You Present like a Drug Addict: Patient and Clinician Perspectives on Trust and Trustworthiness in Chronic Pain Management

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Abstract

Objective. Past research has demonstrated that trust is central to an effective therapeutic relationship, but the role of trust in chronic pain management is not well understood. The objective of this study was to provide an in-depth examination of how adults living with chronic pain negotiate trust and demonstrate trustworthiness with clinicians in therapeutic encounters.

Methods. This qualitative study focused on adults living in an urban setting in British Columbia, Canada. Semi-structured interviews (N = 27) were conducted with participants with chronic low back pain. The results were triangulated by two feedback groups comprising re-contacted interview participants (n = 4) and physicians with expertise in pain and addiction management (n = 6).

Results. Grounded theory analysis of the adult patient interviews and feedback groups yielded four major themes: 1) threats to trustworthiness and iatrogenic suffering; 2) communicating the invisible and subjective condition of chronic pain; 3) motive, honesty, and testimony; and 4) stigmatized identities. The following two themes emerged from the analysis of the physician feedback group: 1) challenges of the practice context, and 2) complicated clinical relationships.

Conclusions. We found that perceived trustworthiness is important in therapeutic encounters as it helps to negotiate tensions with respect to subjective pain symptoms, addiction, and prescription opioid use. An attitude of epistemic humility may help both clinicians and patients cultivate a trustworthy clinical environment, manage the challenges associated with uncertain testimony, place trust wisely, and promote optimal pain care.

Key Words. Chronic Pain; Addiction; Opioid Analgesics; Trust; Qualitative Research

Introduction

Clinician–patient relationships in chronic non-cancer pain (“chronic pain”) management are considered to be among the most challenging in health care [1,2]. Chronic pain management can be time-consuming, frustrating, and distressing for clinicians and patients, as most treatments are ineffective [3]. As a subjective experience that is often refractory to objective assessment, pain is elusive. Patients with chronic pain and clinicians tend to disagree about the meaning, source, representation, and management of pain [4–7]. Clinicians may harbor negative attitudes if the patient also presents with mental illness and addiction-related issues and may label these patients as difficult [8–12]. Crowley-Matoka and True found that physicians narrated “getting burned stories” [13, p702] about patients who deceived them to obtain opioid prescriptions. When deception occurs with one
patient, other patients may also be considered “guilty until proven innocent” [14, p 270].

While scientists, clinicians, and the pharmaceutical industry have advocated for the effectiveness and safety of long-term opioid therapy, and have argued that the potential for opioid misuse and addiction is rare [15–17], these claims have recently been challenged. Research since the 1990s has demonstrated that there are direct relationships between increased prescribing rates of opioid analgesics for chronic pain and opioid addiction, prescription opioid-related overdoses, emergency room visits, diversion, and deaths [18,19]. This research has also demonstrated weak evidence for the effectiveness of long-term opioid therapy for chronic pain [20]. Clinicians thus face the potentially conflicting duties to relieve pain, on the one hand, and to prevent potential harms of prescription opioids on the patient and others, on the other hand [21].

The inherent subjectivity of pain combined with the potential for addiction and misuse of opioids raises questions about trust. Trust is essential for a strong clinical relationship, patient adherence to treatment, and disclosing information to clinicians [22,23]. When one person trusts another person, one holds the expectation that the other is being honest and has good intentions. This expectation makes the trustor vulnerable to the trustee’s testimony and actions [24]. In clinician–patient relationships, both parties are simultaneously the trustee and trustor: clinicians trust that patients are truthful about their symptoms, and patients trust that clinicians will act according to their best interests and not harm them. The challenging and uncertain nature of pain management, however, may threaten clinician–patient trust. For instance, it may be difficult for clinicians to assess the patient’s motive for seeking treatment, or trust the patient’s testimony about medication diversion [25]. Likewise, a patient who may have had negative past personal experiences with certain clinicians or the medical profession may be suspicious about what the clinician thinks of her request for opioids, and how her moral character is being evaluated [10,26].

Trust has emerged as an important finding in recent empirical studies on chronic pain and the clinician–patient relationship. For example, in their study of providers’ perspectives on the patient–provider relationship in chronic pain management, Matthias and colleagues found that provider empathy and patient-centered care could help to build trust and decrease conflict with patients [10]. Upshur, Bacigalupe, and Luckmann found that patients with chronic pain reported feeling distrusted by clinicians and expressed more satisfaction with their care when they felt a provider trusted them [27]. Krebs and colleagues examined patient adherence to opioid monitoring guidelines in primary care and discovered that patients found the monitoring acceptable if they trusted their physician [28]. Yet, in these studies, trust is discussed in a generic manner, and is not the focal point of the research. Despite the centrality of trust to the clinical relationship, the role of trust in chronic pain management is understudied. This gap in the empirical pain literature combined with the rising harms of prescription opioids motivated Rich to state, “in no other aspect of patient care has the fundamental role of trust in the clinician–patient relationship become more of a pivotal issue” [29, p 152]. This paper attempts to heed Rich’s call and provide an in-depth examination of how trust is negotiated in pain management.

Methods

Approach and Research Design

A grounded theory research design [30] was used to explore how chronic pain patients negotiate trust with their clinicians. Grounded theory is an iterative process of cycling between qualitative data, such as interviews, and simultaneously focusing the data and strengthening the theoretical aspects of the analysis. It is an inductive process that provides an explanatory theory grounded in the descriptively rich data acquired from participants [30,36]. Grounded theory is a useful design when there is a paucity of literature or theory to explain a social process, such as the focus of the present investigation: how trust is negotiated between patients and clinicians in pain management. The theory that is generated at the conclusion of a grounded theory study may provide a framework for future research, which is an outcome that is not expected from or possible with other qualitative approaches [31]. The University of British Columbia and Vancouver Coastal Health Research Institute granted research ethics approval.

Patient Participant Inclusion and Exclusion Criteria

Patient participants met the following criteria: English-speaking adults between the ages of 35-64, with self-reported chronic pain in the low back region for two years or longer, and under the care of a primary care physician for pain management. Chronic low back pain was chosen, as it is the most common anatomical location for pain in Canada [32]. The age inclusion criterion was chosen for the high prevalence of pain in this range [32] Older adults (>65 years) were excluded because of additional health concerns that they may face. Those on workplace disability were excluded because of the complex relationship between the sick role and the workplace disability payment process. The sick role includes behaviours based on people’s illness and suffering. It permits them to be relieved from particular role duties and obligations, to receive certain benefits, and to act according to certain normative expectations [33]. The disability payment process often requires continuous demonstration of pain to clinicians and insurance providers. Research indicates that patients are worried that clinicians would distrust their motives if no objective indicators of their pain were found upon clinical investigation [34].
**Recruitment and Sampling**

Patient participants were recruited by print advertisements placed in primary care clinics, community health centers, and physiotherapy clinics across the socioeconomically diverse neighborhoods of The British Columbia Lower Mainland. Additional advertisements were posted online on the Vancouver Craigslist website (http://vancouver.en.craigslist.ca/vol/), and on the Vancouver Coastal Health Research Institute’s website (http://www.vchri.ca). All interested candidates participated in a telephone screening call to determine eligibility.

Thirty-six individuals initially responded during the 8-month period of open recruitment. Twenty-three individuals met inclusion criteria during the telephone screening; however, two individuals did not attend the scheduled interview. Accordingly, 21 individuals were interviewed. Six individuals contacted the research team after the 21st participant had been interviewed. All six met inclusion criteria and were placed on a waiting list. To elaborate and refine the categories of the emerging theory derived from the analysis of the first 21 participants, the six wait-list respondents were interviewed. These additional six interviews helped to achieve theoretical saturation in data analysis [30]. Theoretical saturation was achieved when all data categories were fully developed in terms of properties, dimensions, and variations and no new themes emerged.

**Data Collection and Interview Design**

All patient participants completed a demographics questionnaire, followed by the Brief Pain Inventory-Short Form (BPI-SF). The BPI-SF is a well-validated self-report questionnaire that measures pain severity, its interference in daily life, pain location and medications [35]. The BPI-SF was administered in order to further describe the study sample.

The patient interview guide was designed to achieve a rich and deep understanding of how participants perceive their trust relationships with clinicians. Participants were also probed for their views toward prescription opioid use, addiction, and medication diversion.

Interviews were up to 90 minutes in duration. Participants were interviewed either in a private university conference area (n = 8), at a location convenient for them (n = 16), or by telephone (n = 3). All interviews were audio recorded. Transcripts were de-identified immediately after the interviews.

**Feedback Groups**

After all the patient participant interviews were completed, two feedback groups were conducted to refine the analytic categories and minimize researcher misinterpretation [36]. One group comprised a sample of self-selected patient participants who had been interviewed (n = 4). Patient participants were asked to provide reactions individually to descriptions of the emerging themes of the study, and then engage in dialogue with the other participants. The second group comprised physicians (n = 6) who care for patients with chronic pain and addictions. They were recruited from the professional network of the research team. The first author presented the initial themes based on the patient interviews and feedback group to the physician group and the physicians were then asked to discuss their impressions.

**Analysis**

Grounded theory was used to analyze the data [30,37]. Transcripts were managed in the qualitative data software program NVivo 9 [38]. Analysis began as soon as data were collected and was an iterative process as new interviews were conducted. Grounded theory analysis involves three inductive phases for data coding. First, during initial or open coding, the raw data are organized into broad thematic categories. Second, in the phase of focused coding, researchers determine which codes are analytically salient on the basis of the most significant initial codes, and then categorize, sort, synthesize, and integrate them into large segments of data. During the third analytic phase, axial coding is used to relate categories to subcategories and to bring segmented data back together to describe the studied experience in full depth [30,35]. Rigor was addressed by using a second coder for data analysis, including a process for member checking, and triangulating the data with the physician feedback group [39].

**Results**

**Sample Characteristics of the Patient Participants**

Twenty-seven interviews with 17 women and 10 men were conducted (see Table 1). Fourteen participants self-identified as belonging to two or more sociocultural and ethnic backgrounds, eight as Canadian, European descent or White, and three identified as Aboriginal including one individual self-identifying as Métis. The Métis people are of European and Indigenous descent, with ancestry dating back to the European’s first contact with Indigenous peoples in what is now Canada. Two participants declined to answer this question. The average age was 54.3 years with standard deviation (SD) of 7.31, ranging from 36 years to 63 years. Eight participants achieved a professional or graduate-level degree, five obtained an undergraduate university degree or college diploma, nine participants completed some college or university courses, one participant completed high school, and four did not complete high school.

Participants reported living with chronic pain for a mean of 14.4 years with a SD of 11.31, ranging from two years to 45 years. They reported receiving care from their current primary care provider for a mean of 6.1
years with a SD of 5.34, ranging from one year to 25 years.

Fourteen participants indicated a history of at least one mental health problem. Participants had the option of reporting multiple mental health problems. Eight participants reported depression, four participants reported anxiety, and three participants reported bipolar disorder. Participants had the option of reporting a history of multiple drug use problems. Ten participants reported a history of problem use of at least one drug. Six participants reported a history of problems with cocaine/crack cocaine, five with alcohol, five with cannabis, five with heroin, and four identified problems with other drugs such as morphine, methadone, tobacco, and lysergic acid diethylamide (LSD).

The mean Pain Severity Score on the BPI-SF was 5.5, with a SD of 2.02. The mean Pain Interference Score was 6.4, with a SD of 1.9. These scores indicate that participants’ pain severity and pain interference falls within the moderate range.

**Physician Feedback Group**

Five men and one woman participated, representing the specialties of family medicine (n = 1), internal medicine (n = 2), and psychiatry (n = 3). All physicians were on staff at the same large urban hospital in the Lower Mainland.

**Patient Interview and Feedback Group Findings**

Four themes emerged directly from the combined analysis of the patient semi-structured interviews and patient feedback group. All participant names have been changed to pseudonyms. Gender was preserved for reporting.

**Theme 1: Threats to Trustworthiness and Iatrogenic Suffering**

The first theme describes patient perceptions that their clinicians have demonstrated a lack of care, empathy, and respect. These factors can affect patients’ assessments of clinician trustworthiness, specifically patient trust in the clinician’s interpersonal competence [23]. If a patient does not experience some degree of assurance of interpersonal competence from his or her clinician, patient trust in the clinician can be threatened [40]. Patient participants reported that negative interactions with clinicians caused them further suffering. The literature refers to this phenomenon as iatrogenic suffering, i.e., unintentional emotional harm that can result from negative interactions between clinicians and patients [41].

**SUSAN** recounted how she believed that her primary care physician repeatedly ignored her during appointments:

**SUSAN:** You could just tell that he just didn’t believe me that I was in as much pain as I was. He was just very unsympathetic. He would literally walk away while I was in the middle of a sentence.

**NELL** reported a similar experience:

**NELL:** I would walk in crying about my body, about my pain, about the swelling of my body, about how painful it was, and they [doctors, nurses, social workers] would chitchat, move, you know, go back to whatever room they’d go back to and come back and say, ‘Yeah, well, we’ll see you next week.’ What?…is there nothing you…like, is there any

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**Table 1** Patient sample characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td>Gender (n = 27)</td>
<td></td>
</tr>
<tr>
<td>Women</td>
<td>17 (63%)</td>
</tr>
<tr>
<td>Men</td>
<td>10 (37%)</td>
</tr>
<tr>
<td>Age (M, SD) (n = 26)</td>
<td>54.3, 7.31</td>
</tr>
<tr>
<td>Employment status (n = 27)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>15 (56%)</td>
</tr>
<tr>
<td>Full-time</td>
<td>9 (33%)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (11%)</td>
</tr>
<tr>
<td>Relationship status (n = 27)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11 (41%)</td>
</tr>
<tr>
<td>Common-law or married</td>
<td>8 (30%)</td>
</tr>
<tr>
<td>Separated or divorced</td>
<td>5 (18%)</td>
</tr>
<tr>
<td>In a relationship</td>
<td>3 (11%)</td>
</tr>
<tr>
<td>Highest level of education achieved (n = 27)</td>
<td></td>
</tr>
<tr>
<td>Professional or graduate degree</td>
<td>8 (30%)</td>
</tr>
<tr>
<td>University degree or college diploma</td>
<td>5 (18%)</td>
</tr>
<tr>
<td>Some college of university</td>
<td>9 (33%)</td>
</tr>
<tr>
<td>High school diploma</td>
<td>1 (0.4%)</td>
</tr>
<tr>
<td>Some high school</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>Sociocultural and ethnic background (n = 25)</td>
<td></td>
</tr>
<tr>
<td>Multiple or other</td>
<td>14 (56%)</td>
</tr>
<tr>
<td>Canadian, European descent, or White</td>
<td>8 (32%)</td>
</tr>
<tr>
<td>Aboriginal</td>
<td>3 (12%)</td>
</tr>
<tr>
<td>Years/months with chronic pain (n = 26)</td>
<td>14.4, 11.3</td>
</tr>
<tr>
<td>Years with current primary care physician (n = 24) (M, SD)</td>
<td>6.1 (5.34)</td>
</tr>
<tr>
<td>Personal history of drug use problems (positive) (n = 26)</td>
<td>10 (38%)</td>
</tr>
<tr>
<td>Personal history of mental health problems (positive) (n = 24)</td>
<td>14 (58%)</td>
</tr>
<tr>
<td>Family history of drug use problems (positive) (n = 24)</td>
<td>10 (42%)</td>
</tr>
<tr>
<td>Family history of mental health problems (positive) (n = 21)</td>
<td>8 (38%)</td>
</tr>
<tr>
<td>Brief Pain Inventory-Short Form (n = 27) (M, SD)</td>
<td>Pain severity score 5.5, 2.02</td>
</tr>
<tr>
<td>Pain interference score</td>
<td>6.4, 1.9</td>
</tr>
</tbody>
</table>
other kind of painkiller you can... is there something else you can give me that I don’t have to feel this wrecked, this emotional, debilitating, void, dark?

For participants such as SUSAN AND NELL, the sense of not being believed exacerbated their suffering, threatening their confidence in their clinician’s trustworthiness. Other patient participants described how similar interactions with clinicians eroded their trust in the medical profession:

MARIAN: It’s demoralizing, it’s demoralizing. I get to the point where I have distrust for people in authority, for the medical profession.

Patient participants such as JEAN-PAUL described that he felt taken advantage of, and his perception of ill treatment during clinic appointments. He recalled an encounter with his physician during which he was told that if he came back too early for a prescription refill he would be banned from the clinic:

JEAN-PAUL: It was probably the most stressful thing I’ve been through in my life...And you don’t expect to be helped, and that starts to really get to you...I felt hopeless, like I was never, ever going to get better.

JEAN-PAUL reported that he did not trust his physician because he did not believe that his physician would advocate for his needs. The experience of distrust contributed to his suffering, which JEAN-PAUL reluctantly mitigated by relying on his physician even though he did not trust him.

**Theme 2: Communicating the Invisible and Subjective Condition of Chronic Pain**

The second theme describes the difficulties that participants experience in communicating their pain and the related concern that their clinicians will not accept their reports of pain at face value. This challenge is complicated by the subjective nature of pain:

FREDRO: [It’s] the visual aspect of things...But they don’t see the injuries in my back, you know what I mean? I try to explain that to them and then just, like, they just pass it off...if people don’t see it, they don’t recognize it.

EDMIN: I want to believe that she [my physician] knows what kind of pain I am in. That’s why she keeps prescribing the pills. But, I mean...if I could convince her that my pain is...where my pain is and if I could explain it better ...

Patient participants who reported a history of drug and alcohol use also reported that clinicians would often favor test results over reports of their experiences:

ELANE: Last time I went to the doctor, I just put my hands up in the air and I said, I don’t even know what to say for myself anymore ‘cause I don’t know how to get heard...I had a doctor tell me that some of the tests that he saw, ‘Well, that doesn’t hurt.’ Well, it does hurt. I’m in pain. ‘No, you’re not in pain.’

Some patient participants reported undergoing procedures such as magnetic resonance imaging (MRI) to help diagnose their pain. The MRI produced an image that made some patient participants’ formerly invisible pain objectively visible. The image helped to verify the patient’s subjective report and consequently improve the clinical trust relationship:

PHILIPPA: That went a long ways for me, that he [my doctor] believed me...I’d had surgery and it was on the MRI and everything was visible, I felt so much better when that happened. It just sort of reinforced what I guess I believed.

The objective representation of pain provided the necessary medical rationale for PHILIPPA’s pain to be treated and also influenced PHILIPPA’s perception that her clinician believed she was credible.

**Theme 3: Motive, Honesty, and Testimony**

The third theme reflects participants’ doubts that their clinicians believed that they were being honest about their motives for seeking treatment (e.g., drug misuse or drug diversion). In Theme 1, patient participants perceived their clinicians as being untrustworthy. In the present theme, participants described being perceived as untrustworthy by clinicians:

Interviewer: So, how do you feel when you get a letter that says you’re drug-seeking, double-doctoring?

SIMONE: ...being falsely accused is one of the worst feelings you can have...to be accused of doing something you not only didn’t do, but so vehemently believe is wrong ...

Patient participants reported considering such accusations as being unfair, especially when they may have gone to another clinician for a prescription because the original prescription was insufficient to manage their pain. The concern some participants had was that their motives for legitimately seeking treatment were being interpreted as illegitimate drug seeking.

LUDWIG stated that clinicians are often skeptical about his treatment-seeking motives:

LUDWIG: When I was in [hospital] just a couple of weeks ago...the ambulance drivers just took one look at me and it was, like—the look in their eyes was like, ‘Oh, he’s just a junkie looking to get stoned.’ They didn’t believe that I was actually suffering and in pain. They thought I was faking it completely ...
**Theme 4: Stigmatized Identities**

The final theme reflects the implications that stigmatized identities, such as being a person with chronic pain and a person with an addiction, can influence the participants’ perceived trustworthiness:

**Simone:** If you have ever had an alcohol or drug issue no matter how far in the past it was and how much you dealt with it, if you mention that to any doctor that is dealing with your chronic pain, and your painkillers, they will forever brand you an addict or an alcoholic and in doing so, will completely change the way they approach you with the medicine and their whole attitude and outlook.

**Hannah,** a young Aboriginal woman who reported a history of intravenous heroin use, recalled several encounters with her clinicians when she requested analgesics and was refused. She believed that her medical complaints were not seen as credible:

**INTERVIEWER:** And when you ask for certain medications the doctors won’t…?

**Hannah:** They just look at me, laugh, and say no.

**INTERVIEWER:** No? How does that make you feel?

**Hannah:** Mad and angry, you know, like they, they expect me to live like this, even though I didn’t ask to be born like this and I didn’t ask to be hit by any types of vehicles. I always tell them, imagine being put in my shoes ...

Aboriginal peoples in Canada often face individual and institutional discrimination when interacting with the health care system [42], and **Hannah** stated that being a drug-using Aboriginal person makes her seem particularly untrustworthy to clinicians.

One of **Elaine**’s physicians informed her that her clinical presentation was a barrier to her securing pain relief. Like **Simone** and **Hannah,** **Elaine** had difficulty developing a trusting relationship with clinicians, presumably because she was perceived “like a drug addict”:

**Elaine:** I asked a doctor one time, ‘What am I doing that’s wrong?’ And he says, ‘You present like a drug addict.’ And I’m, like, what? Because of I’m in so much pain, I need something to help me. And because of saying that, it makes me a drug addict rather than a woman who’s in pain.

**Ludwig** described his own experience:

**Ludwig:** Before I became a drug addict—I guess you would call it now, legalized drug addict—before they started me on the opiates, I didn’t have a real problem in the hospitals. I didn’t have so many bad looks or nurses had no problem walking away leaving stuff in sight. But now that whenever I’m in a doctor’s room, office, or the hospital, it’s like they close the door, they close the drawers, they don’t leave you alone…Kind of like they don’t trust you anymore.

**Physician Feedback Group**

The physician feedback group served as a mechanism for data triangulation, through which a validation of the convergence of the data, analysis, and conclusions were tested.
Theme 1: Challenges of the Practice Context

Physicians highlighted the challenging context in which chronic pain management is delivered. They recalled several difficult interactions and the impact these interactions had on their approach to care:

Dr. John: The things that we remember are the times that we got burned, right... You may get burned one in 100, but that one in 100 is enough to burn an impression in your mind that makes you wary of all patients potentially.

The metaphor of being burned was frequently used to describe the concern that physicians shared that patients may not be telling the truth about their motivations to obtain opioid medications. Dr. Ronald reiterated this point and specified that the patient, the physician, and society are all "burned" by untrustworthy patients:

Dr. Ronald: We have a responsibility to be careful with prescribing these medications, so when we get burned, society gets burned, patients get burned.

The physicians described situations of misplaced trust in which patients were dishonest and obtained a prescription for opioids:

Dr. Patrick: Just the being lied to when you really trust a patient and you feel like you’re trying to help them.

While concerning, it was not necessarily the deception itself that was most distressing to the physician; it was the harm that did or potentially could occur to the patient or others as a result of mistakenly trusting the patient. For instance, the harm could be taking more medication than prescribed or planning on diverting the medication to others who could potentially overdose as a result.

Theme 2: Complicated Clinical Relationships

The second theme reflects how the challenging practice context of chronic pain management involving opioid analgesics can prohibit or destabilize the development of trusting clinical relationships. Physicians in the feedback group did not necessarily see their role as a collaborative partner per the contemporary model of the clinician–patient relationship when addiction issues arise or opioid analgesics are prescribed. The physicians saw themselves in a defensive role of interrogator:

Dr. Henry: In most doctor–patient relationships we learn to listen to the patient and accept their testimony... in some instances, to be quite honest, we are interviewing the patient as if we are a police officer or a lawyer and we’re trying to find flaws in their story... So there is a different relationship here.

This atypical role reinforces the epistemic hierarchy between patient and clinician, in which patient testimonies are presumed to be untrustworthy. Uncertainties inherent in the practice context combined with questions about the credibility of patient testimony play out through the dominance of objectivity in biomedical culture:

Dr. Rene: I feel this as a physician, when I see a patient who has, you know, a pathological fracture on an X-ray... if there’s something objectively definable it does change the way that I approach the patient.

Dr. Patrick: We have all had experiences where patients have been misrepresenting their physical findings and there’s been a discrepancy between what they report and what we see. And, unfortunately, it is a very distrusting relationship inherently.

The consensus among the physician feedback group was that a default position of distrust might be defensible when incongruence exists between what the patient believes to be in his or her own best interests (e.g., high-dose opioids), and what the physician predicts would be concrete harm:

Dr. Ronald: Every week I deal with somebody, I admit somebody, and literally I have to distrust what they tell me because if I write down on the chart and order what they tell me to order, I’ll kill them. And doctors have lost their jobs, on my ward, over that issue.

Some physicians maintained that an antagonistic attitude might be mitigated by a strong, pre-existing trust relationship:

Dr. John: Both the patient’s perspective and the physician’s perspective in these issues is largely affected by what is the nature of the relationship between the two before issues around pain medications is involved. So, if the only interaction with the patient is around pain medication, you don’t have a foundation of trust to start with.

The physicians stated that they are on a firmer ground to discern the trustworthiness of patient testimony if there is an established therapeutic relationship. Dr. John elaborated on the “foundation of trust” between patient and physician, calling it a “bank of good will,” a metaphor endorsed by members of the feedback group:

Dr. John: If you’re the family doctor or long-term psychiatrist or internist who’s known them [the patient] for 10 years and now they’ve developed a pain problem, you already have a bank of goodwill both ways.

Taken all together, the themes highlight the arduous and precarious context in which chronic pain care is delivered, and the challenges this poses to both the discerning of patient trustworthiness and the therapeutic relationship.
Discussion

Our qualitative study reveals that chronic pain management promotes, but does not necessitate, a default attitude of distrust among patients and clinicians. The study provides an in-depth understanding of how patients with chronic pain struggle to negotiate trust with their clinicians, a process which is fueled by the inherent subjectivity of pain symptoms and the potential suspicion of drug misuse and drug diversion. Distrust may not have always been the default attitude for patient participants—especially those without concurrent substance use problems—when they first began to receive treatment for their pain. Distrusting attitudes may have been developed over time, as participants learned that their identity as a trusted patient in other areas of health care is not necessarily extended to them in the pain management context. The findings also highlight how some clinicians decide whether to trust patients who have a history of or are at risk of addiction, especially if these clinicians were deceived, by any patient, in the past.

The findings have important overlaps with aspects of the five-part conceptual model of trust proposed by Hall and colleagues [23]. Hall et al.’s first dimension, “fidelity”, is about clinicians acting in a patient’s best interests and not taking advantage of his or her vulnerability. This dimension intersects with patient Theme 1: threats to trustworthiness and iatrogenic suffering. Second, Hall et al.’s “competence” dimension refers to both the clinician’s technical competence (i.e., medical skills) and interpersonal competence (i.e., communication skills). There are commonalities here with patient Theme 1 and patient Theme 3: motive, honesty, and testimony. Third, the “honesty” dimension refers to telling the truth and avoiding falsehoods and who stands to benefit from the dishonesty. This dimension relates to patient Theme 3 and physician feedback group Theme 1: challenges of the practice context. Fourth is “confidentiality”, specifically the duty to protect private information. This dimension did not emerge in our findings. The final dimension is “global trust”, an all-encompassing term for the aspects of trust that relate to the previous dimensions but do not fit exclusively into one. An example is patient Theme 2: communicating the invisible and subjective condition of chronic pain, and physician group Theme 2: complicated clinical relationships.

In this study, many patient participants reported that they were perceived as untrustworthy because of a perceived negative stereotype held by the clinician—for example, the stigmatizing identity of the drug addict—which patient participants claimed unfairly rendered their testimonies unreliable. In contexts such as pain management, where medical uncertainty is common, individuals with pain, particularly those with co-morbid addiction concerns, may not be seen as credible informants [43]. When a negative stereotype causes a hearer to assign a deflated level of credibility to a speaker’s testimony, this is tantamount to a specific kind of injustice called testimonial injustice [44].

Trust and Trustworthiness in Pain Management

The ethical implications of testimonial injustice are pertinent to those with stigmatized identities such as patients with chronic pain and addiction. Individuals with stigmatized identities are often victims of negative attitudes and assumptions, and their testimonies are frequently seen as lacking credibility [45]. For instance, individuals with low back pain are often characterized as disabled, lazy, and attention seeking [46]. When drug-related issues co-occur, patients may be additionally characterized as being weak-willed, out of control, and socially deviant [47]. Rance and Treloar have observed that testimonial injustice in drug treatment settings is part of a larger process by which people who use drugs are discredited by treatment staff [48]. In the current study, the request for addictive forms of pain relief was often regarded as drug-seeking behavior, and reinforced the stereotype of the untrustworthy addict. These accusations allegedly occurred in the absence of evidence of addiction or aberrant drug-related behaviours. Individuals with chronic pain who perceive or experience testimonial injustice may have limited opportunities to demonstrate trustworthiness with clinicians, and may also fail to enjoy the benefits of a trusting clinical relationship.

Certainly, disingenuous solicitations for treatment occur [49]. Given the individual and public health harms that have resulted from prescription opioid use, some clinicians may argue that assuming untrustworthy testimony is prudent. Indeed, physicians in the feedback group endorsed this position. Nonetheless, some clinicians tend to over predict the presence of a prescription drug use disorder in patients with chronic pain [50]. Furthermore, a study by Poole and Craig [51] demonstrated that clinicians, when primed to expect that patients reporting pain were being deceptive, underestimated the level of the patient’s pain. The burden of proof to demonstrate trustworthiness falls more heavily upon patients than clinicians given the imbalance of power inherent in clinical relationships.

Placing Trust Wisely with Epistemic Humility

Placing trust unreflectively in a context framed by uncertainty is risky. Similarly, giving some people undeservedly high credibility may be risky as well. Ethically it is important to cultivate a mutually trusting clinical environment where honest communication can thrive, prescription safety issues are openly discussed, and care plans can be co-developed. We argue that clinicians and patients can collaborate to cultivate a trusting therapeutic environment, manage the challenges associated with uncertain testimony, and place trust wisely, by striving toward epistemic humility.

Epistemic humility is an approach that calls for shared responsibility between patient and clinician in treatment decision-making [24,52]. Being epistemically humble means recognizing that medical judgments are almost always accompanied by uncertainty [53], and that one’s picture of the clinical scenario may be incomplete. This
approach recognizes patient testimony and illness interpretations as relevant and important in determination of the best clinical management [54]. Epistemic humility is intentionally collaborative, as “both the HCP [health care provider] and patient are counting on each other in investigating a full picture of the patient’s experience and determining the most appropriate management strategies” [24, p117]. While clinicians have vast medical knowledge and expertise, they do not have direct access to their patients’ experiences. Epistemic humility recognizes the limits of clinical knowledge and expertise in determining the most appropriate care plans.

The necessity of medical expertise and skill places clinicians in a privileged position to decide how the patient should manage their pain. Many patients have lived with their pain for many years and often have extensive experiences with multiple interventions and clinicians. If clinicians constantly question the accuracy of the patient’s testimony about their symptoms or behaviours, it may reinforce the societal message that the testimonies by people with chronic pain, with or without a co-morbid drug addiction, are not to be trusted.

Striving for epistemic humility does not mean that clinicians ought to trust all patients at all times, or acquiesce to requests for medically non-beneficial interventions. Epistemic humility requires clinicians to extend a bridge: a genuine interest and inquiry into the patient’s experience, intersubjective understanding, and critical reflection about the assumptions made about the trustworthiness of certain patients [55]. When wondering about the legitimacy of the patient’s testimony, clinicians can re-orient the discussion toward their shared goal with the patient—to find optimal pain management that is suitable for the patient’s situation. Patient-centered approaches like epistemic humility that includes strategies such as critical reflection may help minimize interpersonal challenges between the clinician and the patient with pain [10,56].

While the responsibility for epistemic humility falls more heavily on the clinician than on the patient given the inherent power hierarchy in the therapeutic relationship, patients, as participants in the relationship also have responsibilities to demonstrate veracity and trustworthiness. Since clinicians have no direct access to the patient’s subjective experiences of pain and suffering, it is incumbent on the patient to truthfully communicate her experiences, symptoms, and expectations for treatment. Patients need to be honest about their health care and medication histories, as well as their motives for seeking treatment. They also need to recognize and disclose any potential harm that may come to others (e.g., medication diversion). By being committed to an honest therapeutic dialogue, clinicians may trust the veracity of the patient’s testimony. It may also help clinicians to appreciate the severity, quality, and meaning of the patient’s pain in the context of his or her life, and to provide appropriate care accordingly [see e.g., Ref. 57].

One possible approach to help clinicians and patients strive for epistemic humility and negotiate trust is Carel and Kidd’s [54] three-step phenomenological toolkit. The toolkit is intended to help patients to make sense of their illness experience and to articulate it, and is a means for clinicians to better understand and interpret patients’ experiences. The first step, phenomenological reduction, shifts the focus away from the illness (e.g., pain) as an objective disease entity and toward the lived experience of the illness. The second step involves thematizing the illness, in which the patient and clinician attend to the illness’ various cognitive, emotive, moral, or aesthetic aspects as articulated by the relevant stakeholders (e.g., patient, clinician, caregivers). The final third step involves taking the new understanding of illness and examining how it changes the patient’s everyday experiences. Although the toolkit is designed to apply across health care scenarios, given the findings of our study, the toolkit may have particular utility for chronic pain management. Future research can test whether a toolkit such as this would be effective in improving clinician-patient communication as well as trust.

There are three potential challenges in motivating clinicians to adopt an attitude of epistemic humility. First, epistemic humility requires the clinician to be constantly empathic and compassionate, which can be difficult as caring for patients with chronic pain can be time-consuming, frustrating, and stressful. As a result, many clinicians working in pain management may experience burnout and compassion fatigue [58]. Second, clinicians have historically been taught to remain emotionally detached from patients, as subjective empathy was believed to be an impediment to clinical objectivity [59]. Third, studies have identified limitations in communication training in pain management curricula [60]. For example, Leila and colleagues [61] argued that medical student training in pain management tends to focus on developing knowledge without adequate attention to communication skills, which presents a barrier to translating knowledge into practice. Epistemic humility, combined with a biomedical model of objectivity that has historically deemphasized subjective reports of pain, may then be in tension with how clinicians have been trained to practice [62,63]. Attempting to balance patient subjectivity with objective medical assessment and trust patients may thus be challenging for some clinicians. This may be especially true when the clinician is faced with the serious risk of iatrogenic harm to the patient or others, or is overly hesitant due to the potential medico-legal implications of providing addictive medications.

Patients also face barriers in demonstrating trustworthiness and adopting a stance of epistemic humility. Some may not have the cognitive capacity to be epistemically humble, given how pain-associated suffering can threaten well-being, including self-identity. Moreover, during bad pain flare-ups or sedation from medications, patients may not be able to actively participate in a collaborative process. The impact of multiple chronic morbidities including
psychopathology on patients’ ability to be epistemically humble must be acknowledged. To complicate matters further, the aforementioned factors may impair the patients’ capacity to tell their whole story. The latter considerations do not obviate patient responsibility in the therapeutic relationship. Rather, they contextualize the lived experience of the patient with chronic pain.

Not all patients desire to be active participants in their care, and not all patients will be capable of being full participants. As discussed, patients have responsibilities to demonstrate trustworthiness, such as being honest about their medical and psychosocial histories, as well as being honest about their motives for seeking treatment. The patient’s lived experience ought to be in an epistemic equilibrium with the specialized clinical expertise of the clinician. By attending to these considerations, patients may be able to contribute to the discussion and their care may be a legitimate two-way collaborative approach.

Limitations

Qualitative research often forgoes generalizability in favor of in-depth explorations of a phenomenon of interest. Our findings should therefore be interpreted in this light, rather than as a representation of all chronic pain contexts. For instance, our research was conducted in a single urban centre in British Columbia with higher than average rates of addiction, and the findings may not necessarily represent the views of individuals with chronic pain in other geographical areas. Almost half of the patient participants had a personal or family history of drug use or of mental health problems, or both, which over-represents the typical rate estimated in individuals with chronic pain [64]. Future research can explore whether participants who reported a personal or familial history of drug use and/or mental health problems differ from participants without this history in their perceptions and attitudes toward trust in the clinical relationship.

The physician feedback group was recruited from one particular health region and care for patients fitting the patient participant profile. It can be noted, however, that their perspectives are consistent with the physician attitudes toward opioid prescribing in pain management [9].

Although some patient participants reported trusting therapeutic relationships with their clinicians, these accounts were scarcer in comparison to reports of adversarial relationships. Patients with predominantly good experiences may not have participated because they may not have seen the necessity of discussing positive relationships. Future research can examine whether longer-term clinical relationships in pain management are predictive of higher levels of trust. Indeed, one of the physician participants, Dr. John, mentioned that building a “foundation of trust” from the beginning of the relationship might mitigate antagonistic attitudes.

Future research can also explore how trust manifests in non-outpatient settings such as the Emergency Department (ED). Patients often present to the ED with pain complaints, and the number of patients presenting to the ED requesting and suffering the consequences of opioid analgesics has increased dramatically in recent years [65,18]. In the ED, clinicians often do not have adequate access to the patient’s health record to corroborate pain and addiction histories and often have not established a therapeutic alliance. Additionally, the type and comprehensiveness of care possible for each patient may be limited by time and the availability of clinicians with expertise in pain or addiction management. Such factors may influence the trust relationships in the ED and consequently the quality of care provided. For example, Carter and colleagues have hypothesized that clinician distrust of patient subjective pain reports is one reason why pain remains under-treated in the ED [62]. This is a hypothesis worth testing.

Conclusion

The role of trust in chronic pain management is an understudied area of research, despite the importance of trust to the clinical relationship. The patient and clinician narratives in this study provide an in-depth account of the moral and practical importance of trust in a pain management context. The findings suggest that clinical relationships in chronic pain management may be framed by distrust and rely on assumptions about untrustworthy testimony. This framing is a fundamental change to the moral foundation of the clinical relationship that is based in trust. A clinician who adopts a disposition of epistemic humility may thus be well situated to demonstrate trustworthiness, and to place trust wisely.

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