



Original Reports

Chronic Struggle: An Institutional Ethnography of Chronic Pain and Marginalization

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ABSTRACT: There have been several recent calls to re-think chronic pain in response to the growing awareness of social inequities that impact the prevalence of chronic pain and its management. This in turn has resulted in new explorations of suffering as it relates to pain. While laudable, many of these clinically oriented accounts are abstract and often fail to offer a critical theoretical understanding of social and structural inequities. To truly rethink pain, we must also reconsider suffering, beginning in the everyday expert knowledge of people with chronic pain who can offer insights in relation to their bodies and also the organization of the social circumstances in which they live. Our team undertook a sociological approach known as institutional ethnography (IE) to explicate the work of people in managing lives beset by chronic pain and the inequities that stem from marginalization. In keeping with our critical paradigm, we describe participant accounts as situated, rather than lived, to de-emphasize the individual in favour of the social and relational. Through our analysis, we offer a new concept of chronic struggle to capture how pain, illness, economic deprivation, and suffering constitute a knot of experience that people living with chronic pain are obliged to simplify in order to fit existing logics of medicine. Our goal is to identify the social organization of chronic pain care which underpins experience in order to situate the social as political rather than medical or individual.

Perspective: This article explicates the health work of people living with chronic pain and marginalization, drawing on their situated experience. We offer the concept of chronic struggle as a conceptualization that allows us to bring into clear view the social organization of chronic pain in which the social is visible as political and structural rather than medical or individual.

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Chronic struggle: an institutional ethnography of the social relations underpinning marginalization and chronic pain

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Introduction

The Lancet published a special issue in 2021 introducing a call to “re-think chronic pain”.²⁴ The premise for this call was at least partially based on the growing awareness that rising social inequities impact both the prevalence of this condition and its management.^{8,34,49} For example, researchers have long called attention to the stigma associated with chronic pain^{15,52} and opioids,^{3,12,13,54,60} the influence of lifetime experiences of trauma and violence,^{40,61} the prevalence of racism in diagnosis, treatment and management settings,^{1,18,20} and poverty in the lives of those living with chronic pain.^{26,37,55} Many of these issues are intersecting. Nevertheless, most research in this field continues to draw on clinical and biomedical approaches that fail to adequately take into account a critical theoretical understanding of the social and are rarely grounded in the standpoint of people with lived experience.

Models that take into account the social are evolving.⁴⁵ Yet they still often position the social as a separate domain external to people’s health, often described as a binary of the medical/psychological, or conflate the social with the subjective (i.e. individual). The social refers not just to one’s personal context, but to social structures, ideologies and institutions that privilege the interests of dominant groups. In particular, the notion of suffering has been integral to research within the chronic pain field.² Yet, suffering in medicine originally pertained only to an individual’s response to a medical condition. That is to say that the concept of suffering was thus often subject to medicalization,^{6,23} in that suffering was understood to be grounded in or related to only medical experiences (e.g., cancer). The concept of “social suffering”, introduced by Kleinman and colleagues, partially mediates this medicalization and identifies both pain and suffering as having roots in the social world with lasting societal consequences.²² Social suffering, while a powerful concept, is not widely embraced in studies of chronic pain, which continue to reduce the social to the individual and emphasizes individual psychological states in practice.^{25,45} Within these models, the social operates almost as an “other” category to house anything that does not pertain to medicine in biological or psychological terms.

There are many reasons for this tendency to inadequately account for the social aspects of experience in pain research, including variation in how the social can be investigated and understood. While clinicians often acknowledge the role of the social in shaping one’s health and healthcare, they simultaneously work within a largely biomedical system that has sustained a focus on the physical body, pathology and illness.⁵⁷ Medical knowing and intervening at the level of the physical body can obscure the complexity and social character of managing chronic pain.³⁹ For example, biomedical knowledge about pain self-management may not be experienced as a neutral resource by those who are socially and economically disadvantaged. Instead, it may be experienced as a burdensome social constituent in everyday life. Pulling this active and

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concerting character of the social into view calls for a different research approach.²⁸

A meaningful rethinking of chronic pain must be anchored within the lives of people with chronic pain, therefore we take up the standpoint of people living with chronic pain who self-define as being socially and economically marginalized. By explicating the “work”—a sociological concept described below—that these participants undertake in the management of lives beset by pain and marginalization, our data represent a point of entry within the literature which interrupts ideological formulations (i.e., generalized codes, categories or abstractions about pain) in favour of experiential ones.⁴² Our goal is to situate the issue not as medical or personal but rather as political. In doing so, we address the social and material injuries they sustain by and through existing inequitable systems and structures.

Methods

This study utilized the sociological approach of institutional ethnography (IE)^{41–43} which we have described elsewhere.^{53,57–59} An IE approach allows our team to investigate the efforts that people make in managing their chronic pain, from the standpoint of lives that may be constrained by processes of marginalization or marginalized social statuses including mental illness, substance use and/or poverty. In an IE study, standpoint refers to people’s social positioning within institutions characterized by power relations which coordinate everyday activities.³⁵ Standpoint is not understood to be fixed but rather fluid and multiple. In this way, the concept aligns with intersectionality, which posits that marginalization operates and is expressed through intersecting and multiple social systems, structures, and identities (such as class, race and gender).^{9,10}

We describe participants’ accounts as reflecting situated rather than lived experience. The use of this term “situated”, which originated in sociology through the work of C. Wright Mills, draws attention to experience as social, relational and dialectic; it de-emphasizes the idea of internal or individual experience which has come to be associated with phenomenological and other qualitative research. Mills²⁸ wrote that “Neither the life of an individual nor the history of a society can be understood without understanding both”, meaning that a sociological perspective is attuned to the intricate connections between individuals and society. Yet, in much research, this understanding of people’s lives as members of social groups is often under-emphasized and attention is focused instead on individual experiences.

Similar to traditional ethnography, those working in IE want to collect data that display insiders’ experience and knowledge. However, the purpose of data collection extends beyond description to explicate the often-invisible social relations that scaffold and orient those experiences.³⁶ IE is grounded in the belief that the social world is discoverable from *within* people’s lives. In other words, social organization does not happen outside of people

but rather enters into and informs their experience, knowledge, and activity.²⁷ For this reason, data collection employed a focus on “health work,” which refers to what people actually *do* (and how they know how to do it) in particular places, under definite conditions and with finite resources. We focused on the unpaid and informal activities that are rarely addressed in descriptions of people who struggle with health conditions.³⁰ When the work of people is not recognized or conceptualized in this manner, the social relations (or ruling interests in IE terms), informing their lives become invisible and they are viewed simply as unfortunate individuals.

Upon obtaining approval from our Research Ethics Board (REB), we purposively recruited people living in Canada, over the age of 18 years, who spoke fluent English, self-identified as living with chronic pain, and also considered themselves as having difficulty making ends meet. The Canadian health care system has a model of universal health insurance for medical services and all hospital services; it is a federated system with variation in coverage across provinces that creates important disparities in access based on geography; has limitations in coverage for medicines and behavioral/psychological interventions; and persistent limited access to multidisciplinary chronic pain care.¹¹ Participants received an approved Letter of Intent and provided verbal consent at the beginning of the interview, which was recorded by the data collector (LC). We used the term “having difficulty making ends meet” in order to avoid stigmatizing people while still allowing them to self-identify as people who face challenges in meeting their basic needs due to structural and historical barriers.³² Our recruitment strategy was broad, in keeping with the exploratory aims of our study, and as a first step in our data collection. It was not designed to focus on any particular group (such as racialized communities or women), although such focus is planned in our ongoing research. The recruitment of participants occurred in online spaces (e.g. Twitter and Kijiji),⁵¹ in public areas such as laundromats and libraries, through the clinic of one of our team members, and through the newsletters of leading pain organizations (Pain B.C. and Canadian Arthritis Patient Alliance). None of the participants who responded to our call for participation were excluded.

While IE makes use of several types of data and methods of collection, this study relied on telephone interviews due to pandemic restrictions. Telephone interviews were conducted by a trained qualitative interviewer (LC), and de-briefed with the Principal Investigator (FW). Participants were asked to describe what they do as they go about performing their everyday lives (see Appendix A). The purpose of the interviews was not to reveal individual subjective states but to locate “points of connection among individuals working in different parts of institutional complexes of activity”.¹⁶ That is, we relied on the participant’s expert knowledge of their lives in order to identify and document organizational processes in which they participate. All interviews were taped and professionally transcribed. Transcripts were entered in NVivo software for data management.³⁸

Data was transcribed and organized (indexed or mapped) into groups of ideas (similar to codes) about health work. Our analytic focus then moved to tracing the social organization of these activities by paying attention to authoritative texts and discourses embedded in the activities participants described and how these shaped their experiences. Indexing of the first few transcripts was performed by F.W. and L.C. who met by Zoom and telephone. A voiced-over PowerPoint slide presentation was developed (F.W.) to provide training in IE analysis to a diverse and multi-disciplinary team that included two sociologists (F.W. and L.C.); a PhD trained nurse (C.D.); family physicians with expertise in social determinants of health (A.P., A.S. and R.U.), opioid management (A.S.), and bioethics (R.U.); a pain psychologist (J.K.), and a medical anthropologist working in primary care (K.R.). Our team was diverse in sex and gender, sexual orientation, racial group membership, socio-economic background, and training in critical social theory, critical public health, anthropology, medicine, psychology and nursing; this diversity enabled reflection on the assumptions and beliefs we all brought to the study. In future research team development, we will strive to include more individuals from certain groups, particularly Black and Indigenous persons given that existing representation of, and engagement with, these groups in chronic pain research is insufficient yet urgently needed. This larger team met three times as a group via Zoom, and several times individually with F. W., in order to review a sampling of transcripts and further refine codes and identify themes. F.W. and L.C. also met weekly via Zoom and telephone for debriefing, discussing transcripts, and preliminary analysis. An overview of our findings and analysis, as well as a draft copy of this manuscript, was shared with a Patient and Community Advisory Committee, comprised of both people with lived experience of both chronic pain and marginalization and members of community organizations. Meeting notes were part of the audit trail in which the team kept careful track of all interpretative and theoretical decisions that were made.

IE researchers follow sequences of action, with one informant’s interview leading the way to the next or to a text for analysis. For example, an interview with a participant with chronic pain might lead to a conversation with a policymaker. In this first paper from our study, however, we rely more on discourse than text and present only the accounts of people living with chronic pain who have difficulty making ends meet. As we move forward, we are continuing to identify texts and discourses that are present in the language of participants as they describe their everyday work practices in managing chronic pain.

Findings

The following analysis includes the stories of 23 participants, each assigned a pseudonym (see Appendix B for a full list of participants, their known demographic information and health conditions). We have organized our findings first around four aspects of work that were

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required to navigate both their health and social lives. These include the work of: 1) managing chronic pain alongside poverty and subsistence, 2) legitimizing their struggles when dealing with health and social institutions, 3) adhering to biomedical models, and 4) navigating multiple, often ill-fitting, diagnoses. We then move on to combine these themes with a view to explicating how chronic pain and the experience of marginalization overlap seamlessly in people's experience.

The Work of Managing Chronic Pain Alongside Poverty and Subsistence

In our study, chronic pain was intertwined with many participants' experiences of poverty and created forms of work that are rarely accounted for in the medical literature. Participants described extraordinary work in managing poverty and subsistence as well as navigating diverse and complex institutions, such as the healthcare system and social services. This includes the work of finding and maintaining precarious housing, the challenges of obtaining healthy food for themselves and their family members, and the work involved in compensating for prescription medications and alternative therapies that were unaffordable for them, even though access to these therapies would likely help them to better live with their chronic pain. While chronic pain is a contributing factor for financial stress because of how it limits people's ability to engage in paid work, the people we spoke with also called critical attention to the inadequate amounts provided to them through social assistance or wages.

In the following account, which we share in length, Poppy describes her everyday work,

I mean, there are times where I can't walk [due to pain], but I have to go to the store. OK, that means that I have to be prepared to wait at the bus stop. I have to be prepared to deal with people who might not want me to sit in the disabled spot where the bus lowers. [...] When I'm at the store, I just ... focus on my list. [...] I know that I can only do like one to two outings a day on a good day. So, I do have to decide what's more important. If I have to go pick up, say like my medication and pick up my groceries, I have to make sure to go to the furthest thing first and work my way back home. I have to make sure I know where the bathrooms are. I have to go through my route in my head. I have to make sure that I can line up the buses or if I'm going to end up having to call a cab. I have to make sure I have money for that cab. So, a lot of thinking, a lot of planning before I even open my door has to happen. ..So, making the decision on whether or not I can do that, it's something I have to do on a daily basis. (Poppy, 30's, Participant #8).

The conditions for this work are worsened by Poppy's inability to maintain employment due to her chronic pain. In addition to everything else, she must also find income in order to keep her apartment. She describes

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her experiences of living "below the poverty line" and what that means in terms of the work involving in accessing food and medication. She says that,

I live below the poverty line. So I struggle with access to food every month. I go without medical treatments every month ... I don't have access to certain therapies. I struggle with maintaining a healthy diet because of the cost of living and being that my family doctor does not think that it is safe for me to work part time or even volunteer, it is extremely difficult to afford these things. (Poppy, 30's, Participant #8)

Other participants recounted their efforts to manage their pain concurrently with restricted finances. Helen is in her 40's and lives with her husband. She is not working as she is currently on long-term disability due to her struggles with migraines/headaches, fibromyalgia and bursitis. She describes how inadequate income through disability benefits impedes her ability to achieve better health:

My salary is not what it was because I'm on disability, long term disability ... On short term disability you get more money, but when you go onto long term you don't get as much money, but still you have all your bills, you have more expenses because you've got. Like even for physio, I can't afford to go for physio because, you know, I've racked up all my credit cards because I was without pay for so many months and it's like the simple thing of even using my company benefits, I don't even use them anymore. I only use it for the pharmacy stuff, but to go for physio or for chiro, I can't do it. So financially your income is gone. (Helen, 40's, Participant #4)

In addition to her difficulty affording alternative therapy, she is also unable to afford the cost of counselling which is important due to her existing mental health issues.

Food scarcity was often described as necessitating particular forms of work. Specifically, several people highlighted how living in poverty precluded them from eating a healthy diet despite their best efforts, and regardless of their awareness of its importance. For example, Winnie is in her 30s, lives in British Columbia and has lived with nerve pain for the past seven years, which she developed as a result of an injury sustained through inter-personal partner violence. She relies on the Persons with Persistent Multiple Barriers (PPMB)¹⁹ which provides assistance to those who have long-term barriers to employment that are not deemed to be imminently resolvable. Winnie describes PPMB as "the person not to be able to look for work while they're on income assistance." Below she describes how she has come to rely on food banks and how this means adjusting to a diet that is heavy on shelf-stable food:

I have had to make adjustments to how I eat, and it's very hard in that sense when you're low income and in poverty level because you're relying on the food

bank for most of your food and most people donate, unfortunately, those food that's not really good for you to eat—just pasta, Kraft Dinner, cookies, those kinds of things. [...] So, you adjust to that aspect of finding a diet that's better for you that so you're not causing your body to be more inflamed and in pain, right? (Winnie, 30s, Participant #17)

Food scarcity often drove other participants to rely on food banks. This entails extra work for them – such as buying groceries separately for her son in Uma's case below and “adjusting” to food that exacerbates her pain condition:

I have gone without groceries. Like, I've bought groceries for my son and not for me before because I couldn't afford to buy things for me, and then waited until I could get money or just lived off of toast or whatever until I could get by (Uma, 30s, Participant #16).

In each of these narratives we hear the relational work of managing food needs in a family (“I've bought groceries for my son and not for me”); how lack of access to healthy food leads to the work of managing a body that is “more inflamed and in pain”; and how eating a steady diet of processed food exacerbates anxiety that then has to be managed (“processed food aggravates my nerves”).

The Work of Legitimization: From Medicine to Social Benefits

Many participants described the work of making themselves “legitimate” in the eyes of either health care providers or institutions such as the Insurance Corporation of British Columbia (ICBC) or the Ontario Disability Support Program (ODSP). Dealing with these separate institutions complicated and extended the time and energy they spent on managing both the health and social aspects of their lives. Participants' ability to engage in the work of following medical advice was often limited by their social circumstances and their social circumstances were often worsened by inadequate medical support, leading to even worse health outcomes.

Many participants appreciated the intent of the medical advice they were given but also felt that care providers had differing levels of understanding of their inability to follow it due to the many financial restrictions on their lives. This led to patients feeling they were being labelled as difficult or non-compliant. For example, Lisa, who lives with chronic migraines and two neurological pain conditions, which stem from a car accident in 2002, relies on the Canada Pension Plan (CPP) disability benefit and PPMB due to her inability to work. She defines her pain as currently unmanaged and is therefore bedridden. She alludes to the financial restrictions she faces with her treatment plan:

Yeah, so Dr. [name] had set up this pain management plan. There was about 25 different things. Some of them free but most of them cost money, and provided I could do those 25 things on a daily basis I could minimally function” (Lisa, 50s, Participant#15)

Others struggle to have their physicians take seriously their own sense of their bodies or feel misdiagnosed, as in the following two examples.

“It was probably back when I saw the rheumatologist in October the first time and all she wanted to test me for was lupus – oh, you must have lupus, you know, and all she wants to rule out is lupus or arthritis. It's like, no, there's something more going on.” (Helen, 40's, Participant#4)

“There's doctors that don't even believe that fibromyalgia is a thing. There's doctors that think it's all in your head which it kind of is in a way. I mean like when I say it's my trauma you know, but that doesn't help me. Like can we figure out a way to deal with this” (Sophie, 50's, Participant#19)

Several participants described strategies they employed in order to manage their physicians. The work of managing health care professionals ranged from fitting their concerns into office policies set around how many issues could be treated at once, as in Helen's example below, or by asking questions that elicit practical information, such as in Kingsley's case:

“So I needed to ask her more about that right now, but I have other things I have to work on; so, one thing at a time with her” (Helen, 40's, Participant#4)

“But when I go to the doctor, I ask about what could I do, ‘Would this be helpful?’ Like I asked for things when I went to the doctor. ‘Do you think this might help? Do you think that might help?’ When I went to the physio I did the same thing.” (Kingsley, 60's, Participant#11)

The work to legitimize one's claims of living with chronic pain continues through to managing forms of social support. Insurance companies, and other social support bodies, often do not acknowledge the claims of those living with chronic pain. At times they even reject the medical evidence provided to strengthen claims. For example, Helen outlines the extraordinary work she performs in order to obtain and live on disability insurance,

I had six months of short term disability where they cover a certain percentage of what my salary was and then if I'm not getting better, or I don't go back to work, then I can apply for LTD, which is long term disability. So, I applied for that and they extended it for a little bit and then they cut me off completely 'cause I wasn't sick enough. So, I had to appeal three times and I went and saw a lawyer ... And then they sent me for an IME, which is independent medical

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evidence. So the doctor that I go see on their cost to see if I'm actually sick and I'm not making it up [...]. So, I went to see him and he says, 'Yeah, you can't work right now.' So, even though I had gone through all this other testing and shown my medical to them, every test I'd gone to, and all my results, and even seen the psychiatrist, and it's like, "Nope, we don't believe you," and then finally they go and spend the money on the independent medical evidence doctor, and then I finally got approved. But it had taken five months to get actually approved for LTD (Helen, 40's, Participant #4).

Helen describes being considered "not sick enough" for long term disability benefits. She has to undergo a process in which her own physician's assessment were not considered valid and she was required to see an "independent medical evidence doctor". She notes the contradiction in the insurance company spending money on an independent physician but not on benefits that would improve her life. The struggle to qualify for disability insurance also arises in Winnie's story. She recounts how she was unable to go back to work once she was injured and now relies on PPMB program and disability assistance. However, her physicians delayed filling out the paperwork that would allow her to receive benefits for six years.

Some participants spoke to the work of supplementing their inadequate incomes. This generally involved seeking work that could pay "under the table", which enabled people to meet their needs but also resulted in them feeling badly. This then adds to the many burdens already experienced, the additional work of managing stigma – including self-stigma – associated with working outside of the rules. As Alexander states, "I don't like the fact that I have to lie about it":

"There are days when I get a chance to make some extra money you know under the table but it's, [pause] it's welcomed, I love it, it keeps me busy [pause] but I don't like the fact that I have to lie about it. I really don't. You know my close friends know what's up but I do not like the fact that I have to lie about it and my biggest fear is getting caught and being pulled off the system." (Alexander, 30's, Participant#1)

However, securing extra money can be the only way that participants are able to manage their health conditions. As Lisa explains,

"I think just bottom line is if you have a chronic illness, if you have a chronic pain situation, there should be more options for you for affordable healthcare. Because the things that they cover are pharmaceutical, and when it's neurological for me, a lot of pharmaceuticals don't work. So there is no coverage for the supplements I take, even though I have to take them. I'm prescribed them, I have to take them." (Lisa, Participant#15)

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Having one's pain legitimized carried tremendous implications for these participants. Many participants emphasized the extreme frustration of not having their chronic pain conditions understood or believed. When their pain was not legitimized, they could be denied social benefits or adequate medical care.

The Work of Adhering to Biomedical Models

Despite the profound impact of systemic and structural inequities that impeded their lives, participants in our study often described their struggles in medical terms. This often led to unique tensions or contradictions in their stories, given the tendency to describe themselves using biomedical language. This may have been a strategy they developed to support legitimizing their pain experience. Uma, introduced above, who is in her 30's and lives in a subsidized housing complex in B. C. with her son and boyfriend, provides interesting insight into this tendency in her description of how her traumatic childhood is treated through biomedical monitoring and treatment:

I've had a very traumatic childhood and teenage years. My house was very drugs, sex, rock and roll growing up, lots of parties, lots of debauchery and then some sexual assault, and then, in my childhood and teenage years, and then my brother was physically abusive from when I was 12 til 17. [...] And so some of those injuries my body just might be holding on to and that's what this pain is. I don't know. So, yeah, I've been going to counselling to try to work on the trauma stuff, to try to help the pain as well. I go to a trauma informed therapist and have done bio-neuro feedback there to try to help with the pain. I guess the bio-neuro feedback is supposed to be good for people who have trauma and who have pain (Uma, 30's, Participant #16).

Uma separates trauma from pain in this telling, saying that "I've been going to counselling to try to work on the trauma stuff, to try and help the pain as well". She is uncertain as to how individual counselling will help her, noting that "I guess the bio-neuro feedback is supposed to be good" but nevertheless accepts this treatment in order to comply with her physician's suggestions. Similarly, Sophie, a woman in her 50's living with fibromyalgia, chronic fatigue syndrome, and various mental illnesses (anxiety, depression, PTSD, bipolar), discusses the overwhelming stress of being a single mom (with a child failing in school), living below the poverty line, caring for her grandchildren, and working a full-time job that paid sub-standard wage. She goes on to explain how she also understands herself through a psychological diagnosis of post-traumatic stress disorder (PTSD):

"I was diagnosed with PTSD quite recently. But I knew I had it. I've known I've had it pretty much my

whole life. But, I finally had, like, an actual diagnosis from a psychiatrist. So, that's where I'm at right now. And that's all the trauma, that's all the trauma that I'm holding in my body and that's creating all the pain." (Sophie, 50's, Participant #19).

While it is important to treat trauma, the diagnosis overlooks the extraordinary efforts of living in poverty with inadequate childcare support and working long hours both inside and outside the home. Moreover, the biomedical nature of the language of disorder situates the problem within them; they become the problem to be fixed. The solution for structural issues of social inequity cannot be found solely in a diagnosis of PTSD.

The Work of Navigating Multiple Diagnoses

The challenges of legitimizing social concerns within biomedical frames was further complexified by poor fit between the available biomedical pain diagnoses and understanding the actual experiences of pain over participants' lifetimes. For many people, chronic pain did not refer to a single health condition but rather referred to multiple pain and other diagnoses. This is exemplified again in Uma's story. She lives with multiple conditions/diseases, many of them pain related. She shares that,

I think I've been diagnosed with 11 or 13 different pain conditions. I can look that up for you if you'd like. They [are] from what I can remember, fibro, CFS, regional abdominal pain. I forgot the term for it, but like horrible period pain. Restless legs. TMJ. Migraines, I've had since I was two. They're hereditary. (Uma, 30's, Participant #16).

The sheer number of pain conditions with which participants have been diagnosed highlights the problematic nature of medical diagnosis in many instances, which can obscure, simplify and medicalize complex social experiences.^{4,21} People with multiple chronic pain diagnoses often undertake specific forms of work in sorting out how to manage different and even competing suggested treatments. Often, a clear diagnosis is not made or the diagnosis is one that is in dispute, such as fibromyalgia. In the following excerpt, Uma, goes on to describe her experiences with being considered a "medical mystery". Through this account we learn how much time she spends speaking with others, seeking care, and even trying to follow recommendations to "rest over the weekend", all of which involves organizing her life and responsibilities around obtaining a diagnosis:

I had some abdominal pain. It was like a strange sensation I had never had before, and I was very close with my preschool families and one of them was a nurse and she said, you need to go to the hospital immediately. So, I went to the hospital. They ran a bunch of tests, couldn't figure out what was wrong with me and told me to rest over the weekend. ...". (Uma, 30's, Participant #16).

In addition to the challenges of managing multiple, sometimes conflicting pain diagnoses, some of our participants also described the work of managing overlapping medical conditions, such as dependency and addiction to drugs which they originally took up to manage their pain. Alexander, introduced above, is in his 30's and lives in Ontario. He has had a lifelong struggle with chronic pain alongside drug and alcohol use. Currently relying on the Ontario Disability Support Program (ODSP), which provides minimal funding and carries many work restrictions, he has been actively engaged in managing his health and basic needs for many years. He describes how he slowly became dependent on Percocet, saying,

It was nothing for me to sit on the couch at seven o'clock and take two or three Percocet's up until midnight, because not only was the pain gone, I felt like a new person. And then in the morning, the cycle started all over again. Take a Percocet at eight AM and whether I had anything to do or not that day it didn't matter. I was taking another one at noon. I was taking another one at four, and then I was taking another one at eight o'clock that night (Alexander, Male, 30's, Participant #1).

Managing his pain, then, involved the work of balancing not just medication-taking but also managing the effects of the medication on other aspects of his life such as work and sleep. Olive also discussed her struggles with addiction. Olive is in her 40's and lives in B.C. with her fiancé. She has lived most of her life with psoriasis, beginning as juvenile arthritis at the age of 14 and then developing psoriatic arthritis at the age of 18. She describes her pain as being so intense that she had to quit sports, which had been an important part of her life up until that point. She says that because of the loss of this beloved activity, she became depressed and turned to drinking and drugs, eventually becoming addicted to Oxycontin and Percocet, and later, cocaine. She describes below why she turned to drugs:

"Addiction just means I'm trying to cover my pain up somehow. I just got a treatment for cocaine addiction. It's basically just to not think about my—I mean, I have pain every day ... But, I'm just sick of pain all the time and unfortunately, I felt such relief with those drugs." (Olive, 40's, Participant #22)

In all of these accounts, we see that the work of managing chronic pain is not simple or straightforward, as noted by the numerous and multiple diagnostic labels given to the people we spoke with. Managing pain is central to daily life and intersects with other activities such as obtaining food or housing. It often overlaps with other health conditions and in particular mental illnesses and substance use. In several cases, the participant's diagnosis conflicts with their own understanding of their bodies and health, conflicts with a diagnosis by a different clinician or could not be diagnosed at all (e.g. a "medical mystery"). A few times, we

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also noted the role of drug use among those living with chronic pain, which not only assisted in relieving their pain, but was also associated with potentially unsafe usage. In Poppy's case, the combination of multiple drugs actually came to exacerbate the symptoms of her various conditions. As she described it, the medication taking "folded in on itself" and worsened other issues such as sleep and mood. We now describe below how these myriad conditions that accompany chronic pain are situated within, and influenced by, contexts of other material struggles.

Chronic Struggle

In many of the accounts participants shared with us, it was social and structural inequities informing and emerging through poverty/mental illness/addiction, plus chronic pain, that created what we have termed chronic struggle. In the excerpt below, Naomi describes how pain did not prevent her from receiving a steady income but "was an added factor, the straw that broke [her] back".

So it wasn't so much the pain that prevented me, but it was an added factor, like it was sort of the straw that broke my back. Like it's always that one final cherry on top that just sort of breaks my spirit, where I'm just like "That's it, I can't do it anymore, I don't know how I'm going to make this work." And it feels like that every year, like just "How am I going to make this work?" And I always manage to, but every time it feels like it's getting heavier and heavier and I don't – You know, one day I just physically won't be able to pull myself out of the situation and that is super scary. (Naomi, 30's, Participant #20)

Helen offered some insight on the combination of elements—inability to work, poverty, insufficient social support, and unaffordability of therapies—that come together to construct what we term chronic struggle. She highlights the "vicious cycle" that people on disability "need more money to get back to healthy living". Her story also highlights her strength in persistently striving toward the goal of "getting back to health".

People who are on disability, they actually need more money to get back to healthy living, cause that's my goal, is to get back to health if I can and go back to work, but at this point it's like I don't see myself ever going back to work. You know, it's like I'm in pain, I'm not getting help, I can't financially afford to get all these other therapies that people are telling me to do. It's like, no, I can't do those kinds of things, I can't afford that. So, it's like a vicious cycle in a way (Helen, 40's, Participant #4).

Sophie offers a similar description of this cycle:

I know that if I could pay for massage work, minimum once a week, I would probably need it more than that, but minimum once a week, I know it

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would help. But I can't afford it. I just can't. So, it's just not a priority, so, it's hard for me to get on top of it when I can't afford to do what I need to do. That's when the money part comes in, right? And, the stress of being poor just increases everything - increases the pain. So, it's just, like, this vicious cycle (Sophie, 50's, Participant #19).

Running throughout these, and other, participant narratives is an intricately bound connection between chronic pain, marginalized social positions, and the inequities that stem from this connection. We are made aware of how the everyday lives of people living with chronic pain and marginalization involves the work of managing chronic pain, poverty, anxieties of financial struggle, inability to work, and insufficient social support. It is through the theme of chronic struggle that the time and effort involved in actually managing chronic pain is rendered visible along with the inadequacies of existing medical (and psychological) approaches to diagnosing and treating chronic pain. Chronic pain does not come to be the defining issue or concern that demands their time and attention but rather, it exacerbates the challenges of caring for themselves and others, unaffordable alternative therapies, poverty and trauma.

Discussion

Our study is the first to introduce the concept of chronic struggle as an analytic device in the field of chronic pain that decentres the medical and foregrounds the social through explicating the often invisible work that such struggle necessitates. The 23 participants in our study described in powerful terms the experiences of lives marked by chronic pain laid over a lifetime of health issues, poverty, trauma and insufficient medical care, within a context of social and political inequities. They were often caught between agencies offering social support, such as disability insurance, that positioned their pain as "suspect" and favoured outcomes that denied them benefits, and a medical system founded on objectivism that was similarly suspicious of their subjective experiences. Their stories were complex and dense, and we often struggled to organize narratives that defied the tidy beginning-middle-end structure that is a dominant norm for storytelling in much of the Western world. They reflected complexities that could not be easily bound up as reflecting simply one category or another; for example, that one category is about gender and another category is about inter-generational trauma.⁵⁶ We found many of the accounts to be distressing to hear and to read and were reminded of our commitment as ethnographers to bear witness rather than simply to utilize people's stories for our own academic gain.⁴⁸ We also forged connection to our participants aided by their humour, strength and remarkable courage.

By re-thinking chronic pain self-management as situated health work³⁰ comprised of a range of strategies

that inevitably link people to institutions, our findings call attention to the effort involved in managing both chronic pain and marginalization.²⁹ Rather than individual acts of rational choice (e.g., taking medication as prescribed), health work is often “hemmed in and shaped” by extended social networks and structural constraints.²⁹ In the accounts participants shared with us, they position chronic pain as one additional difficulty in a life that is always already defined by health and social complexities. This supports the work of Dasiu and colleagues who found a similar phenomenon in their study of people who use illicit drugs and live with chronic pain.¹⁴ Rather like a knot, the challenges in one aspect of their lives cannot be separated from challenges in another. We suggest that the term chronic struggle better characterizes this knot than the term suffering and define the term as the situated experience of chronic pain and marginalization that is dialogic, material, and informs the subjectivity of those living with it without privileging or ignoring the medical aspects of their experiences.

Analyzing the lives of our participants through the concept of chronic struggle provides the conceptual space to explicate the enormous work involved in managing lives beset by chronic pain, mental illnesses, trauma, addictions and/or poverty within systems that regularly de-legitimize or stigmatize them. These struggles are often ignored by biomedical discourses of “chronic pain” or even suffering that tend to understand people as individuals rather than as members of marginalized groups or that focus solely on their health status or individual lived experiences. For instance, while we know that those who experience poverty are significantly more likely to experience chronic pain,^{17,31,59} such knowledge rarely leads to policies aimed at reducing poverty. Instead, health interventions are developed that are designed to help those who are poor without relieving them of their poverty in the first place or without situating that poverty within historical and structural processes, such as racism. Further, the experiences our participants described challenge biomedical paradigms and highlight diagnostic uncertainty which relate to both the problematic issues of multiple pain diagnoses and multimorbidity. Current definitions of multi-morbidity “neglect syndromes and conditions that are not included in formal disease classifications” and exclude chronic pain from the chronic conditions that are considered to constitute multimorbidity.⁵⁷ They also neglect the complex social and economic circumstances in which many patients live and overlook broader issues of inequity and social justice.

We developed the term chronic struggle in dialogue with existing work on suffering. Suffering was first introduced to medicine through the work of Cassell,⁵ who draws attention to how disease does not cause suffering so much as treatments do. He calls for an end to the mind-body dualism he associates with Descartes and notes that pain is the most common cause of suffering. While this is important work, it still organizes suffering around a medical condition rather than within a medical/political/economic system that organizes lives and

people’s standing within it. Recent excellent work by Stillwell et al.⁴⁶ builds on Cassell in their aim to update and render more coherent the concept of suffering, and offer a more direct link to/with pain. In their reflection on the potentialities of different modes of suffering in pain research, and “interfaced categories of pre-reflective and reflective self-experience”,⁴⁶ their emphasis still remains on internalized experience and does not offer a critique of the medical itself.

The term “struggle” on the other hand, locates suffering within social, political, economic, historical and cultural contexts and integrates the social with the experience of health without privileging the latter, calling attention to the ruling relations of medicine. The word suffering imparts the sense that people have limited agency and little respite. Instead we call attention to the dignity and resourcefulness many people bring to their lives despite the challenges they face, without suggesting that people can or should overcome systematic inequities through individual qualities, such as resilience. We also use the term marginalization to denote systems and structures of oppression rather than to assign a fixed or individual identity. Marginalization used in this way refers to the process in which groups of people are excluded by the wider society. In her proposal of injustice (and broader social experience), philosopher Iris Marion Young asserts that racialized groups are disproportionately marginalized, as are others including but not limited to single mothers.⁶²

New language is an important strategy for breaking out of the predominant schemas that currently inform most of our thinking about chronic pain. It also highlights the need for critical sociological and qualitative approaches that take up people as experts of their own lives and bodies⁴⁷ rather than positioning them as objects of study. Many of the participants in our study describe their own struggles in terms consistent with medical health discourse. Smith refers to this as the ideological circle, which is an interpretation and articulation of one’s lived experience through predominant schemas (such as medical health discourse) that uphold institutional processes.⁴⁰ As Uma does in her reference to the hereditary nature of her chronic pain, people replace what actually happened to them – such as interpersonal abuse, structural violence, stigmatizing practices of insurance companies – with ideas about psychological disorders and other medical terms. As we have outlined, this requires work on the part of people living with chronic pain to fit these rationalities of hegemonic medical and psychological schemas. Those who are unable to frame their experiences in ways that reflect dominant schemas are de-legitimized, as noted, for example, in many of our participants accounts of fibromyalgia which is a stigmatized, gendered, and largely discounted condition in the medical field.³³ Essentially, in clinical encounters, people are required to parse out their experiences into singular narratives, such as ‘disorder’, that can then be assigned a medical diagnosis.

Our analysis supports the idea that we need to rethink chronic pain but emphasizes the need to draw on

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the standpoint of people with situated experience in order for this new thinking to result in systemic and meaningful change. The term standpoint does not individualize as does the term perspective; instead the concept allows us to situate people as embedded within institutions and structures. From standpoint, and using the lens of chronic struggle, we are able to trace the social organization of the lives of those who live with chronic pain and marginalization. This enables an important counter to the individual and often psychological responses to chronic pain that do not adequately take into account social conditions such as poverty. This would allow us to re-imagine a social world in which people's struggles are visible and therefore amenable to change through appeals to social justice rather than through medical interventions alone.

Strengths and Limitations

Our study had both strengths and limitations. Our team is diverse with respect to gender, education and professional training, which enabled us to identify and challenge our assumptions as we proceeded through analysis. Further, we invited feedback from a small Advisory Committee comprised of people living with chronic pain and marginalization (including those who had suffered from poverty; addiction; and who identified as Indigenous) as well as members of grassroots and advocacy groups that represent different marginalized groups (mental health and community health care centers). This group did not suggest any changes but rather engaged in a fulsome discussion of our findings, with which they shared their agreement. This study, and all studies, could benefit from increased and ongoing participant engagement of those with lived experience; thus this was both a strength and limitation. Our study was exploratory and as such did not seek out participants from specific groups, such as those who were from racialized or from Indigenous communities. Rather, as stated previously, we used the term "struggling to make ends meet" to allow people to self-identify as facing economic hardship.

Retrospectively, we acknowledge that this approach might not have adequately conveyed assurances of cultural safety that would have been necessary to recruit members of racialized groups. Consideration should be given in qualitative research to consider how current recruitment strategies might represent colonialist strategies and co-develop new approaches that better achieve inclusivity. Specific strategies might include involving trusted community members or organizations with recruitment; and creating more culturally appropriate recruitment materials. Further, when we do engage people from Black, Indigenous and People of Colour (BIPOC) communities, we must do so in ways that acknowledge and take into consideration their warranted historical mistrust towards systems and structures of domination and oppression, including the healthcare system itself.^{7,44,50} Researchers need to be careful of 'othering' those who are marginalised or falling into the trap of believing 'we are giving them voice'.

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Indigenous researchers have called attention to the necessity of centering Indigenous knowledges and decolonising methodologies into academia and academic research.⁴⁴ This includes learning from and respecting Indigenous knowledge keepers, developing trusting relationships, and recognising cultural protocols.⁷ Ensuring greater involvement of racialized and other marginalized people in research design can be an important pathway towards achieving these important goals. In keeping with this, future research, including our team's research, needs to focus on those with specific social characteristics (such as people from BIPOC communities, non-binary men and women, those with emotional or physical trauma, people who sleep rough and individuals who use drugs or have mental illness), in order to expand our understanding of marginalization. Finally, our study was limited to one country and we imagine that the specific contours of chronic struggle would look different in different health and social/political systems.

Conclusion

Through the narratives of the participants in our study, the work of chronic struggle is rendered visible. By bringing forth this concept, we may be able to meaningfully attend to how and in what ways people experience their encounters with social conditions alongside their chronic pain. The conceptual shift presented through chronic struggle will enable primary care providers and policymakers to better recognize the ways in which one's standpoint influences and/or exceeds experiences with chronic pain, and ultimately improve the lives of those entangled in medical and social knots.

Author Contributions

FW conceived of the study, obtained funding, and led the design, data collection, analysis and drafting of the manuscript. LC conducted data collection and participated in analysis and drafting of the manuscript. KR, AS, AP, JK, RU and CD participated in study design, analysis and contributed to the manuscript. All authors read and approved the final manuscript.

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