

Towards Health Equity for People Experiencing Chronic Pain and Social Marginalization

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Abstract

Objective: For people who experience inequities and structural violence, pain and related care are inexorably linked to experiences of injustice and stigma.

Methods: A community-based qualitative study included four focus groups with 36 people living with pain from groups known to experience high levels of inequities and structural violence including an Indigenous group, a LGBTQ2S group, and two newcomer and refugee groups.

Results: Pain was entangled with and shaped by: social locations and identities, experiences of violence, trauma and related mental health issues, experiences of discrimination, stigma and dismissal, experiences of inadequate and ineffective health care, and the impacts of these intersecting experiences.

Conclusions: Equity-oriented responses to chronic pain would establish pain not only as a biomedical issue but as a social justice issue. The EQUIP Framework is an approach to integrating trauma- and violence-informed care; culturally-safe care; and harm reduction in health care that may hold promise for being tailored to people experiencing pain and social marginalization.

Introduction

It is estimated that one in five Canadians lives with chronic pain while those groups that experience inequities and structural violence are more likely to live with pain and pain that is of greater severity than the general population (1, 2). Very often people experiencing chronic pain experience stigma and limited care options, and, for some people, this stigma intersects with multiple stigmas related to race and ethnicity, class, gender, sexual orientation, mental health, substance use among other forms (2–5).

Pain management has been declared a fundamental human right, with inequities and injustices identified as the greatest challenges to responding to pain globally (6). To acknowledge chronic pain as a human rights issue is to address it as more than a health issue – it is to view it as an issue of equity and justice and inseparable from contexts of structural violence (7) that are reflective of the ways societies are organized that create harm and reproduce racism, poverty and other disadvantages (8). Indeed, chronic pain is a societal issue that is inseparable from the experiences and impacts of racism and colonization (9, 10), the stigma and lack of responses for mental health issues (11), misogyny and intimate partner violence (12), the current illicit drug overdose public health crisis (13) (14), the ongoing crises of homelessness and poverty (15), among other major challenges to realizing a more just, equitable and healthy society.

Despite recognition of the relationships among inequities, pain and pain management, how the experience of pain is shaped by social contexts, including social injustices, has been studied only recently. While it is increasingly recognized that “emotionally difficult experiences, including trauma, interpersonal conflicts, work stress, and social rejection, contribute to chronic pain” (16, 17) (p. 565), as of yet, underlying mechanisms are not well understood (18), and research is only beginning to be conducted

with socially marginalized groups. For example, the unique mechanisms whereby systemic racism become manifest in painful experiences and influence how chronic pain is treated have not been well studied. In the context of low back pain Ziadni et al (16) found pain-related appraisals of injustices mediating these relationships, with prior experiences of racial discrimination positively associated with severity of disability and depressive symptoms. Perceived injustices also have predicted worse self-reported depression and disability outcomes in people with chronic low back pain (19). The experience of pain was linked to discrimination and injustice and as these experiences increased, individuals' perceptions deepened regarding the irreparability of the pain they were encountering and unfairness related to their experiences of care (16).

Experiences of injustice and unfairness can have negative impacts on overall health, with these adverse impacts amplified for people living with chronic pain who may increasingly perceive the care inequities they encounter and the pain they face as reflecting excessive social scrutiny, social judgement and a form of punishment (20). While previous research has recognized systemic inequities in the distribution of pain and pain management, programmatic response to these inequities in the form of improved access to interventions has been minimal and is understudied (9, 19). Understanding the meanings attached to pain is as important to clinical encounters as understanding physical symptoms; understanding pain requires recognizing its meaning as a threat to peoples' bodies and their selves (21). Thus, study of the relationship between chronic pain and diverse experiences of social marginalization as well as its implications for interventions is necessary.

To explore the relationship between experiences of pain and discrimination and stigma, we conducted a community-based qualitative study using focus groups with people living with chronic pain and identifying with one of three groups known to experience high levels of inequity, discrimination and stigma in Canada Indigenous¹ (22, 23), LGBTQ2S (24) and refugees or newcomers (22).

¹In Canada, Indigenous people include diverse First Nations, Inuit and Metis peoples. Royal Commission on Aboriginal Peoples. (1996). *Report of the Royal Commission on Aboriginal Peoples*. Ottawa: Canada Communications Group-Publishing).

Methods

The research was guided by the principles of community-based participatory research (CBPR) with the research team uniquely engaged with the communities invited to participate in the project. Community-based participatory action research (CBPAR) is an approach that engages communities equitably in the research process for the purpose of producing knowledge and taking action for positive change (25, 26). The research was initiated by Pain BC, a province-wide nongovernmental organization that brings together people in pain, their families, health care providers and others to improve the lives of people living with chronic pain in British Columbia (BC) Canada and beyond. Pain BC identified the need to develop contextually tailored responses to chronic pain for populations in BC also experiencing social

marginalization. Throughout the project, Pain BC played the lead role in the research processes and as the principal knowledge user, will use the evidence to inform their current and future programming.

The research team includes community-based researchers with unique, often longstanding, relationships with the communities experiencing social marginalization. The researchers collaborated with community not for profit organizations with which they maintain relationships to recruit participants, for example an Indigenous community health centre in one community, a resettlement and newcomer agency in another and a network of agencies and contacts dedicated to LGBTQ2S communities. Recruitment handouts were distributed by the collaborating agencies to people accessing their sites and services. Focus groups were utilized as a qualitative method that holds the potential for in-depth exploration of issues through shared discussion and potentially shared understandings. With the CBPR approach, the gathering of individuals with shared experiences further holds the potential of creating community connections, building capacity around an issue and a possible foundation for further participation and action.

While recruitment strategies were modified to best fit the community interests and processes, the overall approach was third-party recruitment with outreach from the collaborating groups who linked interested participants with the researchers. An honorarium of \$50 (CAD) was provided to each participant. Within the focus groups, we sought to create a culturally safe social opportunity with the sharing of a meal that included moose stew with the Indigenous group, Persian catering with the newcomer and refugee group and the LGBTQ2S had lunch from a queer-based caterer in the community. The researchers were committed to removing barriers to participation in the groups and to respond to diverse access needs for people living with chronic pain including low lighting, supportive seating, and specific dietary requirements. The focus groups typically exceeded an hour with the meal and socializing being close to another hour.

Four focus groups were held with a total of 36 participants, with the initial group conducted in December 2018 and the final group in March 2019. The criteria to participate in the research were to be an adult (over 18 years), to identify as experiencing chronic pain for three months or longer and to also identify as a member of the population group being gathered (Indigenous, LGBTQ2S, or refugees and newcomers). The Indigenous group and the LGBTQ2S group each had 11 participants, one newcomer and refugee group had six participants, while a second group was organized with 8 refugees from Syria, facilitated in Arabic and translated to English. The research team decided to not include a demographic survey as part of data collection as we considered using predetermined categories antithetical to CBPR processes and our intersectional perspective. Rather, each group began with each individual introducing themselves as they wished, which often resulted in participants more fully presenting their complex selves and identities than a demographic survey might have elicited. The semi-structured interview guide explored three general interests a) To get a better understanding of participants' experiences of barriers (both external/system and personal) confronted in managing their chronic pain, b) to understand what has helped individuals deal with their pain, and c) what can be improved to help them. All groups used the same semi-structured interview guide. The focus groups were facilitated by the researchers or co-facilitated with a community member including an Indigenous Elder with the Indigenous group and a

settlement worker with the newcomer and refugee group. Consent forms were explained and signed and the group discussions audio recorded and then transcribed. Ethical approval for the project was granted from the University of British Columbia Behavioural Research Ethics Board.

The transcripts were analysed by the research team, including Pain BC research collaborators, using an iterative process that made use of both deductive and inductive processes. An initial thematic framework analysis based on the Equip framework (27) provided a priori categories (deductive). These themes were trauma and violence informed care, culturally safe care, harm reduction, and contextually tailored care. Emergent themes (inductive) were identified by the researchers and used to code all of the transcripts in the initial round. Following this process, the research team discussed the emergent themes and the a priori categories to develop an analytic framework. A second round of coding using the analytic framework was conducted. With this second level of coding, the research team once again discussed the themes as a group and collaboratively developed a more detailed thematic analysis that identified overarching themes and sub-themes within and across groups.

Within a month of the final focus group, a one-day workshop was held with an objective of sharing the initial thematic analysis by the researchers with stakeholders who included two or three participants from each focus group, Pain BC, the research team, and a small number of key chronic pain healthcare providers and policy makers. This feedback process provided an additional analytical step as research participants and other stakeholders provided reactions to the findings, including their analyses of what was presented. From this step, the research team met again to refine and finalize the analytical framework and reanalyze the full transcripts.

Results

The experience of pain across these diverse peoples were entangled with and shaped by five key interrelated areas of experience: their social locations, identities and related barriers they faced; their experiences of violence, trauma and related mental health issues; their experiences of discrimination, stigma and dismissal; their experiences of inadequate and ineffective health care; and the impacts of these intersecting experiences, specifically on employment, income and their social lives.

Pain was shaped by and entwined with participants' social locations and identities and related barriers.

These diverse groups of people were brought together because of a single aspect of their social location: identifying as LGBTQ2S, identifying as Indigenous, or being a newcomer or refugee to Canada. While participants identified the ways in which they aligned with the group to which they had been invited (e.g., most newcomers specified from which country they had immigrated), they also often offered multiple dimensions of their social locations and related identities that were inclusive of, but not limited to, the group they had been invited to represent. Indeed, some participants also identified with one or both of the other groups: a transwoman participated in the Indigenous focus group; several Indigenous persons participated in the LGBTQ2S focus group and so on. Importantly, each participant in both the LGBTQ2S and the Indigenous focus groups made clear statements of identity related to these groups; whereas

participants in the newcomer and refugee groups did not, perhaps reflecting varied conventions for introductions and the context. Notably, whereas the Indigenous Talking Circle was guided by a protocol for introductions, and it is common practice within such protocol to name one's clan, community, territory, or nation, most of the Indigenous participants stated their relationship to pain in their introduction. This was unusual, but perhaps in part this was explained by the fact that the focus group facilitators (a local Indigenous Elder, and a researcher) were familiar to most and had introduced themselves formally on other occasions. Also notably, no participants in the refugee and newcomer groups shared aspects of their gender identity or sexual orientation perhaps in part because in many of the cultures that the newcomer participants were representative of, terms such as 'gay' or 'trans' may not be part of the cultural vocabulary, even in the case where they align with those identities (28).

Across these diverse groups, participants expressed the complexity of identity and social location, and the complex relationships among them.

I'm trans, I'm non-binary, I'm Jewish, I'm a singer, I'm going through transition right now and that's something that's been on my mind a lot is that my voice is changing and I've been grieving my singing voice a little bit so just thinking about that before I got here today (LGBTQ2S-1-1)

For some, pain, and disability rights were part of their described identity. "I identify as queer and non-binary and I also identify as a crip, sick, and disabled" (LGBTQ2S 1-6). Indeed, as noted, most of the Indigenous participants opened with a declaration of their long history of pain. "My name is M and I've been living with chronic back pain since 1990" (Indigenous 9).

Perceived identity and social location were described by many as acting as threats to safety and as barriers to pain treatment and support. LGBTQ2S 1-6 went on to say "I've had a lot of interactions with the healthcare system and I've definitely come across times where there weren't resources that really reflected who I was". Another said:

As an Indigenous person I always feel like the health, in totality, the healthcare system is a barrier to me. There's always a risk of – I always feel, I have to measure if there's a threat against my body or even my family just because somebody could make a racist assumption about me. (LGBTQ2S 1-10)

Specific identities or social locations were associated with unique barriers to treatment and support, including specific threats to safety such as accessing gender-affirming care.

I am gender fluid, looking at taking testosterone and I'm curious about, broaching that with my doctor who's already very binary focused and in tandem with all of the mysterious things that cause pain and mental health issues... and then the layer of just very much like not knowing if I'm safe, being seen or willing to be asked to be seen or whatever is a barrier as well (LGBTQ2S 1-7)

Participant's social locations and identities were directly associated with specific structural barriers. For example, Indigenous participants' access to services varied according to whether or not they had status²

under the Indian Act.

When I say I'm Native I have to say non-status. I have to actually specify that, that I'm non-status because... my biological father is not on my birth certificate. I'm actually persecuted by both sides, by the Native side and the Canadian, white Canadians. And I kinda get thrown around by both of them because I'm not either one. (LGBTQ2S 1-11)

Similarly, newcomers' experiences varied with their status governed by legislation related to immigrants and refugees, the benefits to which they were variously entitled, and their experiences with related processes. For example, one newcomer attributed her experiences of chronic pain with the social isolation she experienced as a refugee.

She says before she [came to Canada], when she was in [her country of birth] she never feel anything, she was relaxed enjoying social life, meeting each other occasionally or meeting family, friends, whatever, go to church, go to mosque, whatever, she never feel that. But since she came here all the pain start to come out. (Translator for Newcomer FG2)

Many newcomers described being unable to access treatment due to cost. Newcomers without strong English skills described difficulty in even describing their health issues and pain, particularly given that many health care settings do not provide access to interpreters, with consequent under treatment, delayed treatment, mistreatment and emotional impact.

Emotionally it's very hard when you can't, when the services can't understand you and doctors don't understand you... (Newcomer 2 - 1)

Pain was shaped by violence, trauma and related mental health issues. In all groups, many associated their chronic pain with their trauma experiences and related mental health issues.

I'm a refugee ... from [place]. I went through so many difficult things. I was raped and kicked, I was being kicked with boots, soldiers were kicking me with their boots, I don't know how my life came to be so broken down. After that I had no peace. I came here, I was happy that I'm here...I thought again I'm going to experience joy, happiness but its not easy. I'm going to hospital, just to the hospital and I thought my kids were going to move and come and stay with me in this country. My kids never moved and follow me. My head is not working I have high blood pressure, most of the time the pressure will go up to two fifty, three hundred. I'm taking drugs but the pressure does not come down. And the pain, I'm telling you... All night I'm walking (pacing) in the house while others are sleeping and I'm awake. Then I sleep in the daytime and we are supposed to live as a family and do chores and other things that means we are living as a family, but I can't because I have not slept all night. (Newcomer 1-6)

I live with chronic pain and had pain probably my whole life and diagnosed with learning disabilities, as well as chronic mental illness and trauma, so all those kind of go together. (LGBTQ2S 1-4)

..in addition to like um physical kind of pain stuff, like mental health struggles and complex PTSD and trauma is something I've lived with most of my life as well and I think it's been like a big source or like really important in my um, my resulting chronic pain. (LGBTQ2S 1-NS)

Pain, discrimination, stigma and dismissal. The participants' experiences of pain were described in ways that were inseparable from their experiences of discrimination, stigma and dismissal. As suggested earlier, throughout the focus group, and during the one day workshop, many in the LGBTQ2S group described how cisnormativity and heteronormativity that pervades multiple systems influenced their experiences, and thus the meaning of pain.

...I wanted to share...about being a student and being at post-secondary institutions and experiences like working with the disability resource centres on campuses that I've been at and with various professors and others that are above [laughs] me as a student. And also in combination with my fibromyalgia, which is chronic and constant kind of pain but also having PMS and menstrual issues combined with the gender identity stuff makes just a whole other mixed bag of things to limit you in sort of access to education and to acceptance, yeah. (LGBTQ2S -NS)

All of the Indigenous participants described experiencing race-based discrimination, with most describing being assumed to be "drug seeking", regardless of whether they wanted medication or not.

Well I used to use drugs...I don't do that anymore. I'm on methadone now and I'm in recovery, so. But... because I'm on so much methadone... it's hard for me to manage my pain...when I do go to the hospital and stuff, they look up my past history and my drug life, and ...they always bring that up. It's always like, they won't give me the medications that I should be getting because they think I'm drug seeking. (Indigenous 1).

Participants described how such assumptions were interrelated with their experiences of not being believed which in turn deterred them from seeking and getting care:

For me, I'm having a hard time to ask for help to any doctors because of how they treat me, like [they] say I just want to get pain medication just to get high and all that, and I'm really in pain and I'm telling them and they don't believe me and that, and I'm having a really hard time right now. It is hard for me to ask because of all the things I went through with the doctors and that. They treat me like...I'm just after the drugs to get high and that. They don't believe me, that I'm in pain. I'm trying really hard to ask for help and it's really hard for me to ask for help because of how I was treated before. (Indigenous 3)

These experiences of discrimination, stigma and dismissal were entwined with their experiences of inadequate and ineffective health care, together shaping their understanding, experiences and meanings of pain.

Inadequate and ineffective health care. Overwhelmingly, most participants described being unable to find effective pain management.

Nothing has been working for pain management. I've tried massaging, I've tried IMS, I've tried acupuncture, I tried medicinal marijuana, I've tried like stronger medication, I've tried street stuff and nothing is making it any better. (LGBTQ2S 1–9)

I was finally diagnosed with osteoarthritis in two places in my foot and I'm presently waiting now to see the orthopedic surgeon, which ... is going to be another year or year and a half before I'm getting some help there. At least now I'm getting treatment, like I have physio every Monday, I have Voltaren cream that I can put on my feet; whereas for six years, no physio, no cream, no pain medication. It just kept escalating and escalating. And I think part of the reason why it is as bad as it is now, is because there was nothing for six years. No physio, no suggested anything for it; just waiting for the next doctor. (Indigenous 7)

Most were only able to access pharmaceuticals and many in each group described this as very limited and problematic.

Finally, they put me on 2 mg of Dilaudid twice a day, once in the morning and once in the afternoon, and they told me I could go on 1 mg four times a day, and it was like wow, yeah, okay [sarcasm]. So, I take several different painkillers, but I don't want to be on medication; I want solutions. I want to be fixed. (Indigenous 6)

...like pharmaceuticals don't really work for me and like in my experience like very few practitioners are willing to talk about any other options and are willing to work with like other types of practitioners (LGBTQTS)

I go to complain to the doctor and he give me sleeping pills and I say, no, I don't want to do that, it control me. And he always give me, give me the prescription, prescription all the time but he don't give me the specialist doctor. (Newcomer 1–3)

Participants recounted being disbelieved regarding the existence of pain, their level of pain and the cause of their pain, and dismissed regarding their concerns, needs and preferences. In each group several participants described how the impact of being disbelieved and dismissed had led to misdiagnoses and mistreatment.

Pain. I honestly don't know what it's like to live without pain. I had back surgery a long time ago...They wanted to put those rods in my back and I told them natives tend to reject those rods, so I don't want to go through that. They wouldn't listen to me. Well, at the fourth month after having them in me... I started feeling my body was rejecting the steel. I went in and I told them and they did not listen to me. They said that it was in my head, that ...I was trying to get drugs. ...at the year mark of them being in my body, I was rushed to emergency in [another community]... they had to open me up as soon as I got in there and there was steel and pus and everything, like large amounts... For somebody to have two big jugs of liquid pus come out of them, there has got to be something that can be done before this, and where they had those

bolts, it broke the bones, it ate the bones. So, I've got nine bones in my body that are gone because of this one doctor ... He crippled me. (Indigenous 4)

A newcomer described a six-year quest for treatment of pain. She described being dismissed repeatedly by physicians in primary care, and not believed by other healthcare providers.

So, I told myself I need to go to emergency not [a] walk in clinic because it will take me a long time. So, when I went there, I told them that I have strong headache and I show them the place exactly the place. And I told them that I need, I need help because I can't help all these pain. The doctor he didn't believe me at first, he told me you just have a migraine...I told him, no, its not that, I feel something in my brain it push my brain away. But he didn't believe that, he like I felt he's just feels that I am like acting like I am...

R: You are faking it?

P: Yeah and my husband told him can you please do a CT scan, something better to, to know what she has. Like when they do the CT scan they found the tumor that took all the right side. (Newcomer 2-3)

Many experienced difficulty knowing what to do and navigating the system, reflecting how systems are not organized in ways that are tailored to needs. One newcomer described:

My doctor, after taking x-rays and, yeah, trying to figure out what it was- the first thing the doctor says is "go to a physiotherapist" and then you do that. But you have to choose the physiotherapist, you have to find out which one would be better for you and where to go – you have to do all the research. It's not that they say, okay, this physiotherapist works with me, this doctor, and I know this one is better for this arm and this one is good for the knee, no, they don't give you zero, nothing. And you have to do the research, you have to figure it out... (Newcomer 1-3)

The inadequacies of health care shaped the meanings of pain for participants and worked to deter access to care, and to worsen the impact of pain.

...every time I go to a new practitioner I have to like tell them my whole like life story all over again. And it's like really exhausting...it's like I have to be really vulnerable and if they're not trauma-informed it's just an awful experience, to be that vulnerable they're kind of just like seeing things through a certain lens and, yeah, I don't feel believed or like I'm going to get, like the options they present aren't going to be like what I'm looking for. (LGBTQTS)

The impact of chronic pain: Complex and multifaceted. Participants described the effects of chronic pain in ways that demonstrated how the experience and impacts of pain emerged from the complex intersections among the emotional, mental, physical, social and economic dimensions of their lives as they endured the consequences of multiple forms of stigma and discrimination and structural barriers across systems. For example, one newcomer continued her quest to improve her English in order to deal with a cascade of events stemming from inadequate interpretation.

...it's a very hard way because the government they took away my kids – fifteen years I have no kids, once a year, one hour, they only let me visit my kids, it's hard. And it's because of how the interpreter translated, all I said when I was at the psychiatrist office is that my life is so hard that it looks like it's better if I die. But that does not mean I wanted to kill myself, I was just trying to say that my life was so hard that's all. Life not easy for me, die better than to live. But the interpreter they say I want to kill myself ... and after they took me, put me in an asylum for four years. They destroyed my life, I'm so upset and I say I'm not crazy, I'm normal, I'm not crazy and I don't want to go there, but they put me in and gave me a lot of pills, a whole bunch, and they put me in and that's why I'm very upset. And I said, no, I stop to go to counsellor, I stop going to anything and I say, no way, until when I can speak by myself (in good English) okay?
(Newcomer 1–8)

Specifically, across groups, participants emphasized impacts of the intersections of pain and barriers to support on their mental health, employment, income and their social relationships:

I come from my country, I run away from the war, I came here but now see.... I just want to be human, I want to be like normal people. I don't want to be like people who stay inside the home feeling scary, scary all the time. (Newcomer 1–5)

...my experience of living with chronic migraine is the most limiting of the things that I live with and it's caused really intense social isolation which isn't the greatest for my mental health. (LGBTQ2S 1–8)

The effects on employment included enduring additional pain during work, the challenges of fulfilling work expectations, and for many, being unable to get or continue working.

I have been in pain for well over 20 years so I've kind of learned to just grit my teeth and cope kind of thing. I was working. My job was really, really important to me [sigh]. So, I went from working eight hours a day down to six hours, down to five hours, to four hours, and I had to leave my job about three weeks ago because I just, I couldn't even get in a two-hour shift anymore. (Indigenous 6)

I do nails as a job but now I can't hold the hand to do nails, so I have to stay home. I can't work
(Newcomer 1–3)

...in relation to chronic pain I've been [a specific service provider] and actually just had to, at the end of last year, had to give up my license because I can't afford to carry on that profession anymore. (LGBTQ2S 1–8)

The economic impact was profound across the groups, both as a consequence of the impact on employment, and as a consequence of the costs of support and treatment.

I've had pain since childhood. I became a lot more disabled by it in my early twenties and have been going to school, in quotation marks, part-time to survive, because I can't work and now I can't go to school. (LGBTQ2S 1–7)

Many simply could not afford treatment, even when they found modalities that were effective. A newcomer who had debilitating pain post surgery and chemotherapy for a brain tumour had to stop accessing treatment. "...it was paid from, from me and I just didn't have any more money and I had to stop going". (Newcomer 1–2).

I had a referral to the podiatrist...so I go to make an appointment and everything and then the podiatrist says you have to pay \$50 up front ...I'm like what? I'm on disability, plus I have status. So, the lady at the reception...said well you can get a form filled out from the Ministry to get it paid for. So I go through all the trouble to get that done, call to book an appointment telling them that I have the form filled out so the Ministry can pay for it, well you have to still come, bring \$35 cash to pay for the filing fee...So I never did see the podiatrist because it just wasn't affordable. (Indigenous 6)

Participants' experiences of chronic pain were described in relation to others, including family and community members, both in terms of how others influenced their experiences and how their chronic pain affected others.

I've spent more than half of my life being in severe pain. I've had fibromyalgia for 26 years and I had to relocate because of it. When we lived in (another community) I spent a lot of time in the hospital. My marriage ended because of my health problems. I had a very spoiled husband who for the first four years of our marriage came home and his dinner was made, he didn't have to lift a finger to help, and then when I got sick he had a hard time with it. (Indigenous 6)

Many (mostly women) were caregivers. For example, one newcomer described the impact of caring for her daughter, and how pain in turn affected her caregiving and their wellbeing:

I have a little girl in a wheelchair and she doesn't walk, is non-verbal. She's not such a little girl and she's getting heavy. This has been going on and on and on for so many years – she's fourteen. So, its many years of lifting but now instead of being both sides of my body now I was completely restricted in one and its really damaged... And the stress from [paying for treatment] and the stress of having to spend more money on my daughter than me because you always put others first. (Newcomer, 1–1)

Another woman was at a loss regarding how to manage in the face of her inability to work, her debilitating pain and the need to care for her children on her own.

I'm stuck and I'm stuck and that's why I try. I try to go to school (for upgrading skills) but I cannot go to school because I have three children. I'm a single mum with three children ...I ran away from [an abusive husband] that's why I have to be careful for my children (Newcomer 1–5)

²Indian status is the legal status of a person who is registered as an Indian under the Indian Act 29. Act I. Indian Act, RSC 1985, c I-5. 1876.. The Indian Act is a race-based act of legislation that categorized Indigenous persons and governed all aspects of their lives, and remains in force today, with a few revisions since 1885.

Discussion

The experience of pain for people who face systemic inequities and injustices emerges from the complex intersections of the broader social environment. Chronic pain is as much a social issue as it is a health issue. For participants in the study groups, social locations engendered specific forms of social inequities, dismissal, discrimination and stigma which shaped their experiences and meanings of pain. People described experiencing harms on the basis of their social identities by health care professionals and others in the community. Overall, participants' experiences of pain were deeply informed by experiences of discrimination, stigma, dismissal and social disadvantage. They reported "not being listened to nor believed" by care professionals and others and "violated" by the stigmatization, stereotyping, racism, sexism, heterosexism, cisnormativity and transphobia they faced in the health care system (4). These experiences of injustice were compounded by poverty and inadequate access to supports and resources. Pain was therefore defined by multiple and intersecting forms of systemic violence and discrimination.

Thus, participants' pain was shaped by others, particularly health care providers and broad social systems related to health care, housing, immigration and income, and people's positions within those systems. Fortunately, there is increasing attention being paid to the impact of privilege and disadvantage on experiences of pain and access to care, for example, in terms of race (10), sexual orientation (30) and gender (31). We identify in particular the deleterious impact of care provider actions that the participants experienced as unjust and unfair. When compared with non-minority counterparts, pain-related injustice appraisals are elevated among those who identify with marginalized minority racial/ethnic groups and among individuals with fewer socioeconomic resources (19, 32).

The scope of inequities in health overall and chronic pain specifically is well established with ample recommendations to improve access and outcomes for people who experience inequities and injustices. Further, while the relationship between perceived injustice and chronic pain outcomes has been acknowledged, there remains a paucity of equity-informed interventions that explicitly address inequity at point of care. Based on their findings regarding racial differences in chronic pain experiences and outcomes, Trost et al. (19) call for systems-level interventions that go beyond individual level interventions to address possible antecedents to elevated injustice appraisals both within medical contexts and broader social structures.

Building on the findings from this and other studies, equity-oriented responses to chronic pain would establish pain not only as a health care issue but as a social justice issue. The meanings of pain and power would be inseparable and addressing pain would be addressing privilege and power within the system responses to pain. Addressing pain would be inclusive of identifying and challenging the inequities and injustices that are producing and sustaining the stigma, discrimination, powerlessness and often violence experienced by those also experiencing pain(14).

Equity-oriented health care (EOHC) refers to approaches or practices that aim to reduce the effects of structural inequities by providing alternatives to the dominant approaches to care for people facing

structural inequities and injustices (33). "EQUIP Health Care" is a program of research that describes equity-oriented care as enacting three key dimensions: trauma- and violence-informed care, culturally-safe care, and harm reduction, each of which must be contextually tailored (34).

Analysis of the impact of these key dimensions (35) suggests their potential for explicit adaption to enhance equity oriented responses to chronic pain. These key dimensions were studied in primary care clinics serving highly marginalized populations. Chronic pain was measured using von Korff's 7-item chronic pain scale (36), assessing pain disability in the past 6 months. The project introduced a new measure of equity-oriented health care (the Equity-Oriented Health Care Scale (E-HoCS)). Using longitudinal data from a cohort of 395 patients facing systematic inequities, the study demonstrated that more equity-oriented health care predicted better health outcomes over time, as such care was associated with higher levels of patient comfort with and confidence in their providers and confidence in their ability to manage and prevent health problems including chronic pain (35). Equity-oriented care predicted less disabling chronic pain as well as better quality of life and fewer depressive and trauma symptoms (35). Further, an intervention integrating these key dimensions in primary care was able to increase staff confidence and comfort in providing such care (33). Hence, this approach may be useful to promote equity-oriented care in relation to pain, and support people facing the greatest stigma, discrimination and structural barriers toward improved outcomes.

Contextually tailored care expands the following three key dimensions of equity-oriented care to ensure responses are explicitly tailored to the populations served and local contexts (33, 37–39). While described separately, the three dimensions are interconnected in practice and need to be tailored to each particular context: in this case, people experiencing chronic pain and multiple intersecting forms of social marginalization. The objective is to provide responses beyond the individually focused concept of patient-centered care to orient and adapt services, policies and practices to be optimally responsive and respectful to both those being served and the local, social and community contexts in which care is provided.

Trauma-and-violence informed care (TVIC) expands trauma-informed care to also be explicitly responsive to the violence that most people affected by systemic inequities and structural violence experience, and that can be seen in our data (40–42). Providers seek to create safe environments and foster trusting relationships that build on their awareness of the pervasiveness of trauma and violence and its impacts on health and well-being. Being responsive to current and past trauma and violence includes attention to structural violence, as well as individual and interpersonal experiences of trauma. Providing TVIC to people living with chronic pain can include understanding of the history and context of individuals' lived experiences and recognizing trauma and violence as a risk factor for pain and pain outcomes, and adopting this strategy as a universal provision. The building of trust and respect can begin with recognition of one's power and the impact that marginalised social identities can have on the meaning-making of pain for people living with chronic pain. Pain management would include a respect for the ways that people cope with trauma and violence, its links to mental health and substance use and fostering trust by incorporating safety within care plans.

Culturally-safe care is guided by a deep understanding of the current and historical impacts of inequitable power relations, racism, colonization, marginalization and criminalization of people based on race or ethnicity. Rather than attending to differences based on race and culture as is characteristic of most cultural sensitivity and competence approaches, cultural safety places responsibility on care providers to create safety, including challenging discriminatory values and assumptions. Because equity requires care according to need, then, for example, racialized newcomers with limited official language skills would be accorded the support required to navigate pain care systems. Because cultural safety requires addressing racism, the pernicious stereotypes directed toward Indigenous people that deter health care access and quality (43–46) would be explicitly addressed in relation to chronic pain. Cultural safety is also a framework adapted to LGBTQ2S health (47) as well as to people who use drugs (48–50), among others.

Harm reduction includes the philosophy, policies and practices that seek to prevent the harms related to substance use rather than reducing substance use per se (51). Substance use is viewed as part of society and life, and a health issue. Harm reduction approaches challenge policies and practices that cause unnecessary harm including the harms of inequities, criminalization of drugs and drug use, and refusing care to people who use substances (52). It is an approach that provides pragmatic supports while avoiding judgement and expressing compassion for the dignity of each person. Stigmatizing certain substances and people who consume them causes harm and barriers to care. Substance use and chronic pain are linked and understanding, respecting and responding to these links are integral to providing care that is respectful and to building trust (53). Respectful engagement avoids stigmatizing language and mistrust of people with pain as “drug seeking” while openly supporting individual’s own harm reduction practices by providing harm reduction supplies and ensuring signage conveys respect rather than zero tolerance (intolerance) (44).

These key dimensions of equity-oriented care can be seen as more than ideals. The Equip framework seeks to operationalize these dimensions by identifying strategies for enhancing capacity for equity-oriented services (34). These strategies are recognized as intersecting and flexible enough to be tailored to both local contexts as well as for various health inequities such as chronic pain. Overall, these strategies are relevant to support equity-oriented responses at the organizational, clinical programming and patient-provider interaction levels (34). Organizationally, the strategies have the potential to improve the ‘fit’ between people’s needs and services, increase trust and engagement of clients, and shift from crisis-oriented care to continuity of care (34).

While many of the strategies for equity-oriented care are inexpensive to implement, the uptake of EOHC requires more than strategies to improve access to care. There is a requirement to question the meaning of care and the meanings of care held by people experiencing inequities. How responses to chronic pain are arranged and delivered matters to people experiencing inequities and change requires that providers and organizations adopt a foundational understanding of and commitment to equity-oriented care. Indeed, disruption should be expected and embraced if organizations are to shift meanings of care to more fully reflect equity-oriented dimensions (33). Such productive disruption may be essential to move beyond the ongoing measuring of inequities and well-intentioned calls for health equity (33).

Limitations

There are a number of limitations to this study. The small number of participants cannot be expected to capture the full diversity among the groups represented nor the complete range of experiences and perspectives. The recruitment locations influenced who was able to participate. For example, the Indigenous focus group was recruited from and held in a clinic which also houses a methadone clinic and thus a number of participants reflected these lived experiences. We expect that the study appealed to those who may have experienced the most challenges and were most interested in discussing these issues. At the same time, we are aware that the impacts of chronic pain limited some interested individuals from fully participating or attending at all. Significant accommodations were necessary to reduce barriers to participate but we were aware that some individuals regretted not being able to participate. Finally, as a community-based research project we recognize that community participation varied within the research process⁽⁵⁴⁾ with greater inclusion in some aspects and less participation in others.

Conclusions

This study underscores the complexity of the experiences and meanings of pain for people living with pain and facing social disadvantages, stigma, discrimination and structural barriers to support such as poverty, systemic racism, sexism, cisnormativity and heteronormativity that are embedded in and supported by policies and social arrangements. This analysis emphasizes the inadequacies of an exclusive biomedical orientation to the understanding and treatment of pain, in particular the over-reliance on pharmaceutical management, and points to the need for efforts toward equity in the response to pain. Equity requires treating people according to needs, not treating everyone the same. The specific experiences of these participants highlight the connections among pain, mental health and substance use and shows how stigma, discrimination and dismissal of the meanings and experiences of people living with pain must be tackled through change, not just by care providers, but by innovations in systemic structures.

Declarations

Ethics approval and consent to participate:

Ethical approval for the project was granted from the University of British Columbia Behavioural Research Ethics Board (H18-01481). All participants completed an informed consent process.

Consent for publication:

Not applicable.

Competing interests:

The authors declare that they have no competing interests.

Availability of data and materials:

The datasets used/or analyzed during the current study are available from the corresponding author on reasonable request.

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Authors' contributions:

All authors provided input into the overall conceptualization and operationalization of this research program. BW, CV, CH, MMM performed data collection and all authors collaborated on the analysis and interpretation of the data. BW and CV led the development of the manuscript with CH, MMM, GM, MH, KD providing significant contributions to the development of the manuscript and the final submission. All authors read and approved the final manuscript.

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