



Contents lists available at ScienceDirect

## Social Science &amp; Medicine

journal homepage: [www.elsevier.com/locate/socscimed](http://www.elsevier.com/locate/socscimed)

## Invisible people with invisible pain: A commentary on “Even my sister says I’m acting like a crazy to get a check”: Race, gender, and moral boundary-work in women’s claims of disabling chronic pain

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### ARTICLE INFO

#### Article history:

Received 25 May 2017

Accepted 8 June 2017

Available online xxx

#### Keywords:

Pain

Intersectionality

Gender

Race

Morality

Stigma

### ABSTRACT

This commentary to Pryma’s (2017) article on women with fibromyalgia argues that intersectional approaches to health research can reveal not only how racialized institutions shape illness experience and medical care, but also how these institutions make some individuals visible, while rendering others invisible. Perhaps by adopting an intersectional approach to understanding health, we can start to unpack the multiple jeopardies faced by people of color in pain.

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Pain is chronically undertreated in the United States, in large part because pain is an invisible symptom that each individual experiences differently. The subjectivity of pain all but ensures that individuals struggle to find adequate ways to communicate their distress, especially when their pain occurs in the absence of visible pathology. Worse, the few tools that patients are given to express themselves are grossly inadequate. Who hasn’t had a laugh at the expense of the ludicrous happy/sad faces that illustrate “Wong-Baker FACES Pain Rating Scale?” According to this scale, I’ve only been a “0” when deliriously high on nitrous oxide at the dentist and my normal faculty meeting face registers at about a “4” (see Fig. 1).

But a burgeoning literature on race, gender, and pain has revealed a more serious problem with pain scales like the Wong-Baker FACES® Pain Rating Scale: unlike two-dimensional smiley faces, patients’ complaints emerge from bodies embedded in complex social contexts. So while pain is chronically undertreated for all people, some kinds of people have a much more difficult time getting their pain diagnosed and treated than others. Women are more prone to pain disorders than men, but because pain is interpreted through a gendered lens, women are also much more likely than men to have their symptoms attributed to neuroticism, hypochondria, or emotional distress (Barker, 2005; Kempner, 2014;

Werner and Malterud, 2003; Hoffman and Tarzian, 2001). Likewise, Black patients in pain must overcome the racism endemic to healthcare systems in order to get treated, including healthcare providers’ frequent misunderstandings about race and biological difference. For example, a research article published just last year reported that a rather shocking number of medical students and medical residents continue to hold the false belief that “black people’s skin is thicker than white people’s skin” – a misunderstanding that correlated with racial bias in pain treatment recommendations (Hoffman et al., 2016). In other words, because pain scales flatten social context, they create the illusion that the patient’s choice from 0 to 10 is color-blind and gender-neutral, when research tells us that pain assessments are anything but neutral.

Patients know this and, thus, tweak how they communicate their pain depending on their race and gender. Jane Pryma’s (2017) recent article in *Social Science & Medicine* drives this point home by taking an intersectional approach to understanding how women communicate fibromyalgia symptoms. In an interview study, Pryma asked 24 women with fibromyalgia to describe how they communicated their pain to others, including family, friends, physicians, and, importantly, medical and state institutions. Unlike most other studies of chronic pain, Pryma made an explicit effort to recruit a diverse sample, resulting in a study that included 14 women of color, including 10 who identified as Black or African-American.

Using this sampling strategy elicited important variation in

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<http://dx.doi.org/10.1016/j.socscimed.2017.06.009>

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## Wong-Baker FACES® Pain Rating Scale



Fig. 1. Wong-Baker FACES® Pain Rating Scale (Lee and Baker 1988).

responses: all of the subjects engaged in “moral boundary-work” in order to present themselves as credible and deserving (rather than malingers or frauds) who deserved disability benefits; but the moral boundaries that Black women engaged with differed than the rest of the sample. For example, Black women reportedly had to deal with physicians’ use of racialized stereotypes about opioid addiction, like “everybody knows that Blacks and Hispanics have addictive personalities”; physicians’ reluctance to document and substantiate a disability claim since “[Black people] are always applying for disability” (71); and physicians’ mistaken belief that Black people feel less pain than White people. In other words, the additional burden that Black women face are part and parcel of a broader racialized discourse about poverty and welfare, in which Black people are portrayed as undeserving leeches on a system that perpetuates dependency. White women may struggle to have their pain recognized, but at least their moral boundary-work does not have to navigate this pathologizing discourse. Pryma’s work joins other emerging scholars, like Lara-Millán (2014) and Wildeman et al. (2012), who are beginning to examine how racialized (and racist) institutions, like welfare and mass incarceration, shape the allocation and experience of healthcare.

Pryma’s article does excellent work pointing out how the strategies that individuals use to negotiate pain and disability may vary depending on their social position. But her analysis also suggests that Black women have trouble getting help with pain—an invisible disorder—because their own skin color renders them invisible. For invisibility does not just refer to the physiological limits of vision to perceive a phenomenon, but to the state or condition of being ignored. Tamara, a Black woman in Pryma’s sample, engages this double meaning of invisibility when she says “I know it’s [fibromyalgia] considered the invisible disease, but I’m visible, and this is what I have.” Her insistence that she is visible speaks to her concern that, when doctors see her, they pre-determine her worth from her skin color. Likewise, she believes that her workplace’s refusal to accommodate her disability has more to do with their inability to see her (and, thus, accommodate her needs) as a Black woman than their inability to see her pain. Similarly, Sheila, another Black woman in Pryma’s sample argues that while her doctor is generally dismissive of all fibromyalgia patients, he would have treated a white woman sooner than he did her. What these women experience is an invisibility that extends beyond the problem of “invisible disease”: for them, *race* invokes a kind of *institutional* and *interactional* invisibility. Not only can their pain not be seen, but *they* can’t be seen.

We know why pain is invisible, but what processes obscure Black women in pain from sight? Pryma’s analysis primarily points towards the entanglement of pain in racialized welfare discourse, but she hints at other processes at work, like the history of race and pain. In the 18th century, when racial categories emerged as a way to justify the slave trade (Omi and Winant, 2014), scientists began categorizing people of African descent as a “kind” of human with

innate physical traits that separated them from their European counterparts. Conveniently, these traits including many qualities that made Africans uniquely suited for hard, physical labor, including robust nerves and dull senses that produced an imperiousness to pain (Barker-Benfield, 1992). In an ironic twist, one of the reasons that Americans continue to think that Blacks are “good” at dealing with pain is that they are accustomed to oppressive and painful policies given their long experience living with hardship (Trawalter et al., 2012).

Another important piece of this puzzle has to do with the ways in which pain, generally, and fibromyalgia, specifically, is portrayed to physicians, policymakers and the public. It seems that little systematic research has investigated cultural representations of fibromyalgia, but an unscientific google image search of “fibromyalgia” and an examination of Pfizer’s website for their fibromyalgia drug, Lyrica (<https://www.lyrica.com/fibromyalgia>, accessed May 22nd, 2017), suggests that, like other chronic pain disorders, most images represent people with fibromyalgia as white women. How might these white-washed images affect Black women’s ability to receive appropriate treatment and accommodations? At least one woman in Pryma’s study argues that the lack of Black people in cultural representations of fibromyalgia renders her invisible. Pryma attributes advertisers’ decisions to represent fibromyalgia as white and middle-class as moral boundary-work, implying that, like patients, advertisers must also assert the legitimacy of their disease for which they are selling their product, but I am more cynical. Marketers know that they cannot design promotional materials that will appeal to everyone, so they segment their customers into sectors that they can pragmatically target. White, well-off women — the consumer group well-known for their tendency to seek help from physicians — are not depicted as patients because they convey moral purity, as Pryma suggests, but because marketers seek to harness their purchasing power. As a result, everyone else — men, people of color, the poor — is obscured.

Invisibility may also be produced in clinical trials when people of color and, especially Black people, systematically are excluded from medical research. The reasons for this exclusion are multiple, but in my own fieldwork within headache medicine, I often heard physicians justify the underrepresentation of Black people in trials by arguing that Black people were difficult to recruit and, in any case, clinicians did not “see” people of color in their clinical practices, so the exclusion was moot. (The underlying logic being: why make drugs for those who do not come to the clinic?) Historically, advocates promoted diversity in medical trials as a way to ensure that treatments will work for every body, rather than extrapolating results from a homogenous sample (Epstein, 2007). But what if diversity in medical research also serves another purpose? Recruiting diverse samples in clinical trials could help create a mindset within medicine from the very earliest stages of drug development that *all* patient populations ought to have access to care.

Although recent research has examined how women's experience of chronic pain is shaped by gendered moral discourses, Pryma's research should remind scholars that homogenous samples of white, middle class women produce incomplete results. Intersectional approaches to health research can reveal not only how racialized institutions shape illness experience and medical care, but also how these institutions make some individuals visible, while rendering others invisible. Perhaps by adopting an intersectional approach to understanding health, we can start to unpack the multiple jeopardies (King, 1998; Collins, 2008) faced by people of color in pain.

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