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“I felt like I had a scarlet letter”: recurring experiences of structural stigma surrounding opioid tapers among patients with chronic, non-cancer pain

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Abstract

Background: Efforts to address opioid-involved overdose fatalities have led to widespread implementation of various initiatives to taper (i.e., reduce or discontinue) opioid prescriptions despite a limited understanding of patients’ experience.

Methods: From 2019-2020, we recruited patients with chronic, non-cancer pain who had undergone a reduction in opioid daily dosage of 50% in the past two years at Boston Medical Center or Michigan Medicine. Participants completed semi-structured interviews exploring health history, opioid use, and taper experiences. Inductive analysis, guided by theoretical conceptualizations of structural stigma, identified emergent themes.

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Contributors

AB led the analysis and writing of manuscript. SK and ARB contributed to data analysis, interpretation, and writing of results. ML and ASBB designed the study and received funding for this project. ML, ASBB, and ARB oversaw data collection and analysis, and contributed to manuscript drafting and revisions. PL assisted with interpretation of findings, manuscript drafting, and revisions. SK, ML, ASBB, and ARB contributed to manuscript revisions. All authors reviewed, edited, and approved of the final version of the manuscript.

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Conflict of Interest
No conflict declared.

Results: Among 41 participants, three elements of structural stigma were identified across participants' lives. First, participants identified themselves as overlooked subjects of the U.S. opioid crisis, who experienced overprescribing, subsequent stigmatization and surveillance of opioid use (e.g., toxicology screening, "pill counts"), and various tapering initiatives. Second, during the course of pain treatment, participants felt stigmatized and invalidated by cultural norms linking chronic pain to stereotypes of acting disingenuously (e.g., "drug-seeking"). Finally, during and after tapers, institutional policies and programs further increased participants' feelings of marginalization, producing multiple unintended consequences, including reduced access to medical care and feeling "orphaned by the system."

Conclusions: Opioid tapers may exacerbate the social production and burden of stigma among patients with chronic pain, especially when processes are perceived to invalidate pain, endorse stereotypes, and label previously effective, acceptable treatment as inappropriate. Findings highlight how various tapering initiatives reinforce the devalued status of people living with chronic pain while also reducing patients' wellbeing and confidence in medical systems.

Keywords

Analgesics; Opioid; Chronic Pain; Pain Management; Opioid Prescribing; Stereotyping; Stigma

1. Introduction

High levels of opioid prescribing have been associated with adverse U.S. population health outcomes over several recent decades (Schuchat, Houry, and Guy, 2017). As a result of mounting evidence documenting associations between opioid prescribing, development of opioid use disorder, and overdose deaths (CDC, 2011), and based on evidence that overdose risk is associated with prescribing characteristics such as high dosage (Bohnert et al., 2011; Dunn et al., 2010; Gomes et al., 2011), a proliferation of guidelines, initiatives, and programs have aimed to reduce the number of patients prescribed high opioid dosages.

The current period of heightened attention toward mitigating opioid-related risks, termed "opioid pharmacovigilance," has involved federal and state government agencies, national professional associations, and healthcare institutions (Knight et al., 2017; National Academy of Medicine, 2019). In 2016, the U.S. Food and Drug Administration (FDA) reviewed its opioid policies, released an Opioids Action Plan, and asked the National Academies to support efforts to strengthen the regulatory framework for reviewing, approving, and monitoring opioids (Califf, Woodcock, and Ostroff, 2016). The U.S. Department of Health and Human Services (HHS) released a National Pain Strategy to move away from an "opioid-centric treatment paradigm" (U.S. Department of Health and Human Services, 2016) and the Centers for Disease Control and Prevention (CDC) published guidelines to reground clinical practice in risk-benefit analyses (Dowell, Haegerich, and Chou, 2016). Specifically, these guidelines recommend that clinicians regularly assess the ongoing risks and benefits of opioid therapy and consider tapering or discontinuing opioids when benefits no longer outweigh potential harms.

The emergence of these strategies has marked a turn away from the medically accepted use of opioids for treating chronic pain and into a new period in which opioid prescribing is

“situated in a publicly-mediated politics of regret” (Knight et al., 2017). We refer to these strategies and techniques of “opioid pharmacovigilance” (Knight et al., 2017)—a period when clinical leaders have monitored, scrutinized, and discouraged opioid use for chronic pain—as *various tapering initiatives*.

Within this period, tapering (i.e., reducing or discontinuing) high opioid dosages has become increasingly common (Rieder 2020). Evidence from studies focused on voluntary tapers suggests that opioid tapering may be associated with no worsening of pain intensity and function and sometimes improvement (Frank et al., 2017). More recent studies have raised concerns about associations between opioid tapering and harms such as overdose and suicide, though the observational designs preclude confident causal determination (Mark and Parish, 2019).

In 2018, Human Rights Watch publicly called various tapering initiatives into question and described the “unintended harms” of these initiatives for patients living with chronic pain. Soon after, in 2019, corrective statements were published by CDC, HHS, and several scientific editorial boards that pointed to an evolving recognition that various tapering initiatives were yielding unforeseen and potentially harmful consequences for those subjected (Dowell, Haegerich, and Chou, 2016; Darnell et al., 2018; FDA, 2019; HHS, 2019; Kertesz et al., 2019; Rieder et al., 2020).

Despite the proliferation of various tapering initiatives, their impact on patients has received limited attention. One study identified suboptimal patient-provider communication before and during tapers (Matthias et al., 2017) and another study with providers identified perceived patient mistrust as a challenge to successful tapers (Kennedy et al., 2018). Only one study to our knowledge investigated patient perspectives on opioid tapers, but it included only six participants who could reflect retrospectively on actual taper experiences (Frank et al., 2016). Given the identified association between opioid tapers and patients’ subsequent terminations of care (Perez et al., 2020), the limited research on patients’ experiences is concerning.

To advance research about patients’ experiences in this realm, we interviewed people living with chronic pain who had undergone opioid tapers. Based on widespread perceptions of mistreatment and harm across our sample, which participants connected to social structures and associated policies and practices, we drew from recent a framework of structural stigma to guide this analysis. Stigma generally refers to processes of devaluing individuals or groups, relegating subject(s) to a “tainted, discounted” status (Goffman, 1963). We build on Hatzenbuehler’s conceptualization of stigma as a multi-level construct, which can occur individually, interpersonally, and through policies, practices, and social arrangements that may be referred to as “structural stigma” (Hatzenbuehler, 2016). In particular, structural stigma is defined as the “societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized” (Hatzenbuehler, 2016).

Of note, structural stigma has been underrepresented in the stigma and substance use literatures (Hatzenbuehler, Phelan, and Link, 2013; Tsai et al. 2019). We frame the

experiences of various tapering initiatives among people living with chronic pain—an already marginalized group—as having the potential to create or worsen structural stigma, operating within the social and historical contexts of the U.S. epidemic of opioid-related harms and opioid pharmacovigilance period. This paper offers a novel contribution by describing the ways in which well-intentioned taper initiatives impacted people living with chronic pain, a population already experiencing a well-documented and significant burden of stigma.

2. Methods

2.1. Study design and population

We recruited patients on long-term opioid therapy for chronic pain (hereafter “participants”) from primary care clinics at Boston Medical Center in Boston, MA, and the High Dose Opioid Tapering Initiative, pain management clinic, addiction treatment services, and primary care clinics of the University of Michigan Health System (UMHS, also called Michigan Medicine) in Ann Arbor, MI. We identified eligible participants through chart reviews (18 years old; peak opioid daily prescribed dosage >50 morphine milligram equivalence at some point between 1/1/2017 to 2/1/2020 and with a current opioid dosage 50% lower than the peak dosage). We also received referrals from primary care physicians and reviewed medical charts to confirm participant eligibility. Trained study personnel screened participants to confirm eligibility and obtain informed consent. The Boston University Medical Campus and University of Michigan Institutional Review Boards approved all study protocols.

2.2. Data collection

From August 2019–February 2020, trained interviewers conducted individual in-depth interviews by phone or in private spaces within healthcare centers or mutually-agreed upon community locations. Interviewers administered quantitative assessments of socio-demographics (age, race, gender/sex) and chronic condition histories. Interviewers used semi-structured interview guides containing open-ended questions and probes to explore opioid prescription histories, taper experiences, and recommendations for practice improvement. Interviews lasted ~45 minutes and were audio-recorded. Participants received \$50 gift cards for participating. We continued interviewing until agreeing as a team that we had reached thematic saturation and did not anticipate significantly new findings to emerge through additional interviews (Guest, 2006).

2.3. Data analysis

We used an iterative, collaborative codebook development process (DeCuir-Gunby et al., 2011; MacQueen et al., 1998). We first developed deductive codes based on key topics of interest from the interview guide (e.g., “taper process,” “patient-provider relationship”). From regular team discussions about emergent topics, we also developed inductive codes (e.g., “stigma”). We tested several versions of the codebook on transcript excerpts to establish interpretive consensus. Two coders double-coded four full transcripts to further evaluate codebook completeness, code definitions, and coding consistency, which the team

determined to be high. A single coder then used the qualitative data analysis software NVivo to apply finalized codes to interview transcripts.

Analysis for this study involved reviewing topically related codes (e.g., “stigma,” “trust/mistrust with taper providers,” “advice and commentary to providers”) to identify emergent analytic themes (e.g., “heightened opioid surveillance,” “invalidation of pain,” “provider endorsement of stereotypes about ‘drug-seeking’”). Themes were documented using memos that we regularly discussed within our research team (Bradley et al., 2007). Data were then analyzed alongside a review of stigma theory and literature, with particular attention to specific aspects of structural stigma as defined above.

3. Results

Among 41 participants who had undergone an opioid taper in the last two years, age ranged from 28–76 years; 23 (56%) identified as female (18 as male; 44%); 27 (66%) identified as White, nine (22%) as Black/African American, and five as other or multiple races (12%; Table 1). Participants had been living with chronic pain for multiple years (range 3–36 years) due to multiple injuries and conditions, including but not limited to arthritis; diabetes; fibromyalgia; back, neck, shoulder, knee and hip injuries; Crohn’s disease; Behcet’s disease; Grave’s disease; Crest syndrome; and sickle cell anemia.

From qualitative interviews, three emergent findings aligned with the following theoretical conceptualizations of structural stigma (Hatzenbuler, 2016): (1) societal-level conditions laid ground for various tapering initiatives, (2) dominant cultural norms reinforced the socially devalued status of people living with chronic pain, and (3) institutional policies yielded unintended consequences for patients. These three themes are detailed in sections 3.1–3.3 below.

3.1. Participants identified themselves as overlooked and negatively impacted by measures implemented during the pharmacovigilance period, including various tapering initiatives

Many participants attributed the provision of their long-term, high opioid dosages to the high rates of opioid prescribing that occurred in the 1990s. Some participants described having high doses of opioids “pushed” on them as a result of providers’ close relationships with pharmaceutical companies, detailing benefits (e.g., “airline miles,” “padded pockets”) they believed their providers received in exchange for prescribing opioids. As such, many participants felt that blame should be placed on providers and pharmaceutical companies for overly-high prescribed opioid doses. Although many attributed their original high doses to malign practices, participants did not relate to addiction or overdose as they emerged as defining features of the U.S. opioid epidemic. Instead, several described feeling overlooked and adversely impacted by institutional responses to the U.S. opioid epidemic.

When one participant was asked why her individual opioid taper was initiated, she described the U.S. opioid epidemic as having a central role and she asked the interviewer, “*Why does the opioid crisis affect my medical treatment?*” Other participants expressed more specific awareness of the role of state-level actors involved in establishing various taperer initiatives.

When asked why their taper occurred, one participant answered, *“Because, for some reason, it’s like [providers] get feathers in their cap from the CDC or FDA.”*

Participants spoke with similar displeasure about the U.S. opioid epidemic’s influence on their care, perceiving that their individual opioid tapers occurred as a direct result of the epidemic, “the government clamping down,” “the government watching people,” and negative publicity thrust upon doctors. In other cases, participants described provider-initiated tapers as the result of providers’ concerns about participants’ doses being “too high” or administered for “too long.” Although these provider reasons were perceived as valid in a few cases, many participants felt that these reasons were coded efforts to reduce prescribing overall, without consideration of participants’ individual circumstances or needs. Some participants reported receiving inadequate communication or explanation from providers about their decisions to taper, resulting in some feeling abandoned and “orphaned by the system” as a result of various tapering initiatives.

These societal-level conditions resulted in many participants perceiving that their doctors were attempting to “protect their medical license(s).” Some believed that doctors operated out of fear of repercussions from state-level actors getting them “in trouble” or “shut down.” For a few participants, these perceptions were validated by actual experiences in which clinics they had formerly attended were forcibly closed or previous providers had been sanctioned as a result of opioid prescribing behaviors. When asked for their input into how providers’ might improve patients’ taper experiences, participants suggested that providers suspend these fears of state-level actors and more carefully evaluate individuals’ needs, as one participant explained:

The doctors need to be less afraid of losing their license or getting in trouble. All you hear in the news is about the opioid deaths, but there are a lot of people who take opioids every day to manage their pain and they do okay without abusing them, dying on them. These are the people who are now struggling, too.

3.2. During the course of pain treatment, dominant cultural norms reinforced the socially devalued status of people living with chronic pain and invalidated their experiences

Nearly all participants reported experiencing being perceived as “drug-seeking,” a “junkie,” or an “addict” in both clinical contexts and pharmacies. Participants described receiving “looks” from providers and instances of communication that left them feeling judged for taking opioids or as though they were being “lumped together” with people with substance use disorders.

Participants also described challenges with having their previously acceptable medical care newly perceived as troublesome, unacceptable, or even criminal by providers. These participants articulated feelings of guilt, shame, and humiliation when providers’ perceptions were communicated to them. Some felt unfairly accused during conversations about various tapering initiatives, as one participant explained, *“They were just throwing them [opioids] at me and now all the sudden I’m made to feel like a criminal. I think the system, the state, the way everything happened, was badly done.”*

Other participants described trying to present themselves in ways that would be received well by providers, including significantly tailoring their communication to avoid being viewed as “drug-seeking” or “begging” for medication. Participants nevertheless lived with an ongoing fear of being labeled with a substance use disorder by their providers, as one patient elaborated, *“I didn’t want to have that stigma stack to me that I was a druggie.”*

In many cases, the fear of being mislabeled or misrecognized was related to participants’ perceptions that providers did not believe in their pain. In one instance, a participant described her fear that her pain would be disbelieved or invalidated by providers: *“You always have that fear of ‘are they going to believe you’ or ‘are they going to think that you just want to stay at these higher doses?’”* Other participants’ narratives echoed this experience, including descriptions of being perceived as lying about pain in order to receive opioids. For many, this underlying tension resulted in feeling unheard, uncared for, and accused within clinical contexts. As one patient remarked, *“Pain is real, and to be looked at as if you’re lying or you’ve done something wrong is not helpful.”*

The experience of being dually disbelieved and stigmatized as “drug-seeking” was additionally burdensome for Black women in the sample. Several described the ways in which dominant cultural norms interacted with other forms of marginalization including racism:

As a Black woman, I had the hardest time getting my medicine every month. You got the stress of trying to get out of pain while you’re at heightened of pain, then you have the stress of being treated like a dope addict, then you have the stress of being treated in a racially discriminatory way because you’re a Black female trying to get your medicine.

3.3. During and after opioid tapers, institutional policies and programs further marginalized and yielded unintended consequences for people living with chronic pain

Efforts to monitor patients’ opioid use were received differently across participants, although all described heightened awareness of providers’ monitoring of their opioid use. Examples of heightened surveillance included “pill counts,” the use of treatment agreements or contracts, providers’ review of “state records” (i.e., prescription drug monitoring programs) to ensure participants were not receiving opioids elsewhere, and urine toxicology screening at appointments. These taper initiatives produced unintended consequences including reduced patient autonomy, facilitating mistrust, and reinforcing stigma about addiction.

Some described the inconvenience of randomly assigned “pill counts,” citing difficulty accessing transportation or living many hours away. These “pill counts” placed significant pressure to “be well” or mobile enough to reach the clinic and coordinate logistics with insufficient time to prepare (e.g., “a day’s notice”). These clinical encounters both eroded patients’ trust while providing opportunities, for some participants, to “prove” their compliance. Regarding the latter, for some individuals, “pill counts” were coveted opportunities to demonstrate that they were being a “good patient,” upholding their end of the bargain, and living without a substance use disorder.

In the case of urine toxicology screening, many expected this monitoring but had different reactions to it. Some felt negatively about the monitoring interventions outright, with one participant stating, *“I felt like I was a prisoner being tested for drugs.”* Others felt that the persistence of this monitoring wore at their relationship with their providers over time:

The first time I just thought of it as a way of proving my commitment to treatment. The second time that we did it I started to feel like it was more accusatory. That I was being judged for potentially using drugs that weren't prescribed to me or using them inappropriately. That made me feel a little less understood.

Another participant described a situation in which she contracted the flu and could not take her pain medication for a day or two. Despite communicating this with her doctor at a following appointment, she experienced the following outcome:

I got a certified letter in the mail from them saying, “Your drug test came back and it showed no opioids in your system. None of the medication we prescribed was in your system, and that’s a violation of our policy, so we are discharging you from our clinic.” And I was just shocked, I couldn’t understand it.

The different experiences of treatment monitoring reveal a variety of significant unintended consequences of various tapering initiatives, including patients’ mistrust of medical providers, provider abandonment of patients, and even the potential for patients to become completely disconnected from healthcare. Although some participants viewed treatment monitoring efforts as positive opportunities, they were nevertheless opportunities to distance oneself from the stigma of substance use disorders and stereotypes about noncompliant, “drug-seeking” behaviors. Another unintended consequence of various tapering initiatives was thus the perpetuation of the idea that, in order to be a “good” chronic pain patient worthy of ongoing care, one must actively demonstrate “good” behavior.

The presence of unintended consequences in the context of various tapering initiatives is summarized by the following quote:

I feel very stigmatized. I feel like I’m wearing a scarlet letter. I’m angry. I’m angry at the system, the pharmaceutical company, and my old doctor. I feel like there’s been so much more damage done to me than good, and from people that are supposed to be healers and not cause harm. I’ve had more harm caused to me by doctors...I don’t have a lot of faith in doctors, really. I don’t. And I used to.

4. Discussion

Little attention has been paid to how patients experience the implementation and enforcement of various tapering initiatives. By interviewing people living with chronic pain about their opioid taper experiences, we identified three emergent findings aligned with theoretical conceptualizations of structural stigma (Hatzenbuler, 2016). First, participants were aware of societal-level conditions that laid groundwork for various tapering initiatives, and many placed their experiences squarely within the historical contexts of high-level opioid prescribing and subsequent increased scrutiny, surveillance, and “opioid pharmacovigilance” (Knight et al. 2017). Second, during the course of pain treatment,

dominant cultural norms activated within various tapering initiatives served to perpetuate the socially devalued status of people living with chronic pain, including stereotypes that chronic pain patients are “drug-seeking” or act disingenuously about their pain. Finally, unintended consequences of tapers included patient mistrust of providers, provider abandonment of patients, and patients’ ultimate disconnection from healthcare, as well as the perpetuation of stigma more broadly. Importantly, these consequences are particularly potent for patients burdened with stigma across additional dimensions of identity, including marginalized race, ethnicity, gender identity, and class.

Our first finding, that participants located their experiences within the socio-historical contexts of the U.S. opioid crisis and pharmacovigilance period, illustrates how patients may experience and interpret their distress amidst structural and institutional changes affecting opioid prescribing. The forces behind various tapering initiatives are powerful state figures (e.g., CDC, FDA), and the instruments of these initiatives (i.e., doctors, medical institutions) are positioned with similar authority and legitimacy. Despite the best intentions of these actors, participants in our sample did not experience these initiatives as patient-centered. Rather, by placing their experiences within greater contexts driving various tapering initiatives, they articulated feeling left behind, needing to assert and defend their needs within clinical encounters, and sometimes having to contort their experiences for provider approval. Their stories, often excluded from current renderings of the U.S. opioid crisis, question how our institutional responses may cause additional harms and perpetuate stigma.

Our second finding, that participants widely experienced dominant cultural stereotypes reinforcing their socially devalued status, also raises questions about the implementation and enforcement of various tapering initiatives. Patients’ fear of being perceived as lying about pain for the purpose of acquiring opioids reveals how stigma operates within these initiatives. Structural stigma, on the level of cultural norms, offers a kind of rationalization and utility for the policies of various tapering initiatives. This is not to say the wreckage of the opioid crisis fails to justify changes in opioid prescribing. Instead, when taken together with findings that patients feel they are being perceived as “complainers, malingerers, and drug-seekers” (Dewar et al. 2003; De Ruddere et al. 2012; 2013; Collier 2018) and providers feel less sympathetic and more “suspicious” towards chronic pain patients (De Ruddere et al. 2014), we argue for a critical reexamination of stigma inherent in various tapering initiatives.

Guidelines should clarify that, while evidence supports avoiding the escalation of opioid therapy, it is limited in supporting tapers on a nonconsensual basis or in the absence of individualized, balanced risk/benefit assessments. We recommend the development of less stigmatizing monitoring strategies and the dissemination of research on the risks of involuntary tapers. We suggest safe opioid prescribing training that includes instructions on using non-stigmatizing language, engaging in patient-centered tapering conversations, and safely managing prescribing without abandoning patients when disagreements occur.

Our third finding reflects how the unintended consequences of various tapering initiatives are a gauge of the structural stigma levied against people living with chronic pain. The mechanics of various tapering initiatives, including new efforts to surveil patients, can

facilitate mistrust and strain patient-provider relationships. Many participants described struggling to find providers willing to treat their chronic pain, with the majority visiting numerous providers in order to secure consistent care (Lagisetty et al., 2019). Patients reflected an awareness that clinicians could terminate opioid prescriptions and clinical care relationships based on perceived noncompliance. For this reason, patients who worried about preserving their care described feelings of helplessness and a sense of conspiracy.

These unintended consequences reflect a growing literature through which alarm has been raised over anecdotal reports of provider abandonment of patients with chronic pain, the villainization of these patients, and the epistemic downgrading of their testimonies and lived experiences (Dineen and Goldberg 2018; Lewis 2018). Our findings bolster those from a study with people living with chronic pain that revealed the unique burden individuals carried to present themselves as the “right” kind of patient worthy of adequate care (Huang 2018). Taken together with this literature, our study contributes critical insight that the widespread implementation of various tapering initiatives fosters and exacerbates stigma experienced among patients, who may be treated as a homogenous group (simply on the basis of using opioids).

Our study is limited by several considerations. First, we did not develop the interview guide with structural stigma in mind and may have missed opportunities to probe on this topic. Second, we recruited participants maintaining connections to two clinical sites; thus, our findings may not generalize to individuals who were unable to establish care after prior termination or were otherwise difficult to reach using this approach. Third, this study was carried out at two academic institutions with significant resources to care for patients with chronic pain and/or substance use disorders, also limiting generalizability. Nevertheless, patient histories were extensive and were not necessarily limited to our two research sites. Finally, we only studied patient experiences and did not incorporate provider or policymaker perspectives. Future research should engage larger and more diverse samples of patients, providers, and policymakers and occur in regions where stigma may be exacerbated by resource constraints.

In summary, our findings highlight how broad, sweeping policy initiatives can further marginalize the patients they seek to heal, while sowing mistrust. If not taken hand in hand with serious efforts to destigmatize addiction, opioid use, and chronic pain, various tapering initiatives risk perpetuating stigma against people living with these conditions. Efforts to design similar initiatives should incorporate patient perspectives and address the intersection of multiple marginalized identities.

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HIGHLIGHTS

- Initiatives to taper opioid prescriptions have altered the landscape of opioid therapy
- Various tapering initiatives exacerbate structural stigma experienced by patients
- Stigma especially impacts those with marginalized identities (e.g., race/ethnicity)

Table 1.

Characteristics of patients with chronic, non-cancer pain (n=41)

	Boston Medical Center	Michigan Medicine	TOTAL
n (%)	9 (21.95)	32 (78.05)	41 (100)
Age			
25-44	2 (22.22)	11 (34.38)	13 (31.71)
45-54	1 (11.11)	8 (25.00)	9 (21.95)
55-64	3 (33.33)	8 (25.00)	11 (26.83)
65+	3 (33.33)	5 (15.62)	8 (19.51)
Race			
American Indian/Alaska Native	0 (0)	1 (3.12)	1 (2.44)
Black/African American	4 (44.44)	5 (15.62)	9 (21.95)
White	3 (33.33)	24 (75.00)	27 (65.85)
Other	1 (11.11)	2 (6.25)	3 (7.32)
Mixed (>1 Race)	1 (11.11)	0 (0)	1 (2.44)
Gender/Sex			
Male	4 (44.44)	14 (43.75)	18 (43.90)
Female	5 (55.56)	18 (56.25)	23 (56.10)
Duration of living with chronic condition			
Years (mean \pm sd)	17.7 (10.7)	17.3 (11.0)	17.4 (10.9)