

“Ooh, You Got to Holler Sometime”

Pain Meaning and Experiences of Black Older Adults

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Abstract

Throughout the history of the United States, the Black pain experience has been widely ignored and diminished, by media, medicine, and science. Convergent evidence demonstrates that Black adults shoulder a disproportionate burden of chronic pain and related disability. A structural racism lens shows how conditions such as residential segregation, economic deprivation, experiences of discrimination, and inferior access to high-quality medical care contribute to persistent pain in Black adults, worsen its impact, and impede its effective management. In addition to the negative physical consequences of daily pain, the emotional, social, and spiritual distress caused by unmet pain needs can significantly diminish quality of life. These factors collectively contribute to complex pain meanings that center around dependence and defeat and are countered through social engagement, spiritual coping, and meaningful activity. Consequently, despite reporting moderate to severe daily pain and an increased frequency of catastrophizing—that is, negative emotional responses to pain and perceived exaggeration—Black older adults often report high levels of adaptive coping as evidenced by continued engagement in activities. The following chapter examines the meaning of pain for Black older adults both within and outside of the medical establishment, and in the context of implicit racial bias. The authors examine challenges of effective assessment and treatment, and identify strategies Black older adults engage in to effectively cope with pain and prevent what many fear—becoming dependent on others. Finally, we highlight the need for culturally responsive pain management interventions to effectively address the complex meanings ascribed to pain by Black

older adults, including the need for accessible care that is developed in close collaboration with community members to build on existing strengths and resources.

Clinical Implication:

Culturally responsive care is critical for optimal pain management. This self-reflective practice recognizes the role of bias in care delivery and urges clinicians to empower diverse patients to acknowledge important values, beliefs, and practices related to pain management, and integrate them as appropriate into their treatment plans.

I have pain in my leg. I put it to be arthritis. It hurt, but I try to work it over, and I take aspirins. Then [I] have a lot of cramps and it is so painful. Ooh, you got to holler sometime. It takes awhile to go away, and when it grabs you, it holds you. All you can do is just walk and scream before it go away. It goes away, but then that's painful. ~ Jane⁴

Pain and the Black Older Adult

Living with persistent daily pain is the norm for approximately 2.6 million Black older adults in the United States (Molton and Terrill, 2014; Dahlhamer, Zelaya, et al., 2018). As a multidimensional stressor, pain can affect every facet of a person's life from their ability to earn an income, socialize with others as they would like, or even to manage basic care for themselves. For many, managing chronic pain also means managing depression, anxiety, social isolation, grief, and long-term disability (American Geriatrics Society, 2009; Evans et al., 2019; Fine 2011; Sofaer et al., 2005). This constant physical and psychological distress can be spiritually demoralizing and lead to suffering, or a state of altered perception characterized predominately by a sense of defeat and lack of purpose (del Giglio, 2020). However, despite being particularly at risk for despair and poor quality of life as a result of persistent pain, Black older adults are resilient. Many remain actively engaged within their communities in a variety of ways, including maintaining volunteer roles and caregiving responsibilities (Robinson-Lane, 2020). As one research participant living with chronic headaches and arthritic joint pain

⁴All participant names have been changed to protect anonymity (Robinson-Lane, 2015).

noted, “Like my grandmother said, ‘You ain’t old until you’re cold.’ You keep on living, to the best of your ability” (Robinson-Lane, 2015). However, living as a Black older adult in the US to the best of one’s ability is perhaps easier said than done.

Black or African American persons represent 13.4 percent of the US population and 11 percent of adults aged 65 and older (U.S. Census Bureau, 2020).

Predominantly the descendants of enslaved persons with ancestral roots in Africa, Black adults have a shared history of forced acculturation and racial oppression that distinguishes this group from other cultural groups and influences their behavior, values, lifestyles, and creative expressions (Palmer, 2006). Prior to the US Civil War, medical experimentation (sans anesthesia) on enslaved persons was the norm. In part, this treatment was related to false beliefs about Black persons having, thicker skin and decreased pain perception. John Brown, an abolitionist (formerly known as Fed) who escaped slavery to England, recounted being experimented upon by famed physician Thomas Hamilton:

...[Hamilton] set to work to ascertain how deep my black skin went. This he did by applying blisters to my hands, legs and feet, which bear the scars to this day. He continued until he drew up the dark skin from between the upper and the under one. He used to blister me at intervals of about two weeks. He also tried other experiments upon me, which I cannot dwell upon. Altogether, and from first to last, I was in his hands,

*under treatment, for about nine months, at the end of which period I had become so weak, that I as no longer able to work in the fields.*⁵

In the book *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (Washington, 2006), neurosurgeon Harry Bailey notes during a 1960s medical school talk, “[It was] cheaper to use N___ than cats because they were everywhere and cheap experimental animals.” This de-personification of Black individuals was a primary justification for slavery and arguably has been maintained through today, particularly within pain management practice, where false beliefs about biological differences between races persist and Black adults continue to receive inequitable pain treatment, often having totreat and or advocate for themselves in order to achieve any measurable relief (Hoffman et al., 2016, Meghani et al., 2012, Mack et al 2018, Robinson-Lane & Vallerand, 2018, Booker et al., 2019, Washington, 2006).

Through 1968, Jim Crow laws legalized racial segregation and prevented equitable access to healthcare services based on skin color. Hence, all Black adults over the age of 65 who were born and raised in the United States have lived through a period of lawful racial discrimination in health care. Though no longer legal, the effects of structural racism in the healthcare system have persisted, and many older Black adults have accumulated a lifetime of experiences with discriminatory and often inferior care, including for pain treatment, as noted above. Yet the pernicious effects of

⁵ Brown, 1855 p. 47-48

structural racism also affect the experience and meaning of pain itself, as described in the next section.

Structural Racism as a Context to Black Pain Experiences

Structural racism, also called systemic racism, is a systemic and institutional problem that reinforces policies and practices that perpetuate racial inequity. It encompasses a number of dimensions; e.g., a dominant racial hierarchy, comprehensive White racial framing, and individual and collective discrimination (Feagin & Bennefield, 2014). In the United States, structural racism has yielded laws, policies, and practices, both historical and present-day, which disadvantage and marginalize Black Americans. Manifestations of structural racism include, but are not limited to: residential segregation, economic and educational deprivation, toxic physical environments, and sustained psychosocial stress stemming from all of the above, as well as experiences of individual-level discrimination (Bailey et al., 2017).

Unsurprisingly, when evaluated through systematic review, racism has been found to be persistently associated with negative health outcomes including depression, anxiety, post-traumatic stress disorder (PTSD) and poor overall health (Paradies et al., 2015).- Compounding the health effects of the systemic racism that Black Americans confront in everyday life is the persistence of deep-rooted racism in medical care and public health institutions (Feagin & Bennefield, 2014).

Feagin and Bennefield argue that most health and medical institutions retain a “White frame”, and they cite evidence of ongoing differential treatment and implicit bias,

or attitudes and behaviors based on stereotypes or beliefs a person has that they are not consciously aware of. Preferential healthcare access, delivery, diagnoses, and treatment for White adults has been maintained at varying degrees and has contributed to large disparities in health outcomes between Black and White older adults. As a result, Black adults have suffered from disproportionate levels of disease and death. For instance, the average life expectancy for Black adults in the United States is the lowest of every race and ethnic group—71 years for males. This is 13 years younger than the average life expectancy of Latina women, and 5 years younger than White men (Arias and Xu, 2020).

For Black older adults, pain is also an expectation that comes with aging. As Naomi, a former nail salon owner with diabetic neuropathy, degenerative disc disease, and arthritis noted, “Everything that is wrong with you generates pain” (Robinson-Lane, 2015). As much as 80% of the physical pain experienced by older adults is attributed to chronic diseases, such as chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), cancer, osteoarthritis, rheumatoid arthritis, and peripheral neuropathies (Berry & Paice, 2010; Walke et al., 2006; Davis & Srivastava, 2003; Horgas et al., 2012). Among older Black adults, experiences with racial discrimination are also positively associated with bodily pain (Burgess et al., 2009), and this relationship remains after statistically controlling for socioeconomic and health status. Differential healthcare treatment has resulted in mistrust of medical providers by Black adults.

Medical mistrust

The historical racist perception, poor treatment, and overall mismanagement of chronic pain among Black older adults has led to high levels of provider mistrust, reliance on home remedies, use of over-the-counter medications, and spiritual coping for pain management (Robinson-Lane and Vallerand, 2018, Robinson-Lane, 2020, Booker et al., 2019). In discussing why she did not necessarily trust everything prescribed by the doctor, and particularly pain medications, Monica,⁶ a survivor of a pedestrian motor-vehicle accident, noted:

If [the doctor] had results, then they lose money, because they won't be making no money if they heal-- if everybody feel good, they wouldn't have no reason to go back to the doctor. So I think the doctor just pacifies you with their medicines. And they do all right, but there's nothing really working for the important part. ~ Monica⁷

Monica believed that older adults in particular were over-medicated by physicians, and that the medications mostly served to pacify symptoms rather than cure disease or address the root causes of health concerns. Many of the Black older adults that were interviewed in a qualitative study examining pain management experiences (Robinson-Lane, 2015), believed that doctors were most interested in making money or experimenting on patients. As Zora, another participant noted, "...These doctors use people. 'cause these old people in they 70s, 80s, and 90s and stuff like that. And I feel

⁶ Robinson-Lane, 2015.

⁷ Robinson-Lane, 2015.

sorry for them 'cause they use them just to make money off 'em" (Robinson-Lane, 2015).

Mistrust of medical providers began long before the often discussed US government sponsored Tuskegee Study which took place from 1932 to 1972 (Gray, 2003). Here, Black research participants who had community-acquired syphilis were prevented from receiving penicillin, an effective syphilis treatment, and instead allowed to experience significant disease-related complications, including death, so researchers could study the long-term effects of untreated syphilis. One of the "benefits" of study participation, as promoted by the researchers, was free healthcare. This study began only 69 years following the Emancipation Proclamation that freed enslaved people in 1863.

The long history of mistreatment based on skin color that Black Americans have experienced has perhaps led to vastly different conceptualizations of what it means to experience pain and who one may trust for relief. The continued inferior treatment of Black patients by medical providers is amply documented in the literature, as recently comprehensively reviewed by Morales and Yong (2021). Relative to non-Hispanic White persons, across clinical settings, and amongst both cancer and non-cancer pain, Black pain is treated less aggressively. Morales and Yong's review also cites evidence that Black patients are more closely scrutinized for opioid medication misuse. This finding is echoed in qualitative work in which Black pain patients report experiences in which they had to contend with racialized stereotypes about opioid addiction (Kempner, 2017). Racism has undoubtedly shaped the chronic pain experience for Black adults.

Chronic pain dimensions and linkages to structural racism

Racism is regarded as a fundamental cause of adverse physical and mental health outcomes and health inequities (Williams et al, 2019). Correspondingly, racism should be considered a fundamental cause of chronic pain for Black older adults. In contrast to acute pain, chronic pain is a health condition in its own right, with biological, psychological, and social dimensions (Gatchel et al., 2007). These dimensions are each affected by structural racism.

For example, the biological aspects of pain are influenced by Black adults' disproportionate risk of injury, chronic illness and multimorbidity, which are all associated with the presence of persistent pain and pain severity. In writing about ecosocial racism, Krieger (2012) notes that people literally embody stress exposures arising from their societal and ecological context. Psychological factors that generate or exacerbate pain include sustained stress and socially inflicted trauma, such as the experience of racism. Both untreated and undertreated pain exacerbate psychological distress; namely, symptoms of depression and anxiety (Gatchel et al., 2007). Further, and perhaps unsurprisingly, pain catastrophizing, or experiencing heightened feelings of helplessness, repetitive negative thoughts, and a magnification of pain threat value, is prevalent amongst Black adults with chronic pain (Fabian et al., 2011). Social risk factors for pain include disproportionate bereavement (Umberson, 2017), mass incarceration (Brinkley-Rubenstein & Cloud, 2020), and the public health crisis of police violence toward Black Americans (Fleming et al., 2021). All of these factors converge

and exacerbate one another, resulting in a strikingly disproportionate burden of severe and disabling pain (Morales & Yong, 2021).

Further, in considering the overall effects of chronic pain and various “isms” on Black older adults, the concepts of intersectionality and double jeopardy—that is, the consequences of holding simultaneous marginalized identities, such as being Black and older (Bierman & Lee, 2018; Carreon & Noymer, 2011; Crenshaw 1989)—should be considered and may partially explain pain-related disparities that disadvantage older Black adults. Racism, ageism, and sexism experienced by Black older adults are compounding stressors that affect psychological outcomes such as depression (Burgess et al., 2009; Lyons et al., 2018; Thomas et al., 2008), likely contribute to overall psychological distress, and may exacerbate pain.

Spiritual Coping as a Culturally-Mediated Pain Resource

One way of adapting to the reality of an unreliable and biased medical care system is to turn to culturally-mediated resources and self-care practices for pain management. Culture, or learned patterns of behavior, beliefs, and values, are what allow individuals to cope with the problems that arise, particularly health-related problems, over the life course (Robinson-Lane and Booker, 2017). For Black older adults, these culturally-mediated resources and self-care practices include frequent use of complementary and alternative therapies for pain management and engagement of religious coping strategies, such as prayer and meditation. James, a cancer survivor living with severe chronic pain and related disability following a worksite injury, had a daily meditative practice and spoke about his faith as follows:

My faith played an important part—in the healing I believe. Not that I believe; I know my faith carried me through. Because I had resigned myself...Okay here it is. I'm going out this way. I probably would be dead. So I know that there is strength in faith. - James⁸

For many generations, religion has played a central role in Black American culture and communities by facilitating important social connections amongst members and providing meaning and purpose to lives that are often in distress. Within the Christian faith in particular, pain is viewed as an opportunity to draw closer to God and receive eternal salvation. The New International Bible translation notes:

But as for me, afflicted and in pain--may your salvation, God, protect me. I will praise God's name in song and glorify him with thanksgiving. (Psalm 69: 29-30)

For it is commendable if someone bears up under the pain of unjust suffering because they are conscious of God. (1 Peter 2:19)

For I consider that the sufferings of this present time are not worth comparing with the glory that is to be revealed to us. (Romans 8:18).

If we endure, we will also reign with him. (2 Timothy 2:12)

In his book *Man's Search for Meaning*, (2006) Viktor Frankl, a Holocaust survivor, notes that suffering and stress are inevitable parts of the human experience. Frankl argues that the goal is not necessarily to try to have a life that is free from

⁸ Robinson-Lane, 2015.

suffering, but rather to have a freely chosen and worthwhile goal to pursue through the trials that life brings. Although the practice of ancestral religions was forbidden amongst Black enslaved persons in the US and Christianity was an expected part of acculturation, for many Black Americans, religion afforded hope. Religion, and particularly Christianity, offered the opportunity to dedicate one's life to God and good works in this life in exchange for paradise in the next. Unfortunately, these dreams of lands of milk and honey⁹ often become disrupted with despair for persons dealing with intractable pain.

Chronic Pain and Depression

Chronic depression is a common chronic pain comorbidity. The relationship between pain and depression is well documented both in community-dwelling older adults (Baker et al., 2008; Magni et al., 1993; Williamson & Schulz, 1992), and those in institutional facilities (Cohen-Mansfield & Marx, 1993; Parmelee & Lawton, 1991). Depression symptoms can affect the perception of pain, amplify its intensity, and affect the willingness to engage in adaptive pain management practices (Baker et al., 2008; Woo, 2010). A pain-depression loop is then created that exacerbates symptoms of both conditions as one becomes more deeply entrenched in the cycle. In a study by Bierman and Lee, the pain-depression association was noted as being stronger for Black older adults relative to White adults. Further, Black older adults with severe chronic pain experienced significantly higher levels of depressive symptoms than those without pain

⁹ Numbers 14:8.

(Bierman & Lee, 2018). Particularly among older Black women, depressive symptoms have been positively associated with pain intensity (Baker et al., 2008). Current work has demonstrated that despite generally higher levels of reported disability, Black older adults, and particularly women, have lower than expected incidence of depression, anxiety and other measures of poor mental health (Robinson-Lane, 2020; Wyman et al., 2015; Daly et al., 2021). Interestingly, Black women are more likely to be religious as compared to White adults (Mohamed, et al 2021), and therefore are more likely to engage in spiritual coping, which may improve their mental health. A recent study by Dunn and Robinson-Lane (2020) found three themes reported amongst older adults who engaged in spiritual coping practices: 1) enhanced physical, psychological and social well-being; 2) increased resilience; and 3) self-transcendence, or the highest state of growth and development in later life, where individuals develop the capacity to know who they are, find greater meaning in life, and achieve new dimensions of connectedness with others.

Religiosity is generally a prerequisite for spiritual coping. Spiritual coping is the engagement of spiritual rituals or practices based on a person's relationship with God, Transcendent, and/ or others, in order to control and overcome stressful situations, suffering, or illness (Cabaco et al., 2018). Such coping is an important part of the Black religious experience, and can be categorized as either adaptive (positive) or maladaptive (negative). When adaptive spiritual coping is taking place, the individual is able to effectively manage illness-related stress as evidenced by feelings of connectivity to God/ Transcendent, and/or others, and has a positive world view. Maladaptive spiritual coping, on the other hand, is evident by spiritual struggle (Gall & Guirguis-

Younger, 2013). In an older adult sample of mostly Black adults (74%), maladaptive, or negative religious coping was found to be predictive of anxiety, worry, and depression (O'brein et al., 2018). While pain was not measured in that particular sample, a Swedish chronic pain study found that pain interference predicted the use of spiritual coping strategies such as prayer, and that prayer was predictive of depression (Andersson, 2008).

Pain Catastrophizing, Mood, and Coping

It might be surmised then, that when pain is severe enough to significantly impede physical functioning, social engagement, sleep, life enjoyment and other commonly measured areas of pain interference, that adaptive spiritual coping may become more challenging, and that pain catastrophizing is more likely. In general, pain catastrophizing is strongly associated with both pain intensity and pain interference in older adults (Ruscheweyh et al., 2011; Racine et al., 2016). It also contributes to poor pain adjustment (Sullivan et al., 2001). Black adults with severe chronic pain are also more likely to catastrophize than other racial and ethnic groups (Fabian et al., 2011). However, while the concept of "catastrophizing" implies an unwarranted focus and unnecessarily pessimistic view of pain, given the anticipated disability trajectory of Black older adults with chronic pain, perhaps the pain-related fear and threat value inherent in catastrophizing are not unrealistic.

The complex interplay between mood and pain warrant further investigation in Black older adults given the dearth of empirical literature. In non-Black samples,

psychological indicators of distress, such as anxiety and depression, mediate the effect of pain intensity on pain catastrophizing (Dong et al., 2020). Interestingly, Black adults are more likely to respond to pain with depression than anxiety, a finding interpreted as a consequence of the draining, or physically and emotionally exhausting, component of pain (Bierman & Lee, 2018). Indeed, depression may play a more important role in pain intensity (Baker et al., 2008), and the experience of pain for older Black adults, than once believed. However, cultural variances in the expression of depressive symptoms may lead to under-diagnosis.

In a recent study by Robinson-Lane (2020) aimed at understanding the coping strategies used by Black older adults to manage persistent pain, the ability to maintain a positive mindset was noted as a prominent recurrent theme amongst participants. Esther,¹⁰ a research participant and artist with an unspecified chronic health condition that has caused muscle spasms and debilitating pain throughout her life since she was a child, who was also currently managing arthritis and severe carpal tunnel syndrome, spoke frankly about being depressed as a result of pain. When asked about the ways in which pain affected her, she noted:

Depression...I'm just depressed that I can't do the things like I used to do; just get up and go, and come back home and do whatever I've got to do. Now, if I'm having trouble with my joints or whatever, I can't get up and run and do what I have to do and come back.

¹⁰ Robinson-Lane, 2015.

Interestingly, Esther had no medical diagnosis of depression and had previously spoken rather nonchalantly about making adaptations in her artwork to accommodate her increasingly disabled hands. She had moved from working with typical clay to a homemade paper clay that was easier to manipulate. She most often made jewelry that she frequently wore as conversation starters and gave as gifts to new friends. As she considered whether or not pain had deeply affected her as an artist, she noted:

I don't worry about it anymore. At first, it was depressing. Now I find, "I'm 74 years. I've accomplished quite a bit...I've been having pain over three quarters of my life. I don't think there's too much they can do...I've learned to live with it.

Similarly, Abraham,¹¹ another research participant and former carpenter, who was managing persistent back pain and chronic arthritis in both knees, made the revelation that he believed his history of chronic headaches resolved when he stopped worrying all the time. He noted:

I can't remember when I had the last headache. I don't know, I just don't recall having one for so many years, it's unbelievable. I think that's because I just quit worrying about anything, I just say the hell with all of it.

When asked if there was a particular incident that occurred or how he arrived at this worry-free approach to life, he responded:

No, I just decided, whatever it is, it isn't worth it. If I can take care of it I will. If I can't I won't. But I'm not going to worry about it...Nothing

¹¹ Robinson-Lane, 2015.

monumental occurred. It's just that I woke up one morning and I decided I'm not worrying about anything more, or I'm not going to let anything worry me...I haven't since then.

Unsurprisingly, both of these participants identified with religions associated with Christian faith. This worry-free approach to life is supported by Christian belief and scripture:

Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus. (Philippians 4:6-7).

Living with Pain

As one may begin to see, the relationships between pain, disability, and spirituality, are heavily intertwined for many Black older adults. There is a growing body of literature on the experience of chronic pain among Black Americans, including how it is perceived and managed. Booker, Tripp-Reimer & Herr (2020) conducted in-depth interviews with Black adults over age 50 to better understand their experience living with osteoarthritis, and discovered an overarching theme of “bearing the pain”. Bearing the pain comprised three primary actions: adjusting to pain (including accepting osteoarthritis and “not claiming” it; with the latter being a protective mechanism with a spiritual meaning, rather than denial), sharing pain with others (including careful

decision about when and with whom to share), and trusting God as healer. These themes were echoed in qualitative work by Robinson-Lane (2020).

Having persistent pain often means not being able not being able to work and perhaps becoming dependent upon others. Experiencing increasing pain intensity and interference, despite religiosity, may also lead to spiritual suffering. The meaning ascribed to the pain experienced by Black older adults along with their interpretation of that experience may affect psychological and mood outcomes. Factors likely to influence the personal meaning assigned to pain include: (1) the cognitive appraisal of pain; that is, whether the experience of pain is perceived and interpreted as threatening (e.g., see Lazarus & Folkman's model of stress and coping, 1984); and (2) interpretation of the source and controllability of pain.

In addition, health-related locus of control, which reflects an individual's orientation towards whether their health is a byproduct of their actions versus circumstances out of their control, represents one avenue of investigating the meaning of pain and its relationship to psychological outcome. The Health Locus of Control scale (Fletcher & Scaffa, 2018; Levenson, 1974; Wallston & Wallston, 1982) is an instrument that measures this construct by assessing three independent dimensions of controllability over health: *Internal* (one's behavior directly influences health), *External-powerful* (the actions of others, such as physicians and healthcare providers influence health), and *External-chance* (fate or luck influences health).

Theoretically, one may anticipate that individuals with chronic pain who maintain an internal locus of control would be less emotionally distressed than those who believe they have no personal control over their pain (Seville & Robinson, 2000). However,

among older Black women, higher internal health-related locus of control is associated with greater pain intensity, a factor the authors hypothesize may be related to self-blame for inability to manage the pain condition (Baker et al., 2008). Additionally, when considering Black older adults, who are more likely to engage in faith-based and religious practices involving a relationship with an external higher being (Chatters et al., 2009), the link between religiosity, locus of control, and emotional/health outcomes becomes complex. The literature remains quite mixed, possibly due to the fact that a combination of both internal and external loci are needed in a flexible manner to manage pain and emotional distress, and this may especially be the case for Black older adults who engage in spiritual coping (Clark et al., 2017). Exploration of cognitive appraisal and locus of control represents an important next step in unpacking how the meaning attributed to pain relates to psychological outcomes in older Black adults.

Improving Pain Management in Black Older Adults

Black adults have been persistently underrepresented in pain research (Booker et al., 2020), a fact which has constrained knowledge of optimal ways to alleviate pain in this population. For example, there have been few attempts to test models of culturally-relevant pain care for Black adults, although in recent years this literature has been growing (e.g., Allen et al., 2019). When considering the clinical treatment of pain, a strict biomedical approach fails to account for the complex, multidimensional experience that is pain, thereby reducing pain to pathological changes resulting from an underlying medical etiology, discoverable by the clinician. Conversely, a biopsychosocial approach, which considers the relationship between biology, psychological processes, and social-

environmental factors, is more appropriate for conceptualizing and managing pain for older Black Americans, as this accounts for the stressors unique to being a Black older adult, among other contextualizing factors such as socioeconomic status, and neighborhood/lived environment (Burgess et al., 2009). Further, as noted by the previous discussion, religiosity and other measures of spiritual coping should be incorporated into pain assessment strategies. In addition, culturally responsive pain management approaches should be engaged to prioritize the integration of self-management strategies preferred by the community.

A key component of culturally responsive care is provider self-assessment of bias in which providers are encouraged to think deeply about their own values and beliefs and consider how these perspectives may influence care decisions. At the organizational level, equity assessments may be conducted to evaluate curricula, policies, procedures, and organizational outcomes for the presence of disparities and bias. Standardized treatment protocols and consideration of how social determinants of health, such as income, education, and residence, may affect treatment access and related decisions, can improve equitable pain care across populations. Finally, institutions should consider how diverse perspectives are integrated throughout the organization and amplified—particularly the voices of the most marginalized. With these key principles in mind, and provided the feedback from Black older adults with persistent pain, the authors recommend the development of culturally responsive pain management programs, especially programs that promote pain self-management practice.

Future Research and Practice Directions

Data from research by the authors in 2017-2019 reveals preferences and practices for pain self-management in a sample of Black older adults. These data were collected as part of a pilot study of the feasibility of using wearable activity trackers to promote physical activity for chronic pain self-management among Black older adults in Detroit, Michigan (Janevic et al., 2018). As part of a baseline survey ($n=51$), we assessed participants' use of non-pharmacological methods for managing their chronic pain. These items included a broad array of self-management techniques, including religious and spiritual practices, given their importance as noted above. We also conducted a series of focus groups with a total of 41 participants. Participants were age 60 and over with chronic musculoskeletal pain. The sample was almost exclusively Black, predominantly female, and approximately 9 out of 10 had arthritis. The mean pain level upon study enrollment was close to 6/10 (on a 0 to 10 scale, where 0=no pain at all, and 10=worst imaginable pain).

Table 1 shows the four most common self-management techniques endorsed in the survey for current use: praying/Bible reading, engaging in physical activity, herbal remedies or supplements, and using relaxation techniques. Other techniques currently being used by fewer than 10% of the sample included: support groups (8%), acupressure (4%), magnets or copper bracelets (2%), marijuana (2%)¹², and biofeedback (0%). Other self-care treatments mentioned in focus groups included: rubbing alcohol, heating pad, water flushes, and yoga.

¹² Marijuana use is legal in the state where the study took place.

Table 1: Common self-management techniques (survey data) with illustrative quotes (focus group data)

Technique	Using now	Quote
Praying or reading the Bible	77%	“Because, that’s my friend, is prayer. And I can always go to Him day, the night, morning, any time. So, I throw everything in the universe, and it’ll be handled.”
Exercise or physical activity	77%	“I might do maybe two or three hustle dances. But I try to always keep myself moving, you know I just don’t sit. Even though I have problems and limitations I know that if you just don’t do anything it’s not going to get better, it’s going to get worse.”
Herbal remedies/supplements	53%	“Every morning, I get me a tablespoon full of apple cider vinegar and a glass of water, and I drink that. And that usually helps. If it don’t, I just deal with it.”
Imagery, relaxation, meditation	40%	“Meditation, you have to work with yourself mentally. And I learned how to some times just relax. It was a meditation of the mind, breathing, remind you breath, just relax. And mentally talk to yourself and encourage yourself cause you don’t want to be in pain.”

While these data are from a small sample, findings are congruent with much of the above discussion regarding how Black older adults live with, and manage, longstanding pain. This includes a significant practice of spiritual coping, as well as maintaining a positive mindset and active life. One notable theme that emerged from the focus groups was reluctance on the part of respondents to take opioid pain medications.

Sometimes this related to implied dissatisfaction with encounters with the medical care system:

And this lady told me you're going to feel like a champ now. However, I don't like to take medications. I'm afraid of getting stuck on it.

The V.A. hospital, they want you to start with physical therapy and everything else before they shoot you with pain pills and stuff. When you go to your primary doctor on the outside, first thing he wants is just give me a pain pill.

More often, however, the hesitancy was related to a preference for being self-reliant and believing that self-care was both safer and more effective:

I become immune to pain medicines real fast, so it didn't stop the pain so I stopped taking the pills, and so I found heat and exercising.

I don't want no pain meds because the pain pills, you lose so much quality of life living like that. Your mind doesn't work, it takes away a whole lot of things with you.

These findings have been used to support the development of a non-pharmacologically centered pain intervention led by community health workers.

Community Health Worker Led Pain Interventions

Self-management strategies that improve mood and have positive downstream effects on pain in older White adults such as physical exercise, mindfulness, and music

therapy, have been less studied as interventions for Black older adults (Reid et al., 2008), and warrant greater attention. In an attempt to test a new model of culturally-responsive pain self-management support, Janevic, Robinson-Lane, and colleagues are developing community health worker-led interventions for Black older adults living with chronic pain.

Community health workers (CHWs) are an untapped part of the pain care workforce. CHWs are not licensed professionals, but rather are lay “natural helpers” with formal training for specific health care-related tasks, including: supporting health behavior change, addressing social determinants of health (SDOH), and providing linkages to formal health care services when needed (Perry et al., 2014). CHWs have an advantage over other providers when it comes to teaching pain coping skills in that they typically share a community identity with the clients they serve (Rosenthal et al., 2010). Therefore, beliefs about pain and pain management are culturally congruent, yielding a high level of credibility and mutual trust. In other words, CHWs provide a comfortable, safe environment to discuss factors affecting pain management, and can deliver culturally-appropriate, patient-centered pain self-management support.

Janevic, Robinson-Lane and colleagues have tested two CHW-led interventions to support pain care among African American older adults in community-based settings: STEPS 2 (Seniors using Technology to Engage in Pain Self-Management), in which CHWs teach cognitive-behavioral pain self-management skills to older adults with the support of mobile health tools (Janevic, Robinson-Lane et al., 2021a), and Positive STEPS (Janevic, Robinson-Lane et al., 2021b), in which cognitive-behavioral skills are supplemented with positive affect-inducing activities (consistent with cultural

preferences for leveraging a positive mindset to deal with pain; Robinson-Lane, 2020). In both STEPS 2 and Positive STEPS, participants are introduced to specific pain-management skills via expert-delivered videos on a user-friendly website. Then, CHWs engage with participants over a series of 7 weekly, structured phone calls, helping them apply these skills to everyday life, set behavioral goals, and address any obstacles to pain management, connecting participants to external resources when needed to address obstacles to pain management; e.g., finding accessible places to exercise, getting help with caregiving, or dealing with health insurance issues.

Findings from both the STEPS 2 and Positive STEPS pilots indicate that the interventions were successful at reducing pain interference over a two-month period, and participants reported reduced pain and improved functioning. In both studies, participants were very responsive to the CHWs, and found them to be motivating, encouraging, understanding, and relatable. Many participants felt that it was precisely this support that allowed them to get better control of their pain and to improve their day to day functioning and quality of life. Future scaled programs should continue to engage CHWs as self-management resource liaisons within community-based pain management programs. Another promising pain management treatment strategy for Black older adults is Cognitive Behavioral Therapy.

Cognitive Behavioral Therapy

Cognitive Behavioral Therapy (CBT) is a recommended non-pharmacological treatment approach to managing depression and stress-related contributors to pain (Keefe et al., 2013). Unfortunately, the accessibility of CBT and other psychologically

oriented interventions for Black older adults experiencing comorbid depression and pain is lacking (Ehde, Dillworth, and Turner, 2014). There are few trained providers that work in communities with large Black populations and even fewer culturally tailored CBT programs that embed the language, values, traditions, and practices, of the community served. Further, and perhaps most importantly, there is general under recognition of depression in Black older adults, and the failure of clinical providers to subsequently initiate treatment. The diagnostic accuracy of mental health conditions in Black adults is poor, and Black older adults with depression are less likely to receive the correct diagnosis (Gallo et al., 1998). While the literature on depression prevalence initially suggested lower rates of depression in Black older adults, more recent evidence actually indicates higher or equivalent incidence and prevalence rates relative to whites (Harralson, 2002; Pickett et al., 2013).

Symptom presentation may differ across race, and it takes a culturally attuned provider to assess how pain and depression manifest in Black older adults, and to offer appropriate diagnoses and culturally-congruent treatment. Black older adults are more likely to be diagnosed with psychosis or a related disorder (e.g., schizophrenia) as opposed to an affective or mood disorder such as Major Depressive Disorder (Ahmed & Kramer, 2006; Baker, 1995; Coleman & Baker, 1994). In addition to lacking cultural awareness, poor psychometric properties of assessment instruments and culturally biased diagnostic tools likely contribute to the under recognition of mood and pain disorders in older Black adults. The underlying assumption that self-report instruments or semi-structured instruments measure the same constructs, especially when a

majority of instruments were developed and validated in White samples, is faulty and may further contribute to observed disparities (Williams, Davies, and Chadury 2000).

Lastly, just as with pain treatment, mood disorders are less likely to be adequately treated among Black adults. Black adults are less likely to receive depression treatment within six months of diagnosis (Gallo et al., 2005). In general, Black Americans receive care in mental health settings at about half of the rate of White adults (Lasser et al., 2002), and have inadequate access to depression treatment in spite of more recent contacts within the healthcare system (Alegria et al., 2008).

Persistent pain is a multidimensional experience of which physical discomfort is only one component. As a stressor, pain can easily consume a person as it interferes with their ability to optimally function both physically and socially. The resulting suffering can diminish hope and cause doubts to one's faith or sense of connectivity and purposefulness. For the Black older adult, living with chronic pain is an inevitable part of aging that may also result in depression. Current pain management approaches typically rely on analgesic medication management alone, and do not address other important dimensions of the pain experience. Further, many of the important pain treatment traditions and approaches that have been bringing comfort to generations, such as movement, rest, prayer, and heat are not actively incorporated into pain management plans, and thereby do not acknowledge their current cultural value regardless of current perceived clinical benefits.

Sustainable and culturally informed pain management practice is person and community centered. An ideal pain management practice is able to effectively provide wholistic care—that is, care for the whole person and supporting their pain management

goals. In recognizing that provider mistrust continues to be a concern, and the need for maintenance independence is high, clinicians can facilitate trusting relationships and restore power imbalances by offering balanced information and accessible choices about pain management options. Clinicians can also follow-up to determine treatment effectiveness. Excellent pain management has not been the norm for the average Black older adult. It is our hope that culturally responsive wholistic pain care, care that recognizes and supports the unique contributions individual bring to the management of their own physical-psycho-social-spiritual-health, and that is sensitive to the meanings of lived pain experiences, becomes the standard for all persons with pain in the future.

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