



## Research Paper

## Taking opioids in times of crisis: Institutional oversight, chronic pain and suffering in an integrated healthcare delivery system in the U.S.

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## ABSTRACT

**Background:** Opioid treatment for chronic pain has garnered heightened public attention and political pressure to control a devastating public health crisis in the United States (U.S.). Resulting policy changes, together with ongoing public and political attention, have pushed health care systems and providers to lower doses or de-prescribe and taper patients off opioids. However, little attention has been paid to the impact of such practice changes on patients who had relied on opioid treatment to manage their chronic pain. The aim of this article is to explore experiences with opioid-related care under aggressive tapering efforts and concomitant heightened monitoring and institutional oversight among patients with chronic pain in an integrated delivery system through in-depth interviews.

**Methods:** We interviewed 97 patients with chronic pain who were assigned to the usual care arm of the Pain Program for Active Coping and Training (PPACT) study. These patients had been prescribed opioids as part of their treatment regimens and taken opioids closely monitored by their health care providers. We followed the framework method for coding and analysing transcripts using NVivo 12.

**Results:** The experiences of these patients during this period of change can be understood through three interconnected themes: (1) many patients taking opioids experience debilitating physical side effects; (2) navigating opioid treatment contributes to significant emotional distress among many patients with chronic pain and; (3) the quality of patients' relationship with their primary care provider can be negatively affected by negotiations regarding long-term opioid treatment for chronic pain.

**Conclusion:** We highlight the importance of utilizing communication approaches that are patient-centered and include shared decision making during the tapering and/or de-prescribing processes of opioids and ensuring alternative pain treatments are available to patients with chronic pain.

## Introduction

Chronic pain, experienced by approximately 20% of U.S. adults (Dahlhamer et al., 2018; Pitcher, Von Korff, Bushnell, & Porter, 2019), causes suffering beyond physical pain. It can change perceptions of self and impacts relationships with others (Corbin & Strauss, 1987; Smith & Osborne, 2007; Snelgrove & Liosso, 2013). The importance of alleviating chronic pain has been recognized (Pizzo & Clark 2012), yet providing effective treatment remains a challenge (Roth, Geisser, & Williams, 2012; Schneiderhan, Clauw, & Schwenk, 2017). The aggressive marketing of opioids, relative ease of prescribing them and affordability of short-term opioid treatment helped fuel a rapid increase of such care over the last 30 years. A limited, yet widely cited case study was used as the primary evidence that opioids could be prescribed

safely as long-term pain relievers, easing the way for widely accepted use of opioids as long-term treatment for pain (Kolodny et al., 2015; Portenoy & Foley 1986).

Recently, the escalating public health crisis related to opioid use has drawn increased public attention to the risk for abuse, addiction and even death (Bonnie, Kesselheim, & Clark, 2017; Psaty & Merrill, 2017; U.S. Department of HHS, 2018). Among patients with chronic pain who are newly prescribed opioids for longer than 90 days, approximately 6% develop opioid use disorder, with the likelihood increasing dramatically with increasing duration and dose (Edlund et al., 2014). Diversion of physician-prescribed opioids is common (Compton, Boyle, & Wargo, 2015; Shei et al., 2015; Volkow & McLellan, 2016). In 2017, prescribed opioids accounted for 17% of all drug overdose deaths (National Institute on Drug Abuse, 2019). The social and economic

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costs of the opioid crisis have been well-documented (Florence, Zhou, Luo, & Xu, 2016; National Institute on Drug Abuse, 2019; Quinones, 2015) and calls to action have followed (Murthy, 2016). All 50 U.S. states have established prescription drug monitoring programs, eleven states have laws regulating pain management clinics, and six states have declared an opioid emergency (Rutkow & Vernick, 2017). In 2016, the Centers for Disease Control and Prevention issued guidelines for prescribing opioids for chronic pain which restricted dose levels and recommended clinical practices related to assessing harms of use and abuse, including urine drug testing for prescribed medications and other controlled prescription and illicit drugs (Dowell, Haegerich, & Chou, 2016).

These policy changes, together with ongoing public and political attention, have placed great pressure on health care systems and providers to lower prescription doses, deprescribe and taper patients off opioids. The experiences of patients with chronic pain have been sidelined in the face of the public health crises. Understanding their experience is critical to fully understanding opioid use beyond the predominant national conversation in the U.S. regarding addiction and abuse. One recent study investigated patient perceptions of how state-legislated opioid prescribing rules impacted their pain management among a small sample. It highlighted the disruptive power these policies had on patients' pain management and ultimately the importance of understanding further how new regulations affect patients' experiences (Al Achkar et al., 2017). Thus, an in-depth exploration of how individual patients are being affected by quickly changing opioid policies and practices is needed.

Our study used in-depth interviews to explore patients' experiences with long-term opioid treatment of chronic pain in an integrated delivery system. Kaiser Permanente (KP) is an integrated healthcare delivery systems in the U.S., in which primary, specialty, and hospital care, as well as pharmacy and laboratory services, are provided to health plan members. KP utilizes one electronic health record across all health care services. Our study interviewed 97 patients who had been prescribed opioids for pain and took opioids while closely monitored by their health care providers during a time of increasing pressures on providers to reduce opioid doses among patients who had often been on stable opioid doses for extended periods without identified safety concerns. We focus on stories patients with chronic pain shared about the effects of opioid use under aggressive tapering efforts, with heightened monitoring and institutional oversight. Specifically, we ask: In the midst of the opioid crisis and concerted efforts to lower prescription doses and deprescribe opioids, how do patients experience taking prescribed opioids for the treatment of chronic pain?

## Methods

### *Study setting and participants*

Data for this study were collected from March 2016 to March 2017 among patients with chronic pain who were randomized to the usual care group of the PPACT study at the Kaiser Permanente Northwest (KPNW) location. PPACT was a pragmatic clinical trial conducted at three Kaiser Permanente (KP) health care system sites which evaluated the effectiveness of a behavioural intervention in real-world healthcare settings (see DeBar et al., 2018 for more information about the study and its design). The study was approved by the KPNW Institutional Review Board, and all study procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation and with the Helsinki Declaration of the World Medical Association. Patients were eligible to participate in PPACT if they: (1) were 18 years or older, (2) were a KPNW health plan member with at least 180 days of membership, (3) had received long-term opioid treatment in the six months prior to recruitment (defined by at least two dispensings of long-acting opioids or at least a cumulative 90-day supply of short-acting opioids during any 4-month period within the 6

months prior to recruitment), and (4) were diagnosed with a pain-related condition in the 12 months prior to recruitment. In addition, at the time of screening and recruitment, to be eligible patients had to report a pain interference level of 4 or higher for the general activity item of the PEG scale, a validated, 3-item pain-intensity and pain-related interference composite measure assessing pain intensity, as well as pain's interference with enjoyment of life and general activity (Krebs et al., 2009, 2010). Reporting pain interference above this threshold suggested that opioid treatment was not fully successful in managing participating patients' pain.

### *Qualitative data collection*

This paper reports on a sub-study of the PPACT study based on qualitative interview data from participants who were randomized to the usual care group at the KPNW integrated delivery system. As part of the study activities for those who were randomized to the usual care group of the study, patients were given the opportunity to share their expert feedback about the chronic pain-related care they had received at KPNW during an in-depth, semi-structured interview. All KPNW usual care participants (119 in total) who enrolled from February 2016 to February 2017 were invited to participate in this one-time telephone interview with study staff. Ninety-seven participants completed the phone interview, which lasted between 20 and 60 minutes.

Participants were not compensated for their participation in the interview. Respondents met the eligibility criteria for the PPACT trial, as described above, and were at varying stages in their use of long-term opioids at the time of the interview (i.e., still prescribed, dosage decreased, completely tapered).

Telephone interviews were conducted by a member of the study team (AF) who has 20 years of experience in qualitative research. She had no prior relationship with any of the participants and was introduced to participants as a study team member. The interview guide contained seven questions that broadly prompted patients to share their experiences about receiving primary and pain care services at KPNW related to their chronic pain conditions (see appendix for interview guide). The interviews were recorded with participants' permission.

### *Qualitative data analysis*

For the analysis, we followed the framework method (Ritchie & Spencer, 1994, 2002), focusing on research participants' narratives about their opioid-related care experience that emerged throughout the interviews. All data were first transcribed, then coded and analyzed according to the five stages of this method. As part of the first stage (familiarization), the qualitative research team (IG, AF, CM) familiarized themselves with the data by reading transcripts and developed a coding dictionary reflecting categories emerging from the transcripts. As part of the second stage, identification of a thematic framework, the three researchers independently coded transcripts, met to discuss codes and definitions and revised the thematic framework based on their discussions. The coders agreed on four high-level themes (individual, institutional, relational factors and other) and nine sub-themes. The thematic framework was then applied by one researcher (IG) to all transcripts with help of the qualitative software NVivo 12 (stage 3). This researcher then selected the two codes that were relevant for answering the research question (individual factors: (1) personal experience of and relationship to chronic pain, (2) psycho-social effects of pain and pain care) and created a matrix by summarizing the data for each of the two codes and cases (each interview transcript was considered a case) (stage 4: charting). As the final step (stage 5: mapping and interpretation), the researchers met to review the content of the matrix and made connections across codes and cases resulting in the three themes discussed in the results section below.

**Table 1**  
Patient characteristics.

	Mean (SD) or N (%) (n = 97)
Age [mean (SD)]	61.3 (12.1)
Female	76 (78.4%)
Race	
White	90 (92.8%)
Black or African American	5 (5.2%)
Other	2 (2.1%)
<b>Co-morbidities</b>	
Chronic medical conditions	
Cardiovascular disorder	10 (10.3%)
Chronic pulmonary disease	10 (10.3%)
Hypertension	8 (8.2%)
Diabetes	6 (6.2%)
Two or more of above chronic medical conditions	12 (12.4%)
Mental health co-morbidities	
Depression	30 (30.9%)
Anxiety	20 (20.6%)
PTSD	5 (5.2%)
Other mental health diagnoses	3 (3.1%)
<b>Non-malignant chronic pain (NCP) types</b>	
Back and neck pain	58 (59.8%)
Fibromyalgia and general pain	56 (57.7%)
Limb/extremity pain, joint pain and arthritic disorders	53 (54.6%)
Other types of pain	46 (47.4%)
Two or more of above NCP types	61 (62.9%)
<b>Outpatient utilization</b>	
Total primary care contacts in past 6 months [mean (SD)]	6.3 (4.6)

#### Electronic health records data collection and analysis

All participants in the PPACT study agreed to the use of their electronic health records (EHR) data for the 12 months prior to enrollment. EHR data was used to identify participants' demographic and clinical characteristics; these are summarized in [Table 1](#).

## Results

### Participant characteristics

Participant demographic characteristics are provided in [Table 1](#). The majority of participants were female (78.4%) and white (92.8%) and the mean patient age was 61.3 years (SD = 12.1); these demographics mirror the population who receive long-term opioid therapy for chronic pain ([Campbell et al., 2010](#); [Pletcher, Kertesz, Kohn, & Gonzales, 2008](#)). Over sixty percent of patients had been diagnosed with more than two conditions known to cause chronic pain; the most frequent diagnoses were back and/or neck pain (59.7%), fibromyalgia and/or widespread muscle pain (57.7%); and limb or extremity pain, joint pain and arthritic disorders (54.6%).

### Qualitative interview themes

Through analysis of the interviews, we identified three main themes that captured the effects of opioid treatment on participants' health and well-being:

- (1) Many patients taking opioids for chronic pain experience debilitating physical side effects;
- (2) Patients with chronic pain experience significant emotional distress as a result of their opioid use; and
- (3) The quality of patients' relationships with their primary care providers can be negatively affected by negotiations around opioid-related treatment.

These themes emerged organically during the interviews and were not systematically assessed with all participants. They are presented here as they provide a meaningful shared experience for many patients with chronic pain who participated in our study. We describe each theme in detail below.

**Theme 1.** *Many patients taking opioids experience debilitating physical side effects.*

Opioids are prescribed to patients with chronic pain to aid in the process of achieving pain control. Patients emphasized that they perceived that opioids were successful in helping them manage their pain, but also experienced considerable physical side effects as a result of taking opioids.

These side effects interfere with everyday routines and activities such as sleep and sex as well as patients' ability to think clearly. One patient said that taking the medication at night time rendered her unable to sleep before 3:30am. Other patients described the side effects of taking opioids as so severe that they preferred living with pain over receiving opioid-related treatment: "I mean, a morphine patch. But I don't want to do that because it would scramble my brain. That's what my doctor and I talked about before. Increasing pain medication doesn't help with other things, you know. And so I just have accepted it. The mornings are the worst. And that's when the tears come and the frustration comes." Other patients requested a taper to bring an end to the side effects they were experiencing: "Tapering down was uncomfortable. They put me on like four different medications to kind of counteract that feeling. But I mean, my energy came back. Moods came back. I wasn't so down. I wasn't depressed. I wanted to do things. I felt like getting out more. And surprisingly enough, my pain was actually lower on a smaller dose than a high dose. And the only thing I can think of is when I was on a super-high dose, I did nothing but sit down and do nothing. And when I'm on a lower dose, I'm out doing things." Finally, some patients even initiated an unsupervised taper to bring an end to experiencing side effects: "And before I was on the pain killers, I was taking Aleve. And I went, you know, I wonder what would happen if I quit the pain killers and went back to taking Aleve. And within a few days my back quit hurting. My knees aren't hurting. My mind is much clearer because I'm not taking this stuff that...the pain killer that works on your mind. So I am doing so much better."

**Theme 2.** *Patients with chronic pain describe significant emotional distress as a result of their opioid use.*

Another reported result of opioid treatment was emotional distress, at times severe enough to prompt seeking mental health counselling. One cause of this distress was patient worry that stricter prescription regulations might limit their access to prescription opioids. The tight monitoring practices triggered by federal guidelines surrounding opioid treatments are a likely contributor to this. Patients perceived this monitoring as an impending threat to their well-being. When asked about additional support they desired from their primary care physician (PCP) for pain management a patient responded that: "The only thing I can think of would be more Vicodin. And he [PCP] says, you know, there are federal guidelines that keep us from giving more than x. And I haven't reached that level, yet. And I'm hoping I don't reach it, because I don't know what I'll do after that." Another patient explained their reasons for seeking mental health counselling to the interviewer as follows: "I would say it's probably a third of the reason that I decided I needed to get into counselling, because it's quite distressful. I know what it's like to have not enough medication and feel that you're being pushed to a place, mentally, emotionally, physically, that you either start thinking suicide thoughts or you start thinking what kind of illegal substances do I need to go for? And I hate that idea..."

For other patients, emotional suffering resulted from the social stigma associated with opioid use. They perceived that stigma from media portrayals as well as from their PCPs. In these instances, experiencing social stigma caused some patients to limit their reports of pain to the PCPs for fear of drawing attention or suspicion: "But part of

the problem is I have some serious concerns about my medication. Because the medication is not covering the pain, especially when I was in that acute stage when I could...I literally couldn't roll over in bed. I couldn't do anything. Like I said, I couldn't brush my hair. I couldn't do my job. And I was in panic mode, basically. You know, like god, this is awful. And there was no...nothing from her [PCP]. And, you know, I thought at least an increase in the medication would help. But I'm always afraid to even ask, because you always feel like you're demonstrating, quote-unquote, 'pain behaviour'. You know, the whole being on pain medication is a horrible thing. And it's nice that it helps. But the way you're treated and all the hoops that you have to jump through is just...is awful. And if I were diabetic and I needed diabetic medicine, I wouldn't be treated this way. And I firmly believe that."

Being on long-term opioid treatment also can be an emotional burden on patients who do not want to rely on medications for their well-being, as the following quote illustrates: "It's probably the biggest thing that gnaws at me every single day. You know, I hate having to take pain medication. But, you know, there are just times where I would just have to sit, all day long if I didn't, you know. So I probably...I guess I'm in the middle of the road with that, as to where you would put it on the spectrum, you know, it's...Well, I guess it's very helpful. But it's certainly not something I want to do. I wish there were something else." These quotes highlight the conflict between patients' reliance on opioids, which they perceive as positive for controlling their level of pain, and their understanding of the social unacceptability that recently has branded them as problematic patients and potentially at risk for opioid addiction.

**Theme 3.** *The quality of patients' relationship with their PCP can be negatively affected by negotiations around opioid-related treatment.*

The PCP plays a central role in negotiating and determining the opioid regimens of patients with chronic pain. Interviewees frequently described that their relationships with their PCPs increasingly centered around the issue of opioid prescriptions and consequently deteriorated. One patient described feelings of anger toward their PCP for enforcing a required opioid agreement: "I was taking Tramadol, which was very, very helpful. And then in January, I went to visit my daughter. In Tucson...It was in my hip. I have a bad hip. I'm in the queue for a replacement. And it was just I guess because I sit on the plane for two and a half hours. I don't know, but when I was down there I didn't have any medication with me. So my daughter's partner gave me – I can't remember – like a tranquilizer-type medicine. And it did help the pain. And when I got back, I went to see my provider and told her about it. Next thing I knew I was on an opiate agreement. And so, I've weaned myself off the Tramadol. Took it back into my provider. And I'm now just using Advil because I didn't want to...I did not want to be on that agreement. I found it insulting. And it irritated me and made me angry."

Another patient described that they did not feel like their PCP continued to see them as an individual, and instead regarded them primarily through the lens of potential opioid abuser: "I think I've been lumped in with a bunch of other people that I shouldn't be with, the abuse and things like that. And it's hurting me, who really desperately needs the medication. And it's...It just gets to a point where your tolerance goes. And they just don't work unless you get an increase in it. And I've tried everything, medication, that they've offered. I found out I was allergic to a couple of kinds. And some just...Most of it doesn't work. The particular one I'm on is the only one I've found out of the, oh, half a dozen that does work for me. But, you know, I get to this point where without an increase, not really much at all. So that's the only thing I can think of is doctors should be a little more discriminating when they decide to cut people off. [...] I know what happened is the CDC came out with guidelines. And she [PCP] is following those guidelines, which is probably due to [the fact that the] management wants her to follow those. And I've read them too. And I don't agree with all of it. So, you know, I'm stuck basically. [...] I mean, I'm to the point where I've considered changing my insurance to see if I can get

another doctor that would allow it."

Another patient explained that they felt that the pressure by the healthcare system to regulate opioid prescriptions undermined their ability to build mutual trust in their relationship with their PCP, particularly in light of a history of addiction: "Well, my pain level is still higher than is comfortable. [...] But I don't know if they would be more flexible with me or not. [...] But I do understand, you know, there are guidelines. I guess it's because I'm a person that can be trusted. It would really have to be trust, I think. I don't know if they could have any guidelines saying, well, you know, if they're two years sober, then – you know, then they qualify for this or that. I think it probably does have to be an individual thing. And I'm not a doctor hopper, you know. Just because it doesn't go the way that I would like it to go doesn't mean that I switch doctors. I don't do that. So I try to work with the one that I have and have them get to know me."

Other patients perceived that their reliance on medications for pain treatment reduced the intimate patient-provider relationship to a focus on upholding institutional protocols: "[Sighs] I loved my doctor, the last one I had, —. I really, really liked her because she was...She really connects to the patient. And it's pretty much like how do you feel? What do you think your care should be...and you know whatever? But being Western medicine as it is, you know... I got Percocet. So they put me on a green protocol, whatever that is. Like, oh, you've got to take this medicine. Because if you don't...We test your urine and if we find that it's not in your system, then you're selling it. You know, and it's like I don't need it every month. I take it maybe twice a month if I need to, because my knees really hurt really, really, really bad. And so it kind of conflicts a little bit, because they want to give you, you know, medication to solve all your problems."

## Discussion

Through in-depth interviews with 97 patients with chronic pain who had taken long-term opioids, we found that in the current social and regulatory context, opioid treatment does not resolve patients' pain-related suffering, but rather may channel it into other forms of intra- and interpersonal suffering. The suffering described – physical, emotional and interpersonal – serves as a reminder that chronic pain is a biopsychosocial phenomenon (Beneitez, 2017; Jackson, 2011). Patients described debilitating effects on their bodies, psyche and relationships with their PCPs.

This study contributes an important, and often absent, patient perspective to the current national dialog regarding opioids. Earlier studies have focused on the potentially devastating consequences of opioid use and addiction among both prescription and non-prescription opioid users (Firestone & Fischer, 2008; Mazhnaya et al., 2016; Stumbo, Yarborough, McCarty, Weisner, & Green, 2017; Yarborough et al., 2016). Other studies of prescription opioid users focus on PCP – patient communications about tapering opioids (Frank et al., 2016; Hughes et al., 2015; Matthias et al., 2013, 2017). The findings from our study resonate with an earlier study that found that changing opioid policies are disruptive to patients' pain management experiences and negatively impact the patient – provider relationship (Al Achkar et al., 2017). Al Achkar and colleagues' study was conducted among patients at federally qualified health centres, who are generally Medicaid insured or underinsured. The consistency of our findings with those of Al Achkar's study suggests that patients, regardless of insurance status, experience similar disruptions in their care when the primary focus of patient – provider interactions is about opioid prescribing; our sample of insured patients in an integrated health system voiced similar challenges. Further, our study emphasizes that policy changes not only affect patients' pain management experiences within the health care setting, as analyzed by Al Achkar et al. (2017), but disrupt their daily lives beyond the health care context. Patients, for example, may feel that they have to plan travel around refill dates of their opioid prescriptions.

Our interviews indicate that many patients continue to perceive opioids as a central tool in addressing chronic pain. In addition, patients find comfort in knowing they have continued access to opioid prescriptions as part of their pain treatment. Access to effective and affordable chronic pain treatment continues to be a challenge, and many patients rely on opioids as an accessible and affordable means to manage their pain. At the same time, patients generally understand the limits of opioid treatment in providing a long-term solution. Many patients describe severe physical side effects that negatively impact their daily life that they see as a direct result of their opioid treatment.

The interviews also reflect patients' high awareness of the institutional structures of power that they are embedded in—including a healthcare system striving to implement a CDC guideline and PCPs needing to follow regulations stipulated by their employer—and remind us that patients' reactions to suffering are formulated in response to these very power structures (Hollan, 1994; Kleinman & Kleinman, 1991; Ware, 1992). The public attention surrounding opioid addiction and related death has created pressure on politicians, health care systems and providers alike to respond quickly and decisively (Madras, 2017). Comments by participants reflect awareness of the current regulatory climate and ongoing stigmatization of opioid consumption which have contributed to heightened levels of physical, emotional and interpersonal suffering that adversely affect their overall health and well-being.

Other research studies that focus on the unintended consequences of tightening opioid prescribing highlight problems such as driving opioids user to illicit markets (Mendoza et al., 2016). Limiting access to opioids without expanding access to alternative treatment modalities is unlikely to result in harm reduction for patients (Kertesz & Gordon, 2019). Others note that prescription control is too narrow a platform for controlling opioid addiction (Mundkur, Gordon, & Kertesz, 2017). Drug supply may not be the primary driving force behind this crisis that has deep economic and social roots (Dasgupta, Beletsky, & Ciccarone, 2018).

There are research and clinical reports that health care system-imposed structures around opioid prescribing even when these include pressure to taper can sometimes improve patient-provider relationships (Matthias, Krebs, Bergman, Coffing, & Bair, 2014). Our research does not corroborate these findings, but points to an emerging distrust between patients and PCPs surrounding opioid related treatment. This is disconcerting as a positive relationship between patients and their PCPs is fundamental to good patient care, especially for patients with chronic pain (Brown, Stewart, & Ryan, 2003). This is also problematic in light of the broader care needs that many of these patients must navigate with their PCPs due to their multimorbidity (see Table 1). Thus, deteriorating PCP – patient relationships caused by tension and possible disagreements about opioid treatment have a risk of affecting broader health care needs for patients on opioid treatment by negatively affecting the overall PCP – patient care relationship.

Patients' experience of physical distress as a result of opioid consumption can be an important starting point to initiate personalized conversations about avoiding potentially harmful consequences of opioid consumption and, if desired, achieve opioid tapering. Existing research about patient – provider conversations already suggests that explicit discussion of harms and benefits of opioid consumption may decrease patients' reliance on such medications (Hughes et al., 2015; McCarthy, Cameron, Courtney, Adams, & Engel, 2015). Eliciting the individual experiences of patients during these conversations might improve the willingness of patients to further consider and engage in tapering of opioids.

Many patients' mental health suffered in response to what they perceived as the impending threat of opioid tapering. Fear was a prominent emotion that surfaced during the interviews – patients' fear of experiencing high levels of pain, fear of losing access to pain medication, fear of becoming an addict, and fear of experiencing stigma associated with opioid use. Empowering patients to participate in

decision-making about the deprescribing process can be an important way to alleviate patients' fears. Shared-decision making research provides guidance on how to achieve patient participation during these conversations (Jansen et al., 2016). Expanding institutional resources to achieve opioid tapering through for example pharmacist-led interventions might be beneficial to patients; yet more research is needed to understand patients' experiences of care in rapidly changing policy landscapes.

If lowering doses and tapering opioids remains the predominant public health response to the opioid crisis, it also is important – as mentioned above – to expand access to safe, effective, and affordable treatment alternatives. Patients will remain reluctant to taper opioids if PCPs are unable to offer alternative treatments that effectively address their chronic pain conditions. Non-pharmacological treatment options for chronic pain are available (Skelly et al., 2018), but integrating these into current health care system structures is challenging (Nahin, Boineau, Khalsa, Stussman, & Weber, 2016).

The emphasis that has been placed in the public health discourse on tapering opioids has drawn attention away from the possibility that opioids may also be prescribed and used safely and effectively for controlling non-cancer chronic pain for some patients (Chou et al., 2009). Critics of the 2016 CDC guideline have pointed out that not all recommendations were evidence-based and may have left patients with chronic pain without access to adequate analgesia (Busse et al., 2016; Pergolizzi et al., 2019). Our study illustrates the importance of seeking balanced solutions to the opioid crisis that meet the care needs of patients with chronic pain while also limiting harmful effects of opioids consumption as much as possible.

Our study has some limitations. We only interviewed trial participants for this sub-study who may be different from the broader population of patients with chronic pain. Data for this sub-study also were collected in one delivery system only (Kaiser Permanente Northwest) and patient narratives might not be reflective of patient experiences in other health systems. However, the fact that patients demonstrated a high level of awareness of national discourses and guidelines and saw these as central to their fears and concerns, suggests that patient reported experiences were trustworthy. More research is needed to understand how specific institutional context affects patient experiences of opioid-related treatment.

Patient narratives suggest that while patients may find opioids helpful for addressing physical suffering, they introduce new sources of physical, emotional and intrapersonal suffering. The socio-political circumstances within which patients continue to take opioids for chronic pain may contribute to the high levels of suffering patients experience. In addition to known side effects, patients also experience the burden of public discourse and associated institutional changes in opioid prescriptions as extremely stressful, placing a burden on their emotional health and relationships with their primary care providers. Chronic pain is a biopsychosocial phenomenon, requiring multi-faceted approaches and solutions.

#### Declaration of Competing Interest

None.

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## Appendix

### PPACT: Patient Feedback Survey for Participants in the TAU Group

Thank you for taking the time to speak with me today. We will be conducting the “expert feedback” interview that was described to you as part of your participation in the study.

Before we get started I would like to know if I have your permission to audio-record the interview and have it transcribed. We want to be able to understand your experience as best we can. If you do not wish to be audio-recorded, we can still do the interview and I will not record it. Quotes from the interview may be used in presentations or publications of research results but will not identify you in any way. All recordings will be destroyed at the end of the study.

#### Verbal Consent to Audio-Record and Transcribe

Please say ‘YES’ that we have your permission to audio-record and transcribe this interview.

Yes, patient gives permission to audio-record and transcribe the interview.

#### SCRIPT FOR INTERVIEWER ADMINISTERED

We'd like to understand how Kaiser Permanente can best serve people with chronic pain. I'm going to ask you some general questions about your experiences with health care services at Kaiser. By services we mean any of your interactions with the Kaiser health care system. For example, office visits to your primary care provider or specialists, medications you've been prescribed, or even materials or handouts that you have received.

1. What are the things you do on your own to manage your pain?
  - a. IF PARTICIPANT DESCRIBES ACTIVITIES, ASK: How do the things you do to take care of yourself fit or conflict with the care that you receive from health care providers?
2. Which services provided by or paid for by Kaiser Permanente have been the most helpful to you in managing your pain?
3. Which services provided by or paid for by Kaiser Permanente have been the least helpful to you in managing your pain?
4. What is the most useful thing that Kaiser Permanente could do to help you manage your pain?
5. What is the most useful thing that your primary care provider could do to help you manage your pain?
6. What services would you like Kaiser Permanente to offer for managing your pain that are not currently available?
7. Please tell me anything else you'd like to share about your experiences with pain management services at Kaiser.

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