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# A progressive agenda toward equity in pain care

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#### ABSTRACT

**Background:** There are inconsistencies documenting the pain experience of Black adults and other racially minoritized populations. Often disregarded, pain among these groups is characterized by misconceptions, biases, and discriminatory practices, which may lead to inequitable pain care.

**Methods:** To address this issue, this professional commentary provides an overview of pain reform and the need to declare chronic pain as a critical public health issue, while requiring that equity be a key focus in providing comprehensive pain screening and standardizing epidemiological surveillance to understand the prevalence and incidence of pain.

**Results and Conclusions:** This roadmap is a call to action for all sectors of research, practice, policy, education, and advocacy. More importantly, this progressive agenda is timely for all race and other marginalized groups and reminds us that adequate treatment of pain is an obligation that cannot be the responsibility of one person, community, or institution, but rather a collective responsibility of those willing to service the needs of all individuals.

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The experiences of some Americans have been dictated by a historical backdrop embedded in slavery, Jim Crow, Civil Rights, and other acts of discrimination, prejudice, oppression, biases, and exclusion.1,2 The impact of these events and behaviors have long standing emotional and health consequences. To address this issue, actions are needed to focus more on restructuring a fragmented social system that is dictated by power and wealth, and exposes deeper systemic issues of inequities, social injustices, and economic hardships (Williams, Lawrence, and Davis, 2019). This however, cannot be the responsibility of one person, community, or institution, but rather a collective obligation of those willing to serve as 'change agents' in improving the health and care needs of the more disenfranchised.

Moving forward, it's necessary that we refocus our efforts on models that promote pain equity as opposed to those that simply describe pain disparities. The Institute of Medicine (IOM) calls this movement a 'cultural transformation' of pain care (Institute of Medicine, 2011). Yet, in order for this to take place there must be a narrative as to

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why this change is necessary and how it will happen. The National Pain Strategy (NPS, 2016) for example, highlights several objectives and action items regarding disparities and pain equity. The report describes that those experiencing pain are often stigmatized (with pain being inadequately treated) and are more likely to occur among those with limited access to care, racial and ethnic groups, and older adults.

Two proposed recommendations to address these issues are to increase access to highquality care and to better understand the influence bias has in the diagnosis and treatment of pain. Similarly, the 2019 report by the Pain Management Best Practices Inter-Agency Task Force, highlights disparities in the prevalence, treatment, progression, and outcomes of pain-related conditions among certain race and ethnic populations. Similar to the NPS report, the task force recommends developing culturally targeted intervention programs, based on the biopsychosocial model, to reduce pain disparities. Although these recommendations are well intended, the question remains as to how do you increase access to high quality pain care, when specialty pain care is often neither accessible, available, acceptable, adequate nor affordable to some historically excluded or underrepresented (Institute of Medicine, 2011) (e.g. Black adults, older adults, low income) groups?

To address this issue, a progressive pain care agenda is needed, whereby change and continuous improvement builds on existing care, while also proposing strategies that guides future pain treatment. In this professional commentary, a progressive pain agenda is outlined addressing some of the current efforts aimed at improving pain treatment, while recognizing the need for inclusive research efforts and pain care models that allow the person experiencing pain to have a 'voice' in making decisions about their health (pain care).

## Biases in defining the pain experience

The International Association for the Study of Pain (IASP) defines pain as an 'unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage'. (Interagency Pain Research Coordinating Committee (IPRCC), 2019; Treede et al., 2015). This revised definition highlights that pain can have adverse effects on one's social and psychological well-being and quality of life, and that those experiencing pain need to be respected. This broader definition allows us to consider the influence certain factors (e.g. history of the illness, duration of the medical condition, type of pain, pain variability, physiological changes, cultural background, sociodemographic characteristics, etc.) have in the diagnosis, treatment, and management of pain (Treede et al., 2015).

These factors, of course, contribute to our understanding of pain as a complex process interconnected with affective, cognitive, and behavioral patterns (Treede et al., 2015). Although commonly regarded as a symptom of a disease diagnosis or injury, chronic pain can also be considered a disease in itself. While many patients are diagnosed with a primary pathology (e.g. arthritis, diabetes mellitus), the changes to the peripheral nervous system may result in secondary pathology. Therefore, the individual may then develop persistent pain as a disease, meeting diagnostic criteria with established symptomatology, such as mood and sleep disturbances (Clauw et al., 2019; Cousins, 2007). This secondary pathology may have implications in understanding the association of pain and other chronic medical conditions. This is even more relevant when discussing the short –

and long-term implications of a painful medical diagnosis, particularly among those that have been historically excluded or intentionally minoritized.

### Intersection of race and gender

## Pain and the lived experiences of black women: the case of dr. Susan moore

To reframe how we promote progressive pain care, we must acknowledge the influence intersecting identities (e.g. race, gender identity, age, ability) have in how pain is experienced. While race is recognized as a physical identity used in perpetuating disparities and inequities, it is not however, only race that defines how pain is diagnosed, managed, and treated. The intersection of multiple identities among older global majority adults may add to the complexity of how pain is experienced. When an older Black woman, for example, presents with pain complaints, she is not just seen as a person in pain, but rather as an adult who is (1) Black, (2) a woman, and (3) older. With these intersecting identities it is difficult to determine which has a greater influence over the other, particularly when presenting with a medical complaint. Yet, it is important for clinicians, as well as researchers, to recognize the influence these identities have in decision-making and health outcomes. Acknowledging such is important as we continue to confront countless scenarios, whereby biases and discriminatory practices are encountered based on multiple intersecting characteristics which often lead to less than favorable outcomes. Data show for example, that a significant number of Black patients reporting pain are viewed through a lens of deviant and criminal-like behaviors (e.g. drug abusers and seekers, doctor-shopping) rather than someone presenting with legitimate pain pathology (Aronowitz et al., 2020). This is not merely speculation, but rather a demonstration of historical inequitable care. The recent case of the late Dr. Susan Moore, a Black family medicine physician in Indiana, illustrates the risks faced by an increasing number of patients whose diagnosis and treatment are based on stereotypes, biases, and/or false and mis-leading information (ABC News, 2020; New York times, 2020) (Box 1).

#### Box 1. The case of Dr. Susan Moore.

Dr. Moore contracted COVID-19 and was subsequently hospitalized in an academic medical center with complications from the disease. While in the hospital, she reported to her care team that she was experiencing severe pain and requested analgesic medication. Her request was denied. The white physician in charge of her care told her he was not comfortable with giving her 'more narcotics' and said that she would soon be discharged. From her hospital bed, and while continuing to suffer excruciating pain, Dr. Moore recorded an account of her experience on video and shared it on social media, so that her experience could shine a light on the experiences of Black patients. In Dr. Moore's searing words, the attending physician made her feel 'like a drug addict' – even while she was desperately ill.

Dr. Moore's video was widely shared and was met with outrage and shock. If a physician, who was intimately familiar with the health care system, and who could communicate with her care team 'doctor to doctor', was not believed; if her pain was denied and her attempts to advocate for herself futile, what does that imply for African American patients without Dr. Moore's background, resources, or advocacy? Tragically, Dr. Moore passed away due to COVID-19 on December 20, 2020.

Because of her bravery in posting the video, Dr. Moore's ill-treatment came to the attention of the nation, as so many similar incidents do not. Some observers contrasted the official statements made by health care institutions during the summer of 2020 in support of the Black Lives Matter movement with the reality of happens with on-theground patient care.

Dr. Moore's heart wrenching experience is a stark rejoinder to those who would claim that disparate treatment no longer happens but also claim to hold true to the Hippocratic oath. Profound emancipatory change in pain care and in society is needed to ensure that one day, such unequal treatment finally will be a thing of the past, and no Black patient will ever have to say, as Dr. Moore did in her video: 'If I was white, I wouldn't have to go through that.'

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It is without question that the experience and treatment of Dr. Moore was unacceptable. Her intersecting identities, being Black and a woman, reminds us that the social positioning of Black women exposes them to discriminatory practices that dismiss their medical, social, and psychological needs. The experience of Dr. Moore, and the long history of medical mistreatment of Black women in the US, is neither new nor isolated. In Savitt's essay, 'The Use of Blacks for Medical Experimentation and Demonstration in the Old South', the reader is presented with examples of the unethical treatment of (enslaved) Black women solely for the purpose of training White medical students (Savitt, 1982). Reports show that many of these women were subjected to disturbingly painful medical procedures, and labeled as 'clinical material', thus placing them in situations of physical pain and vulnerability. Experiments on Black women by men such as J. Marion Sims, who developed a method for treating vesico-vaginal fistulas (breaks in the wall that separates the bladder form the vagina) and his contemporaries - Nathan Bozeman, and Ephraim McDowell - would lead them to become medical 'pioneers' in gynecology. Despite this and other medical discoveries, it was at the expense of their unethical and painful experiments on Black women. Savitt's misuse of women serves as a reminder of how Black women were, and still to this day, are considered expendable (Savitt, 1982).

The unfortunate circumstances of Dr. Moore is an obvious reminder of these illfated perceptions and actions by others who consider the well-being of women, who are intentionally minoritized, as less than. The many historic (and current) examples serve as a reminder of the need to redefine our efforts to ensure that all persons, particularly those experiencing pain, receive equitable pain treatment and relief.

### Intersection of age- and racism

Data show that older Black adults and those of lower socioeconomic status (SES) report a higher burden from chronic pain, with an increased prevalence of pain severity and pain-related disability.(Grol-Prokopczyk, 2017; Reyes-Gibby et al., 2007; Vaughn et al., 2019) Furthermore, these groups similarly report having less access to and receiving adequate pain treatment (Grol-Prokopczyk, 2017; Meghani et al., 2012).

It is well recognized that historical, cultural, and social factors have a significant impact on how one ages (Elder et al., 2003; Stowe & Cooney, 2015). Health inequities experienced in older adulthood for example, including those related to the treatment of pain and/or other health conditions, can be the result of systemic racism (and ageism) experienced across the life span (Gee et al., 2012). Structural racism can be thought of as the unofficial 'rules of the game', whereby laws, policies, and practices yield inequitable conditions such as residential segregation, economic deprivation, and inferior medical care.(Gee & Ford, 2011; Krieger, 2019; Phelan & Link, 2015) These conditions may impact how US racially minoritized groups experience and manage chronic pain across the lifespan. While there is much that needs to be done and understood about pain across various age cohorts, our focus highlights how we address this pain narrative among older Black adults. These experiences are often guided by three primary domains: biological, psychological, and social.

#### **Biological factors**

These factors include increased allostatic load (a physiological measure of wear and tear on the body) (Baker et al., 2017; Geronimus et al., 2006; Krieger, 2019) that often results in disproportionately higher rates of multimorbidity, functional impairment, a difficulty in managing pain; particularly among older Black adults (Booker et al., 2020; Janevic et al., 2017). A lifetime of inferior treatment and adequate access to high-quality medical care often leaves pain under reported, misdiagnosed, and untreated, which may lead to persistent pain and pain-related disabilities. These may be directly linked to the influence social determinants of health (SDOH) have on the health/outcomes of certain race groups (detailed below; Impact of Social Determinants of Health on Pain Care).

## **Psychological and social factors**

Distress and trauma – including historical trauma from racial oppression and discrimination (Gee et al., 2012; Gee & Ford, 2011) have been found to increase reports of physical pain in older Black adults (Walker-Taylor et al., 2018). While these accumulated factors address the psychological outcomes of older historically excluded adults, we must also acknowledge the link between social factors and pain reports. Stressors resulting from destructive social ties, bereavement (Umberson, 2017) cumulative economic disparities, familial stress (e.g. custodial grandparenting), for example can trigger negative pain outcomes.

Acknowledging the impact of racial inequities and social threats in the health of older Black adults reminds us that we are long overdue in understanding the underlying mechanisms that define the pain experience among those whose ability to manage pain has been defined by cultured and social experience(s) immersed in historical tradition, reflection, generativity, and resilience (Booker et al., 2020). Recognizing the influence of these factors and social domains calls for an urgent need to restructure how our systems and institutional settings care for racially minoritized groups in need of pain care.

### A need for reform

The need for reform in pain care must begin with remediation of racial/ethnic and socioeconomic disparities. The narratives of those from diverse race and ethnic populations continue to be undermined and/or ignored despite numerous studies describing the profound mismanagement of pain (Hoffman et al., 2016; Shavers et al., 2010). As a result, individuals living with pain, particularly those from diverse race and ethnic groups, frequently lack access to specialized (pain) care. Data show that some predominantly Black communities for example, experience provider bias(es), high out-of-pocket healthcare costs, and pharmacies that are not adequately stocked with opioid analgesics (Green et al., 2005; Jefferson et al., 2019).

While the lack of access to pain medications is seen as a detriment to the Black community, there are those who interpret this as a protective factor, whereby the lack of access reduces the risk of misuse and/or addiction. There are however, two issues with this argument. First, a lack of access to healthcare should never be considered equity in care, even if it unintentionally decreases the risk in selective harmful outcomes. Secondly, the lack of available analgesics supports the ideal that unequal access is acceptable, thereby devaluing the need to address the root cause(s) of differential access. Understanding the cause for these disparate behaviors taps into the role social determinants of health have in pain outcomes.

### Impact of social determinants of health on pain care

Recognizing the influence of social determinants of health (SDoH) allows us to not only explain 'how', but 'why' these disparities continue to immobilize communities in receiving adequate pain care. Attention to this issue should focus understanding how macrosocial determinants (e.g. corporate practices, political ideologies, economic philosophies, industrialization, taxation) influence access and availability to pain care and treatment, particularly to those in marginalized communities (Hughes et al., 2019).

Therefore, to improve the health of our most vulnerable groups, we must gain a better understanding of the 'root causes' of health, well-being, and distributed inequalities, inequities, and disparities. SDoH comprises five key domains (economic stability, education, health and health care, neighborhood and built environment, social and community context) that define areas by which people are born, grow up, live, work, and age (Centers for Disease Control (CDC). Community Health and Program Services, 2008;. Centers for Disease Control (CDC). Community Health and Program Services, 2008) These domains allow for a better understanding of not only the disease onset, but also the individual circumstances by which these illnesses occur. For example, neighborhood environments with quality housing, reduced exposure to crime and violence, and better environmental conditions (i.e. green space) is often associated with improved quality of and availability of specialized pain care.

As previously described, these factors are recognized in having a direct impact on biological, social, and psychological factors, as previously described. Yet, if we are to take a 'deeper dive' into the direct connection between biological factors, SDoH, and pain, we can show that 'wear and tear' on the body for example, may be related to the type of job/ occupation the older Black adult may have had in their younger/middle-aged years. As a SDoH, the physical strain and/or activities related to the job (possibly being more labor intensive) may have contributed to the physical and biological changes of the body, which, in turn, influences pain severity, frequency, and overall health outcomes. Until these determinants are prioritized, disparities in health and pain care will continue to persist across generations. Therefore, an agenda outlining the 'next steps' to equitable pain care for all racially minoritized Americans and other socially marginalized groups, is needed.

# A plan for equitable pain care

Recognizing pain as a public health concern calls for restructuring preventive, rehabilitative, and palliative care models. According to Gereau et al. (2014) a current pain agenda should be prevention focused and include early diagnosis, developing new treatments, optimizing current pain treatments, identifying the impact of health policy, and advancing pain education research (World Health Organization, Commission on Social Determinants of Health, 2008). More importantly, these initiatives should be aimed at promoting high-performing interdisciplinary care that incorporates a personalized, evidence- and outcomes-based approach that is intended for all patients (Interagency Pain Research Coordinating Committee (IPRCC), 2019). Despite these efforts, there remains significant inequities in patient care and pain-related disability(-ies). This is particularly true among racially minoritized groups, as well as those negatively impacted by societal and systemic consequences (i.e. income and educational inequities, (un)employment, impoverished communities).

Addressing this issue requires a progressive movement that strengthens the current pain care efforts. We propose a series of specific actions designed to address pain disparities/inequities through inclusive policies, while refocusing attention on the underlying influences SDoH have on pain and health outcomes that may be applicable for US and global populations. These strategies include:

- (1) Re-shaping the more traditional conceptualization of pain and operationalization of pain theories in ways that are relevant to diverse populations. The experiences, perceptions, and responses of a person living with chronic pain must be considered together with the biological mechanisms of pain. The so-called 'experienceome' is the felt impact of chronic pain, and the living conditions that contribute to and/or exacerbate the pain experience(s). This is highlighted in a 2020 commentary outlining the integration of these mechanisms, while also providing suggestions in moving forward in how we address the needs of pain patients: continue the search of objective pain measures (e.g. blood tests using biomarkers), remove individual discretion (using clinical guidelines and system-wide protocols), establish educational programs (clinicians and trainees learning about disparities in pain management), identify individual biases (self-awareness/examination of biases), and collect data (systems need to review data regularly and create strategies to address disparities) (Stabin, 2020). This perspective allows for a more thorough assessment of the social and cultural influences of pain.
- (2) Using innovative modes to remove the structured and virulent systems of inequity through multi-level, multi-generational public health interventions. These include, but are not limited to, policies to reduce inequities in wealth and economic resources; actions to reform the racist criminal justice system in the US; and massive investment in housing and job opportunities in communities that lack the necessary resources, particularly those that have been intentionally excluded by generations of discriminatory housing policies.
- (3) Fostering health liberation (and reducing the cycle of chronic morbidity and mortality), through integrative, collaborative, and community-engaged models of care. To accomplish this, it will be necessary to transform how health care providers and health researchers are trained to support progressive approaches to health care. For example, developing a community-based chronic pain management program that is specifically tailored to the available resources in that community. This approach would be in partnership with local care coordination health and academic institutions to leverage the navigation to critical pain research studies. Specifically, the program would engage with a standing community-advisory board and scientists to ensure that the program remains community-centered, while optimizing utilization of resources that would allow the individual to live well with pain.

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In addressing these initiatives, it's important to ask; 'how should 'systems' bring about actions that establish efforts to emancipate individuals from the adverse health outcomes resulting from biased pain care?' As outlined, the US healthcare systems must move from 'sick care' to 'well-care'. This will emphasize patient health empowerment in managing pain that counters inequities created by societal stigmas, stereotypes, and healthcare biases. This, of course, requires a sustained national response:

- Continue to recognize chronic pain as a critical public health issue as an epidemic in the US that requires an urgent and coordinated plan to mitigate it.
- Mobilize health outreach to all points in the community- rural, urban, suburban. One important way this can be done is through increased use of community health workers, (Peretz et al., 2020) who have a unique ability to connect communities with formal health and social services in a culturally congruent manner.
- Require that equity be a central tenet of all healthcare institutions' and national agencies' mission. This should be operationalized in specific metrics so that goals can be set and tracked over time, per institution/agency.
- Provide comprehensive pain screening to all patients, particularly those with Medicare, Medicaid, and other federally sponsored programs; accompanied by referrals to accessible, comprehensive, patient-centered pain treatment. An example of this would be to include agencies like the Centers for Disease Control, insurance companies, and national pain committees to convene, define, and develop a comprehensive baseline pain screening tool that can be used across various clinical settings and patient groups.
- Offer alternative payment models and methods based on socioeconomic status.
- Understanding how multiple levels of these injustices impact the pain process: cultural injustice, structural injustice, interpersonal injustice, and intrapersonal processes (Mathur et al., 2022)
- Integrate technology for real-time assessment and management of pain and promote policies that reduce the current digital divide along age, socioeconomic, and geographic boundaries (e.g. rural vs urban).
- Standardize epidemiological surveillance systems to understand the prevalence and incidence of pain, particularly high impact chronic pain as recommended by the NPS and expand census data to collect indicators of health status and risk and protective factors. This may include for example, expanding census data to collect health indicators. Meghani et al., (Meghani et al., 2012) outlines key article addressing an agenda toward equitable pain treatment:
- Improved training of health care workforce in both cultural humility/implicit bias as well as in how to treat and manage pain
- Promoting health care workforce diversity
- More attention on pain-related advocacy efforts of professional and private groups in addressing pain disparities
- Improve evidence-based best practices in eliminating disparities in pain care. This may include increasing the level of research that is focused on developing and testing novel interventions that target formidable SDoH or develop interventions that are aimed at targeting pain and multiple chronic conditions. This is a novel approach as opposed to single treatments and interventions, which are not sustainable.

These initiatives focus on the success of a progressive pain care roadmap in attending to multiple sectors: research, practice, policy, education, and advocacy. This call to action serves as a reminder that timely and adequate pain treatment should be a moral obligation of all healthcare professionals, (Institute of Medicine, 2011) with reform focusing on emancipatory social action. More importantly, this restructuring should aim to assess the direct effects of proximal and distal social and environmental determinants that have dictated our nation's suboptimal treatment of pain among racially minoritized groups and other historically excluded populations. Recognizing these efforts allows us to move beyond describing the issue surrounding pain disparities to that of finding solutions.

## **Ethics statement**

Content in this professional commentary did not include data from any human subjects. Therefore, ethics/Institutional Review Board approval is not required.

### **Author contributions**

The first draft of the manuscript was written by the corresponding author. All authors contributed content and commented on previous versions of the manuscript. All authors have read and approved the final manuscript.

### **Disclosure statement**

No potential conflict of interest was reported by the author(s).

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