Attitudes and Beliefs of Working and Work-Disabled People with Chronic Pain Prescribed Long-Term Opioids

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Abstract

Objective. This study was designed to gain insight into the apparent contradiction between the perspectives of researchers and policy makers, who have questioned the efficacy and safety of chronic opioid therapy for non-cancer pain patients, and the patients themselves, who often indicate that the therapy has value.

Subjects. A convenience sample of 54 patients on chronic opioid therapy was studied.

Methods. Participants completed a questionnaire specifically designed for the study, and also several standard instruments that addressed functional interference, emotional functioning, and possible misuse of opioids. Their treating physicians rated the participants on the severity of their disability and the success of their opioid therapy.

Results. Although participants reported significant ongoing pain, they gave positive global ratings to their opioid therapy, and reported little concern about addiction or side effects of opioids. They strongly endorsed the beliefs that opioids helped them control their pain and allowed them to participate in important activities such as work. They expressed the belief that their pain would be severe if they did not have access to opioids, and reported negative experiences with tapering or discontinuing opioids in the past. Work-disabled participants reported higher levels of affective distress, catastrophizing, and functional interference than working participants, and were judged by their physicians to be relatively less successful in managing their pain.

Conclusion. The results of this study suggest several tentative hypotheses about why patients on chronic opioid therapy value opioids, and identified several areas for systematic investigation in the future.

Key Words. Beliefs; Long-Term Opioid Therapy; Misuse; Opioids

Introduction

The appropriateness of long-term opioid therapy (LOT) for chronic non-cancer pain (CNCP) has received substantial attention from researchers and policy makers. Short-term randomized controlled trials suggest that opioids reliably reduce pain, although the average reduction in pain is only about 35% [1,2] and functional improvement from opioids has not been consistently reported [3–5]. Moreover, clinical observation suggests that the maintenance of pain reduction appears to diminish over time [4,6] and many patients who are prescribed LOT drop out of randomized controlled trials [2] and open-label extensions [6]. Epidemiological studies have painted a bleaker picture—these studies have shown that use of opioids is a risk factor for poor functioning among people in the general population [7], and
for prolonged work disability among injured workers with workers’ compensation claims [8]. Poorer outcomes in rehabilitation programs for those prescribed opioids have also been reported [9,10].

Moreover, as opioids have been prescribed more liberally for CNCP over the past 2 decades, there has been growing concern about morbidity (e.g., impact on sex hormones, risk of fractures, opioid induced hyperalgesia) [11–15] and mortality associated with prolonged use and high dosages of opioids [16,17]. In response to these concerns, some jurisdictions (e.g., State of Washington) have initiated a process of retrenchment regarding opioid therapy [18]. The US Food and Drug Administration has initiated a policy that all long-acting opioids should have specific Risk Evaluation and Mitigation Strategies that include the availability of prescriber education [19,20].

In contrast to the skepticism and concerns about LOT among some prescribers, researchers, and policy makers, many patients seem to perceive LOT as beneficial and even essential. For example, in a web-based survey of fibromyalgia patients, 75% of respondents who had been prescribed hydrocodone/acetaminophen reported that the medication was “helpful,” and 67% of those prescribed oxycodone/acetaminophen found that medication helpful [21]. These ratings can be contrasted with clinical practice guidelines for fibromyalgia that specifically recommend against prescription of opioids [22]. The insistence by patients that they are deriving benefit from opioid therapy is frequently observed in clinical practice, and creates pressure for providers to prescribe opioids, even when they may be skeptical about the extent of the benefits of the medications.

Although a majority of chronic pain patients prescribed opioids continue to report high levels of pain, suggesting that their pain remains largely unrelied, they rate their medication as beneficial and even essential [23]. The apparent disconnect between the modest, if not questionable benefits of LOT found in research and the enthusiasm for LOT among many CNCP patients despite persistent high levels of pain highlights the need to understand the ways in which CNCP patients perceive these medications. Surprisingly, research on the perceptions of opioids among CNCP patients and the ways in which the patients use opioids has been relatively sparse. The most systematic study involved telephone interviews of over 1,100 patients from a managed care facility [24]. The interviews included a 15-item Prescribed Opioid Difficulties Scale to assess concerns that the patients had about LOT. Consistent with the previously mentioned web-based survey of fibromyalgia patients [21], the investigators found that 61% of participants reported that opioids were “very helpful” or “extremely helpful” in relieving their pain. Similarly, Watson et al. [25] studied a cohort of 84 CNCP patients on LOT and found that the patients generally indicated that opioids were effective, with the majority reporting that their medications caused at least a 50% reduction in their pain. Moreover, patients reported few significant long-term adverse effects of LOT. Finally, qualitative studies on small cohorts of patients with CNCP have suggested that many of them perceive LOT as beneficial, although they often feel criticized and stigmatized by others because of their LOT [26–28].

One possible explanation for the mismatch between perceptions of researchers and those of LOT patients is that the patients might be physically and psychologically dependent on opioids, or might be using them for reasons other than pain control and improved function. Although a proportion of LOT uses demonstrate misuse their opioids in various ways [e.g., 4 and 16], we believe that focusing on these patients draws attention away from the fact that many LOT patients without a history of abuse or addiction seem to value their opioids highly. This study was designed to provide insights into the attitudes and behaviors of nonabusing LOT patients by administering: (1) a detailed questionnaire that explored patients’ early experiences with LOT, their perceptions regarding the benefits they derive from opioids in several domains, their concerns about side-effects from opioids, and their interactions with family members and physicians regarding their LOT; (2) a standardized set of questionnaires to assess patients’ affective distress, activity interference because of pain, and concerns about opioids and potential misuse of opioids; and (3) a questionnaire that assessed perceptions of treating physicians of their patients who participated in the study.

Some patients receiving LOT appear to function well, in that they are able to continue working or engaging in other important roles despite their chronic pain and medication. In contrast, other LOT patients demonstrate significant disability despite the prescribed medication but who did not appear to be misusing them. In this study, we used “work status” as a proxy for the ability of LOT patients to function despite pain and opioid prescriptions. We hypothesized that working LOT users would differ from work-disabled ones in functional impairment and emotional functioning. Also, we anticipated that treating physicians would perceive the two groups differently, and would be more reluctant to continue prescribing opioids for work-disabled patients than for working ones.

Methods

Participants

A convenience sample of 54 patients receiving LOT at the University of Washington Center for Pain Relief (CPR), a tertiary care pain treatment facility, referred by their treating physicians participated in this study. Attending physicians were requested to refer any of their patients who met the following inclusion criteria: (1) presence of CNCP for at least 3 months; (2) current treatment with LOT for at least 3 months; (3) no psychiatric hospitalization in the 6 months prior to study...
Participants provided demographic information (e.g., age, sex, race) and descriptive information related to their pain history, current pain, and previous treatments received for their pain. They also completed a set of standardized questionnaires administered to assess domains related to their pain and opioid use. These measures were: (1) pain severity and pain interference scales from the Brief Pain Inventory (BPI) [29]—to measure pain intensity and functional impairment because of pain; (2) the Hospital Anxiety and Depression Scale (HADS) [30]—to measure emotional distress; (3) the Pain Catastrophizing Scale (PCS) [31]—to measure the severity of participants' tendency to catastrophize regarding their pain; (4) the Beliefs about Medications Questionnaire-Specific (BMQ) [32]—to measure participants' concerns about using pain medications, and the extent to which they consider medication use to be necessary; and (5) the Current Opioid Misuse Measure (COMM) [33,34]—to measure the likelihood that participants were misusing their opioids. Each of these instruments has been widely used with diverse chronic pain samples and has been shown to have very good to excellent psychometric properties.

Finally, participants completed the Opioid Beliefs and Behaviors Questionnaire (OBBQ), a 59-item questionnaire created by the authors specifically for this study to cover a wide range of beliefs and behaviors of participants in relation to opioids, initial experiences with opioids, changes in usage over time, interactions with their treating physician, perceptions about future treatment and current opioid regimen, and factors influencing their decisions to take as-needed doses. Twenty-seven of the questions were designed to cover five specific areas related to the potential impact of opioids, including perceived: (1) effectiveness and overall satisfaction with opioids for pain management, (2) functional benefits of opioids (e.g., helping with sleep and concentration), (3) social benefits of opioids (e.g., helping with getting along with other people), (4) side effects, and (5) worries and concerns about opioid treatment and continued use. All items of the OBBQ were assessed on a 0–10 scale (0 = completely disagree, 10 = completely agree).

Based on participants' self-reports of their working status, a binary categorical variable of “work status” was created. Participants who reported that they were working full-time (n = 11), were carrying out all duties as homemakers (n = 6), or were working part-time (n = 3) were categorized as “working,” while those who reported that they were categorized as “work-disabled from work because of their pain (n = 19) or had retired early because of pain (n = 8) were classified as “work-disabled due to pain.” The work status of seven participants was indeterminate (e.g., ones who reported that they were retired, but for reasons other than pain). The indeterminate group were included in analyses of the total sample but were excluded from the comparisons of working and work-disabled.

Treating physicians of study participants completed a questionnaire in which they indicated (1) their patient’s primary pain diagnosis and (2) his or her medication regimen, including opioids and other medications. The physician also rated the severity of the participant’s disability (1 = Completely Disabled to 7 = Fully Capable), how well they believed the participant was managing his or her pain (-3 = Very Poorly, 0 = About Average, and 3 = Very Well), how helpful they perceived the opioids were for the participant (-3 = Very Ineffective, 0 = About Average, 3 = Very Effective), and the likelihood that they would change the participant’s opioid regimen during the next 6 months (-3 = Almost Certain Not Change, 0 = Neutral, 3 = Almost Certainly Change).

Based on information provided by the treating physician, the daily dose of opioids was calculated for each patient. Specifically, the opioid calculator developed by the Washington State Agency Medical Director’s Group [35] was used to calculate a daily morphine equivalent dose (MED) for each participant.

Participants were paid a total of $25.00 for their time. The study was approved by the University of Washington Institutional Review Board.

Statistical Analyses

Descriptive statistics were calculated as means and confidence intervals (CIs) for continuous variables and percentages for categorical variables. Independent samples t-tests were conducted to compare working and work-disabled LOT users on all total scale scores for standardized questionnaires, and on several items of the OBBQ. Because these analyses were considered exploratory and descriptive, no corrections for multiple testing were made.

Results

Demographic and Psychometric Characteristics

Demographic and descriptive characteristics of the sample are presented in Table 1. The majority of the participants were white (85%), non-Latino (87%), and female (72%), with ages ranging between 25 and 79 years (M = 50, SD = 13). The mean age at pain onset was 30 years (SD = 12) and the average pain duration for the sample was 20 years (SD = 13). Primary pain diagnoses were provided by treating physicians. The largest number of participants (n = 27) were diagnosed with spinal pain. Other diagnoses were peripheral joint pain (e.g., shoulder, knee, n = 6), fibromyalgia (n = 5), visceral pain (mainly abdominal, n = 6), rheumatologic disorder (e.g., lupus, RA, n = 5), neuropathy (e.g., brachial plexopathy,
n = 3), complex regional pain syndrome (n = 1), and headache (n = 1). The average pain intensity was 5.65 (CI = 5.2–6.1).

The mean total scores and standard deviations for the standardized self-report measures (i.e., BPI, CPS, HADS, COMM, and BMQ) are summarized in Table 2. Total scores rather than subscale scores were analyzed for the PCS and the HADS.

Early Experiences with Opioids and Usage Patterns over Time

Twenty-eight percent of participants reported that they began taking opioids within 1 week of the onset of their pain, 30% during the first year after pain onset, and 42% more than 1 year after pain onset. Forty-one percent of participants indicated that they took opioids continuously after they were first prescribed, whereas, 33% reported a break in opioid therapy sometime after they started taking opioids, and 26% reported more than 1 break. Thirteen percent of participants noted that they realized they would be taking opioids for an extended time period within 1 month of initiating the therapy, whereas 56% did not come to this realization until a year or more after initiating the therapy. Participants reported having moderate levels of concern or worry about opioids when they started taking them (M = 4.1; CI = 3.1–5.1), and indicated that their opioids were initially effective in relieving their pain (M = 6.9; CI = 6.1–7.7). Forty-three percent of participants reported that their current dose of opioids was higher than the dose they took during the first 3 months of their opioid therapy, whereas 57% reported that their current dose was equal to (25.5%) or less than (34%) that dose. They rated the current efficacy of their opioids as slightly greater than it was when they started opioid therapy (M = 5.7; CI = 5.1–6.4).

Almost three-quarters of participants (35 of 47) reported that they had “cut back” on their opioids or “stopped them altogether” at some time since starting LOT. Of these individuals, 67% reported that they decided “on their own” to cut back; whereas 33% said their treating physician required them to do so. The 41 participants who reported cutting back on their opioids were asked about the results of their self-initiated taper. Six of them gave responses that could not be coded. Of the remaining 35 participants, 22 (63%) indicated that their pain increased, 7 (20%) reported specific withdrawal symptoms, and 3 (8.5%) reported negative outcomes (“ill,” “terrible,” and “tired”) that could not be coded specifically as either increased pain or withdrawal symptoms. Three participants (8.5%) reported no untoward effects of their opioid reduction.

Present Usage

The distribution of opioid doses was highly skewed. The mean MED was 174 (CI = 106–242); the median MED was 90 mg/day. Participants reported taking an average of 4.65 (SD = 2.4) pills per day; most reported a mixture of scheduled doses and doses taken on a prn basis. They gave ratings in the mid-range (not significantly different from 5.0) when asked how often they took doses
on the basis of their pain at the moment, or just before challenging activities in order to prevent pain. They were also asked how often they took opioids when they anticipated interacting with family or friends. Their mean rating (2.9; CI=2.0–3.8) indicated that they did this relatively infrequently.

Perceived Benefits of Opioids: Pain Relief

Participants rated (from 0 to 10) the extent to which opioids benefitted them in several domains (See Table 3). They did perceive opioids as reducing their pain. When asked about the effectiveness of opioids in providing pain relief during the previous 24 hours, their average rating was 6.4 (CI=5.8–7.0), where 0 = “no relief” and 10 = “complete relief.” As expected, they experienced significant relief shortly after taking pills, as indicated by their mean rating of 6.2 (CI=5.4–7.0) to the question: “How much benefit do you get shortly after taking an opioid pill?” They also made it clear that the prospect of being without opioids was threatening, as indicated by their mean rating of 8.9 (CI=8.6–9.2) to the question: “How much pain do you think you would have if you had not taken your opioids in the past 24 hours?” It should be noted that participants’ relief was far from complete, as indicated by their average pain levels of 5.6, and their rating of 6.1 (CI=5.2–7.1) in response to the question: “Do you think you would get better pain relief if your opioid dose was increased?”

Perceived Benefits of Opioids

Other. As far as other benefits are concerned, participants expressed their strongest agreement (M = 8.6; CI = 8.1–9.1) with the statement: “Opioids provide me with some control over my pain”. This rating was significantly higher (t = 3.67, P < 0.001) than the benefit given the second highest rating: “Taking opioids allows me to perform usual daily activities.” Other items to which participants gave relatively positive ratings were: “Taking opioids makes it easier for me to work at a job or home,” and “Taking opioids allows me to be less dependent on others.” They indicated only modest agreement (not significantly different from 5.0) to statements that opioids helped them participate in recreational activities, sleep, relax, concentrate better, feel less depressed, or get along better with people.

Perceived Adverse Effects of Opioids

Participants rated how concerned they were (0 = “not a problem” to 10 = “a very big problem”) about several potential adverse effects of opioids—constipation, drowsiness, dry mouth, confusion, reduced sex drive, and moodiness (Table 3). The adverse effect given the highest rating (M = 3.8, CI = 2.8–4.8) was constipation; the one given the lowest rating (M = 1.0) was confusion. Overall, the ratings were quite low suggesting that participants were not especially concerned about adverse effects of their opioids.

Social Interactions: Family Members and Friends

As noted above, participants expressed only moderate agreement (M = 4.4, CI = 3.4–5.4) with the item “Taking opioids improves my ability to get along with people,” and indicated that they rarely took opioids in preparation for social occasions. As far as support vs. conflict with family members was concerned, the vast majority (52/54 participants) reported that family members knew they were taking opioids. Their mean rating was 7.6 (CI=6.7–8.4) to the item “Do you think your family takes your pain seriously enough?” and 7.6 (CI=6.8–8.3) to the item “Does your family approve/disapprove of your taking opioids?” Thus, it appeared that the participants perceived their families as supportive. In response to the item “Has anyone ever told you that you should stop taking opioids for your pain?” 35% (19

Table 2 Scores on standardized questionnaires for all study participants, and for working vs. work-disabled participants

<table>
<thead>
<tr>
<th></th>
<th>All Participants (n = 54)</th>
<th>Working (n = 20)</th>
<th>Work-Disabled (n = 27)</th>
<th>t-test†</th>
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<tbody>
<tr>
<td></td>
<td>Mean + 95% Confidence Interval</td>
<td>Mean</td>
<td>Mean</td>
<td></td>
</tr>
<tr>
<td>HADS Total</td>
<td>12.6 (10.9–14.4)</td>
<td>9.7</td>
<td>14.7</td>
<td>t = 2.77*</td>
</tr>
<tr>
<td>PCS</td>
<td>31.5 (28.5–34.4)</td>
<td>25.6</td>
<td>36.8</td>
<td>t = 3.94*</td>
</tr>
<tr>
<td>BPI—Interference Scale</td>
<td>4.9 (4.2–5.5)</td>
<td>3.8</td>
<td>6.0</td>
<td>t = 3.68*</td>
</tr>
</tbody>
</table>

† t-tests compare working to work disabled participants (n.s. = nonsignificant). HADS, Hospital Anxiety and Depression Scale; PCS, Pain Catastrophizing Scale; BPI, Brief Pain Inventory.

* P < 0.01.

** P < 0.001.
Table 3  Scores on selected questions of the opioid beliefs and behaviors questionnaire for all study participants, and for working vs. work-disabled participants

<table>
<thead>
<tr>
<th>All Participants</th>
<th>Working (n = 20)</th>
<th>Work-Disabled (n = 27)</th>
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<tbody>
<tr>
<td>(n = 54)</td>
<td>Mean + 95%</td>
<td>Mean</td>
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<tr>
<td>Confidence</td>
<td>Mean</td>
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<td>Interval</td>
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<tr>
<td>When you first started taking opioids, were you concerned or worried about taking them?</td>
<td>4.1 (3.1–5.1)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>When you first started taking opioids, how effective were they in relieving your pain?</td>
<td>6.9 (6.1–7.7)</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>Compared to when you first started taking opioids, how effective are your opioids now in controlling your pain?</td>
<td>5.7 (5.1–6.4)</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>How often do you take an opioid pill based on your activities at the time?</td>
<td>5.0 (4.1–5.9)</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>How often do you take an opioid pill just before a challenging physical activity, so that you can stay ahead of your pain?</td>
<td>5.1 (4.2–6.0)</td>
<td>3.8</td>
<td>6.0</td>
</tr>
<tr>
<td>How often do you take an opioid pill when you know you are going to be visiting with family, friends, or relatives?</td>
<td>2.9 (2.0–3.8)</td>
<td>1.4</td>
<td>4.3</td>
</tr>
<tr>
<td>In the last 24 hours, how much relief from pain have your opioids provided?</td>
<td>8.9 (8.6–9.2)</td>
<td>7.0</td>
<td>5.7</td>
</tr>
<tr>
<td>How much benefit do you get shortly after taking an opioid pill?</td>
<td>6.2 (5.4–7.0)</td>
<td>n.s.</td>
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<tr>
<td>How much pain do you think you would have if you had not taken your opioids in the past 24 hours?</td>
<td>8.9 (8.6–9.2)</td>
<td>8.4</td>
<td>9.1</td>
</tr>
<tr>
<td>Do you think you would get better pain relief if your opioid dose was increased?</td>
<td>6.1 (5.2–7.1)</td>
<td>5.0</td>
<td>7.2</td>
</tr>
<tr>
<td>Opioids provide me with some control over my pain</td>
<td>8.6 (8.1–9.1)</td>
<td>9.2</td>
<td>8.1</td>
</tr>
<tr>
<td>Taking opioids allows me to perform usual daily activities</td>
<td>7.3 (6.7–8.0)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Taking opioids makes it easier for me to work at a job or at home</td>
<td>7.1 (6.3–7.9)</td>
<td>8.1</td>
<td>6.4</td>
</tr>
<tr>
<td>Taking opioids allows me to be less dependent on others</td>
<td>6.8 (5.8–7.7)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Taking opioids allows me to participate in recreational activities that I enjoy</td>
<td>5.8 (4.8–6.7)</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>Opioids help me sleep</td>
<td>5.6 (4.6–6.6)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Opioids help me relax, and reduce my stress level</td>
<td>5.0 (4.1–5.9)</td>
<td>4.0</td>
<td>5.8</td>
</tr>
<tr>
<td>Opioids allow me to concentrate better</td>
<td>4.8 (3.8–5.8)</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>Opioids help me feel less depressed</td>
<td>4.5 (3.5–5.6)</td>
<td>3.5</td>
<td>5.7</td>
</tr>
<tr>
<td>Taking opioids improves my ability to get along with people</td>
<td>4.5 (3.4–5.4)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Severity of problems with opioid side effects: Constipation</td>
<td>3.8 (2.8–4.7)</td>
<td>n.s.</td>
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<tr>
<td>Severity of problems with opioid side effects: Sleepiness</td>
<td>2.4 (1.6–3.2)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Severity of problems with opioid side effects: Confusion</td>
<td>1.0 (0.5–1.4)</td>
<td>n.s.</td>
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<tr>
<td>Severity of problems with opioid side effects: Dry mouth</td>
<td>2.8 (2.0–3.6)</td>
<td>n.s.</td>
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<tr>
<td>Severity of problems with opioid side effects: Reduced sex drive</td>
<td>3.1 (2.2–4.0)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Severity of problems with opioid side effects: Moodiness</td>
<td>1.9 (1.3–2.6)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Do you think your family takes your pain seriously enough?</td>
<td>7.6 (6.7–8.4)</td>
<td>n.s.</td>
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<tr>
<td>Does your family approve/disapprove of your taking opioids?</td>
<td>7.6 (6.8–8.3)</td>
<td>n.s.</td>
<td></td>
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<tr>
<td>Do you think your doctor is taking your pain seriously enough?</td>
<td>8.1 (7.3–9.0)</td>
<td>n.s.</td>
<td></td>
</tr>
<tr>
<td>Have you had any conflicts with any doctor who has prescribed opioids for you about your prescriptions for opioids?</td>
<td>2.8 (1.8–3.8)</td>
<td>n.s.</td>
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</table>

5.0 (4.0–6.0) 3.6 6.0 t = 2.59*
participants) responded “Yes.” Ten of them attributed the admonition to a physician; five to a family member; two to a friend; and two to other people. Thus, a small percentage of participants reported receiving pressure from family members regarding their opioid use.

Social Interactions: Physicians

Participants gave high ratings (M = 8.1, CI = 7.3–9.0) to the item “Do you think your doctor is taking your pain seriously enough?” and low ratings (M = 2.8, CI = 1.8–3.8) to the item “Have you had any conflicts with any doctor who has prescribed opioids for you about your prescription for opioids?” These responses suggested smooth interactions between the participants and their physicians. However, almost half of the participants (25/54) indicated that they had asked their physician for a dose increase. Also, 46% answered “Yes” to the item “Has a doctor ever expressed concern about your use of opioids?” These responses suggested some tension between participants and their physicians (though not necessarily the physician currently treating them).

Worries and Future Prospects

Participants were asked how concerned they were about various possible adverse consequences of their opioid use. They expressed moderate levels of concern that opioids might lose their effect over time (M = 5.0, CI = 4.0–6.0), and that their physician might refuse to continue prescribing them (M = 4.6, CI = 3.5–5.7). They expressed low levels of concern about addiction/opioid dependence (M = 3.7; CI = 2.7–4.6), side-effects of opioids (M = 2.6; CI = 1.8–3.3), and negative perceptions that others might have of them because of their opioid use (M = 2.5; CI = 1.6–3.4). As far as the future was concerned, participants expressed moderate agreement (M = 5.3, CI = 4.2–5.9) with the item “Do you think you will need higher doses of opioids (in the future)?” and 45 participants (86%) reported that they did not think they would ever be able to stop taking opioids.

Overall Satisfaction

Although, as noted above, participants’ pain levels were substantial despite their LOT (M = 5.6) and they indicated that they would get better pain relief if they had higher opioid doses, they expressed high levels of overall satisfaction with their opioid regimens. They indicated that opioids were effective in managing their pain (M = 7.8, CI = 7.3–8.4), expressed a high level of agreement with the statement “Taking opioids improves the quality of my life” was 8.1 (CI = 7.4–8.7), and gave a mean rating was 8.4 (CI = 7.9–8.9) to a global

Table 3 Continued

<table>
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<th>Concerns or worries about opioids: They may lose their effect over time</th>
<th>All Participants</th>
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<tr>
<td></td>
<td>Mean</td>
<td>95% Confidence Interval</td>
<td>Mean</td>
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</tr>
<tr>
<td>Concerns or worries about opioids: Physician will stop prescribing opioids</td>
<td>4.6 (3.5–6.7)</td>
<td>3.6</td>
<td>6.0</td>
<td>t = 2.59*</td>
</tr>
<tr>
<td>Concerns or worries about opioids: Addiction/dependence</td>
<td>3.7 (2.7–4.6)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Concerns or worries about opioids: Side effects of opioids</td>
<td>2.6 (1.8–3.3)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Concerns or worries about opioids: How others will view you</td>
<td>2.5 (1.6–3.4)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Do you think you will need higher doses of opioids in the future?</td>
<td>5.1 (4.2–5.9)</td>
<td>3.6</td>
<td>6.0</td>
<td>t = 2.59*</td>
</tr>
<tr>
<td>Taking opioids improves the quality of my life</td>
<td>8.1 (7.4–8.4)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Overall, how effective have opioids been in managing your pain?</td>
<td>7.8 (7.3–8.4)</td>
<td>8.6</td>
<td>7.4</td>
<td>t = 2.11*</td>
</tr>
<tr>
<td>Overall assessment of your opioid regimen</td>
<td>8.4 (7.9–8.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

† t-tests compare working to work-disabled participants (n.s. = nonsignificant).
* P<0.01.
** P<0.001.

Beliefs about Opioid Use

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Comparisons between Working and Work-Disabled LOT Participants

We used work status as a proxy for the ability of participants to function despite their pain. Several comparisons were made between the 20 participants who reported that they were working vs. the 27 who reported that they were disabled from work. Work status of seven participants could not be assessed (e.g., ones who reported that they retired for reasons other than their pain). As indicated in Table 1, working and work-disabled participants did not differ significantly in gender, education level, or average opioid dose. Work-disabled participants had lower incomes than working ones, were younger, reported that their pain had started at an earlier age, and reported higher average pain levels. Analyses on standardized instruments (Table 2) revealed that work-disabled participants had significantly higher scores than working ones on the HADS, CPS, and BPI. The two groups did not differ on the BMQ or the COMM.

On the OBQQ, working participants reported better pain relief than work-disabled ones from their opioids during the previous 24 hours, more strongly endorsed statements that opioids gave them control over pain and made it easier for them to work, and gave higher ratings to a global question about the effectiveness of opioids in managing their pain.

Work-disabled participants expressed greater agreement with items “Opioids help me feel less depressed,” and “Opioids help me relax, and reduce my stress level.” They were more likely than working participants to take an opioid dose as a way of preventing anticipated pain in the future, or when they were going to visit family or friends. They gave higher ratings to a question about how bad their pain would have been during the previous 24 hours if they did not have opioids. Also, they expressed greater agreement with a question about whether an increase in their opioid dose would produce better pain relief; more worry that in the future their opioids would lose their effect, and greater agreement with the item: “Do you think you will need higher doses of opioids in the future?” Working and work-disabled participants did not differ with respect to their perceptions regarding the extent to which their physician took their pain seriously, the frequency with which the physician had expressed concern over their opioid use, the amount of conflict they had with their physician about opioids, or their worry that their physician might stop prescribing opioids in the future.

Physicians’ Perceptions of LOT Participants

When treating physicians were asked to rate how disabled their patients were from 1 (completely disabled—needs assistance with almost all activities of daily living) to 7 (fully capable of engaging in work, family, and recreational activities), physicians’ mean rating was 4.7 (C.I. = 4.2–5.1), slightly above the midpoint of the scale). They also gave mildly positive ratings when asked to rate how well their patients were managing their pain, and how much benefit they were getting from their opioids. Physicians gave quite different ratings to working vs. work-disabled patients. As might be expected, working patients were rated as less disabled, as managing their pain better, and as being helped more by their opioids. Interestingly, when asked how likely they were to change patients’ opioid regimens during the next 6 months, treating physicians did not indicate different expectations for working vs. work-disabled patients.

Discussion

This exploratory investigation examined the beliefs, attitudes, and behaviors of patients who are receiving LOT and were not believed to be abusing or misusing their medications. It also examined treating physicians’ perceptions of their patients who were participating in the study. The study was undertaken to obtain detailed information about how and why patients not known to be misusing or abusing opioids use their medications, and to gain insights into their beliefs about their medications and how their medications influence their lives. There is a dearth of published literature on these subjects. Another goal of the study was to compare attitudes and beliefs of working patients to those of work-disabled patients.

The average pain intensity level of 5.65 (CI = 5.2–6.1) in our sample was somewhat lower than that given by chronic pain patients in some cohorts [36,37], but is consistent with that of patients treated at the University of Washington CPR [38]. Scores on the BPI interference scale of (M = 4.9, CI = 4.2–5.5) and the HADS total affective distress scale (M = 12.8, CI = 10.9–14.4) were somewhat lower than scores reported on other chronic pain cohorts [e.g., [39] and [40]]. Total PCS scores (M = 31.5, CI = 25.6–36.8) were comparable to those obtained by Sullivan et al. [41] in a cohort of patients evaluated at a pain center. COMM scores (M = 10.3, CI = 10.8–13.2) were comparable to ones obtained in a cohort of chronic pain participants by Butler et al. [42], when reporting on the development of the COMM.

A major purpose of the study was to explore the extent to which participants perceived a wide range of potential benefits and adverse effects from opioid therapy. They gave decidedly positive overall ratings for their opioid therapy, indicated that opioids relieved their pain, and identified several other benefits from their opioids. Specifically, they indicated that opioids provided them some control over their pain, and were effective in permitting them to function, to engage in daily activities, to work at a job or at home, and to be less dependent on others. We were interested in the possibility that chronic pain patients might find opioids helpful for a variety of other reasons—including beneficial effects on social
functioning, emotional functioning, cognitive functioning, and sleep. However, patients gave much lower ratings to these benefits than they did to items dealing with control over pain and ability to work and perform activities of daily living.

We were particularly interested in participants’ perceptions that regarding the influences of important people in their social environments. As patients with chronic pain often experience irritability, depression, and social isolation, we postulated that they might value their opioids in part because they perceived the medications as allowing them to interact more constructively with partners, relatives, and friends. As a corollary, we anticipated that they might take pm doses of opioids when they were planning to engage in social interactions. Our results did not support these hypotheses. Instead, consistent with the results reported by Skinner et al. [43] for Veterans in primary care recently prescribed opioids, they suggested that our participants did not view their opioids as having much value in promoting positive interactions with others, and did not routinely take opioids in anticipation of social engagements.

Another issue regarding the social environment is whether LOT patients perceive their immediate families as supportive of their opioid therapy. Previous research has pointed out the complexities of interactions between patients on LOT and family members, with some investigators noting the social support that these patients get from family members [44,45], and others pointing out conflicts that the patients have with family members [46–48]. Our participants appeared to perceive family members as supporting their use of opioids and taking their pain seriously.

Mistrust between prescribing physicians and patients on LOT has been noted by several investigators. Providers worry that they might cause their patients to become addicted, or that their patients might be exaggerating their symptoms in order to obtain opioids for nonmedical use [49–53]. Some LOT patients express concern that providers do not appreciate the extent of their suffering, and fear that treating physicians might stop providing their opioids [53,54]. Participants in our study indicated that their interactions with their physicians were generally positive. They perceived their physicians as taking their pain problems seriously, and denied having significant conflict with the physicians. However, there were some indications of tensions in their interactions with physicians regarding their LOT. For example, 45% of participants indicated that at least one physician had expressed concern about their opioid use. Moreover, they indicated a moderate level of concern that their treating physician might at some point refuse to continue prescribing opioids.

Almost half of our participants reported that they did not initiate LOT until a year or more after the onset of their pain, and more than half reported that they did not realize they would be on LOT until they had been receiving opioids for a year or more. Although we are unaware of any published data on this issue, our participants’ reports are consistent with our clinical impression that patients and physicians often slide unintentionally into LOT. That is, physicians often start prescribing opioids with the expectation that the therapy will be temporary, and renew prescriptions because patients report that they still need the medications. After this scenario has been repeated several times, the patients are in fact receiving LOT.

Another interesting finding was that 56% of our participants reported that they believed that they were taking the same amount of opioid or even less opioid at the time of the study than they had during the first 3 months of their LOT. We question the accuracy of our participants’ recall regarding their dosing, because other investigators have found that LOT patients increase their doses over time [23], and because our participants were, on average, taking substantial doses of opioids at the time of the study. But whether accurate or not, their perception that their doses had not increased, in conjunction with their perception that their opioids are about as effective now as they were at the initiation of LOT, may have contributed to participants’ low levels of concern about the risk of drug dependence or progressive opioid tolerance.

A surprising finding was that patients generally gave low severity ratings for several side effects of opioids, and expressed little concern about the impact of these side effects, the possibility of drug dependence, or the possibility of social stigma because they were on LOT. Their rather modest perceptions of negative aspects of opioid therapy were quite different those reported by other cohorts of LOT users [23,24,48,53]. A majority of participants reported tapering or entirely discontinuing their opioids at some time after they started LOT. Consistent with other research on chronic pain patients [55] and opioid addicts [56], they reported a litany of negative consequences when they made their attempts, with increased pain and opioid abstinence symptoms being most common. A related point is that patients indicated that they imagined their pain would have been very severe if they had not had access to opioids during the previous 24 hours. Given their negative past experiences and their dire expectations about being without opioids, it understandable that patients on LOT may well resist efforts by physicians to taper them.

In summary, our data paint a picture of LOT patients who found opioids helpful in providing control over their pain and promoting daily activities and work activities. In congruence with findings of other studies of LOT patients [24,25], our participants were generally satisfied with the effectiveness of their opioids. They were not especially concerned about adverse effects of opioids, and, contrary to findings in other studies on LOT patients [23,24,48,53], they did not express great
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concern about addiction to opioids. They perceived their families and their physicians as generally supportive of them.

We anticipated that work status, an objective indicator of success of LOT, would influence the way treating physicians perceived and interacted with LOT patients. Consistent with this expectation, treating physicians rated working participants as being less disabled, as managing their pain better, and as having received more benefit from their LOT than work-disabled participants. However, contrary to expectation, we found that working and work-disabled participants gave similar ratings regarding the extent to which their physician took their pain seriously, the frequency with which the physician had expressed concern over their opioid use, the amount of conflict they had with their physician about opioids, or their worry that their physician might stop prescribing opioids in the future. Thus, although ratings by treating physicians indicated that they viewed disabled patients as less successful than working ones, there was no support for our expectation that the work-disabled patients would experience less support from their physicians and more pressure to reduce their opioid intake.

It is also plausible to assume that work status would correlate with other indices of success of LOT, such as patients’ emotional functioning and perceptions regarding their LOT. Not surprisingly, work-disabled patients reported higher levels of pain, affective distress, catastrophizing, and functional interference than working ones. Also, they were more likely than working ones to indicate that opioids helped them feel less depressed and less stressed, and that they took opioids prior to visiting loved ones. In contrast, they were less likely to report that opioids provided them control over their pain, or that the medications permitted them to function better in daily activities or work. As a broad generalization, these results suggest that working patients value opioids because the drugs help them function and give them some control over their pain, whereas work-disabled participants value opioids because the drugs help blunt their affective distress. The results also raise the possibility that work-disabled participants were misusing opioids by taking doses to blunt emotional distress or function better in social situations, rather than to reduce pain.

Of the many findings described above, one of the most intriguing relates to the perception by participants that opioids gave them some control over their pain. This perception was shared by both work-disabled and working participants, although working ones were more emphatic. A related finding was that participants indicated great concern about the possibility of being without their opioids, as manifested by their ratings that their pain would have been substantially worse than it was if they had not had access to opioids during the previous 24 hours. This pattern of results suggests that LOT patients place great value on the control over pain that opioids provide, and fear being without opioids. It would not be surprising for participants to report that opioids gave them control over their pain if in fact their pain was well controlled. But it is paradoxical that our participants indicated that their opioids controlled their pain, while at the same time indicating substantial average pain intensity levels (M = 5.6). One way to resolve this paradox is to hypothesize that those participants who did not perceive short periods of pain relief after taking opioid doses and thus could exercise some control over their pain. This hypothesis is consistent with research showing that both chronic pain patients and pain-free adults value having control over painful stimuli, and experience the stimuli as less intense and less distressing when they can exercise such control [57–59]. It is also consistent with research showing that people adapt better to a wide range of stressors if they perceive themselves as having some control over the stressors [60]. The hypothesis that patients on LOT value opioids because the medications provide short periods of control over pain may explain why such patients report benefit from the medications, whereas research has not been especially sanguine about their efficacy. In research, especially research on functional outcomes of opioid therapy such as return to work, success is typically measured by improvements that accumulate over long periods of time. It is possible that CNCP patients value opioids because of repeated experiences in which opioids produce short-term benefit, even if they do not experience progressive benefit from opioid therapy that leads to long-term functional recovery. Research is needed to examine the validity of this interpretation.

Participants’ scores on the COMM were high, with 51% scoring in a range suggesting that they were misusing their opioids, and 30% receiving scores indicating “definite” misuse. This was surprising, as patients who were invited to participate in the study were not suspected by their treating physicians to be abusing or misusing their opioids. One possible explanation of the COMM scores was that patients had misled the treating physicians. This would be consistent with the observation that physicians are not good and predicting opioid misuse and abuse [61,62].

However, the results also raise questions about what scores on the COMM actually mean. Our data clearly suggest that study participants made their own choices about how to use their opioids. Other investigators have found that such behavior is common among patients on LOT [63]. In this respect, our results are consistent with research on the behavior of patients taking a wide range of medications, including many with no addictive potential [64]. Abundant data support the conclusion that patients often choose to take medications in ways that deviate from the instructions they are given about how to take the medications [65]. Although salutary attempts have been made to clarify the meaning of “misuse” and related terms such as “abuse” and “addiction” [66], the term still conjures images of patients on LOT who are deliberately deceiving their physicians or are addicted to...
their opioids. The term also has implications for the behavior of prescribing physicians. If a physician learns that his or her patient is misusing the opioids prescribed, the provider presumably has a responsibility to take corrective measures, such as refusing to continue prescribing opioids, or referring the patient to a drug rehabilitation facility. We believe that “misuse” and related terms should be deconstructed, so that relatively minor deviations from instructions are distinguished from more serious ones [67], and the strategies leading to various unauthorized behaviors are explicated. As an example of the complexity of behaviors that represent deviations from physician instructions, interviews with our participants revealed that several of them created “opioid budgets” that they construed as analogous to financial budgets. Specifically, they would take less than the prescribed amount of their opioid on most days, and save the residual doses to cover themselves when their pain levels were especially high. They communicated the sense that they perceived the strategy of saving some medication for a rainy day as a responsible, restrained pattern of use. Although this usage pattern puts patients at risk for overdoses, it does not, in our opinion, represent willful disregard of physician instructions implied by the term “misuse.”

This study was designed as a preliminary, descriptive investigation. Our goal was not to provide definitive answers but, rather, to identify issues that could be explored more rigorously in future research. Because of the exploratory nature of the study, it has several limitations. First, the participants in the study represented a sample of convenience, and most of them had received opioids from the same physician for an extended period of time at a tertiary care pain facility and had experienced pain for a long period of time. It is possible that differences between our cohort and the cohorts of LOT patients studied by other investigators might account for the fact that our participants were less concerned about adverse effects of opioids or the possibility of addiction than participants in other LOT studies [23,24,48,53]. They might also account for the relatively positive perceptions that our participants had of their interactions with treating physicians and significant others [49–53]. Second, although patients were nominated for participation in the study in part because they were not suspected of misusing or abusing opioids, scores on the COMM were quite high, suggesting that a significant proportion of them were actually engaging in aberrant behaviors regarding their opioids. Although, as discussed above, the meaning of high scores on instruments like the COMM is not entirely clear, it is possible that a basic goal of our study – to examine beliefs and attitudes of LOT patients who were not abusing their opioids – was not achieved. Third, the OBBQ was designed specifically for this study. Although the items on the questionnaire have face validity, we did not conduct preliminary research to assess its psychometric properties. Moreover, we did not have ancillary sources of data to determine the validity of participants’ responses to the OBBQ. Finally, since this was an exploratory study, we performed multiple univariate analyses to compare working vs. work-disabled patients. Thus, the probability of Type II errors is substantial.

Despite these limitations, we believe that our study raises several questions that deserve systematic investigation. To our knowledge, it is the first study to examine in depth behaviors and attitudes toward opioids among chronic pain patients who are believed to be responsible participants in opioid therapy rather than drug abusers. Among the many questions raised by our results, the following stand out: (1) Is the perception that opioids provide some control over pain central to the value that chronic pain patients place on the medications? (2) To what extent is the preference of patients to continue using opioids driven by fear of what might happen to their pain if they were without the medications? (3) Is it true that LOT patients tend to discount the severity of opioid adverse effects? If so, what kind of educational input might help them appraise opioids more realistically? (4) Is it the case that working LOT patients perceive opioids as providing control over pain and promoting their ability to function, whereas work-disabled patients perceive opioids as providing relief from emotional distress? Our hope is that this study stimulates investigation of these and several other questions that our results invite.

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