room occupancy hotel
06	Health treatment facility, e.g. hospice
07	Drug treatment facility or recovery home
08	Someone else's house or apartment
09	House or apartment that you rent
10	House that you own
11	Other
77	Don't Know
88	Refuse to Answer
99	Not Applicable

If GG6 is equal to 1 and GG3 is not equal to 1 then READ: "[INTERVIEWER: Earlier client said that they had not slept in a squat, car, or street for at least one week in the past year; you will be return to check this response]" and skip to GG3.

If GG6 is not equal to 11, then skip to GG8.

GG7. [INTERVIEWER: Record type of place where client is currently living]

— —
— —
— —
— —
— —
— —
— —

GG8. **In the past year, have you always felt safe in your house or apartment?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG9. **Do you get housing assistance or a housing voucher from the government or social service agency for staying at this place?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG10. **How long have you been staying there?** (Choose one)

1	Less than 1 month
2	1 to 6 months
3	7-12 months
4	1-2 years
5	3-5 years
6	Over 5 years
77	Don't Know
88	Refuse to Answer
99	Not Applicable

If GG10 is equal to 5 or GG10 is equal to 6, then skip to GG12.

GG11. **How many times in the past 2 years have you moved?**

— — —	times
777	Don't Know
888	Refuse to Answer
999	Not Applicable

GG12. **Have you ever been in jail, prison, or a correctional facility?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

If GG12 is equal to 0, then skip to GG14.

GG13. **In the past 6 months were you in jail, prison, or a correctional facility?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG14. **What is your current employment status? Are you:** [READ RESPONSES] (Choose one)

1	Employed full time
2	Employed part time
3	Unemployed but seeking work
4	Unemployed - not seeking work
5	Disabled
6	Retired
77	Don't Know
88	Refuse to Answer
99	Not Applicable

READ: Now I want to ask you about the different ways that you got money in the past 30 days?

GG15. **In the past 30 days, did you receive <u>food stamps</u>?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG16. (In the past 30 days), **did you get <u>SSI</u>** (Supplemental Security Income) **checks or <u>SSDI</u>** (Social Security Disability) **checks from Social Security?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG17. (In the past 30 days), **other than food stamps or Social Security, did you get checks from <u>welfare or public assistance, such as</u>** (TANF, TEMHA, or AFDC)?

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG18. (In the past 30 days), **did you borrow or get money from your <u>family or friends</u>?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

GG19. **In the past <u>30 days</u>, how much money did you get altogether from all sources including wages and food stamps?** (Choose one)

01	No income
02	Less than $250
03	$250-$499
04	$500-$999
05	$1,000-$1,499
06	$1,500-$1,999
07	$2,000 or more
77	Don't Know
88	Refuse to Answer
99	Not Applicable

If GG19 is equal to 1 and (GG14 is equal to 1 or GG14 is equal to 2 or GG16 is equal to 1 or GG17 is equal to 1 or GG15 is equal to 1 or GG18 is equal to 1) then READ: "[INTERVIEWER: Are you sure client has no income?; please go back and check previous responses]".

INTERVENTION INTEREST

READ: Before I end this interview, I would like to explain that in the next part of the study, we want to develop a program to improve the well-being of people living with HIV and the main people in their lives.

HH1. **Would you be interested in participating in a program about living with or caring for someone with HIV?** [SHOW CARD 11] (Choose one)

0	Not at all
1	Just a little
2	Somewhat
3	Very much
7	Don't Know
8	Refuse to Answer
9	Not Applicable

HH2. **Would you be interested in participating in a program about pain management and improving quality of life?** [SHOW CARD 11] (Choose one)

0	Not at all
1	Just a little
2	Somewhat
3	Very much
7	Don't Know
8	Refuse to Answer
9	Not Applicable

HH3. **Would you be interested in participating in a program about stress reduction and coping with chronic illness?** [SHOW CARD 11] (Choose one)

0	Not at all
1	Just a little
2	Somewhat
3	Very much
7	Don't Know
8	Refuse to Answer
9	Not Applicable

HH4. **Would you be interested in participating in a program about finding meaning and dignity in chronic illness?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

HH5. **Would you be interested in learning about planning for the future?**

1	Yes
0	No
7	Don't Know
8	Refuse to Answer
9	Not Applicable

HH6. **Do you think any of the main people in your life would be interested in participating in a program about . . . . ?** [INTERVIEWER: Read items A-D, waiting for a response after each item; if client says "Yes" check that item.] (Check all that apply)

__ living with or caring for someone with HIV
__ pain management and improving the quality of life
__ stress reduction and coping with chronic illness
__ finding meaning and dignity in serious chronic illness
__ None of these
__ Don't Know
__ Refuse to Answer
__ Not Applicable

If (HH6A is equal to 1 or HH6B is equal to 1 or HH6C is equal to 1 or HH6D is equal to 1) and HH6E is equal to 1 then READ: "[INTERVIEWER: You may not check the last box if any other boxes are checked]" and skip to HH6.

CONCLUSION OF BASELINE SURVEY

II1. **This concludes our survey. Thanks for participating.** [INTERVIEWER: If you are ready to end this part of the survey click "Yes" and then save the data] (Choose one)

1	Yes
7	Don't Know
8	Refuse to Answer
9	Not Applicable

APPENDIX C: IN-DEPTH INTERVIEW & FOCUS GROUP GUIDE

The AFFIRM Study *(formerly Partners in Care)*

In-depth/Focus Group Interview Guide: Persons Living with HIV/AIDs (PLHAs)

[Note: The participant will have just completed the informed consent process. This intro can be used to summarize before the interview session begins.]

Thank you for participating in our study. We're interested to learn about your health and your opinions about how HIV has affected you and other people in your community -- including those living with serious chronic conditions. We'd like to learn about your experiences with the people who offer you support with your health and well-being. And we're also interested in the types of information & resources that may make it easier for people with HIV to get the help & support they need.

There are no right or wrong answers to these questions and all information is kept confidential. Do you have any questions for me before we start?

As we begin, I'd like to learn a little more about you. Can you please start by telling me when you found out you were HIV positive?

1. How has your life changed since you were diagnosed with HIV?
    a. How has it changed for others you know who have also been diagnosed with HIV?

2. How has HIV affected your family, and community?

3. Have you needed to rely on others for help and support?
    a. Who are these people who have helped you?

4. How has your health changed over time since your diagnosis?
    a. How have these changes affected your relationships <u>with family and friends</u>?
    b. ... <u>with your caregiver</u>?

5. Can you tell me how your HIV affects you on an average day?
    a. What kind of symptoms do you experience (e.g. pain)?
    b. How does it impact your relationships with others (e.g. family, caregivers)?

6. What have your interactions with medical providers been like since you were diagnosed with HIV?
    a. In what ways are your <u>medical needs being met</u>?
    b. ...<u>medical needs *not* being met</u>?

7. Right now, what is your greatest wish for your health? ...and in the future?

Thank you for all of your responses so far. As we discussed earlier, we are interested in your experiences as someone living with HIV. We are also interested in how the health care needs of people with HIV change as they get older. And, we are interested in any health care decision making that you have done with family members or trusted supportive people in your life.

8. Can you please describe your typical HIV care medical visit?

9. Have you included others in your health care decisions?
   a. Who are they, and how have you included them?

10. What have doctors shared with you about the health care needs of people with HIV as they get older?

11. Have you found information on your own about living with HIV and getting older?
    a. What information would you want to know about the needs of people with HIV as they age?

12. Have you heard about palliative care? (or heard of advance directive)
    Palliative care is a term used to describe medical care that helps improve the quality of life of patients and their families, and to assist patients and family to make treatment decisions with their health providers. This can include relieving pain and other symptoms for people living with chronic conditions.

    a. What have you heard? Who shared this information with you?

13. Have you heard of Maryland MOLST?
    "MOLST" stands for Medical Orders for Life-Sustaining Treatment. This is a form which all Maryland hospitals are required to complete for patients at discharge to a care facility (since 7/1/2013). This is a medical order that lets a patient indicate heath care preferences in extreme situations.
    a. What have you heard?
    b. Have you thought about your care preferences?
    c. Have you heard of advance directives?
    d. Who (family/caregiver) knows what your care preferences are?

14. What would make it difficult to talk to your family about planning?
    a. What would help you and your family talk about MOLST care?
    b. ....to talk about advance directives?

Do you have any other questions for me? Thank you very much for your time.

End of interview

APPENDIX D: REVISED IN-DEPTH INTERVIEW GUIDE

The AFFIRM Study *(formerly Partners in Care)*

In-depth Interview Guide: Index Participants
Version 2

[Note: The participant will have just completed the informed consent process. This intro can be used to summarize before the interview session begins.]

Thank you for participating in our study. We're interested to learn about your health and your opinions about health issues such as chronic pain management, going to the health clinic for HIV and other healthcare, and getting the support you need as someone who is living with HIV. And we're also interested in your suggestions to improve care and communications with healthcare providers and other people in your life who provide you care and support.
There are no right or wrong answers to these questions and all information is kept confidential. Do you have any questions for me before we start?

If you don't mind, I would like to audio record this section. Can I turn on the recorder now?

[TURN ON RECORDING DEVICE]

Thank you. I have turned on the recorder now. In case you would like me to stop recording, I am happy to turn it off at any time during the interview.

As we begin, I'd like to learn a little more about you. Can you please let me know how long you have been living with HIV? [Mark on a timeline on paper]

Pain History

1. Have you experienced any pain problems in your body? Can you tell me more about it? *(Probe about current and past experiences with long term pain)*
    1) Where in your body are you experiencing pain right now? If not now, where do you usually experience pain?
    2) When did the pain first start/ how long have you had the pain? [Mark on timeline]
    3) Could you describe the frequency *(probe: constant vs. on and off pain)* and severity *(probe: rate severity on 0-10 scale)* of the pain? How often do you have pain flairs?
    4) How does the chronic pain affect your daily life, in terms of activities and relations with family and friends?
    5) What do you think caused the pain (for the most severe place or form of pain)?

    6) Could you tell me any diagnoses your doctor has given you about your pain?

Help Seeking Behavior

1. What do you usually do when you have pain flairs/ bad pain? How do you usually manage your pain?
    1) Have you tried any medication for your pain? What were the experiences like?
    2) What are the other treatments that you've tried? Could you tell me more about your experiences with the treatments? What's been most helpful for managing pain?
    3) What else have you tried that's been helpful?
    4) Where have you gone when you had pain problems?
    5) Have you been to emergency departments for treatment for your chronic pain? *(Probe about circumstances and nature of pain to make sure that it was related to chronic pain and not acute pain)*
       What were your experiences with ER doctors? Did you get what you needed? If not, tell me more about what happened.
       (Probe: who denied and how)

2. Thinking about your main health care provider (your primary care physician or your HIV doctor).
    1) Where do you get care from? How long have you been seeing this provider? [Mark on timeline] Tell me about your relationship with this provider?
    2) How often do you and your doctor talk about your pain? When it's brought up at medical visits, who brings it up?
       (Probe: Is the provider the one who actively manage this? Do feel like they need to bring this up?)
    3) How did the communication go when you and your provider talked about managing your pain?
    4) How well did your provider listen to your needs in managing pain? How well did they explain the options for managing chronic pain to you?
    5) Have you ever had disagreement with your provider about how to manage your pain? Could you describe what happened?
       (Probe: How was the disagreement handled? What made it hard to communicate with your provider? Have you ever switched doctors because you were not satisfied with the way your doctor managed your pain?)
       In your understanding, what might be your provider's considerations?
    6) What would be the ideal way to manage your pain (from your main provider or others)? How do you wish your pain had been addressed? How do you think your pain management could have been improved?

    7) What are some treatments, such as medications or other therapy, that you think could be helpful to you now but you are not getting, and would like to get from a provider?
       (Probe about type and amount of treatment, dosage)
    8) In your opinion, what made it hard for you to get the pain treatment that you think would be helpful?

3. Now I would like you to think about your experiences with any healthcare providers.
4. Have you been treated differently by any healthcare providers because of your skin color?
    1) Have you ever felt that you were treated unfairly because you were in pain?
    2) Do you think having HIV or having used drugs also affected how you were treated?
    3) Have you ever felt that you were treated with disrespect by any healthcare providers for other reasons, such as the way you speak?

    For each experience mentioned:

    4) Could you tell me more about the experience (probe: when/ where/ how)
    5) How have these experiences affected your relationship with the doctor you have now? If your doctor is aware of the situation, what have they done to help?

5. Thinking about the main person in your life (the person who gives you most support).
    1) Does the person have chronic pain themselves? What kind of pain do they have? Do they have diagnoses?
    2) How do they manage their pain?
    3) Do they also have HIV?

6. Would you be interested in participating in a pilot program for pain management?
    1) Would you want to do it alone or with someone in your life? Who? Do you think they would be interested in doing it with you?

Drug Use History

A lot of people have used medications or other drugs at one time or another. I would like to know about your experiences with drugs.

1. Has there ever been a time when you used heroin or prescription opioids (OxyContin, Vicodin, etc.)?
    1) Have you ever used heroin daily?
    2) How long and when did you use heroin? [Mark on timeline]

    3) Could you tell me about your use of prescription opioids? (Probe: when, what, for how long, dosage and frequency, source, purpose)

2. Have you ever been in a methadone program/ on methadone or suboxone (and for how long)?
3. Have you ever had (another) drug habit? What was your drug of choice? Can you tell me about that experience?
4. How has your use of drugs affected your pain symptoms?

Is there anything else about your pain or pain management, and experiences with healthcare providers that you’d like to share?

Is there anything else that you would like to say?

Do you have any other questions for me? Thank you very much for your time.

End of interview

CURRICULUM VITAE

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EDUCATION

Johns Hopkins University, Bloomberg School of Public Health, Baltimore, MD
PhD in Health, Behavior and Society, expected 2022
Dissertation: Challenges to patient-provider relationships and managing chronic pain of African Americans with HIV and a history of drug use in Baltimore

New York University, Graduate School of Arts and Science, New York, NY
Master of Arts in Psychology, 2008
Thesis: Residential satisfaction, participation in neighborhood activities and quality of life among people with histories of homelessness

National Taiwan University, College of Life Science, Taipei, Taiwan
Bachelor of Science in Life Science, 2005

PUBLIC HEALTH EXPERIENCE

Research

Johns Hopkins Center for Communication Programs (JHCCP), Baltimore, MD
Data Analyst, Aug 2020- Present

- Managed datasets from two large-scale, repeated cross-sectional global surveys: the COVID-19 Beliefs, Behaviors, & Norms Survey and the COVID-19 Trends and Impact Survey.
- Participated in the design, development, and data process for the JHCCP's KAP COVID Dashboard and the COVID Behaviors Dashboard.
- Assisted in the preparation of manuscripts and reports for WHO, World Bank, USAID, and local governments to support COVID response.
- Presented KAP COVID findings at American University of Beirut's Communication for Development workshop for Lebanon's UNICEF's roving team of field officers, ministries counterparts and partners.

The Lighthouse Studies at Peer Point, Johns Hopkins School of Public Health, Baltimore, MD
Graduate Research Assistant, Sep 2015- Present

- Analyzed longitudinal surveys including network data of the AFFIRM Care study (2014-19), which examines social environmental factors associated with health outcomes and well-being among socio-economically disadvantaged PLHIV (people living with HIV) in HIV care at Johns Hopkins and their informal caregivers; assisted in focus group guide development and data collection.
- Analyzed cross-sectional data of the TIDE (Tobacco Use in Drug Environment) study to understand the economic, social and cultural context of tobacco use among a low-income, urban population.

Institute for Global Tobacco Control, Johns Hopkins School of Public Health, Baltimore, MD
Graduate Research Assistant, Oct 2017- Jan 2018

- Assisted in the design of health messages, in-depth interview guide and survey for a large-scale study on cigarette health warning labels in China.
- Participated in formative in-depth interview data collection with smokers in China.
- Trained field data collectors in three Chinese cities (Beijing, Shanghai, Shenzhen).

NYU School of Medicine, Department of Population Health, New York, NY
Senior Research Coordinator, Oct 2011- Aug 2015

- Managed several intervention studies including a double-blind randomized controlled trial using electronic cigarettes as a harm reduction strategy, and a NIDA funded study utilizing text messages and phone counseling sessions to improve adherence to smoking cessation medication among PLHIV.
- Coordinated a provider intervention study using a web-based decision support system to help dentists treat tobacco use.
- Designed and utilized REDCap (Research Electronic Data Capture) and Velos eResearch databases to manage participant's study visits and to collect research data.
- Collected data and modified survey design in ACASI (Audio Computer-Assisted Self-Interview Software).
- Analyzed quantitative and qualitative data.
- Oversaw research activities to assure protocol and IRB compliance.
- Supervised interns from MPH/ MD/ DDS programs, as well as junior research assistants and data associates.

NYU College of Dentistry, Department of Cariology and Comprehensive Care, New York, NY
Junior Research Scientist, Mar 2010- Oct 2011; *Consultant*, Dec 2008- Feb 2010

- Analyzed longitudinal EMR (electronic medical record) data from community- based health care settings using multivariate analysis to assess predictors of blood pressure control among people with hypertension.
- Evaluated a community-to-clinic referral model that aims to increase access to oral health prevention and treatment services among older adults; assisted with oral health screening outreach events; conducted data collection and analyses.
- Recruited study participants from a number of homeless shelters/ program sites to a smoking cessation intervention; collected survey data and assisted in quality assurance for group therapy intervention; created and maintained a long term participant tracking database in MS Access; achieved a high (88%) post-intervention follow-up rate using an intensive follow-up protocol.
- Designed and conducted post-intervention qualitative interviews with study subjects and participating providers/ key informants; coded and analyzed interview transcripts using Atlas.ti and MAXQDA.
- Assisted in manuscript preparation, IRB application and grant writing.

Partnership for the Homeless, New York, NY
Research Associate, Feb 2009- Feb 2010; *Research Assistant*, Sep 2007- Feb 2009

- Worked with a database technician to develop, implement, and maintain an electronic case management and research records system for several service sites.
- Performed housing and community integration studies with a special emphasis on homeless individuals who are also suffering from other life crisis, such as homeless HIV patients and homeless families led by single moms who were victims of domestic violence; recruited and interviewed over 200 currently or previously homeless individuals.
- Coded, entered, and analyzed quantitative data using SPSS; interpreted results; wrote literature reviews and organizational/ academic reports.
- Mentored research interviewers and undergraduate-/ graduate-level interns.
- Assisted with organizational reform to emphasize the research and client advocacy components of the service delivery program.

Pathways to Housing, New York, NY
Intern, Feb 2007- May 2007

- Interviewed individuals with homeless histories and with mental disorders who were receiving services at one of the nation's first Housing First programs; entered and analyzed survey data.

Teaching Assistant

Johns Hopkins School of Public Health, Department of Health, Behavior, and Society, Baltimore, MD
Course title: Leadership in Tobacco Control, Oct 2019- Dec 2020

Johns Hopkins School of Public Health, Department of Health, Behavior, and Society, Baltimore, MD

Course title: Health and Homelessness, Jan 2017- Mar 2019

Johns Hopkins School of Public Health, Department of Health, Behavior, and Society, Baltimore, MD
Course title: Fundamentals of Health, Behavior and Society, Aug 2016 - Oct 2016

PUBLICATIONS

Peer-Reviewed Article

- Guttentag A, **Tseng TY**, Shelley D, Kirchner T. Analyzing trajectories of acute cigarette reduction post-introduction of an e-cigarette using ecological momentary assessment data. *Journal of Nicotine and Tobacco Research*. (under review)
- Mitchell M, **Tseng TY**, Cruz-Oliver D, Hansen E, Catanzarite Z, Knowlton A. Family conflict and HIV disclosure associated with ART adherence in a disadvantaged population living with HIV. *AIDS Care.* (under review)
- Olapeju B, Hendrickson ZM, Rosen JG, Shattuck D, Storey JD, Krenn S, Shaivitz M, Serlemitsos E, **Tseng TY**, Tsang SW, Rimal RN, Babalola S. Trends in handwashing behaviours for COVID-19 prevention: Longitudinal evidence from online surveys in 10 sub-Saharan African countries. (2021). *PLOS Global Public Health.* Published online: November 12, 2021. https://doi.org/10.1371/journal.pgph.0000049
- Mitchell M, Hansen E, **Tseng TY**, Shen M, Catanzarite Z, Cruz-Oliver D, Parker L, Knowlton A. (2021). Care Giving Role Strain in Caring for Vulnerable Persons Living with HIV: Correlates of Caregiver and Care Recipient Reports. *AIDS Care, 1-7.*
- Davey-Rothwell MA, Crossnohere N, Hammond O, **Tseng T**, Whittington M, Tobin K, Latkin C, and Knowlton A. (2021). Exploring the role of sex differences in the relationship between sex partner attitudes and current quit attempt among a sample of smokers. *Tobacco Prevention and Cessation,* 7.
- Knowlton AR, Nguyen TQ, Catanzarite Z, Maragh-Bass A, Isenberg S, **Tseng TY**, Mitchell MM, Cruz-Oliver D. (2021). Quality of life among caregivers of a vulnerable population living with HIV/AIDS Caregiving and relationship factors. *AIDS and Behavior,* 25(2), 360-376.
- Crossnohere NL, Davey-Rothwell M, Latkin C, Czaplicki L, **Tseng T**, Knowlton A. (2020). The interaction of smoking cessation norms and nicotine dependence on quit attempts: gender-stratified results for low-income smokers in Baltimore, MD. *Substance Use and Misuse,* 55(3), 424-428.
- Cruz-Oliver DM, **Tseng TY,** Mitchell MM, Catanzarite Z, Budhathoki C, Smith TJ, Rushton C, Knowlton A. (2019). Support network factors associated with naming a health care decision-maker and talking about advance care planning among people living with human immunodeficiency virus. *Journal of Pain and Symptom Management,* 58(6), 1040-1047.
- Mitchell MM, Hansen ED, **Tseng TY**, Shen M, Rushton C, Smith T, ... & Wissow L. (2018). Correlates of patterns of health values of African Americans living with HIV/AIDS: implications for advance care planning and HIV palliative care. *Journal of Pain and Symptom Management*, 56(1), 53-62.
- Latkin CA, **Tseng TY**, Davey-Rothwell M, Kennedy RD, Moran MB, Czaplicki L, ... & Knowlton AR. (2017). The relationship between neighborhood disorder, social networks, and indoor cigarette smoking among impoverished inner-city residents. *Journal of Urban Health*, 94(4), 534-541.
- **Tseng TY,** Ostroff JS, Campo A, Gerard M, Kirchner T, Rotrosen J, Shelley D. (2016). A randomized trial comparing the effect of nicotine versus placebo electronic cigarettes on smoking reduction among young adult smokers. *Nicotine & Tobacco Research*, 18(10), 1937-1943.

- **Tseng TY,** Krebs P, Schoenthaler A, Wong S., Sherman S, Gonzalez M, Urbina A, Cleland CM, Shelley D. (2016). Combining text messaging and telephone counseling to increase varenicline adherence and smoking abstinence among cigarette smokers living with HIV: a randomized controlled study. *AIDS and Behavior*,1-11.
- Shelley D, **Tseng TY**, Gonzalez M, Krebs P, Wong S, Furberg R, Sherman S, Schoenthaler A, Urbnia A, Cleland C. (2015). Correlates of adherence to varenicline among HIV+ smokers. *Nicotine & Tobacco Research,* 17(8):968-974.
- Krebs P, **Tseng TY**, Pham H, Wong S, Sherman S, Furberg R, Wolfe H, Shelley D. (2015). Formative evaluation of a text messaging intervention to promote varenicline adherence among tobacco-dependent persons with HIV. *Journal of Health Communication*, 20(9):1021-1025.
- Montini T, **Tseng TY**, Patel H, Shelley D. (2014). Barriers to dental services for older adults. *American Journal of Health Behavior*, 38(5):781-788.
- Shelley D, **Tseng TY**, Pham, H, Nguyen L, Keithly S, Stillman F, Nguyen N. (2014). Factors influencing tobacco use treatment patterns among Vietnamese health care providers working in community health centers. *BMC Public Health*, 14(1):68-68
- Shelley D, **Tseng TY**, Matthews A, Wu D, Ferrari P, Cohen A, Millary M, Kopal H. (2011). Technology-driven intervention to improve hypertension outcomes in community health centers. *American Journal of Managed Care*, Dec;17(12 Spec No.):SP103-SP110
- Millery M, Shelley D, Wu D, Ferrari P, **Tseng TY**, Kopal H. (2011). Qualitative evaluation to explain success of multifaceted technology-driven hypertension intervention. *American Journal of Managed Care,* 17(Special issue):SP95-SP102
- Shelley D, **Tseng TY**, Andrews H, Ravenell J, Wu D, Ferrari P, Cohen A, Millery M, Kopal H. (2011). Predictors of blood pressure control among hypertensives in community health centers. *American Journal of Hypertension,* Dec;24(12):1318-1323
- Shelley D, Anno J, **Tseng TY**, Calip G, Wedeles J, Lloyd M, Wolff M. (2011). Implementing tobacco use treatment guidelines in public health dental clinics in NYC. *Journal of Dental Education,* Apr;75(4):527-33

Professional Report

- **Tseng TY**, Babalola S, Krenn S, Rimal RN, Rosen G, Serlemitsos E, Shaivitz M, Shattuck D, Storey JD, Tsang S. (2021). *COVID-19 risk perceptions, Behaviors, and vaccine hesitancy among youth in the WHO Western Pacific Region: comparisons across countries, over time, and between men and women.* WHO.

Website & Dashboard

- Babalola, S, Krenn, S, Rosen, JG, Serlemitsos, E, Shaivitz, M, Storey, D, Tsang, S, **Tseng, TY**, Shattuck, D. *COVID Behaviors Dashboard.* Johns Hopkins Center for Communication Programs in collaboration with Facebook Data for Good, Delphi Group at Carnegie Mellon University, University of Maryland Social Data Science Center, Global Outbreak Alert and Response Network. Published September 2021. https://covidbehaviors.org
- Lu TY & **Tseng TY.** *新冠肺炎（COVID-19）接觸史調查員訓練繁體中文資源 COVID-19 Contact Tracer Chinese Training Resources – Adapted from Coursera: COVID-19 Contact Tracing.* Published May 2021. http://covid-19-contact-tracing-zhtw.info/

Media Appearance

- Lu TY & **Tseng TY.** (2021, May 30). *台灣防疫的下一步：疫調能量的提升刻不容緩｜「接觸史調查員訓練課程」中文化簡介與說明。Taiwan's next step in COVID-19 prevention: the urgent need for contract* *tracing capacity expansion | An introduction of the online training course "COVID-19: Contact Tracing" Chinese version and the translation project*. PanSci 泛科學. https://pansci.asia/archives/322373.

CONFERENCE PRESENTATION

- Guttentag A, **Tseng TY**, Shelley D, Kirchner T. (2021). Association of day-level volatility in cigarette and e-cigarette use on 50% smoking reduction amongst adult smokers enrolled in a reduction challenge trial. Poster presentation at the 27th SRNT (Society for Research on Nicotine and Tobacco) Annual Meeting, Virtual.
- **Tseng TY,** Chander G, Winiker A, Knowlton A. (2020). Clinician perspectives on challenges managing chronic pain of persons with HIV who use drugs: A qualitative study. Poster presentation at the 148th APHA (American Public Health Association) Annual Meeting, Virtual.
- **Tseng TY,** Mitchell M, Beach MC, Chander G, Knowlton A. (2020). Patient-centered, patient-provider engagement as mediator of effects of healthcare discrimination, depression and pain on later pain-related outcomes and quality-of-life among African Americans with HIV who use drugs. Oral poster presentation at the 23rd International AIDS Conference, Virtual.
- Guttentag A, **Tseng TY**, Shelley D, Kirchner T. (2019). Trajectories of Switching from Cigarettes to E-Cigarettes amongst Adult Smokers in New York City. Poster presentation at the 11th International Conference on Epidemiology & Public Health, Copenhagen, Denmark.
- Hardesty J, Cohen J, Peng J, **Tseng TY,** Kennedy RD. (2018). Household rules for smoking in Chinese Homes: a cross-sectional survey highlighting the need for educational interventions. Oral presentation at the 12th APACT (Asia Pacific Conference on Tobacco or Health), Bali, Indonesia.
- Hardesty J, Cohen J, Peng J, **Tseng TY,** Kennedy RD. (2018). Pictorial cigarette health warning labels in China: effective messages for future policy. Oral presentation at the 12th APACT (Asia Pacific Conference on Tobacco or Health), Bali, Indonesia.
- Hardesty J, Cohen J, Peng J, **Tseng TY,** Kennedy RD. (2018). Cigarette health warning labels with anti-gift giving messages: an experimental cross-sectional survey in China. Poster presentation at the 12th APACT (Asia Pacific Conference on Tobacco or Health), Bali, Indonesia.
- **Tseng TY,** Mitchell M, Knowlton A. (2017). Perceived discrimination, pain, and drug misuse for pain in association with restricted access to pain treatment among disadvantaged African American PLHIV. Oral presentation at the 145th APHA (American Public Health Association) Annual Meeting, Atlanta, GA.
- Mitchell M, **Tseng TY,** Knowlton A. (2017). Family communication and HIV disclosure predicting art adherence among a vulnerable population living with HIV/AIDS. Oral presentation at the 38th Society of Behavioral Medicine Annual Meeting, San Diego, CA.
- **Tseng TY,** Czaplicki L, Kennedy RD, Davey-Rothwell M, Latkin C, Knowlton A. (2016). The Chemosensory appeal of menthol cigarettes among low-income population of African Americans. Poster presentation at NIH TRSC (National Institutes of Health Tobacco Regulatory Science Conference), Bethesda, MD.
- **Tseng TY,** Czaplicki L, Davey-Rothwell M, Latkin C, Kennedy RD, Knowlton A. (2016). Home smoking rules among low income, African American smokers in Baltimore City. Poster presentation at the 22nd SRNT (Society for Research on Nicotine and Tobacco) Annual Meeting, Chicago, IL.
- Czaplicki L, Kennedy RD, Davey-Rothwell M, **Tseng TY,** Latkin C, Knowlton A. (2016). Measuring nicotine dependence among a population of low-income menthol cigarette smokers in Baltimore City. Poster presentation at the 22nd SRNT (Society for Research on Nicotine and Tobacco) Annual Meeting, Chicago, IL.

- Shelley D, Krebs P, Schoenthaler A, Urbina A, Gonzales M, **Tseng TY**, Cleland C. (2015). Correlates of adherence to varenicline among HIV+ smokers. Oral presentation at the 21st SRNT (Society for Research on Nicotine and Tobacco) Annual Meeting, Philadelphia, PA.
- Krebs P, **Tseng TY**, Pham H, Wong S, Wright D, Wolfe H, Shelley D. (2013). Formative evaluation of a text messaging intervention to promote cessation medication adherence among tobacco-dependent persons with HIV. Poster presented at the 141st APHA (American Public Health Association) Annual Meeting, Boston, MA.
- Shelley D, **Tseng TY**, Pham H, Hager M, Eisenberg E. (2013). Usage of a web-based clinical decision support system for tobacco cessation counseling. Oral presentation at the 141st APHA (American Public Health Association) Annual Meeting, Boston, MA.
- Shelley D, Jannat-Khah D, Pham H, Hager M, **Tseng TY**, Eisenberg E. (2013). Dental provider experiences using a web-based clinical decision support system for tobacco use treatment. Oral presentation at 141st APHA (American Public Health Association) Annual Meeting, Boston, MA.
- Shelley D, **Tseng TY**, Jannat-Khah D, Hager M. (2012). Web-based Clinical Decision Support to Improve the Quality of Tobacco Use Treatment in Dental Clinics. Poster presented at mHealth Summit, Washington, D.C.
- **Tseng TY**, Gulcur L**.** (2010). The Impact of Self Esteem, Perceived Choice in Housing, and Building Quality on the Quality of Life of Individuals with Histories of Homelessness. Poster presented at EPA (Eastern Psychological Association) Annual Meeting, Brooklyn, NY.
- Gulcur L, **Tseng TY**. (2009). Impact of housing and service use on the well-being and community integration of homeless individuals with and without mental illness. Oral presentation at the 137th APHA (American Public Health Association) Annual Meeting, Philadelphia, PA.
- Chang NA, **Tseng TY**, Tang A, Serper MR. (2007). Predictors of symptom severity in Chinese-American inpatients with schizophrenia. Poster presented at the 41st Annual ABCT (Association for Behavioral and Cognitive Therapies) Convention, Philadelphia, PA.

SERVICE

Committees & Appointments

Johns Hopkins Suicide Prevention Awareness, Response and Coordination, Baltimore, MD
Student Advisory Board Member, Mar 2019- Sep 2019

- Worked closely with the Johns Hopkins Counseling Center executive director, School of Public Health faculty, and a licensed clinical social worker to inform a university-wide mental health campaign with a focus on suicide prevention.

Abstract Mentor for AIDS 2022, the 24th International AIDS Conference, the International AIDS Society

Manuscript Reviewer for American Journal of Public Health, AIDS and Behavior, the American Journal of Pharmacy Benefits, the American Journal of Managed Care, Journal of Dental Education.

Abstract Reviewer for American Public Health Association (APHA) Annual Meeting & Expo, Society for Research on Nicotine and Tobacco (SRNT) Annual Meeting.

Other Volunteer Activities

Bellevue Program for Survivors of Torture, New York, NY
Volunteer Interpreter, Nov 2008- Feb 2009

- Interpreted between a clinical psychologist and a Mandarin-speaking patient during therapy sessions.

NYU Medical Center, Department of Psychiatry, New York, NY
Research Assistant to Dr. Nadine Chang, Feb 2007- Jun 2007

- Interviewed schizophrenic patients on acute inpatient psychiatric ward at Bellevue Hospital.
- Interpreted between a clinical psychologist and Mandarin-speaking patients; coded and entered diagnostic/ research data.

AWARDS

- Vice Provost's Dissertation Completion Award, Johns Hopkins University, 2021
- Dean's PhD Tuition Scholarship, Johns Hopkins Bloomberg School of Public Health, 2020
- Doctoral Distinguished Research Award, Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health, 2018-2019, 2019-2020
- Dissertation Enhancement Award, Center for Qualitative Studies in Health and Medicine, Johns Hopkins Bloomberg School of Public Health 2018-2019
- Taiwan Government Scholarship to Study Abroad 2017-2019

SKILLS

- Data analysis software: Stata, Mplus, R, SAS, SPSS, Atlas.ti, MAXQDA
- Data collection and management application: REDCap (Research Electronic Data Capture), Velos eResearch
- Language: native in Mandarin Chinese