

Opioid cessation and chronic pain: perspectives of former opioid users

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Abstract

Current guidelines for addressing opioid cessation in the context of chronic pain management recommend that opioids be discontinued if the risks outweigh the benefits. However, few studies have focused on understanding opioid cessation from the perspective of individuals with chronic pain. This mixed-method study included 49 former opioid users with chronic pain and used quantitative survey data and qualitative focus group data to identify themes pertaining to former opioid user's experience before, during, and after opioid cessation. Participants described several reasons for wanting to stop opioids including lack of efficacy, impact on quality of life, and concerns about addiction. Barriers to cessation included concerns about inadequate pain management and concerns about the impact of stopping opioids on mood. After opioid cessation, the sample was mixed regarding the benefit of cessation. Half of the former opioid users reported their pain to be better or the same after stopping opioids; however, 47% of the sample reported feeling worse pain since stopping their opioids. As the pendulum swings from pain control to drug control, we must ensure that the response to the opioid epidemic does not cause harm to individuals with chronic pain. Novel opioid cessation interventions are needed in combination with methods of addressing individual challenges and barriers to adequate pain relief including access to and provision of nonopioid alternatives for pain management.

Keywords: Opioid cessation, Chronic pain, Pain management, Opioid epidemic

1. Introduction

Over the past 20 years, there has been an increase in the use of opioid therapy to treat chronic pain.^{4,31,41} Although opioids can be an effective component of pain management, especially for acute and cancer-related pain, there is little empirical evidence supporting the long-term use of opioids.^{23,26,29,30} Not only do opioids pose significant risks, most studies with chronic pain patients have failed to demonstrate sustained improvement in pain or functioning with long-term opioid use.^{8,19,24,29} As part of a broader push to reduce the harms associated with opioids, expert guidelines for addressing opioid use in the context of chronic pain management suggest that opioids only be started as a last resort and be discontinued if the risks outweigh the benefit.⁹ Although good in theory, once a physician has considered the risk:benefit ratio for a current opioid user and determined that the patient is not benefiting sufficiently, few tools exist to help the provider and patient follow a different therapeutic path. Therefore, a significant challenge facing physicians across all specialties is what to do with patients who were started on opioids for

therapeutic use (ie, pain relief), but continue to use opioids when benefit is not apparent.

Determining how to support opioid cessation in patients with chronic pain is complicated by knowledge gaps between expert guidelines and clinical practice. This lack of understanding may lead to unintended clinical consequences, such as inadequate cessation support, patient dissatisfaction, nonadherence, and conflictual doctor–patient relationships. To address these gaps, foundational research is needed to identify the potential barriers and facilitators to opioid cessation from the perspective of the individual with chronic pain. We know of only one qualitative study that solicited feedback from both current and former opioid users about tapering opioids.²⁰ In this study, Frank and colleagues identified several barriers to tapering, including fear of pain and withdrawal symptoms, and facilitators for cessation, including psychosocial support.²⁰

This study was conducted to further advance our understanding of how best to approach opioid cessation in the context of chronic pain by soliciting feedback from former opioid users about their opioid cessation experience. This mixed-method study had 3 primary quantitative aims: (1) to describe the clinical characteristics of former opioid users including current pain, functioning, mood, and sleep, (2) to evaluate former opioid users' opioid use history and most recent cessation experience, and (3) to assess the impact of stopping opioids on key clinical domains. In addition to quantitative surveys, we also conducted 4 focus groups with a subset of participants to gain a more in-depth understanding of the opioid cessation experience. Using qualitative data, this study explored what factors motivated former opioid users to stop using opioids, identified the challenges associated with cessation, and described the pros and cons of not using opioids for pain management.

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

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2. Methods

2.1. Design overview

We used a convergent mixed-method design,¹³ an approach in which both quantitative and qualitative data are collected, analyzed, and then compared for validation and complementarity.^{13,15,43} In this study, quantitative survey data and qualitative focus group data were compared to identify themes pertaining to former opioid users' experience with opioid cessation.

2.2. Eligibility criteria

Inclusion criteria included being between 18 and 70 years of age, a history of taking opioids every day for 3 months or longer, and no current opioid use. There were 138 former opioid users who met the initial inclusion criteria. Of these potentially eligible patients, 40 were excluded because of the following exclusion criteria: non-English speaking (N = 1), current medical or psychiatric conditions that would prevent meaningful participation (N = 10), a history of recreational opioid use (N = 2), involvement in litigation relating to current pain condition (N = 7), prior use of opioid medication was for surgery-related pain only (N = 2), and most recent opioid use was 10+ years ago (N = 5). In addition, patients were excluded if tramadol was the type of opioid they previously used (N = 7), Suboxone or buprenorphine was used as a replacement opioid when they transitioned off opioids (N = 3), or they stopped because the prescription ran out (N = 3). Of the 98 eligible patients, 30 declined to participate. This resulted in a total of N = 68 patients who enrolled in the study. Of the 68 participants, 15 participants were lost to follow-up, 3 participants had resumed opioids during the time between enrollment and data collection, and 1 participant no longer had Internet access. See **Figure 1** for STROBE flow chart of participants.

2.3. Sample selection

This study included 49 former opioid users with chronic pain. Participants were recruited from the Back and Pain Center (Department of Anesthesiology, University of Michigan) and the Fibromyalgia Patient Education Workshop (Chronic Pain and Fatigue Research Center, University of Michigan) between January 9, 2017, and October 10, 2017. The Back and Pain Center is an outpatient tertiary care pain clinic where patients are evaluated and treated for a range of chronic pain conditions. The Fibromyalgia Workshop is a 2-hour workshop that is open to the public and provides an overview of what is currently known about fibromyalgia and discusses evidence-based treatment options. The workshop takes place monthly and is for patients diagnosed with fibromyalgia and other chronic pain syndromes (eg, irritable bowel syndrome and headaches). Of the 49 participants, 44 were recruited from the Back and Pain Center and 5 were recruited from the workshops. This study was approved by the institutional review board at the University of Michigan, and written informed consent was obtained for all participants.

2.4. Study procedure

Patients recruited at the Back and Pain Center were approached by a study coordinator in the examination room before being seen by a provider. The purpose of the study was explained, and interested patients were screened for eligibility. Attendees at the Fibromyalgia Workshop were informed at the end of the presentation about the study and were directed to a private room where research staff explained the study and assessed eligibility.

All participants provided contact information, and the study coordinator followed up via telephone to schedule the focus groups. Once enough participants were identified for a focus group (ie, N > 5), the focus group was scheduled. Participants were informed that the focus groups would last between 1 and 2 hours. All focus group participants (N = 24) were emailed a link to a 20-minute online Qualtrics survey 1 week before the date of the focus group and instructed to complete the survey before attending the focus groups. Participants not able to attend any of the focus groups or those who enrolled after the focus groups were closed upon reaching data saturation, completed only the online Qualtrics survey (N = 25). Participants who completed the online survey and participated in the focus group were paid \$100. A small incentive was provided to participants who completed the survey only (\$20).

2.5. Measures

2.5.1. Demographics and clinical characteristics

Demographic information and clinical characteristics were collected including age, gender, race, ethnicity, marital status, employment, primary pain diagnosis, duration of primary pain, and current medication use.

2.5.2. Pain severity and physical functioning

Pain severity was assessed using the 4-item Brief Pain Inventory subscale that asks about body pain at its worst and least in the past week, average pain, and "pain right now".^{10,42} For each item, participants were asked to rate their overall pain on a scale of 0 (No Pain) to 10 (Pain as bad as you can imagine). The average of the 4 scores was used as a single composite measure of pain severity. High pain was considered to be scores greater than or equal to 7 on the continuous scale. Physical functioning was assessed using the PROMIS 4a physical function scale, a 4-item measure that assesses one's ability to do daily activities (eg, "Are you able to do chores such as vacuuming or yard work").⁷ Each item is measured on a 5-point scale ranging from 1 (without any difficulty) to 5 (unable to do). The scores are summed, and total raw scores range from 4 to 20, with higher scores indicating worse functional impairment. Poor functioning was considered scores greater than 11 on the continuous measure.

2.5.3. Fibromyalgia survey criteria

The 2011 Survey Criteria for Fibromyalgia were used to assess the presence of symptoms associated with fibromyalgia.⁴⁴ The fibromyalgia survey criteria include the Widespread Pain Index (WPI) and Symptom Severity scale. The WPI was calculated using the Michigan Body Map, a two-sided body image with check boxes for 35 body areas, including the 19 body areas relevant to the WPI (scored 0-19).⁵ The Symptom Severity scale was calculated by summing responses to 6 items (scored 0-12) that assessed: past-week fatigue, trouble thinking or remembering, and waking up tired (rated from 0 = no problem to 3 = severe); and the presence of pain or cramps in the lower abdomen, depression, and headache over the past 6 months (rated 1 = yes and 0 = no).

2.5.4. Symptoms of depression

The Center for Epidemiologic Studies Depression (CES-D) scale is one of the most widely used screening tests for identifying

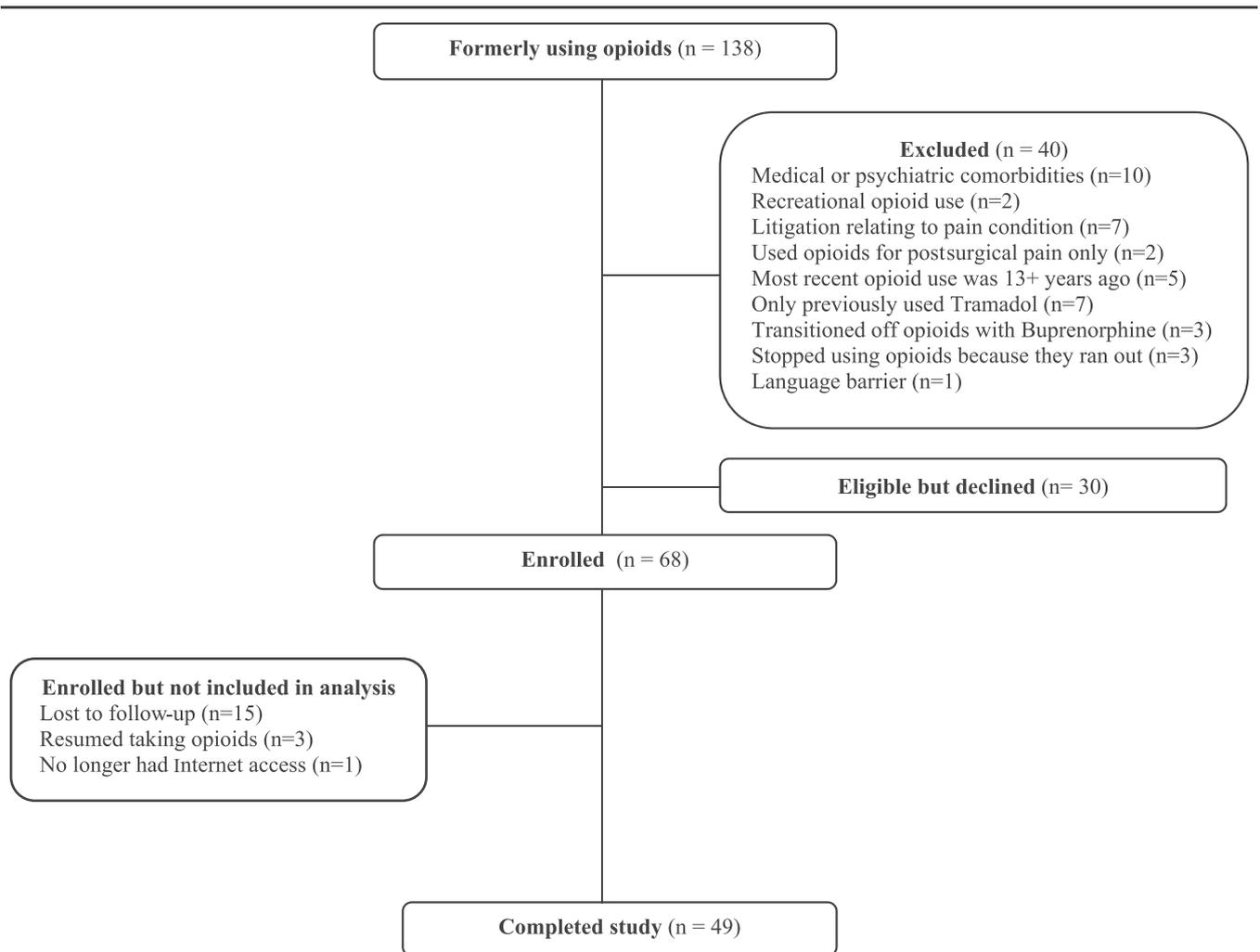


Figure 1. STROBE flow chart of participants.

symptoms of depression in general and medical populations.^{32,33} The 10-item CES-D (CES-D 10) is a short form of the 20-item CES-D and has been validated for reliability and validity. Cutoff scores for depression for the short form are greater than or equal to 10 on the continuous measure.

2.5.5. Symptoms of anxiety

The Generalized Anxiety Disorder (GAD-7) scale is a brief and reliable tool for screening and assessing for anxiety.³⁶ Questions ask about the severity of symptoms of anxiety over the past 2 weeks (0 = not at all, 1 = several days, 2 = more than half of the days, and 3 = nearly every day). A total score is calculated with scores indicating mild, moderate, or severe anxiety. A clinically relevant score for anxiety was considered to be scores greater than or equal to 10 on the continuous measure.

2.5.6. Sleep disturbance

The PROMIS 8a sleep disturbance scale is an 8-item measure to assess sleep difficulties, trouble falling asleep, and trouble staying asleep in the past 7 days.⁷ Each item is measured on a 5-point scale ranging from 1 to 5. The scores are summed, and total raw scores range from 8 to 40, with higher scores indicating worse sleep impairment.

2.5.7. Current and lifetime substance use

Smoking history was assessed using a single item (“Please choose the statement that best characterizes your tobacco use: I do not smoke cigarettes and have never smoked; I used to smoke cigarettes but I no longer do; I smoke cigarettes some days; I smoke cigarettes every day”). Alcohol use was assessed using the 3-item Alcohol Use Disorders Identification Test (AUDIT-C). The AUDIT-C is a brief alcohol screen with good reliability that identifies patients who are problem drinkers or have an active alcohol use disorder.^{6,35} The AUDIT-C is scored on a scale of 0 to 12, with higher scores associated with a greater likelihood hazardous drinking. Current and lifetime cannabis use was assessed using the cannabis items from the Alcohol, Smoking, and Substance Involvement Test (ASSIST).¹ The ASSIST provides a risk score (low, moderate, and high) for each substance assessed.

2.5.8. Opioid use history

Opioid history was assessed using the following items: lifetime use of short-term opioids (# of times you took an opioid for less than 3 months), lifetime use of long-term opioids (# of times you took an opioid for more than 3 months), longest duration of daily opioid use, and most recent opioid use (name, dose, reason for use, and time since stopped).

2.5.9. Most recent opioid cessation experience

Participants were asked to recall the most recent time they stopped taking opioids and answered the following questions: did a physician recommend you stop taking opioids or did you stop on your own (check box), was a taper used to gradually reduce dose (yes/no), and was a different medication for pain initiated before stopping opioids (yes/no; if yes, name of medication).

2.5.10. Impact of stopping opioids on current pain, functioning, and mood

Using a 6-item scale developed by the researchers, participants were asked to rate how they are doing now compared with when they were taking opioids on the following clinical domains: pain, ability to do daily activities, overall quality of life, mood, anxiety, and sleep (eg, Compared to when I was taking opioids, my pain now is). Participants rated each domain from very much worse (–3) to very much improved (+3). For descriptive purposes, this scale was reduced to 3 response options: worse (–3 to –1), stayed the same (0), and improved (1–3); however, the original scale was used for correlation analyses.

2.5.11. Motives for future opioid use

Motives for future opioid use were assessed using the following questions: I wish I was still taking opioids (1 [strongly disagree] to 7 [strongly agree]), opioids worked better than other medications I have tried for pain relief (1 [strongly disagree] to 7 [strongly agree]), and how likely is it that you will start using opioids in the next year (1 [definitely will not] to 4 [definitely will]).

2.6. Qualitative data collection and procedure

All focus groups were held in an easily accessible private conference room at the University of Michigan Back and Pain Center between February and June 2017. Focus groups were conducted in-person by 2 trained interviewers (J.G. and M.D.). The number of participants in each group ranged from 5 to 6. We developed and refined a semistructured focus group protocol that used broad open-ended questions with follow-up probes as recommended by Krueger and Casey.²⁵ Questions were structured to elicit both individual responses (where each participant was asked to respond to the prompt) and more extended group discussion (where participants could respond to each other and elaborate on the topic). The focus group protocol explored the following domains: motivators for opioid cessation (eg, “*In your own words, tell me the story of why you decided to stop taking opioids*”), barriers to cessation (eg, “*What was your greatest fear when you thought about not using opioids anymore?*”), facilitators of cessation (eg, “*What was making you want to stop?*”), cessation experience (eg, “*Tell me about the biggest challenge you experienced while stopping*”), physician–patient communication (eg, “*If your physician recommended stopping opioids, what reason did they give for why he or she wanted you to stop opioids*”), and current pain management (eg, “*Think about your life now that you are no longer taking opioids. Tell me about some of the benefits of stopping*”).

Focus groups were audio-recorded and transcribed verbatim. When speaking initially, each participant stated an ID number that could be used to identify their voice. Extensive field notes also documented the speaking order so that quotations could be attributed to the correct participant. Consistent with qualitative

approaches, preliminary analysis occurred concurrently with data collection so that small changes could be made to the protocol as needed (eg, rewording or removing a repetitive question).

2.7. Statistical analysis

Descriptive statistics were calculated for the quantitative variables of interest. Bivariate associations were assessed using Pearson product–moment correlations for continuous–continuous associations, point–biserial correlations for binary–continuous associations, and phi coefficients for binary–binary associations. Independent samples *t*-tests were used to compare likelihood of resuming opioid use in the future. Significance was set at $\alpha = 0.05$. All analyses were conducted with IBM SPSS version 24 and StataC version 15.^{11,38} We analyzed the focus group interviews using an inductive, thematic analysis. Focus group transcripts were read in their entirety and discussed by 2 researchers (J.G. and M.D.) to grasp overall themes in the data immediately following each focus group. We used these initial discussions to formulate a list of salient codes to apply across transcripts. After all the focus groups were conducted and transcribed, we began line-by-line descriptive coding. During this process, codes were eliminated, added, and modified based on the content of the focus groups. Emergent themes were compared across individuals, within groups, and across focus groups. MAXQDA 12 software facilitated coding and data analysis procedures.²⁷

3. Results

3.1. Quantitative data

3.1.1. Sample demographics

A total of 49 patients completed the online survey. Sample demographics are provided in **Table 1**. Participants had a mean age of 49 years ($M_{\text{age}} = 49.3$, $SD = 10.2$), and 32 (65.3%) were females. The majority of participants were married (63.3%, $n = 31$) and identified as white (79.6%, $n = 39$). Approximately one-third of the sample had graduated from college (32.7%, $n = 16$), and less than half were currently employed (42.9%, $n = 21$). The most common primary pain condition for which participants were being seen was back pain (44.9%, $n = 22$). Most participants have experienced their primary pain for over a year (85.7%, $n = 42$), with over half reporting the presence of pain for more than 5 years (59.2%, $n = 29$). The 3 most commonly used current medications included nonsteroidal anti-inflammatory drugs (64.6%, $n = 31$), anticonvulsants (47.9%, $n = 23$), and serotonin and norepinephrine reuptake inhibitors (38.3%, $n = 18$).

3.1.2. Clinical characteristics of former opioid users

Scores on continuous measures of pain, physical functioning, fibromyalgia survey criteria, depression, anxiety, sleep, and substance use are presented in **Table 2**. Approximately one of 5 participants reported having high pain (22.5%, $n = 11$). Participants generally reported poor functioning, with 66.7% ($n = 32$) exceeding the clinically significant cutoff for poor functioning. Comorbid mental health symptoms were also common; 71.4% of participants ($n = 35$) met criteria for depression, and approximately one of 3 participants met criteria for anxiety (32.7%, $n = 16$). Scores on the PROMIS sleep disturbance scale were also elevated ($M_{\text{sleep disturbance}} = 14.1$, $SD = 2.9$). As seen in **Table 2**, 31% of participants ($n = 15$) reported being a current smoker and 32.7% ($n = 16$) indicated that they used to smoke cigarettes, but no longer do so. Approximately 31% ($n = 15$) of participants

Table 1
Sample demographics of former opioid users (n = 49).

Variable	M (SD)	Range	n (%)
Age	49.3 (10.2)	28-69	
Female			32 (65.3%)
Married			31 (63.3%)
White			39 (79.6%)
College graduate			16 (32.7%)
Employed			21 (42.9%)
Primary pain			
Neck or back pain			25 (51.0%)
Fibromyalgia			6 (12.2%)
Other musculoskeletal pain			5 (10.2%)
Complex regional pain syndrome			4 (8.2%)
Headache/migraine			1 (2.0%)
Other pain			8 (16.3%)
Length of primary pain			
Less than 3 mo			1 (2.0%)
3-6 mo			3 (6.1%)
7-12 mo			3 (6.1%)
More than 1 y but less than 5 y			13 (26.5%)
More than 5 y			29 (59.2%)
Current medication use			
NSAIDs			31 (64.6%)
Anticonvulsants			23 (47.9%)
SNRIs			18 (38.3%)
Muscle relaxants			12 (25.0%)
Benzodiazepine			10 (20.8%)
SSRIs			10 (20.4%)
Sleep aids			8 (16.3%)
Stimulants			4 (8.3%)

NSAIDs, nonsteroidal anti-inflammatory drugs; SNRIs, serotonin and norepinephrine reuptake inhibitors; SSRIs, selective serotonin reuptake inhibitors.

reported that they never consumed alcohol. Of those who do use alcohol, most use monthly or less (58.8%, n = 20). Of those who report any alcohol use, AUDIT risk scores were low on average (M_{AUDIT risk score} = 2.1, SD = 1.3). Most participants indicated a lifetime history of marijuana use (60.4%, n = 29), with 51.7% (n = 15) of those reporting lifetime use also reporting marijuana use in the past 3 months.

3.1.3. Opioid use history and most recent cessation experience

As seen in **Table 3**, when asked about lifetime use of opioids, the median number of times opioids were used short term was 6.0 times and for long-term use 2.0 times. The longest amount of time that an opioid was taken daily was a median of 410.5 days. Most recently, opioids were taken for a median length of 98.8 days, and participants stopped opioid use a median of 273.6 days before survey administration. The daily oral morphine equivalent for the most recent opioid used was a median of 20 oral morphine equivalent. The most common recently used opioid was hydrocodone (59.2%, n = 29); oxycodone (16.3%, n = 8) and codeine (12.2%, n = 6) were also commonly reported. The most common reason for recent opioid use was back pain (26.5%, n = 13).

Most participants indicated that they stopped taking opioids on their own (75.5%, n = 37) vs after the recommendation of a physician. A minority of these participants began taking

a different medication before going off opioids (18.9%, n = 7), including cannabinoids, ibuprofen, acetaminophen, Zolof, and gabapentin. Less than half of participants who stopped on their own tapered off of the opioids (37.8%, n = 14). The taper took a median of 14 days. Alternatively, 12 participants indicated that their physician recommended they stop taking opioids (24.5%). Of these participants, 41.7% (n = 5) were put on a different medication before stopping opioids, including baclofen, doxepin, Lyrica, Soma, and tramadol. Half of these participants tapered off of opioids (50.0%, n = 6) and the taper took a median of 44 days.

3.1.4. Impact of stopping opioids on key clinical domains

Participants were asked to report on their current pain, functioning, quality of life, sleep, and mood compared with when they were taking opioids (**Table 4**). Approximately half of all participants indicated that their pain and sleep stayed the same or improved (53.1%, n = 26; 46.9%, n = 23, respectively), and the other half reported pain and sleep are worse compared with when they were taking opioids (46.9%, n = 23; 53.1%, n = 26, respectively). A majority of participants reported improvement or no change in their ability to do day-to-day activities (61.2%, n = 30), overall quality of life (65.3% n = 32), and anxiety (63.3%, n = 31), compared with when they were taking opioids. Conversely, approximately one-third of participants indicated that their ability to do day-to-day activities (38.8%, n = 19), overall quality of life (34.7%, n = 17), and anxiety (36.7%, n = 18) are worse compared with when they were taking opioids. Similarly, the majority of former opioid users reported their mood improved or stayed the same (73.5%, n = 36), and about one of 4 participants indicated that their mood is worse (26.5%, n = 13) since stopping opioids.

3.1.5. Bivariate associations between clinical characteristics, cessation experiences, and perceived impact of cessation on outcomes

Table 5 displays post hoc analyses investigating the bivariate associations between clinical characteristics, cessation experiences, and perceived impact of cessation on outcome domains. Current pain severity was significantly associated with lower scores on pain, ability to do day-to-day activities, overall quality of life, mood, anxiety, and sleep since stopping opioid use. Current fibromyalgia survey criteria were significantly associated with lower scores on overall quality of life and anxiety since stopping opioids. Current depression was significantly associated with lower scores on anxiety and sleep since stopping opioids. Current anxiety was significantly associated with lower scores on mood and anxiety since stopping opioids. Current sleep problems were associated with lower scores on sleep since stopping opioids. In addition, self-initiated cessation was negatively associated with current tobacco use. Tapering was associated with lower current pain severity and with higher scores on change in mood after opioid cessation, indicating greater improvement. All other associations between tapering and self-initiated cessation and clinical outcomes related to opioid cessation were nonsignificant. Finally, current tobacco and marijuana use were not associated with outcomes after opioid cessation. Yet, we caution against a strong interpretation of these results due to the small sample size for this subset of patients (n = 49) and the post hoc nature of the analyses.

Table 2
Clinical characteristics of former opioid users (n = 49).

Variable	M (SD)	Range	n (%)
Pain severity	5.5 (2.1)	0.75-9.25	
Physical functioning	13.1 (4.2)	4-20	
Fibromyalgia survey criteria	12.9 (5.4)	3-31	
Depression	12.7 (5.6)	4-27	
Anxiety	7.9 (5.4)	1-21	
Sleep disturbance	14.1 (2.9)	7-20	
Tobacco use			
I do not smoke cigarettes and have never smoked.			18 (36.7%)
I used to smoke cigarettes but I no longer do.			16 (32.7%)
I smoke cigarettes some days.			4 (8.2%)
I smoke cigarettes every day.			11 (22.5%)
Alcohol use			
Never			15 (30.6%)
Monthly or less			20 (40.8%)
2-4 times a month			8 (16.3%)
2-3 times a week			5 (10.2%)
4 or more times a week			1 (2.0%)
AUDIT alcohol risk score (n = 34)	2.1 (1.3)	1-5	
Lifetime marijuana use			29 (60.4%)
Past 3 mo marijuana use (n = 29)			
Never			14 (48.3%)
Once or twice			6 (20.7%)
Monthly			2 (6.9%)
Weekly			1 (3.5%)
Daily or almost daily			6 (20.7%)

Higher scores on the continuous scales indicate greater symptom severity.

3.1.6. Future intentions to start using opioids

Approximately half of participants strongly disagreed that they wished they were still taking opioids (51.0%, n = 25). About 26% (n = 13) strongly disagreed that opioids worked better than other medications tried for pain relief, whereas 24% strongly agreed that opioids worked better (M = 4.1, SD = 2.3). In addition, about half of participants indicated that they definitely will not start using opioids in the next year (45.8%, n = 22). Responses on this item were dichotomized, such that scores indicating any level of likelihood were collapsed. Comparing individuals who indicated no likelihood with those indicating any likelihood of using opioids in the next year, there were differences in pain severity, with those indicating any likelihood of beginning opioid use again in the next year reporting greater pain severity (M_{no likelihood} = 4.8, SD = 2.1; M_{some likelihood} = 6.1, SD = 1.9, t [46] = -2.29, P = 0.027). There were no differences between groups in terms of current physical functioning (M_{no likelihood} = 12.8, SD = 4.2; M_{some likelihood} = 13.4, SD = 4.3, t [45] = -0.50, P = 0.619), fibromyalgia survey criteria (M_{no likelihood} = 12.6, SD = 7.0; M_{some likelihood} = 13.3, SD = 3.9, t [46] = -0.45, P = 0.656), sleep (M_{no likelihood} = 13.8, SD = 2.9; M_{some likelihood} = 14.2, SD = 2.9, t [45] = -0.51, P = 0.616), depressive symptoms (M_{no likelihood} = 13.1, SD = 6.5; M_{some likelihood} = 12.3, SD = 4.9, t [46] = 0.47, P = 0.641), or anxiety (M_{no likelihood} = 7.7, SD = 5.4; M_{some likelihood} = 7.7, SD = 5.5, t [46] = 0.02, P = 0.983). Current tobacco use was not significantly associated with likelihood of resuming opioid use in the next year (ϕ = 0.04, P = 0.791). Current marijuana use, however, was significantly negatively associated with likelihood of resuming opioid use in the next year (ϕ = -0.36, P = 0.013).

3.2. Qualitative focus group data

We conducted 4 focus groups with 24 total participants. The focus groups lasted an average of 98 minutes, with a range of 88 to 107 minutes. All participants described their motives and barriers for discontinuing opioids, experience with opioid cessation, and the benefits and challenges of stopping opioids. **Table 6** summarizes the primary themes and subthemes resulting from the qualitative analysis.

3.2.1. Factors that influenced motivation to stop opioids

3.2.1.1. Ineffective pain management

Most participants reported that opioids were insufficient or ineffective in managing their pain (eg, “It didn’t have any difference. They didn’t work.” [Participant 18]; “They started to lose their effectiveness, and I didn’t know where to go with that” [Participant 5]; “It’s not that it took the pain away, it just made me not care that I hurt. Like I could just push myself through” [Participant 9]). Some participants reported frequently increasing the dosage to experience more relief:

“I found myself taking more than one at a time, but taking more than one at a time would make me go to sleep. I was taking Vicodin, and I didn’t want to be asleep all day, but taking one wasn’t really helping, you know, and the pain was just so unbearable.” (Participant 17)

“But we kept going up and up, and there wasn’t much else to give me, at that point, and we knew I couldn’t stay on it forever” (Participant 2)

Table 3

Previous opioid use and opioid cessation experiences (n = 49).

Variable	n (%)	Median (Q1, Q3)	Range
Lifetime history of short-term opioid use (less than 3 mo)		6.0 (3.0, 10.0)	0.0-25.0
Lifetime history of long-term opioid use (daily for at least 3 mo)		2.0 (1.0, 3.0)	1.0-20.0
Longest duration of daily opioid use (in day units)		410.5 (182.4, 1444.8)	91.2-5289.0
Duration of most recent opioid use (in day units)		98.8 (58.4, 410.5)	5.0-5110.0
Time since opioid cessation (in day units)		273.6 (91.2, 730.0)	1.0-1460.0
Daily oral morphine equivalent before most recent opioid cessation (n = 23)		20 (11.25, 40)	5.0-200.0

Did a physician recommend that you stop taking opioids or did you decide to stop on your own?

My physician recommended I stop	12 (24.5%)		
Did your physician put you on a different medication for pain before you stopped opioids? (n = 12)			
No	7 (58.3%)		
Yes	5 (41.7%)		
What was the name of the medication? (n = 5)			
"Baclofen"	1 (20.0%)		
"Doxepin"	1 (20.0%)		
"Lyrica"	1 (20.0%)		
"Soma"	1 (20.0%)		
"Tramadol"	1 (20.0%)		
Are you still taking this medication? (n = 5)			
No	1 (20.0%)		
Yes	4 (80.0%)		
Did you taper? (n = 12)			
Taper	6 (50.0%)		
Just stopped	6 (50.0%)		
How long did the taper take? (in day units) (n = 6)		44.4 (14.0, 60.8)	7-243.2
I stopped on my own.	37 (75.5%)		
Did you start a different type of medication for pain before you went off opioids? (n = 37)			
No	30 (81.1%)		
Yes	7 (18.9%)		
What was the name of the medication? (n = 6)			
"Cannabinoids"	1 (16.7%)		
"Ibuprofen"	1 (16.7%)		
"Monthly lidocaine infusions and gabapentin"	1 (16.7%)		
"Tylenol"	1 (16.7%)		
"Zoloft"	1 (16.7%)		
"Gabapentin"	1 (16.7%)		
Are you still taking this medication? (n = 7)			
No	2 (28.6%)		
Yes	5 (71.4%)		
Did you do a taper? (n = 37)			
Taper	14 (37.8%)		
Just stopped	23 (62.2%)		
How long did the taper take? (in day units) (n = 13)		14.0 (7.0, 42.0)	2-182.4

Table 4
Impact of stopping opioids on clinical domains among former opioid users (n = 49).

Variable	n (%)
My pain now is...	
Worse	23 (46.9%)
Stayed the same	11 (22.5%)
Improved	15 (30.6%)
My ability to do day-to-day activities now is...	
Worse	19 (38.8%)
Stayed the same	20 (40.8%)
Improved	10 (20.4%)
My overall quality of life now is...	
Worse	17 (34.7%)
Stayed the same	16 (32.7%)
Improved	16 (32.7%)
My mood now is...	
Worse	13 (26.5%)
Stayed the same	20 (40.8%)
Improved	16 (32.7%)
My anxiety now is...	
Worse	18 (36.7%)
Stayed the same	18 (36.7%)
Improved	13 (26.5%)
My sleep now is...	
Worse	26 (53.1%)
Stayed the same	14 (28.6%)
Improved	9 (18.4%)

3.2.1.2. Negative impact on functioning and quality of life

Participants also described that opioids had negatively impacted their functioning and quality of life. For example, participants often did not feel safe or able to engage in daily activities (eg, “I didn’t feel safe getting in the car and driving” [Participant 5]; “I stopped because it seemed to control my body too much, and I didn’t like that idea where I couldn’t function too much” [Participant 7]). Impaired functioning included an inability to sleep or fear related to sleeping while taking opioids: “I was afraid to sleep because I would think I would die because of the opioids would put me in too far of a deep sleep” (Participant 7). Some participants had also experienced a negative impact or frequent fluctuations in mood that influenced their reasoning for quitting:

“I think you get off because you’re so mad for being so mean. So, you decide if I don’t take it, maybe I wouldn’t be so mean and evil to people. I mean, you do stuff that you just never thought in a million years you would say or do to the people around you that you know love you. That was the part that just really ate at me. It’s like I’m living on a pill.” (Participant 19)

“I was noticing a lot of mood changes because I would only take them in the evening. And then in the day I was like all the happy was gone. It was all used up at night, so I was just feeling really depressed.” (Participant 22)

3.2.1.3. Fear of addiction

Some participants described fear of addiction or overdosing as motivation to quit. Participants who were worried about addiction often had previous experiences with addiction (eg, family members or personal addiction) or had experienced some addiction/withdrawal while on opioids. For example:

“I could tell that I was getting addicted, so I wanted to get done with it.” (Participant 22)

“When I decided on my own, there was an element of fear about it, you know. I think there is somewhat of a psychological addiction too.” (Participant 4)

“I stopped because I’d been on them for so long, about 10 years. And I started abusing them, and I’ve got kids. And I was up to probably 25 pills a day, taking them all at once. And it was to the point where I’d pass out from taking so many. And probably on the, you know, death’s door there, you know. And I finally woke up once with my daughter over me, and, you know, that’s a wakeup call so... And it wasn’t the first time so. It was my choice as time to quit.” (Participant 21)

3.2.1.4. Stigma

Many participants described a desire to stop taking prescription opioids due to the stigma associated with opioid use. One participant explained:

“Because of kind of all the stigma and all that stuff, I didn’t really want to be on them for a prolonged period of time. So, my initial thought was probably that I was optimistic that I could find something else that was as effective without it being an opioid” (Participant 6).

For many, there has been a noticeable shift in the perceptions of opioid use among medical professionals and the broader community. For example, one participant observed: “I think the climate was different then, even in the medical community 20, 30 years ago. And now it’s just, you know, it’s a whole different climate” (Participant 18). Several participants had difficulty obtaining or filling prescriptions.

“They treated me like I was a dope fiend instead of a patient” (Participant 12).

“Before I could fill my prescription—which was a legitimate prescription and like I was getting it at the right time and everything—they had to make all these calls, and they kept looking at me from behind the [counter]. Do I really look dangerous? Like, I don’t know why the pharmacists feel like they’re... like are they the police force? It was like, if a doctor is prescribing it, it’s your job to fill it. Not to make me feel bad about my life” (Participant 21).

Stigma was salient enough that some hid their opioid use, and cessation, from family and friends: “I feel like the stigma is so great around opiates that like I kept it to myself that I was even quitting taking them. I just dealt with it myself” (Participant 22).

3.2.2. Barriers to opioid cessation

3.2.2.1. Fear of worsening pain

The majority of participants indicated that they were worried about increasing pain after stopping opioid use. For example, one participant who stopped use before a medical procedure described the anticipation he felt: “I was scared shitless. I thought that I was going to suffer for those 6 days, and then I thought that as soon as that test was over, I would have a pill ready to take as soon as I was done” (Participant 10). Even those who reported ineffective pain management were worried about increasing pain:

Table 5
Bivariate associations among study variables (n = 49).

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1. Pain severity	—																	
2. Physical functioning	0.51	—																
3. Fibromyalgia survey criteria	0.44	0.27	—															
4. Depression	0.31	0.29	0.43	—														
5. Anxiety	0.37	0.24	0.51	0.75	—													
6. Sleep problems	0.27	0.00	0.00	0.23	0.33	—												
7. Current tobacco use	0.21	0.03	0.34	0.05	0.17	0.06	—											
8. Any alcohol consumption	-0.03	-0.07	0.10	0.10	0.11	-0.18	0.06	—										
9. AUDIT alcohol risk score	-0.39	-0.41	-0.24	-0.25	-0.33	0.13	-0.03	—	—									
10. Lifetime marijuana use	-0.22	0.13	0.08	0.13	0.08	-0.08	-0.14	0.28	0.09	—								
11. Past 3-mo marijuana use	-0.02	-0.10	0.14	0.22	0.11	-0.04	0.06	0.16	-0.10	0.55	—							
12. Self-initiated cessation	-0.16	-0.18	-0.11	-0.05	0.03	-0.22	-0.34	0.03	-0.20	-0.04	-0.27	—						
13. Taper	-0.31	-0.16	-0.03	-0.16	-0.25	-0.05	-0.10	0.01	0.18	0.17	0.07	-0.11	—					
14. My pain now is...	-0.37	-0.18	-0.14	-0.26	-0.15	-0.24	-0.04	0.02	0.04	-0.01	-0.09	0.17	0.13	—				
15. My ability to do day-to-day activities now is...	-0.31	-0.16	-0.24	-0.24	-0.13	-0.08	0.06	-0.01	0.36	0.00	-0.08	-0.01	-0.03	0.65	—			
16. My overall quality of life now is...	-0.43	-0.23	-0.30	-0.25	-0.24	-0.14	0.08	0.07	0.39	0.13	0.07	0.04	0.23	0.71	0.72	—		
17. My mood now is...	-0.48	-0.11	-0.16	-0.26	-0.32	-0.19	0.00	-0.09	0.37	0.23	0.03	-0.08	0.34	0.59	0.66	0.65	—	
18. My anxiety now is...	-0.47	-0.08	-0.31	-0.34	-0.52	-0.18	-0.07	-0.13	0.34	0.13	-0.03	-0.05	0.21	0.53	0.53	0.57	0.82	—
19. My sleep now is...	-0.29	-0.07	-0.10	-0.35	-0.25	-0.35	0.03	-0.09	0.18	0.09	-0.06	0.15	0.18	0.76	0.64	0.60	0.74	0.70

Boldfaced values are significant at $P < 0.05$. Sample sizes vary due to missing data. *Current tobacco use* recoded to be 1 (*I smoke cigarettes some days* or *I smoke cigarettes every day*) and 0 (*I do not smoke cigarettes and have never smoked* or *I used to smoke cigarettes but I no longer do*). *Any alcohol consumption* was recoded to be 1 (\geq *Monthly or less*) and 0 (*Never*). *Past 3-month marijuana use* was recoded to be 1 (\geq *Once or twice*) and 0 (*Never*). *Self-directed cessation* was recoded to be 1 (*I stopped on my own*) and 0 (*My physician recommended I stop*). *Taper* was recoded to be 1 (*Taper*) and 0 (*Just stopped*) and combined across physician-recommended cessation and self-directed cessation. Pearson product-moment correlations are displayed for continuous-continuous associations. Point-biserial correlations are displayed for binary-continuous associations. Phi coefficients are displayed for binary-binary associations.

“Even though it didn’t seem to help, I was worried it would get worse”. (Participant 9)

“I knew I couldn’t stay on them forever, but yet the pain was excruciating, and I couldn’t do anything if they didn’t stop the pain. So, I was more afraid of what would happen to me after. If I could still function in my job.” (Participant 4)

Mixed-method analyses that integrated the quantitative results with the focus group data revealed that participants who stopped taking opioids without the guidance of a physician were most likely to describe a fear of worsening pain during cessation as a barrier.

3.2.2.2. Fear of impact on mood

Some participants reported that using opioids positively impacted their mood, making participants worried about depression and worsening mood after cessation. One participant explained:

“You could get through half of the day with the pain, and then when it got real bad, you’d take your pill and then the happy comes, and you could just make it on through. I started trying to figure out how was I gonna just make it through the rest of that day, you know, ways to do it, and it was very difficult. It was extremely difficult to do. It seemed like when you stop, you become depressed. I mean, you’re already depressed because you’re in pain, but there’s something about that... you just become depressed for no reason.” (Participant 19)

Other focus group participants agreed, referring to their opioid medication as “happy in a bottle” (Participant 21) and immediate “relief from depression” (Participant 23). One participant described taking more medication to experience relief from depression:

“I upped the meds on my own trying to see if that could help take some of the pain away that...it wasn’t working, and it did, but it didn’t really help with the pain, it helped with my mood. It made me happy.” (Participant 21)

These participants reported worry about worsening their depression during opioid cessation. As one participant explained, “I was really, really scared because I was also taking them to keep from thinking about the other problems I had. And being...they just kind of numbed me so I didn’t have to think about dying” (Participant 5).

3.2.3. Description of opioid cessation experience

3.2.3.1. Recommendations and guidance of physicians

Most patients stopped taking opioids without the recommendation or guidance of a physician. Some participants described that their physicians had discouraged them from quitting or wanted to increase their dosage:

“My doctor wanted to increase the dosage, but I had to go to work, and it was so painful at work. She wanted to increase it,

Table 6**Summary of themes and subthemes from focus groups.**

Theme	Subtheme
Factors that influenced motivation to stop opioids	Ineffective pain management Negative impact on functioning and quality of life Fear of addiction Stigma
Barriers to opioid cessation	Fear of worsening pain Fear of impact on mood
Description of opioid cessation experience	Self-initiated cessation was common Increased pain during cessation Experienced withdrawal symptoms
Pain severity, functioning, and quality of life after opioid cessation	Improvements in pain, function, and quality of life were common but not universal Importance of alternative pain management strategies

but at that point, you know, when you start increasing and increasing. No, no, no, no, no. I just got irritated and just quit.” (Participant 19)

Among those who had been recommended to stop opioid use, several had quit in preparation for a surgery or procedure or due to another medical condition (eg, *“I had stopped because I had liver issues, and they just asked me to stop for that reason. Everything came back okay with that...with the liver so, but I don’t want to go back on them”* [Participant 20]) or because the provider spoke with them about opioids being ineffective (eg, *“He said if it’s not doing any good, why take it?”* [Participant 11]). Several participants described being “coached” or “supported” through quitting. For example, 2 participants described their experiences:

“I was the one that brought it up to my physician, and he was very supportive, and so we’re trying another medication that is non-opioid.” (Participant 18)

“Well, he told me to contact him on email if I had any problems so he could slow down the taper or if I was fine maybe he could get me off it quicker, but I was always in contact with him.” (Participant 2)

Some of the participants who received guidance from a physician had received information from a pain specialist, not the prescribing physician. For example:

“The doctor who “took me off” or not forced me to come off of them but really was coaching me to come off them was not the doctor who prescribed them. It was a different doctor, and it was...it was part of that pressure of saying that these really aren’t good for you to be on and you need to get off them, but it was not the doctor that originally prescribed the medication in the first place.” (Participant 6)

“I first saw him for my neck, and he asked me at that time what I had been taking, and at that time I was still, you know, taking Vicodin and oxycodone, and he suggested...he said it doesn’t work anyway, does it? And I said no. And so he put me on medications that help with nerve pain.” (Participant 13)

3.2.3.2. Pain during opioid cessation

Many participants experienced worsening pain symptoms, as they tapered their opioid use:

“My pain was much worse because they really did work for me pain wise.” (Participant 22)

“I was learning about opioids, and I didn’t really want to take them, but every time, like after...between 5 and 6 hours after I took them, I would start to feel really painful. I would start to feel this body pain. I always had to make sure that pill was somewhere so that I didn’t have to experience that, you know, traumatic pain.” (Participant 10)

Not being able to find an effective treatment often meant spending more time trying procedures, surgeries, or other medications. For example, *“The pain has gotten worse and the fact that I’ve had to see more specialists and had to talk about more surgeries and more injections, and the injections didn’t really help me heal”* (Participant 12). Worsening pain and ineffective alternatives also had an impact on mood for some.

“I think what happened to me wasn’t a positive effect, it was a negative effect, was that my depression increased because at first I thought this is the way I’m gonna have to live the rest of my life. There’s nothing else that will work.” (Participant 13)

“I arrived at opioids after having taken a lot of other pain management medications before I got them, and so when this physician took me off opioids, they put me back on a medication that was similar to one of the medications I was on previously, and I had no confidence and have no confidence that it’s going to manage my pain as effectively as the opioids. It wasn’t like I just started taking opioids.” (Participant 6)

3.2.3.3. Withdrawal symptoms

Some participants experienced withdrawal symptoms that made quitting difficult to manage:

“I [had withdrawal] even though I tapered. Probably because I’d been taking it for so long and so much. It’s like skin crawling. Leg cramps, can’t stop moving them, and it lasted a long time. I ended up with anxiety attacks, still have them. I have to take medications for it” (Participant 21).

“It was really intense. I mean, that was the first time I felt like a drug addict because it was really, really hard... I was just like kicking at my bed and I had all this physical energy that couldn’t go anywhere” (Participant 22).

Table 7
Joint display of quantitative and qualitative findings of experiences after opioid cessation.

Quantitative measure	N (%)	Representative quote
Pain after opioid cessation		
My pain has improved or stayed the same	26 (53.1)	My pain has gotten a lot better. There is still some, but it's something I can manage without having to take something. (Participant 5) I don't feel any less pain. I didn't feel any relief when I was on it. I haven't felt a whole lot of relief being off it (Participant 18)
My pain has worsened	23 (46.9)	I definitely felt as though (the opioids) had lost their effectiveness, but I do think that they are still better than, even being less effective, I think they're still better than what I'm on now (Participant 6).
Functioning after opioid cessation		
My ability to do daily activities has improved or stayed the same	30 (61.2)	I can drive. (laughter) I would not drive while on...so physical aspects like that. I didn't feel safe getting in the car and driving. I mean, nobody told me not to, but... I didn't want to drive like that. (Participant 5)
My ability to do daily activities has worsened	19 (38.8)	I don't sleep. (Participant 19)
Quality of life after opioid cessation		
My quality of life has improved or stayed the same	32 (65.3)	I kind of like stayed to myself a lot [before], but after changing a lot of things, I became more sociable. A lot of things changed. I interacted a lot more with my family, went out a lot more. (Participant 3)
My quality of life has worsened	17 (34.7)	I was happier while I was on it and then not as happy when I wasn't on it. (Participant 22)

When integrated with the quantitative results, all participants in the focus groups who discussed experiencing withdrawal symptoms during cessation indicated they stopped taking opioids on their own, without the guidance of a physician. Participants reported not knowing what to expect while quitting or not knowing that they should taper to reduce withdrawal symptoms.

"I kind of just went on my own and just when my prescription ended I just stopped taking it. And I'd been taking it for a year, and I was taking 1 pill a night, so it wasn't like I was taking a ton of medication, but still, I had a pretty crazy night the first night that I stopped taking it. So, I think that if my doctor would have been helpful with some advice about tapering, that would have made it a lot easier." (Participant 22)

"I didn't have any fears, but when I stopped I had like 3 days of cold sweats, hot sweats, stuff like that. It was a pretty coming down thing. But you know, you got through it, but you just don't know that you're gonna have that stuff happening." (Participant 15)

3.2.4. Perceptions of pain severity, functioning, and quality of life after opioid cessation

3.2.4.1. Current pain management

See **Table 7** for a joint display of quantitative and qualitative findings of experiences after stopping opioids. After stopping opioid use, current pain, functioning, and quality of life were variable. Because opioids were ineffective in relieving pain for many participants, some described that their current pain was the same or better after stopping opioid use (eg, *"It blew my mind when I realized I didn't have the pain I had before when I was on opioids"* [Participant 10]). Some participants had identified treatments that were more effective (eg, *"One of my best*

painkillers is moderation, you have to know when to sit" [Participant 14]), whereas others are no longer dealing with pain:

"I felt no pain. It was unbelievable. I was like, this is...this is crazy. To this day, I don't have the pain I had. I have neck pain, shoulder pain, but I don't have that pain that was all over my body, that malaise, you know, that you feel? So, you know, I'm just really, really surprised. So, you know, I'm thinking maybe I was going through withdrawal, and that was causing it. I don't know what it is, but man do I feel better." (Participant 10)

Consistent with the quantitative results, some of the focus group participants are currently experiencing worse pain than when they were using opioids.

"As stigmatized as opioids can be, they're very effective. That just the way I would say it. I have not found, in working through a lot of different other non-narcotic medication, I have not found anything that's been as effective at assisting the pain as an opioid." (Participant 6)

He continued to explain that opioids give immediate relief, whereas alternative treatments often have a delayed effectiveness:

"Opioids work quickly where a lot of the other medications that I'm on, Cymbalta and various other ones that I've tried, you have to take them for a very long period of time before they become effective. It's frustrating knowing that I'm gonna be, you know, I'm gonna be back at my old pain level for at least, you know, 30 to 45 days before this other one may or may not work, and then we get to 45 days, and we evaluate it, and then we go okay, nope, that doesn't work, so let's try this other one, and again, it's that 30 to 45 a day. The opioids work and work very quickly." (Participant 6)

Furthermore, participants who reported that they quit taking opioids without the guidance of their physician in the quantitative data also frequently described in the focus groups that alternative treatments were not working or that there were no viable alternatives available.

Several participants reported a desire to start taking opioids again because they effectively managed pain. When asked if they would want to leave the clinic at this point in time with an opioid prescription, about half of participants agreed. In the first focus group, we asked “Let’s say you could walk out of here with an opioid prescription, how many of you would want to go back on opioids?” Participants from the first focus group explained their reasoning for wanting to resume opioids:

“I believe an opioid works. I know they work. To get the pain to stop, I know they work.” (Participant 6)

“To get the pain to stop.” (Participant 1)

Participants who stated they did not want another opioid prescription either had found an alternative that worked for pain relief (*“I finally found something that was effective,”* Participant 4) or were unwilling to risk opioid use (*“I’m still in pain, but I guess I just have to deal with it until we figure out something. I don’t think it’s a good choice for me,”* Participant 3).

3.2.4.2. Current functioning and quality of life

Consistent with the survey results, the majority of focus group participants reported that their functioning and quality of life stayed the same or improved after opioid cessation. Improvements included *“being more present and involved”* (Participant 9) and *“being more in control”* (Participant 8). For individuals who had experienced problems in sleeping or cognitive difficulty while taking opioids, functioning often improved. Similar results were described among participants who quit opioids because of the negative impact on their mood. One participant explained: *“I wasn’t so mean, pissed off at the world [after stopping], you know?”* (Participant 20).

Many participants described being able to spend more time being active, engaging with friends and family, and being able to work.

“I was missing out going places with my daughter and my grandson. I only have 1 grandson, 1 grandchild, you know, and they would go out, you know, and do things. And I’d be like, ‘I can’t, I can’t today. My neck is hurting so bad. I just gotta lay down.’ There were a lot of things that I missed, and there were a lot of things that I did go to when I was in pain anyway. And now I haven’t missed a football game, I haven’t missed a basketball game, you know, anything. They want to go somewhere and do something, I go.” (Participant 17)

A smaller group of participants described feeling increased pain and poorer functioning after quitting opioids (eg, *“I’m in a lot of pain”* (Participant 2)). Participants who were still experiencing the same or increased pain discussed feeling frustrated or disappointed that they still had not found an effective treatment. Two patients described this experience:

“You don’t know what’s gonna happen, what’s gonna stop this pain. Where do I turn to? And yeah, that’s stress. That’s a lot of stress because the pain’s still there. You’re taking the pills, and the pain is still there, and you stop taking the pills, and the pain is still there. And so, it’s just a vicious circle, and it’s very stressful, very stressful.” (Participant 17)

“I’d been on, you know, those pain meds for so long. It’s just like, what’s next?” (Participant 21)

4. Discussion

Chronic pain affects over 100 million people in the United States, and as the pendulum swings from pain control to drug control, we must ensure the response to the opioid epidemic does not cause harm.³⁴ This mixed-method study provides novel information about opioid cessation from the perspective of individuals with chronic pain who have successfully stopped taking opioids. Several important themes emerged from the focus groups and were supported by the quantitative data.

4.1. Motivators and barriers to opioid cessation

Participants described several reasons for wanting to stop opioids, including lack of efficacy, negative impact on quality of life, and concerns about addiction. In addition, participants wished they had known about the risks associated with long-term opioid use before starting. Major barriers to cessation were concerns about pain not being well managed and impact of cessation on mood. These findings are consistent with barriers identified by current opioid users from Frank et al.’s²⁰ qualitative study. Increasing motivation and decreasing barriers is critical for intervention development.^{2,17} This study offers a roadmap for targeting motivation by providing patients with information about the risks of long-term opioid use, including loss of efficacy over time and risk of addiction. As patients are presented with the rationale for stopping opioids, addressing concerns about the impact of cessation on mood will also be critical in allaying barriers. Some patients may be using opioids to self-medicate for depression.⁴⁰ Thus, for patients with comorbid mental health diagnoses, opioid cessation will pose unique challenges, unless psychiatric issues are targeted as part of the cessation process.

4.2. Pain, functioning, and quality of life after opioid cessation

When it comes to pain, functioning, and quality of life after opioid cessation, impact is not uniform: some are better off opioids, some stay the same, and some are worse. For instance, half of former opioid users reported their pain remained unchanged or improved after stopping opioids. However, the other half reported worse pain since stopping opioids. Similarly, about one-third reported their ability to perform day-to-day activities was worse since stopping opioids. What factors may lead some patients to do well after opioid cessation and some to do worse? Current pain severity was negatively associated with all postcessation outcomes, suggesting that persistent pain after cessation is a key modifiable risk factor. One possibility is that some patients who report worse pain and functioning after cessation were deriving benefit from opioids. If the benefits (eg, pain relief) outweighed the risks, perhaps a subset of patients should not stop taking opioids. Another important consideration is whether patients have found an effective treatment alternative to opioids. If patients lack alternatives to pain management, many will have persistent pain after cessation, even those not deriving clinically meaningful benefits from opioids. Finally, emotional factors may influence cessation outcomes. Current depression and anxiety were not significantly associated with lower scores for pain, functioning, and quality of life after stopping opioids. Yet, correlations suggest a small to moderate negative association between these variables, and the analyses were likely underpowered for small

effects. Also, lower scores on changes in mood and anxiety since stopping opioids were associated with lower scores on pain outcomes. Although these data are correlational, we can hypothesize that patients using opioids to self-medicate mood may experience a worsening in mood symptoms after cessation, which in turn could impact pain outcomes after cessation due to the bidirectional nature of pain and psychological distress.

4.3. Clinical implications

Providers should regularly reevaluate opioids with patients. However, a significant challenge is how to identify patients to taper. The CDC guidelines state that opioids should be tapered when risks outweigh benefits, but how to determine this ratio is not clear.¹⁶ Another challenge is how to initiate a conversation (ie, cue to action) about opioid cessation with patients they have determined could benefit from cessation. Importantly, a critical issue from the focus groups was being treated like an addict and the stigma associated with opioids. If patients come away feeling like they are seen as addicts, this “cue to action” is unlikely to be successful. Physician-initiated conversations about opioid cessation will impact the patient’s motivation to consider stopping opioids. Providers thus require tools to help them engage patients around the topic of cessation.

Unfortunately, there are limited data to guide provider and patient decision-making when it comes to opioid cessation. Some patients may benefit from a physician-assisted taper, whereas others may be able to stop without any assistance. Interestingly, most (75%) former opioid users in this study stopped on their own. On one hand, this suggests that patients are able to stop opioids without the help of a physician, and we found no association between stopping on one’s own and cessation outcomes. On the other hand, there are likely benefits to working with physicians to reduce opioids. Such benefits may include access to nonopioid medications, assistance with tapering, and general encouragement from the provider. Several unique themes emerged from the focus groups among those who stopped on their own, including fear of unmanaged pain, withdrawal symptoms during cessation, and no alternatives for managing pain. When opioids were stopped without direction from a physician, only 37% reported tapering (compared with 50% working with physicians). Tapering was associated with lower pain severity and higher scores on changes in mood after cessation, indicating greater improvement. Although definitive statements cannot be made, these results highlight potential benefits of working with a physician as well as tapering. Larger studies designed to test hypotheses about tapering and the role of physicians in supporting cessation are needed.

Participants in this study who indicated a likelihood of resuming opioids in the next year were more likely to report worsen pain after cessation. This drives home the point that insufficient pain management puts patients at risk of resuming opioids. To address this, opioid cessation interventions should include alternative pain management strategies in conjunction with opioid tapering. Alternatives such as nonopioid pharmacotherapy and evidence-based psychotherapy interventions such as cognitive behavioral therapy and acceptance and commitment therapy for pain may prove especially important in helping patients successfully transition off opioid medications.^{18,37,39}

Finally, 30.7% of former opioid users report current cigarette smoking, which is higher than the general population but comparable to smoking rates in patients with chronic pain.^{21,22} Somewhat surprising was the high rate of cannabis use, with 31.3% reporting past 3-month use and 12.2% reporting daily or

almost daily use. Observational studies suggest patients report using cannabis as a substitute for opioids,³ and so patients here may be using cannabis as a replacement for opioids. Another possibility is that the high rate of cigarette smoking and cannabis use reflects a reliance on addictive substances to cope with pain and mood. We found that current marijuana use was negatively associated with some likelihood of resuming opioids in the next year, corroborating the former hypothesis that marijuana may be used as an opioid replacement.

4.4. Strengths and limitations

The use of a mixed-method study design is a strength of this study, allowing us to compare participant scores using validated scales with details of participant experiences and beliefs. Use of mixed-method research is increasingly recognized as necessary to understand both the breadth and depth of complex phenomena.^{12,14,28} Themes from the qualitative focus groups confirmed several quantitative findings that can be tested in a larger, generalizable sample in future research.

This study also has several limitations. Patients were recruited from an outpatient pain center and a fibromyalgia workshop, suggesting these patients may have more long-standing and complex pain conditions. In addition, the majority of patients stopped on their own, so perhaps they were deriving less benefit or experiencing more side effects than patients who stopped after a recommendation from a provider. Another limitation is that these patients were required to have stopped taking opioids, making these findings not necessarily representative of patients who lower their opioid dosage but do not stop opioids. Finally, participants self-selected to participate. Therefore, the findings may not be generalizable to all former opioid users.

4.5. Conclusions and future directions

As awareness grows about the risks of opioid overprescribing, the need remains to develop and deliver treatments that effectively address pain and improve functioning in those with chronic pain while minimizing the individual and societal burden associated with opioids. Opioid cessation may be the best clinical path forward for many patients; however, as providers increasingly recommend stopping opioids, it is important to consider the patient’s experience. In this study, half of former opioid users reported their pain as better or the same after stopping opioids. However, this is not the case for all former opioid users, as 46.9% reported their pain was worse since stopping opioids. Importantly, current pain severity was associated with intention to resume opioids within the next year, suggesting poor pain management is a risk factor for returning to opioid therapy. Based on feedback from former opioid users, novel opioid cessation interventions must include individualized cessation messages that address barriers and pharmacological and nonpharmacological alternatives for pain management.

Conflict of interest statement

Dr D.J. Clauw has received consulting fees from Pfizer, Cerephex, Tonix, Abbott, Aptinyx, Daiichi Sankyo, Samumed, Zynherba, Astellas Pharma, Williams & Connolly LLP, Intec Pharma, and Therevance. He has also received research support from Pfizer, Aptinyx, and Cerephex. Dr D.A. Williams serves as a consultant to Community Health Focus Inc. He is also on the Board of Directors of the American Pain Society. Dr C.M. Brummett serves as a consultant to Tonix and Recro Pharma Inc,

receives research funding from the National Institutes of Health and UM Michigan Genomics Initiative, and has a patent for peripheral perineural dexmedetomidine. Dr A.L. Hassett has received research funding from Bristol-Myers (Princeton, NJ) and is a consultant for Lexicon Pharmaceuticals (The Woodlands, TX). The above disclosures are not associated with the content or preparation of this manuscript. The remaining authors (Drs J. Goesling, M. DeJonckheere, and J. Pierce) have no disclosures.

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