

Exploring the lived experience of adults using prescription opioids to manage chronic noncancer pain

Erica A Brooks BPHE MA¹, Anita Unruh BSc(OT) MSW PhD¹, Mary E Lynch MD FRCPC²

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BACKGROUND: Chronic noncancer pain (CNCP) and prescription opioid use is a highly complex and growing health care issue in Canada. Many quantitative research studies have investigated the effectiveness of opioids for chronic pain; however, gaps remain in the literature regarding the personal experience of using opioids and their impact on those experiencing CNCP.

OBJECTIVE: To explore the lived experience of adults using prescription opioids to manage CNCP, focusing on how opioid medication affected their daily lives.

METHODS: In-depth qualitative interviews were conducted with nine adults between 40 and 68 years of age who were using prescription opioids daily for CNCP. Interviews were audiorecorded and transcribed, and subsequently analyzed using interpretive phenomenological analysis.

RESULTS: Six major themes identified positive and negative aspects of opioid use associated with social, physical, emotional and psychological dimensions of pain management. These themes included the process of decision making, and physical and psychosocial consequences of using opioids including pharmacological side effects, feeling stigmatized, guilt, fears, ambivalence, self-protection and acceptance.

CONCLUSION: Although there were many negative aspects to using opioids daily, the positive effects outweighed the negative for most participants and most of the negative aspects were socioculturally induced rather than caused by the drug itself. The present study highlighted the complexities involved in using prescription opioids daily for management of CNCP for individuals living with pain.

Key Words: Chronic noncancer pain; Lived experience; Opioids; Pain management

Chronic pain is one of the most common reasons that individuals access the health care system (1,2) yet the management and treatment of it continues to be a challenge for the individual with pain and for health care providers (3). Chronic noncancer pain (CNCP) is a non-cancer-related pain that has been present for ≥ 3 months or lasts longer than would be expected to heal tissue or resolve the underlying disease (4). Some of the more common types of CNCP include osteoarthritis, rheumatoid arthritis, low back pain, shoulder and neck pain, headache, myofascial pain syndromes, chronic regional pain syndromes, phantom limb pain, neuropathic pain, diabetic neuropathy, temporomandibular joint disorder, angina pectoris and chronic visceral pain syndromes (5). CNCP has physical consequences (eg, decreased mobility, anxiety, lack of sleep, fatigue) and, over time, often psychological, emotional, social, occupational and recreational consequences (eg, impaired activities, including walking or being active, shopping, dressing, and maintenance of relationships and sexual activity, as well depression and an overall decreased quality of life) (6). In 2002, persistent pain affected approximately 29% of Canadians (7). A more recent telephone

Explorer l'expérience vécue par des adultes utilisant des opioïdes sur ordonnance pour gérer leur douleur non cancéreuse chronique

HISTORIQUE : La douleur non cancéreuse chronique (DNCC) et l'utilisation d'opioïdes sur ordonnance sont un problème de santé croissant et très complexe au Canada. De nombreuses recherches quantitatives ont porté sur l'efficacité des opioïdes pour soulager la douleur chronique. Cependant, il reste des lacunes dans les publications au sujet de l'expérience personnelle des opioïdes et de leurs répercussions sur ceux qui souffrent de DNCC.

OBJECTIF : Explorer l'expérience vécue par des adultes qui utilisent des opioïdes sur ordonnance pour gérer leur DNCC, en s'attardant sur les effets des opioïdes dans leur vie quotidienne.

MÉTHODOLOGIE : Les chercheurs ont réalisé des entrevues qualitatives approfondies auprès de neuf adultes de 40 à 68 ans qui prenaient quotidiennement des opioïdes sur ordonnance pour soulager leurs DNCC. Ils ont procédé à l'enregistrement sonore des entrevues, qu'ils ont transcrrites, puis examinées par analyse phénoménologique interprétative.

RÉSULTATS : Six grands thèmes répertoriaient les aspects positifs et négatifs de l'utilisation des opioïdes dans les dimensions sociales, physiques, émotions et psychologiques de la gestion de la douleur. Ces thèmes incluaient le processus de prise de décision et les conséquences physiques et psychosociales découlant de l'utilisation d'opioïdes, y compris les effets secondaires pharmacologiques, le sentiment d'être réprouvé, la culpabilité, les peurs, l'ambivalence, l'autoprotection et l'acceptation.

CONCLUSION : Même si de nombreux aspects négatifs entouraient l'utilisation quotidienne d'opioïdes, les effets positifs l'emportaient sur les effets négatifs pour la plupart des participants. Par ailleurs, la plupart des aspects négatifs étaient attribuables à des problèmes socioculturels plutôt qu'à la médication. La présente étude faisait ressortir la complexité de l'utilisation quotidienne d'opioïdes sur ordonnance pour aider les personnes qui vivent avec la douleur à gérer leur DNCC.

survey revealed that 38.4% of Canada's general population reported experiencing pain on a daily or near-daily basis (8). Not only is chronic pain a significant burden that negatively affects an individual's well-being (2,9), it is a major public health problem globally (10).

A variety of coping mechanisms and treatment strategies are typically needed to reduce pain and regain psychological and physical well-being (11,12). Treatment of severe pain often involves pharmaceutical approaches including opioids. The goal of long-term opioid therapy for CNCP is to reduce pain to regain function and improve the quality of life for the individual (13). A growing body of quantitative evidence provides some support for the use of opioids as a management strategy for CNCP because they have been shown to decrease the physical pain and improve function for the individual (14-20). Little is known about the emotional, social and psychological impacts of long-term opioid use from the standpoint of the lived experience of the individual who uses them to manage CNCP (19).

There has been growing concern in Canada regarding an increase in the rate of prescription opioid misuse in Canada (22-25), along with

¹School of Health and Human Performance; ²Departments of Anesthesia and Psychiatry, Dalhousie University, Halifax, Nova Scotia

Correspondence: Dr Mary E Lynch, Pain Management Unit, Queen Elizabeth II Health Sciences Centre, 4th Floor, Dickson Centre, Room 4086, Halifax, Nova Scotia B3H 1V7. Telephone 902-473-6428, fax 902-473-4126, e-mail mary.lynch@dal.ca



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increasing concern regarding an increase in prescription opioid-related deaths and harms (3,19,20,26,27). Other authors have pointed out that CNCP is a complex issue requiring solutions that do not cause further harm to individuals living with pain (28). The media's portrayal of opioid use for pain has focused on the negative effects, such as stigma and misuse, rather than the positive benefits of increased pain relief and improved quality of life (29-31). Due to the negative connotation that opioids receive, patients may feel stigmatized or may be viewed by others as drug addicts (16,32-34), although the estimated risk of addiction is approximately 4% (35). Patients may also fear that the adverse publicity may encourage doctors to stop prescribing opioids altogether (36). Many health care professionals are reluctant to prescribe opioids due to their own negative perceptions, fears of diversion and addiction risks, as well as fear of scrutiny by regulatory bodies (16,36-40). Physical dependence and tolerance to opioids are often misunderstood as evidence of addiction; however, addiction involves drug-seeking behaviour to obtain a psychological high from these drugs (12,41). The undertreatment of chronic pain conditions continues to be a major concern within our health care system (42), leading to needless physical and emotional distress, increased burden to the health care system, economic costs and strain on relationships (5,43).

Understanding the perspective of the person living with CNCP involves "getting inside the experience of such (chronic) illness" (44). Few studies have addressed the patient's perspective of using opioids to manage chronic pain. Vallerand and Nowak (2) used a qualitative approach to explore the impact of opioids on the quality of life of individuals living with chronic pain. This study revealed that opioids improved quality of life and overall functioning, but were also associated with many struggles resulting from stigma and barriers related to opioid use.

The purpose of the present study was to examine individuals' lived experience of using prescription opioids to manage CNCP and their effect on the psychological, emotional, social and physical aspects of living with CNCP. When individuals experience major change in their lives, they begin to reflect on the significance of this change to manage its impact. Exploring this experience allows the researcher to engage in these reflections and examine how people come to terms with major events or transitions (45).

METHODS

Participants for the present study were recruited from an outpatient pain clinic in a teaching hospital located in Nova Scotia. From 2011 to 2012, there were 1843 clinic visits for CNCP at this pain clinic. A generic recruitment letter, along with contact information, was given to approximately 100 patients at the pain clinic by staff during clinic appointments occurring during the recruitment period. Participants contacted the first author if they decided to participate in the study. As a secondary recruitment strategy, posters advertising the study were displayed in both the treatment rooms and the waiting area of the clinic to enhance recruitment. Inclusion criteria were: current use of prescription opioids, age ≥ 18 years, currently a patient of the pain clinic and willingness to take part in two interviews. Twelve individuals contacted the researcher to participate in the study. Two individuals failed to attend scheduled interviews and another did not meet the inclusion criteria. Nine participants (four men and five women) between 40 and 68 years of age participated in the present study. All were currently using or had recently used opioids to manage their CNCP. Following completion of informed consent, a demographic and medical data form providing information about age, sex, marital status, occupation, origin or cause of pain, number of years in pain, type and amount of opioid currently using, and duration of daily opioid use was completed by each participant before beginning the interviews. Informed consent was obtained and interviews were conducted by the first author, who was not a staff member of the facility.

A semistructured interview guide using open-ended questions with probes and prompts was used to facilitate the interview. The

guide was developed with guidance from the literature regarding interpretive phenomenological analysis (IPA) examining lived experience (2,45), as well as consultation with other members involved in the current research.

The data from the interviews were audiorecorded and transcribed verbatim for analysis. All data were made anonymous before being made available to team members. Ethics approval for the present study was obtained from the Ethics Review Board of the institution in which the pain clinic is located.

IPA was used to analyze and interpret the data (45). IPA is a qualitative framework for examining the unique experiences of individuals in the context of their lives through in-depth interviews. Approaching the topic of opioid use through an interpretive phenomenological lens sheds light on how patients are experiencing their everyday lives with the use of opioids to manage their chronic pain conditions. Often, the experiences of individuals who are experiencing a certain debilitating condition or who are from a marginalized population are neglected or suffer needlessly due to their social context. Giving individuals who experience chronic pain an opportunity to tell their story reveals not only the lived experiences they face daily, but also empowers participants whose voice may rarely have been heard. In IPA, the researcher seeks to understand how the participant's lived experience has influenced the choices they make, specifically with opioid use, and takes into account the various contexts that may influence these decisions. To fully gain an understanding of each participant's lived experience, IPA recommends a smaller sample, no larger than 10 participants, to focus attention on each case individually and to then explore themes shared among cases. A six-step thematic analytical process is then used in IPA to analyze the data (45). As applied to the present study, step 1 involved listening to the audiotaped interview and reading through the transcript to ensure transcription was accurate. Rereading interview texts immersed the researcher in the data. In step 2, initial notes were made of the ways in which the participant talked about, understood and thought about their personal experiences and concerns related to CNCP and opioid use. A line-by-line content analysis was conducted alongside the data to facilitate coding, categorization, and synthesis of the data. Step 3 focused on examining the interrelationships, connections and patterns among exploratory notes in individual transcripts to develop emergent themes. Step 4 considered the connections across emergent themes within the transcript to identify the participant's meanings and connections and cluster themes. Once the analysis of one transcript was completed, the next step (step 5) involved moving to the next participant's transcript and repeating the process. In IPA, each transcript is analyzed separately to ensure accurate interpretation, completeness of data and to reduce bias in interpretation from one transcript to another. A notebook was kept during the analysis process to record and set aside the researcher's own thoughts and emotions about the data. Step 6 identified patterns and connecting themes across the participants and connecting themes. This process assisted with working toward revealing both the individual's experience, and the common experiences and shared meanings of using prescription opioids to manage CNCP. Data analysis was an ongoing process through the data collection stage, with interview summaries prepared for a second interview with each participant (45).

RESULTS

Finding balance was the overarching theme revealed in these interviews. Participants in the present study sought to balance pain with function in daily life. Similarly, they struggled to balance the negative effects of the opioids with the relief from pain that opioids provided. Often, other strategies were added or removed in this process of balancing positive and adverse effects. Finding balance also meant achieving better stability in daily function along with use of pain management strategies to achieve optimal pain relief (preferably a cure) and a better quality of life. The challenge in finding balance is illustrated by participant 3 and typifies the experience of other participants:

There were a lot of plates. Like the guy in the circus running around you're trying the acupuncture, the massage, in the pool, seeing the psychologist, taking some pharmacology, and where are we going? Because as a pain sufferer, we'd love not to be in pain! And we try anything and exhaust almost all our finances to try to find that cure.

Finding balance acted as a pivotal point for interpretation of the lived experience of prescription opioid use in the context of managing chronic pain. Eight themes in these interviews reflected participants' efforts to finding balance in managing CNCP.

Theme 1: Process of decision making regarding opioid use

Deciding to use opioids was not a straightforward process, and not typically initiated by the participants. Some participants were offered prescription opioids fairly quickly before the pain was diagnosed as a chronic problem; others were offered opioids as a last resort after all other management techniques were exhausted. Most participants began using opioids because their physicians suggested it. At the time of the present study, eight of the nine participants were using prescription opioids such as morphine, oxycodone, hydromorphone, fentanyl and methadone daily to manage CNCP, and four of the eight also used cannabis. One participant used only cannabis after previous unsuccessful trials with opioids. Although it took several attempts with various opioids before finding adequate relief, eight participants decided to continue using opioids despite the adverse side effects (eg, sweating, constipation, sedation, dizziness, nausea) they experienced. Participant 2 summarizes the desperation participants felt to find pain relief along with their hesitancy to use opioids:

This was the first time I was given drugs to use on a regular basis. I was a little concerned about that but realized that I was...(pause), I don't want to use the word 'helpless' but I was really unable to function very well because of the pain. And I was concerned that if I started these drugs, where would it end? I was becoming aware that I had a condition that was not going to go away and there was not a treatment that was going to relieve it. It was a matter of dealing with it in the best way possible and that was up for grabs at this point.

Making the decision to use opioids exposed participants to the benefits and the side effects of their use.

Theme 2: Benefits and side effects of opioid use

Overall, prescription opioids had a very positive effect on the participants' physical pain; however, many participants also reported negative effects. With the use of opioids, most participants regained a quality of life that had been lost. Often, this quality of life meant living with more comfort and regaining the ability to do routine tasks of daily life such as mowing the lawn, going to appointments or cleaning the house:

I have to say that these drugs give me a quality of life that I did not think I would ever have again. It allows me to live my life to the fullest I can, to take part in things...and be as active as I can. I can't picture doing it without the drugs now. (Participant 2)

Typically, opioids did not relieve all pain, and did not cure pain. Participant 7 spoke about the pain relief from opioids but focused more on this disappointment of not being pain free:

It helps. I mean I shouldn't say it doesn't do anything. To tell you the truth, I probably wouldn't be here right now if I wasn't taking it. I probably wouldn't be able to walk or get out of bed cause the times that I do let my dose go or don't take it, it just, I can tell right away and umm so if it wasn't for that [opioids] I would have no quality of life.

The daily use of opioids came with many negative effects for the participants including nausea, vomiting, itching, constipation,

drowsiness, mood changes, sweating, changes in sexual functioning, feelings of fatigue, sluggishness and, sometimes, reduced motivation to do things. Participant 7 described the problem of sweating and mood changes:

It comes with consequences and side effects for sure. It's, you know, I wish it didn't have but, the sweating alone is just ah, it just, it's so uncomfortable to wake up and your pillow is just soaked with sweat and your bed. And I know that mostly, it's gotta be from the morphine and it makes you moody and cranky and everything.

Sweating and changes in sexual function due to opioids affected sexual activity and intimate relationships, as illustrated by these participants:

When I was first on opiates I couldn't, couldn't have an erection. And once I got used to the medicine I could have the erection but I couldn't have an orgasm or anything like that. So it affected the relationship in a manner that I wasn't ready for because the woman I was living with at the time thought she was inadequate. (Participant 9)

My sex life, it hasn't been there lately. Because we are both in chronic pain all the time, you know. He has the sweats all the time. I've got the sweats all the time. (Participant 6; both partners had chronic pain)

To offset side effects and provide additional pain relief, participants used other pharmaceutical agents with their opioids. Five participants included cannabis (with government-issued licenses) on the advice of their physician. One participant used cannabis for pain following initial recreational use. Cannabis was reported to be helpful for many opioid side effects:

I'm very embarrassed to go into grocery store, to go anywhere, to do anything, cause I'm soaked all the time. So a lot of the times in the afternoon, I'll have to lie down and get a blanket and I have to take marijuana and that will usually, within a minute, the sweats are gone. Like that. And I'm feeling a little bit back to normal again. (Participant 6)

...that [cannabis] helps me some days, believe it or not. I would say almost as much as the morphine does. It helps with my appetite which I don't have any of, usually, because of the medication...general stress from being in pain I think all the time. So it does help with my energy, and it helps with my anxiety. It helps with my sweating. (Participant 7)

Well the marijuana is only for the nausea cause with methadone...the nausea is unbelievable and that's never stopped. The pain is under control to a degree with the methadone, but, the nausea, the vomiting. I had that the whole 10 years, that's still there. (Participant 8)

Cannabis was described to alleviate some side effect of daily opioid use such as nausea, sweating and increasing appetite. Chronic pain often involves several different mechanisms (eg, tissue damage or nociceptive pain, neuropathic pain, inflammatory pain) and, in this case, opioids alone are often inadequate to provide adequate relief (46). Often other agents need to be added such as antidepressant or anticonvulsant analgesics, or other medications to assist with side effects such as constipation or sweating (46). These may include medicinal cannabis.

One of the unexpected side effects of opioids was the negative social impact.

Theme 3: Feeling stigmatized

Media reports contributed to participants feeling stigmatized. Such reports typically emphasized potential harms associated with prescription opioids, with a strong focus on addiction, without presenting a balanced perspective that included the benefits of opioids

for an individual living with CNCP and the limited risk for addiction when using opioids as prescribed. Participant 1 expressed the anger an individual living with pain may feel in response to such negative publicity:

I get mad when I see the articles in the paper about people, and oh everybody in pain is addicted. And the stats, I always say only one to four percent of people in chronic pain ever get addicted to the medicine and that happens for a number of reasons. And you know what? I wouldn't give a shit if I was addicted to the medicine. Like, at this point, 30 years of this who the hell cares?

For participant 1, even addiction would be acceptable as a consequence of opioid use if there was relief from chronic pain.

Sadly, in addition to the stigmatization of opioid use in media reports, all of the participants felt stigmatized at times by health professionals, as illustrated by these comments:

I frequently have difficulty with the residents (doctors in training) explaining why these drugs, this many drugs...Finally Dr. [family physician] wrote a note in my file – stop harassing [participant's name]. This is what she gets and why she gets it. And they did stop but it was inconvenient. For instance, they would not prescribe me three months at a time. I would be dispensed one month at a time. And for someone who had been taking the same drugs for 10 years I found that condescending. (Participant 4)

They [ER staff] said, "Well we know that you're on a lot of pain medicine, so we can't give you any." I said, "I didn't ask you for any. I just want to know what's wrong with me." So I almost felt like, I felt like I was being treated like a junkie in the emergency room when I was in an accident because they found out I was on pain medicine. They automatically assume that I was coming in to try to sneak an extra prescription or something. (Participant 9 attended the emergency room after a fall).

Apparently there is a book, they write your name down if you're, if you come there [emergency room] too much... but god, what if I had to, what if I had to come there every week until this thing settled down. Do you know what? I wouldn't. That was so stressful in itself, cause I never knew how I would be treated. (Participant 1)

As a result, participants often felt judged rather than supported by a health professional who was not their pain specialist. Participants feared that their family physician might also be affected by negative media reports:

I think she's [prescribing doctor] just freaked out about all the shit in the news and a couple bad apples are making it hard for people who legitimately need pain medication...but other than that she's supportive and she sent me to the pain clinic here and all that. (Participant 7)

Exposure to such stigma caused some participants to be ambivalent about their own use of an opioid medication for pain as illustrated by the comments of participants 8 and 9, both of whom were prescribed methadone:

...when you get methadone you definitely, you know, what do you call those people? What do they call those people? When you're on methadone... junkies! [people say] "She was a heroin addict and is now on methadone trying to get off of it." I've had that said to me in the city, at the hospitals, that you know, the reason I was taking that, you know, I have a problem. And as an RN, that's a big problem right? And I said, "My god! What are you talking about?" I said, "I don't do that, I have chronic pain." (Participant 8)

...at one time they were talking about putting me on methadone pills. And I was like wait a minute. Dr. [name of pain specialist] wanted that and he said it's a better and longer lasting pain medicine. Right then and there I said, "Oh methadone! People are going to think I'm a heroin addict, or coke addict, or something like that." So that's when I started thinking, well wait a minute, what are people really saying or really thinking and that's when I started thinking how am I going to be viewed by people? (Participant 9)

Unfortunately, feeling stigmatized and fearing being wrongly labelled as addicted, increased participants' uncertainty about opioid use and added feelings of guilt for using opioids.

Theme 4: Guilt

Feeling stigmatized was a strong component to feeling guilty about using opioids and sometimes other medications to manage pain, but personal contexts compounded feelings of guilt.

Two participants feared that their pain was not sufficiently severe enough to warrant such medications. One participant diminished the severity of her pain by comparing it to the cancer-related pain experienced by her mother in the last months of her mother's life:

My biggest hang-up was me. I guess I could relate to my mother. I guess I would say my pain is nowhere near what my mother's did, what my mother went through. And she had to take the narcotics cause she had a terrible bout with breast cancer...and I saw all the medication she was on and I kept saying to myself, I don't have cancer, it's just back pain, you should be able to do this without taking those drugs. Well that didn't last long.

Participant 6 was stressed and anxious about taking prescription opioids for pain, relating it to feelings of self-worth:

It's a big deal for me to have to go on these medications because I felt very bad. You know you hear all this stuff about narcotics and stuff so I felt like I was a bad person for a long time actually.

This participant sought out psychological intervention to work through these feelings.

Participant 9 felt guilty not about taking opioid medication but because he resisted family pressure to give some of his opioid medication to a nephew who was experiencing daily pain:

He's asked me for some pain medicine when his Percocet don't work and I say "I'm not allowed to give that to you. I'm sorry. I can't. It's against the law. I can go to jail..." And then I get in trouble for not helping out. And what I mean by getting in trouble is I get flack from my sister-in-law because they know I can help him with the pain but they also know I shouldn't...

Using cannabis to provide pain relief and manage opioid side effects added other concerns about its side effects, and guilt about needing to hide it and using a drug that might be viewed as illegal by others:

...it [cannabis] is very, very hard on the body. Smoking and hacking and coughing and being a criminal cause I have to hide around the side of the house and hide it [cannabis] from everybody. And this is my pain relief and it's really sad when you think that you have to go that route to get some relief and then you get the odour that comes from it and then you get the stigmatism that comes from it.

The stigma and guilt associated with opioid and cannabis use were often coupled with a level of fear of not only using these substances but also of being in possession of them.

Theme 5: Fears

Study participants had fears about two issues. One fear related to addiction and the other to victimization.

I was afraid of getting hooked on the drugs. I was afraid of becoming dependent. And I knew that my condition was not going to

get better and I realized that if I got on these drugs, I could be in for a series of problems with them. I knew about addiction and I knew of people who have been caught in this web and I was just really leery of it. (Participant 2)

You know I have to be careful on how I take this 'cause I've seen a lot of good people get addicted to pain medicine. I've seen a lot of lives destroyed because of it. And a good buddy of mine died because of it, buying pills off the street. (Participant 9)

Fears of addiction were compounded by the fears of significant others. The former partner of participant 9 had concerns about his opioid use and acted on them:

The woman I was living with is a [name of occupation], and she knows how addictive these pills were and she actually took them from me. She was giving them to me, but wasn't giving them to me, to the point where I actually needed them 'cause I was in significant pain for three years because she didn't want me to become addicted to them.

The experience of participant 9 illustrates the potential for the fears of others to cause real harm for someone who is using opioid medications to manage pain. Other fears concerned the impact of the street value of opioids.

Several participants had concerns about becoming victims of criminal activity because of their opioid use. The daughter of a participant 4 witnessed a robbery outside a pharmacy causing additional concern for family and others:

... I became a little bit anxious and felt a bit vulnerable because we pick these drugs up and, you know, my kids pick them up, my husband picks them up, I pick them up, my homecare worker. I spoke to my pharmacist about this and he suggested maybe I just get them delivered. And he said, "Oh but then they will know where you live" which was a little anxious making.

This participant was also concerned about the lack of privacy and confidentiality about her opioid medications in this pharmacy:

The pharmacist spoke loudly and in the presence of others how my MS-Contin prescription was not complete and that I would be getting the balance later but here is what you'll need for the next two weeks. And I did feel vulnerable because there were people around watching me fill out the form and knowing what the drug I was taking.

Participant 9 was victimized: "One time we came home and the house was broken into and ah, basically my pain medicine was gone. So someone knew..." This person felt directly targeted because of his possession of opioids within his home. Such experiences compounded the stress of living with pain:

We've really had a hard time as a pain community to get access to medications due to the fact of the legalities and misuse of property from outsiders. So that's the start of the bad name. But if you are fortunate to get it, then it's like oh geez, we have to worry about someone else trying to steal this stuff. And I've heard stories of people. Someone scooped their meds or watched them get their meds [from the pharmacy] and when they came out, scooped them out of their hand. And who pays the price? And it's the pain person. (Participant 3)

Stigma, guilt and fear resulted in participants becoming vigilant and developing protective strategies to shield themselves from needless additional anxiety.

Theme 6: Self-protection

Participants in the present study became selective in their communication about opioid use with others, sometimes even with family members. Participant one gave this explanation:

I do it for my own protection by not telling them because I see how they react by reading something in the paper...and it's just their ignorance. And I don't have time. Well they know what's going on but they don't get it to this day. So you have to pick your battles. They're not one of them and if they don't get it now they are never going to get it.

Unfortunately, not being open caused this participant to feel increasingly isolated:

So it was hard to always be secretive and then I started to isolate myself from people and I didn't like that.

Some participants felt they were 'wearing a mask' when they acted in ways that differed from how they felt, but doing so was an effort to avoid being in more pain or distress. Participant 1 approached the emergency department with extra care:

...I'm thinking ok, there may be those addicts and they may slip by you but everyone that's coming to the ER is not a friggin' addict, what's wrong with you guy, you know? But of course I would never be grumpy or grouchy. You're always like, "Oh thank you dear", you know, trying to be sweet and I have to act, put on a show, when dealing with this horrible issue and trying to be nice to them cause I may not be treated well.

Side effects, stigma, guilt, fear and self-protective strategies contributed to an overall ambivalence for some about using opioids for pain management.

Theme 7: Ambivalence

The realization that opioids would not resolve pain, that they may be needed indefinitely and that they caused other problems generated an ongoing internal conflict for some participants about using opioids at all to manage the pain. One participant stopped and turned to cannabis exclusively, although this did not change this person's feelings of secrecy. Others waited until the pain was intolerable before using their opioids:

I think it's more of a power struggle, to see who's stronger. Whether it's me or the [pain], and not only that but I just hate that I have to take something to get through the day. I have to put this patch on every couple days just to get through or I'd be in the ground right now, you know, so yah, it's hard, it's very hard. ... I still fight with myself, like I still let it go to the very, as long as I can, there is always that fight, like I'm stronger than you sort of thing. And I never win though." (Participant 6)

It's always a fighting game; you know how long can I go without having to increase it [opioids] or even taking my medication. I normally don't take it till five or six o'clock, my second dose at night, but sometimes I try to take it as late as I can so I'll sleep a little bit longer but it's always a fighting game with the pain right? (Participant 7)

Participant 2 commented about the natural hesitation of people living with pain to use opioids:

They don't want to get into the drug scene so they hold back not realizing they aren't helping themselves.

Nevertheless, most participants in the present study, while remaining hopeful that their pain might eventually end, came to a place of acceptance of pain and the necessary continued opioid use to manage pain.

Theme 8: Acceptance

Searching for pain relief was described as exhausting and frustrating. The journey in seeking relief was full of trial and error with pharmacological, physical and alternative therapies. Individuals in the present study often expressed their desire for a 'cure'. As the pain persisted, it became essential to them to move toward acceptance to be open

to long-term pain management strategies and improve function. Participant 3 illustrates this process toward acceptance:

I still hope that one day there is something out there for me, but I have to accept the part that I can't do what I used to do. I have to accept those limitations on me. Though, until I accepted it, a lot of things didn't change.

Participant 8 was thankful to have opioid medication to help cope with his pain:

But opiates, that's my way of life. There would be no life if I didn't have this. And I thank God for them because without them I'd be...well I wouldn't be. I just couldn't go on. I would have committed suicide a long time ago. And I say that truthfully cause you could not live like that, with that constant, constant pain. But, with the opiates it's made it possible to be able to have a part of a life, you know.

Participant 9 reconciled the positive and negative aspect of opioid use and accepted that, overall, they were helpful to manage his pain:

For me, personally there are benefits and well I can say the pros outweigh the cons in this case. Umm because I wouldn't be able to do anything without them and I know that and my doctors know that too.

For most participants, the realization that they will live with some degree of pain occurred despite earlier expectation that opioids would eliminate the pain. Participant 1 stated:

I'm happy with my decision, with opioids. I finally got over the fact that it's not a cure-all and I have to do other things besides medication...

For these participants, acceptance of pain and the persistent negative consequences of opioid use led to a continuous cycle of appraisal and reappraisal of the stress of living with pain in the hope of finding balance in pain relief to achieve adequate function and quality of life.

DISCUSSION

The findings of the present study revealed some of the complexities of using prescription opioids for the management of CNCP from the perspective of the individual who lives with it. Living with CNCP was a stressful life experience that had a major impact on participants' quality of life and interfered with their ability to function. In this group of individuals using chronic opioids (in one case, a cannabinoid only at the time of the study), opioids assisted with participants gaining sufficient relief to move toward acceptance of pain despite incomplete pain relief, negative pharmacological side effects, stigmatization, guilt and fear. To do this, participants were engaged in a cyclical process of appraisal and reappraisal of pain as they attempted to balance pain, opioid use and its sequelae toward a lifestyle that could be managed. Lazarus and Folkman (47) first described this appraisal-reappraisal process as a transactional theory of stress. Negative appraisals of a stressful life event focus on the harm or loss associated with the stress and efforts to manage it, resulting in a perceived threat (48). The negative pharmacological side effects of opioid use along with stigma, guilt and fear heightened the worry associated with opioid use and led to self-protective strategies to reduce these effects. These issues led some participants to feel ambivalent about using opioids and uncertain as to whether they could find a tolerable quality of life again. Ambivalence about opioid medication and resulting underutilization was also reported by McCracken and Vowels (49). Despite ambivalence, most participants in our study did, over time, develop a set of strategies such as exercising, meditating, limiting or adapting their activities, creating healthy boundaries to decrease stress, and finding social support through loved ones and support groups that balanced their need for pain relief, and thus enabled a sufficient quality of life that led to acceptance through a process of appraisal and reappraisal as various strategies were attempted, modified, continued or dropped.

Participants described living with CNCP as almost impossible without accepting new limitations and finding a level of pain that may be tolerable in daily life. Not all individuals with CNCP are able to accept that there may be no cure for chronic pain (6,50). Vallerand (19) described acceptance as essential to continued functioning in daily activities. Although acceptance benefits overall well-being, little is known about how individuals arrive at a state of acceptance, although time is likely to be a contributing factor (50,51).

In our study, acceptance occurred as participants challenged their beliefs about opioid or cannabis use, and found ways to manage the physical, emotional and social consequences of using opioids. Most participants described acceptance of their new life in chronic pain and using opioids as being the only way to move forward. Other participants remained ambivalent and were searching for a cure. The participants who have been using opioids for CNCP for many years often compared their life with pain before and after using opioids for pain management. Their previous life represented a very dark time of isolation, depression and uncertainty. Some participants described previous suicidal thinking. Without the assistance of opioid medication, they would not have been able to carry on. Their present life gave them a sense of hope, freedom and a new found purpose in life. These findings are similar to the findings reported by Vallerand and Nowak (2), in which participants described being thankful for their opioid therapy regimen because it allowed them to regain their quality of life. In Vallerand and Nowak (2) and in our study, participants spoke about the need to change their focus from constant pain and seeking a cure to finding purpose and living their life again less focused on pain. Similarly, Risdon et al (52) described acceptance by their participants as due to acknowledging one's limitations, realizing that there was more to life than pain, and relinquishing the fight against battles that cannot be won. For our participants, sufficient pain relief, often with opioids, sometimes with the addition of cannabis, and in one instance eventually cannabis alone, was a catalyst toward acceptance, not sufficient on its own but not possible without it.

Finding balance is essential to maintaining stability and achieving a quality of life that is tolerable (9). Vallerand and Nowak (2) described finding balance as achieving equilibrium between pain management and level of functioning in life domains. Some of our participants discussed a 'failed expectation' of opioids. They were shocked that opioids were insufficient to relieve all pain and caused further problems. Finding balance through active coping strategies was a very lengthy yet important process for participants because unmanaged pain is so destructive. This process enabled participants to regain control of their own sense of well-being.

IMPLICATIONS FOR CLINICAL SETTINGS AND FUTURE RESEARCH

To date, there have been remarkable advances in our understanding of pain; however, the management of CNCP remains a significant problem (20,53-55). A comprehensive and multidimensional approach is essential to achieve management of CNCP and to reduce the adverse social consequences associated with opioid use (16,34,56). One of the most reported barriers to adequate pain management for those with CNCP is lack of guidance and education related to the use of prescription opioids for chronic pain (2,14,26,30,57-60). The current system for training physicians and other health care professionals is limited and inadequate (61). Currently, student veterinarians receive five times more education about pain assessment and treatment than medical doctors in Canada (61). This gap in pain education results in many health care professionals feeling underqualified to assess and treat CNCP, and compromises patient safety (34,62). These issues likely contribute not only to the undertreatment of pain but to misunderstandings about pain, which may, in turn, lead to professional behaviours and attitudes that contribute to the stigma and guilt experienced by individuals living with CNCP and needing opioid pain management.

Although the benefits of opioids for pain are well documented (2,16,20,63,64), when an individual requires an opioid as part of their

management program, there is an additional layer of negative judgement and consequence that they experience from medical health professionals and society at large that contributes to the overall problem and level of suffering (32). A better understanding of the magnitude and characteristics of opioid use for CNCP can contribute to improved pain management programs, and enable both health care professionals and individuals who are using opioids for CNCP to better understand the needs and supports required to reach an optimal state of health.

A limitation of the present study was the lack of follow-up by participants to provide a second interview for further elaboration or clarification of themes from their first interview. All participants committed to participating in two interviews but only four did so, despite repeated efforts to contact the other five.

Further research is needed to understand the lived experience of individuals who use opioids to manage CNCP. The present study revealed details of the lived experience of these participants in a particular social and health care context. Replicating the present study in other settings and with more diverse populations would provide a broader understanding of the experience of using opioids to manage CNCP, particularly with regard to issues of stigma, guilt and fear that may be exacerbated by sex, age, poverty and ethnicity. This research would assist health care providers in understanding not only the benefits and physical side effects opioids may have on pain, but also the physical, social and psychological stress with which it is associated.

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Future research should also focus on examining ways to alleviate barriers and disparities within the health care system for those seeking support and treatment of chronic noncancer pain.

Using opioids to manage CNCP is a challenging experience for people who live with CNCP. The potential negative side effects are well understood, although not always easily managed. The social and emotional consequences that these participants reported are particularly troubling because they present additional burdens and barriers to optimal pain management. The solution must include a comprehensive educational initiative within a national strategy for pain (64), as a call to action for educators and clinicians alike. The overall goal of pain management is no longer simply to decrease one's pain, but to recognize the need for improving psychological and emotional functioning as well. As demonstrated in the present study, opioids cannot be the only mode of treatment for individuals with chronic pain, but can be used as a tool to reduce pain. This reduction in pain then enables individuals to better cope with their physical and psychological pain through a variety of other modalities in conjunction with opioids.

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