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Self-efficacy and dependence in personal & clinical relationships: a qualitative analysis of narratives about life with chronic back pain

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by

Elizabeth Clare Cummings

2018

Abstract

Objectives: People with chronic back pain encounter considerable psychological and social challenges. Through personal narratives, this project examines the ever-evolving relationship between chronic back pain, sense of self-efficacy, and perceived role in interpersonal relationships, both in the community and within the health care system.

Methods: In-person semi-structured interviews were conducted with 20 adult patients attending a specialized interventional spine pain clinic. The interview transcripts were subjected to inductive thematic analysis, and themes were labeled descriptively. Participant responses were intentionally not analyzed within the context of an existing theoretical framework, so that the content of participant responses would directly drive the emphasis of the findings.

Results: Participants described chronic back pain as a lonely struggle amid diminished capacity to work, enjoy leisure time, and contribute to social relationships. Feelings of needing to handle pain independently contrasted with the reality of having to rely on others for help, and this tension created anxiety. Participants negotiated these emotional complexities in their relationships with treatment providers as well, needing to advocate for themselves in a system that often presented inadequate treatment options, and where providers varied in responsiveness to participants' psychosocial experience of pain.

Discussion: The lived experience of chronic back pain was characterized by a conflict between the desire for self-efficacy, a sense of isolation, and the paradoxical need to rely on others. Participants found existing biomedically focused treatment modalities to be largely inadequate in reducing pain, improving function, or enhancing their quality of life. Interdisciplinary interventions that allow patients to navigate chronic back pain by seeking help for their diminished capability, while rebuilding and retaining a sense of autonomy and self-worth, are indicated.

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Table of Contents

Introduction 7

Statement of Purpose & Hypothesis 12

Methods 14

- Table 1: Sample Interview Questions 16
- Table 2: Demographics of Participant Sample 17

Results 18

Discussion 32

- Summary of main findings 32
- Strengths and limitations 33
- Comparison with existing literature 34
- Implications for future research and clinical practice 40

References 42

Introduction

Pain is the primary reason individuals seek medical treatment, affecting 100 million Americans and accounting for about 80% of all physician visits in the United States (1, 2). Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage. Important to note in this definition is that pain is always an emotional experience in addition to a physical one (3). Chronic pain is associated with high levels of distress and carries very different psychological, social, and emotional implications from acute pain episodes. Acute pain often results from acute tissue injury, whereas chronic pain often reflects a central nervous system dysfunction rather than a local nociceptive insult. Chronic pain can thus become a disease in its own right, where the ongoing sensation of pain rather than physical injury defines the patient's disability (2). A questionnaire-based study by the American Pain Foundation in 2006 found that 51% of respondents felt they had little or no control over their pain, and that for 59% of respondents, pain had impacted their overall enjoyment of life (4). Back pain is the most common type of pain reported in the US, with 28 percent of American adults experiencing frequent back pain (5). Back pain is the most frequently described problem in primary care (6). It has been posited that individuals with chronic low back pain may experience "unique societal prejudice" compared to others with chronic pain, and are thus subject to a unique set of social sequelae (7).

Psychosocial factors are central to the experience of chronic back pain

It is well documented that chronic back pain patients experience disproportionately high rates of depression, anxiety, and personality disorders. Systematic reviews by Pincus et. al. and others have found a strong connection between distress, depressive mood, and the transition from acute to chronic low back pain (8). The National Center for Health Statistics reports that adults with low back pain are three times as likely to be in fair or poor health and more than four times as likely to experience serious psychological distress as people without low back pain (5). This relationship is bidirectional. Factors related to patients' mental health and social context are thought to influence their capacity to manage pain, and chronic pain in turn may influence both emotional well-being and capacity for successful social function (9).

Self-efficacy and chronic back pain

The concept of self-efficacy, defined as people's beliefs or confidence in their ability to produce desired outcomes by their behavior (10), has been widely studied as related to chronic illness. In a 2001 study in Ontario that evaluated coping, self-efficacy and control, Endler and colleagues found that individuals with chronic illnesses like diabetes, asthma, and cancer tend to have a lower sense of self-efficacy than those with acute illnesses (11). In other words, these chronic illnesses are associated with a sense of being unable to accomplish desired goals that extends beyond the illness itself to encompass general life experience.

The structural relationship between self-efficacy, psychological adjustment, and the physical condition of the patient with chronic back pain is complex and ever-evolving. There has been recent emphasis on linking patient subgroups to tailored pain treatment interventions in order to maximize outcomes (12). Specific demographic, medical, and psychosocial factors that better define individual patients' sense of vulnerability and hopelessness may be important for personalizing pain interventions. Additionally, to the extent that treatment models may seek to emphasize self-efficacy (13, 14), it is critical that patients and providers develop a mutual understanding around the role of self-efficacy in adapting and coping with chronic pain. The relationship between patients' baseline self-efficacy and their psychosocial experience of chronic back pain must be appreciated before a treatment modality seeks to change that relationship.

Existing chronic pain treatments are often inadequate

Unfortunately, existing commonly used treatment modalities have not encountered widespread success. A 2011 Institute of Medicine report on pain found that large numbers of Americans receive inadequate pain prevention, assessment, and treatment. Some factors that account for this disparity include a lack of valid and objective pain assessment measures and treatment options; poor patient-provider communication and understanding; and financial incentives that work against the provision of the best, most individualized care (2). Chronic back pain can be difficult for providers to evaluate since it is based on a subjective patient experience, and the lack of objective measures for the condition can lead to issues with trust and communication between patients and providers. Providers who are not reimbursed for time spent with patients may not take the time to develop rapport and to address the complexity of patients' psychosocial experience.

Medical providers are ill-equipped to treat chronic back pain

The HHS-commissioned National Pain Strategy notes that although pain is one of the most common reasons for health care visits, many clinical training programs have yet to give it adequate attention (3). The fact that pain generally receives little focus in medical education contributes to the problem of undertreatment (2, 15). Medical providers may be well-versed in the biomedical aspects of care, but often are not properly equipped for the challenges of understanding the psychological, social, and cultural dimensions of chronic illness (16, 17).

Concerns about chronic pain are often dismissed

Clinicians often overlook the complex interplay of biological, behavioral, environmental, and societal factors involved in chronic back pain. Chronic pain treatment typically focuses on physical pathology alone, and largely neglects more complex biobehavioral factors (6). The Institute of Medicine's 2011 report *Relieving Pain in America* highlights that many health care providers lack a comprehensive perspective on pain, and that when people experience pain symptoms that cannot be ascribed to a defined disease, their pain is more likely to be categorized as an overreaction or a manifestation of emotional instability (2).

Drawbacks of pain medication

Opioid medications are an especially complex aspect of pain management, with abuse of opioids presenting a significant public health issue (18). Despite the fact that opioids have not been demonstrated effective in treating chronic pain, they continue to be prescribed for this indication. The last twenty years have seen a rapid escalation in prescription opioid abuse in the United States, leading to high rates of overdose deaths and a dramatic increase in the number of people seeking treatment for opioid dependence (19). Even patients treated with opioids who do not exhibit dependence still report a high level of pain, a low quality of life, and a high level of disability (6, 20).

Introduction summary

Chronic back pain has significant psychosocial impacts, including diminished self-efficacy and decreased capacity for social functioning. Despite its high prevalence, chronic back pain is often inadequately addressed and treated, likely due to a combination of unprepared providers, ineffective commonly used treatment modalities, and misaligned financial incentives.

Statement of Purpose & Hypothesis

In studying patient narratives, the goal of this study was to better understand not only the ways in which patients consider chronic back pain to have impacted their psychological functioning, but also how they understand the nature of the relationship between their pain and other aspects of their lives, especially with regard to self-efficacy. The uniquely subjective nature of pain makes patient narratives a particularly salient data source in understanding how patients make sense of the fact that their pain has effects that go beyond primary physical impairment, and requires adequately comprehensive interventions. The conclusions of this study have intentionally been drawn from subject matter brought up by the participants, in order to most accurately reflect common themes in narratives about life with chronic back pain. The interview technique was deliberately designed to elicit participants' perceptions of their own self-efficacy, but otherwise was completely open to what participants brought up about their own experiences. Discussions often ended up centering around participants' relationships with loved ones and friends, and with healthcare providers.

It is well known that chronic back pain and psychosocial functioning are irrevocably intertwined. Numerous qualitative projects have examined the richness of the chronic pain experience, and have provided insight into the frustration, shame, and guilt associated with chronic pain (17, 21-25). A 2014 meta-analysis by Froud et. al. about the impact of low back pain on people's lives encourages clinicians to better appreciate the social component of the biopsychosocial model when treating low back pain, for instance by considering social outcome measures like loss of independence, worry about the future, and experience of discrimination by others (7). However, critical gaps exist in our understanding of how social factors like self-efficacy and psychological adjustment may appear salient from the patient perspective. No qualitative study has yet examined self-efficacy as it relates to psychosocial functioning in patient narratives about the experience of chronic back pain.

In addition to expanding understanding about self-efficacy and everyday life in the community for people with chronic back pain, this study explores the challenges of receiving treatment for chronic back pain. It is known that treatments for chronic pain are often inadequate, and can even, at times, worsen clinical outcomes (26). Participants in this study were recruited from an interventional spine pain clinic because, presumably, they had to have had multiple interactions with the health care system and to have been referred to the interventional clinic for pain that was refractory to other therapies. We were not specifically interested in participants' experience of care at the interventional clinic from which they were recruited; rather, we wanted to examine the overall treatment experience of people who had been seeking care over a period of time for chronic back pain. There is an urgent need to develop better treatment strategies for patients with chronic pain, and to increase access to quality interventions. This study examines how psychosocial factors related to self-efficacy can play out in patient-provider relationships, and highlights important considerations for providing effective treatment.

Methods

<u>Design:</u> All study procedures were approved by the Yale Human Investigations Committee (HSC #1505015835). This author conducted semi-structured phenomenological interviews with 20 adults currently enrolled as patients at an interventional back pain clinic. The clinic offers injections, spine surgery, and other procedural interventions for back pain refractory to conservative therapies. Interviews were designed to elicit narratives about the psychosocial experience of chronic pain over time, both in the community and in the treatment setting. Interviews were structured to elicit perspectives on self-efficacy and participants' perceived ability to engage in daily activities and in treatment, with the ultimate goal of eliciting themes most important to the participants themselves. The exact interview questions varied based on each participant in order to focus on themes brought up by that participant. Sample interview questions are shown in ***Table 1***. The sample size was determined based on thematic saturation.

<u>Participants:</u> Participants were recruited from a pool of patients visiting the clinic over a 2-month period and were referred for the study by their primary clinicians, with an in-person handoff to the interviewer. Recurrent or chronic low back pain lacks a consistent definition in the literature (27), but for this study, the inclusion criterion was having experienced repeated episodes of low back pain over a period of at least one year. Individuals under age 18 were excluded from the study. The sample included 4 males and 16 females, with an age range of 29-78. More detailed demographic information is shown in ***Table 2***.

Procedure: The interviewer (EC) was not involved in the participants' treatment, and met with them in a private room in the clinic after their appointments had concluded. After complete verbal and written description of the study, participants provided verbal informed consent per Human Investigations Committee recommendation. Participants were given a copy of the consent form to take with them. Interviews ranged from 25 minutes to one hour in duration. The interviews were recorded.

Data analysis: After the conclusion of all the interviews, they were transcribed, and then were analyzed using NVivo data analysis software. Inductive thematic analysis was employed, whereby the data were subject to repeated rounds of coding and themes were allowed to emerge organically. Results were intentionally not analyzed within the context of an existing theoretical framework. This, along with the use of open-ended questions, maximized this study's ability to give voice to the perspectives of participants and to derive meaning from their narratives. Analysis was done by this author and reviewed by colleague GvS. Any disagreements about coding were resolved by consensus with other investigators. Prominent themes were organized into hierarchies, and themes that emerged consistently across the sample were given emphasis. Subsequently, the codes were presented by EC and GvS and reviewed by all the co-investigators. Self-efficacy, particularly with regard to social role, emerged as one of the most prominent themes in participants' narratives.

Table 1: Sample Interview Questions

What brought you here to the clinic today? What has that experience been like?
When did you first start thinking that you might need help with your pain?
What has happened since you started seeking help?
Have you tried anything on your own for your pain? How did that go?
What is your pain like these days?
[In what ways] does your pain interfere with your day-to-day life?
Have you found anything *you* can do about the pain?
What support have you had throughout this experience?
What are your hopes for the future?
Is there anything I didn’t think to ask you that you think is important for me know?

Table 2: Demographics of Participant Sample

(N=20)

Gender	male	4
	female	16
Age	29-39	3
	40-49	2
	50-59	5
	60-69	5
	70-79	5
Race	White	14
	Black	2
	Asian	2
	Native American	1
	Other	1
Marital Status	Single/never married	4
	Married	11
	Widowed	3
	Divorced	2
Education Level	High School	7
	Some college	7
	Bachelor's degree	5
	Graduate degree	1
Employment Status	Working	5
	Unemployed/not working	7
	Retired	8
Health insurance	Private	6
	Medicare + private supplement	7
	Medicare + Medicaid	2
	Medicaid	5

Results

Participants often perceived the experience of living with pain as a solitary struggle amid diminished capacity and low sense of self-efficacy. There was a clear conflict between the perceived necessity to endure pain independently and the practical necessity of relying on help from others for carrying out daily activities. Participants recognized the subjective and sometimes invisible nature of chronic pain, and despite this physical intangibility of the condition, felt a sense of unity with others experiencing chronic pain and a desire to connect over this shared experience.

Diminished function

Inability to engage in paid work & complete daily tasks

Almost all participants described how fears of worsening their pain had significantly limited their ability to perform daily activities.

> You can't do the things you want to do anymore. Your mind is still there, but you can't. You're worried, am I going to make it worse? (Participant 8, 59 y/o woman)

Over half the participants had stopped working, either by leaving their jobs or retiring early, because their pain made them unable to work. One participant described how she could no longer fill the demands of her job:

> It's very hard to walk. Before, in my job, I used to clean 19,000 square feet a day. Seventeen flights of stairs. I used to run up and down a lot of them. I used to be able to carry fifty pounds up those stairs. I've got a ten-pound weight limit right now. For awhile there, making it up one flight of stairs was very

> difficult. I used to stub my toe trying to lift my leg. So that's fairly tough. It feels like losing a hand. (Participant 14, 54 y/o woman)

Even for jobs that did not involve physical labor, concentration on tasks was difficult:

> It got to the point that it was very disruptive. The fact that it was always there, either as background noise or really, you know, really fired up, just makes it hard to concentrate and stay focused on what you're doing. (Participant 10, 61 y/o man)

Chronic pain also limited participants' abilities to care for loved ones and maintain households. This challenge of filling social roles and demands could become a significant source of anxiety.

> On top of being injured, I'm a single mother. So I still have my household finances, and then taking care of everyday activities with my kids. And it's difficult, because you're in pain some days, can't go to work. How are you going to take care of bills, and so forth? So it's like a domino effect. So it takes a toll on you physically and mentally. And your mind is saying, I want to do this, why cant we do this? But your body's like, no, we can't do that today. So it's like a war between your mind and your body. (Participant 13, 38 y/o woman)

Loss of favorite leisure activities

In addition to being less able to engage in paid work and to fulfill household duties, participants often described losing the ability to engage in pleasurable activities.

> I used to walk all over—I love walking. Where I live, it's near the beaches. So at a certain time, you can just go, no tourists there, and walk on the sand, and the water, and you feel refreshed. I don't chance that anymore. (Participant 3, 75 y/o woman)

And,

> I want to be a good father. I really want to be able to do things with my son. You know, run around, and play catch, and do these things that I always wanted to do. And with this pain it's like, oh my God, how am I going to get through this? Or do I bite the bullet and just not walk the next day? (Participant 6, 29 y/o man)

Decreased social engagement

Participants especially cited not being able to go out to social gatherings as a source of stress:

> I used to love going country line dancing. I used to love going out, hanging out with my friends. And just to either stand for awhile or sit for awhile, either or, is painful. And it just gets obnoxious, like, why even bother going out? You get to the point where you're just like, why even bother? Is it worth it? Because then the next day, you're twice as broken. (Participant 11, 49 y/o woman)

Inability to participate in social activities led to a sense of missing out, and ultimately strained participants' relationships with friends and acquaintances.

> Socially, you want to go out and be with friends. For instance, I have a high school reunion coming up, and I'm just not up for it. I know it means a lot of being on my feet, a lot of up and down, standing long, so I'm like, I'll pass on that. Relationship-wise, it's a lot of stress. I get frustrated. (Participant 13, 38 y/o woman)

Low sense of self-efficacy

Lack of control over onset & timing of pain episodes

One of the most frustrating aspects of pain was its seemingly random onset. Almost all participants felt they had little control over the amount of pain they felt at certain times. Medication was often the only thing that made a difference in the severity of pain episodes, but participants tended to be dissatisfied with pain medications for a variety of reasons. In moments when participants were not in pain, they still anxiously anticipated its recurrence.

> Chronic pain is my life. I tell my husband, if I wake up and tell you I'm in no pain, check for a pulse. Because it's pain every day, some days worse than others. (Participant 19, 57 y/o woman)

Pain episodes and labile mood

Pain decreased participants' sense of control over their emotional outlook. They drew attention to instances in which the pain made them feel extremely depressed:

> It definitely is an emotional rollercoaster. I have really good highs and really, really bad lows. And it has nothing to do with things around me, it's just the pain. Pain sucks. (Participant 11, 49 y/o woman)

And conversely, in which low mood made their pain worse:

I gotta think about me, myself too. Because if I get depression, forget it. I feel worse. When I'm depressed, I have more pain. It's not going nowhere. (Participant 2, 57 y/o woman)

Powerlessness in social relationships

For many participants, having so little perceived control over their condition created a sense of low self-worth. Many felt they were less able to contribute in a valuable way to their relationships with acquaintances, friends, and partners, and thus had become less worthy of friendship or love.

> When you live with chronic pain, you don't have a lot of self-worth. You can't do anything. So it's hard. It was hard on my marriage. That was part of the problem with me, was I felt insignificant. I was looking for a reason why I was here. Give me a reason to be here. Give me a reason to live. And I don't have a reason. I can't do much. And I did attempt suicide once. I had been arguing with workman's comp, they weren't approving things. My husband and I were arguing. I knew I was going to do it. (Participant 19, 57 y/o woman)

Lack of control over many aspects of life

For some, this sense of lack of control over pain episodes, mood, and social relationships pervaded their lives.

I don't feel like I have control over anything. I don't have control over my body anymore, because I can't do what I want to do with it. I love to run; I can't run. I can't go for a long walk. I can't socialize the way I want to. I don't have control over how many hours I work. I don't have control over where I work. Because of this injury, I can't work at the job I was working at. I don't have control over where I live, because it affected my finances, so where I was living--I had to move, because I couldn't afford it anymore. I don't have control over what I wear, because I can't wear certain clothing. Not being able to be active the way I was--clothes don't fit. So it's just a lack of control, and it gets depressing. And if you already have a diagnosis of depression, it makes it worse. So you don't have any control. (Participant 13, 38 y/o woman)

Contrast between enduring pain independently and relying on others

Participants described a clear tension between feeling the need to endure pain independently and without complaint and, at the same time, increasingly having to rely on others. Participants perceived pain as a solitary struggle that needed to be endured without complaint:

> I don't talk about my pain very much. I really don't. I try not to complain, because nobody wants to hear it. I'm not a complainer. That's not me. (Participant 7, 75 y/o woman)

Diminished function and the desire to deal with pain independently led to a sense of isolation.

> Being at home, looking at four walls, it's like being in a jail cell. Very difficult. (Participant 14, 54 y/o woman)

> It's not for me, just being home. It's so boring. You only can clean so much. And you don't feel like anything. Your life is being wasted. You can't keep up with the day. Like, I don't know what the date is. And you feel useless, just sitting. (Participant 18, 50 y/o woman)

> It’s frustrating because you don't feel like doing anything. Because a lot of the things you're trying to do hurt. It makes it really easy to just kick back and say, I'm not going anywhere today. You start to isolate. And that has a negative effect on the pain. (Participant 10, 61 y/o man)

Paradoxically, this sense of isolation and needing to be self-efficacious competed with a sense of needing to be more reliant on others. Participants spoke about feeling less independent, and increasingly counting on other people for help with daily activities and emotional support.

> I can't do the gardening, because if I bend over too long, the pain comes back. I can't walk my daughter's dog. And my daughter who lives across the street from me took away my driving. She drives me, and I hate it. (Participant 3, 75 y/o woman)

> It's depressing, because I do things myself. I'm not one to wait for somebody to do it for me. And to not be able to do these things, the simple things that you're sitting around and saying, this gotta be done, that gotta be done. You're waiting for somebody to come home to do it for you. It's frustrating. (Participant 8, 59 y/o woman)

Others described a capacity to tap into social networks in a more positive way, e.g. by fulfilling caregiving responsibilities.

> Pain totally takes over your life. When I was really hurting, I didn't want to get out of bed, because of the pain, but I knew I had to. I think if I didn't have the two little ones, it would have been a lot harder on me. They have to go to school, and they have to go to daycare. I'm happy that I have them, because [otherwise] you could get yourself in a bad funk. (Participant 16, 38 y/o woman)

Finding support from individuals similarly affected was particularly helpful. Many participants hadn’t understood what chronic pain was like until experiencing it themselves, and this made them much more empathetic toward others with a similar experience.

> Pain is something you feel on the inside. If you're not the person that's physically feeling it, you can't really understand what someone else is feeling. You can't judge a book by its cover. The cover can be all nice, and you open it up, and the pages can be all shredded. (Participant 13, 38 y/o woman)

Participants reported being relatively unable to identify or access others who were having similar experiences. Unlike support groups offered for other medical conditions, such as cancer or substance use disorders, participants were at a loss as to how to find others with whom they would be able to share support in a mutual fashion. In fact, while receiving their pain care at a top academic medical center, almost none of the participants in our study described receiving behavioral health intervention of any kind related to their pain.

Lack of viable treatment options

Most participants had a history of many interactions with the health care system in an attempt to get control of their back pain. Many described hesitancy to resort to invasive procedures for underlying causes of their pain.

> You need to do your homework. It took me three months of research before I finally found a clinical trial. Before that, all they wanted to do was cut me open, put the rods in. I said, there's gotta be an alternative. So I was searching, searching, trying to figure out what to do that was minimally invasive and still would help me. (Participant 4)

Participants' pain had largely persisted despite the therapies they had pursued.

> Maybe the pain will go away for a few days, and it'll come back. So nothing's really worked. And I've been told by three doctors that it's not surgically reparable. So I deal with it, because I don't have a choice. (Participant 7)

> The treatments have helped my pain, but haven't taken it away. The littlest thing could aggravate it. It's still there. It's just a matter of how you deal with it. (Participant 8)

Concerns about medication side effects & therapeutic ineffectiveness

Participants described avoiding or limiting use of opioids and other neurologically active pain medications due to worries about the medications limiting their functional abilities.

One doctor put me on a very high dose of morphine, as well as doing the injections. I said, I can't be doing this, because I'm falling asleep doing everything. At the time, I was volunteering at my church. But I found it really hard to do, because I couldn't focus on anything. (Participant 15)

I try not to take a lot of meds. I don't live on them. If I took them the way they prescribe them, I'd probably be Gumby without wires. You're just too looped to do anything. (Participant 19)

The addictive nature of narcotic medications was also cited as a reason to take lower doses or not to take them at all.

I'm trying not to get hooked on medication. It happens to people all the time. I refuse to get hooked on medication. Pills, this and that. Just let me make it through the night, that's all I need. The rest of the day, I'll be okay. You almost want to feel that pain, so you don't overdo it. (Participant 14)

Some shared accounts of past opioid addiction and withdrawal, and of the associated stigma.

I'm really cautious when it comes to taking pain medication, because I've had so many problems in the past. They had me on Vicodin at the beginning, and I got addicted. And I had to get off. I wouldn't wish that upon anybody. Especially when I had to go to the emergency room. They make you feel so small. (Participant 19)

Participants expressed frustration with medications seemingly being prescribed blindly when better options had been exhausted. Many felt that pain medications were overprescribed, and that providers had resorted to giving them medications in lieu of proposing interventions that would help their emotional well-being.

> The first provider I saw wouldn't treat me. She just threw medication at me, and I'm not one for medications. I want to try other things first. And at least give me some options, and there wasn't. And then she didn't see me anymore. (Participant 13)

> I worry about pain management, and the medications. Sometimes, doctors--and I'm not blaming them-they hit a block. And they say, we've done everything, this is all we can do. And they prescribe pain meds. I think we're in trouble. Because people become addicted, and then we have even more problems. I could see where you could get into some deep trouble. Just because you want to be pain-free, you want to live your life again. And it becomes a bad habit. It's just so sad. (Participant 16)

Many of those who took pain medications regularly remained unsatisfied with their effectiveness as a mainstay of treatment.

> Pain is depressing. It takes a toll on you. And you can't live off [the medication], because it eats your stomach away. And then it doesn't even work, so it's like eating gummy bears. You're just taking it for the sake of the whole action. (Participant 13)

> I think, psychologically, the meds make you feel better. Whether they actually work or not, I don't know. You do sometimes get a little relief, but not very much. (Participant 19)

Providers failing to validate the psychosocial experience of chronic pain

Participants often mentioned having seen several providers in the past. Besides changing providers due to logistical or scheduling issues, they would also change providers after disagreeing about the course of treatment, being unsatisfied with their pain relief, or perceiving that a given provider was not responsive to their emotional needs. This created a fragmented treatment experience, which participants found frustrating and inefficient. Potentially as a result of lacking dependable, consistent providers, some participants had logged multiple visits to the emergency room for acute back pain episodes.

> I woke up in the middle of the night in excruciating pain. Worst pain I've ever felt in my whole life. I don't wish it on anyone. When I walked into the emergency room, people were just moving aside. I don't know what my face looked like, but I must have looked like a monster or something. Because people could tell I was in pain. (Participant 14)

Participants cited some negative aspects of their past relationships with providers, including when providers did not validate the severity of participants' back pain.

> Participant 18: I'm not lying, or faking. It hurts.
> Interviewer: Do people ever think you're lying, or faking?
> Participant 18: I think they do. But I wish they could feel me for a minute, you know? It's hurtful. People just don't care, that's all. It's not concerning them, so they don't give a darn.

Other providers failed to make participants feel heard in their interactions.

> The doctor just wasn't interested. It seemed to me like he would give me appointments late in the day. And then he was always in a hurry to get to his tennis game. (Participant 12)

> He came in and said, hi, I'm Dr. so-and-so, this is what we're going to do today, do you understand all this? And I would try to explain to him what I had learned about my condition from all the doctors that I had

> seen, and what they had told me to tell new doctors when I saw them. And he was brushing it off. He was like, I'm a neurologist, what are you telling me this for? And I thought, well, why don't you want to hear me? Because what you're doing is not helping me anymore. Either you're doing it wrong, or my body is saying it's not working. (Participant 15)

Providers listening non-judgmentally & responding to input

Participants described positive experiences with providers who genuinely listened to and validated their concerns without judgment. It was especially helpful when providers appreciated the social and emotional concerns associated with chronic back pain.

> The doctor was just sitting and listening, and asking, where is that pain? How is that pain? You know, he really dug into understanding where the pain was, and how to treat it, until he really understood what the problem was. And then he was able to treat it. And that meant a lot. So bedside manner is huge, especially for chronic [pain]. It's not just, here's your pills and go away. This type of pain, there's a lot of emotion. There's a lot of being able to understand it yourself, it takes a lot. (Participant 16)

Participants tended to value providers who were willing to explore multiple pain management options with their patients, and who supported patients pursuing alternative therapies if helpful.

> Intervention is good, and repair and all that, but there's got to be something else that you can go to. You need something to fall back on. So I try to keep a pretty full toolbox. Acupuncture, acupressure. But it's something that isn't prevalent in Western medicine. We're looking at, give me a scalpel, give me a pill, give me a shot. (Participant 10)

Many participants were acutely aware of how their back pain inherently affected their minds as well as their bodies, and they expressed appreciation for providers with a similar outlook.

> You can't treat just the body. You have to treat the mind. It's like having an infection. You get a cut. What do you do? You just put a Band-Aid over it to close it up, but the infection is still in there. You have to treat both pieces. And if you treat the pain, well, the pain comes from your nerves, and it's all related to your brain. So let's start with the brain, and talk about it, and then treat the body. You have to treat them as one. There's a lot of great doctors, and they're focused on, let's fix this. But that's only a small piece of the puzzle. You've got to treat the mind. (Participant 13)

Many participants took accountability for their own role in communicating their needs with providers. Some participants preferred to drive the direction of their own treatment.

> I think one of the key things, particularly when you're dealing with pain, because it's such an amorphous statement--know exactly what your problems are. Don't figure the doctor's going to guess, because you know your own body best. (Participant 5)

Others entrusted the direction of their treatment to their providers, especially once they felt cared for by those providers.

> I've felt like I trusted the doctors that were taking care of me. I trusted that they knew what they were doing. And I believe they did. (Participant 15)

> If you've got a good doctor, listen to them. Definitely listen to them...if you find the right doctor, I think you're really in good hands. But if you get someone else, that doesn't give a hoot or a holler, you're in trouble. (Participant 3)

Discussion

Summary of main findings

Participants' narratives about their daily lives with chronic back pain fell into two major thematic categories: diminished function and sense of self-efficacy, and the paradoxical conflict between wanting to endure pain independently and needing to rely on others. For participants in this study, pain was an all-encompassing phenomenon that limited their ability to perform jobs, chores, and their favorite leisure activities. Very few of the participants described any degree of personal control over how much pain they felt or when they felt it. Participants described very low levels of self-efficacy with regard to their pain and, by extension, in their daily activities and relationships. For many, this created paradoxical difficulties in coping with their pain, whereby they needed to try to independently endure a difficult emotional experience while equipped with a very low baseline sense of self-efficacy and self-worth.

This difficult interplay between low self-efficacy and forming and maintaining social relationships also became relevant in the treatment setting. Participants described a fragmented treatment experience that was potentially exhausting in itself, and which required them to advocate for themselves in seeking out appropriate treatment. Since their chronic back pain often hindered their sense of self-efficacy at baseline, it is not surprising that barriers existed in finding effective treatment and maintaining productive patient-provider relationships. Many participants had not found success with the medications and other biological treatment modalities they had been offered, and desired more emphasis on therapies that would address their quality of life and the emotional impact of their chronic back pain.

Strengths and limitations

By relying on open-ended phenomenological interviewing and inductive analysis, this study was able to extend existing theory in a data-driven manner, and thus broadened existing descriptions of the chronic pain experience. The study highlights the multi-dimensional nature of the psychosocial impairments individuals with chronic pain may experience and, of particular interest, the tension between loss of capacity and the need to maintain a sense of self-efficacy. The importance of provider acknowledgment of the psychosocial complexity of the chronic back pain experience is also highlighted in these patient narratives. This is a small qualitative study; our findings should be thought of as pointing to areas for further investigation rather than as conclusive in and of themselves. Participants were referred by their providers and not randomly selected from the patient population of the clinic. It is inherent to our qualitative methodology that statements about the frequency of different themes in the population cannot be made. Qualitative studies such as this one should be thought of as preliminary to such follow-up investigations involving larger, more diverse samples.

Comparison with existing literature

In this qualitative study of adults with chronic low back pain, participants described a number of themes that are consistent with the existing literature about chronic pain, including decreased social functioning, psychological distress, and dissatisfaction with conventional pain treatments such as opioid medications. They also highlighted salient aspects of their experience that had not been widely noted in the literature, most notably the conflicting relationship between the need to rely on others while still maintaining a sense of self-efficacy and still feeling they contributed valuably to their relationships. This conflict affected participants' experience of treatment as well, where they had difficulty connecting with providers about their psychosocial concerns. This difficulty is likely due to a combination of patient limitations, e.g. limited self-efficacy and ability to self-advocate, and practitioner limitations, e.g. failure to listen and empathize.

Diminished function and diminished sense of self-efficacy

Participants' perception of pain as all-encompassing, and the fact that many gave up pleasurable activities as a result, matches existing descriptions of fear-avoidance in chronic pain (28). Fear-avoidance behaviors worsen social isolation and are associated with a worse prognosis in people with subacute lower back pain (29). Participants' anxiety, depression, and anger related to their social isolation are consistent with psychological comorbidities of chronic pain described in the Institute of Medicine Pain Report and elsewhere (2). In fact, the process these participants went through, whereby the experience of powerlessness and vulnerability extended beyond the pain experience to include other aspects of life, is resonant with experiences of patients with post-traumatic stress disorder as well. Individuals with PTSD may experience expansion of distrust and fear related to the focus of an initial trauma that involves increasingly large groups of people and settings (30). This parallel with PTSD, wherein distrust and fear grow from the initial experience of chronic back pain into many other aspects of life, such as the ability to complete tasks in the workplace and maintain lasting friendships, represents an important and underutilized focus for psychotherapeutic, and in particular, cognitive-behavioral intervention.

It is well established that people with chronic pain who have low self-efficacy have a worse prognosis. Quantitative tools like the Pain Self Efficacy Questionnaire can be used to inform chronic pain treatment plans (31). Although interventions focusing on improving self-efficacy and self-esteem are available and have been associated with increased quality of life for patients with chronic disease (32), in reality, these psychosocial components of chronic pain are often overlooked when medical care is considered (33). Many patients, including the participants in our study, may lack access to or awareness of comprehensive psychological and social pain treatment. Our study expands current understanding by highlighting multiple dimensions of functional limitation, which clearly extend beyond physical activity and include a global sense of low self-efficacy and self-worth in a range of life-defining activities and social relationships. These complex social factors merit close attention in treatment interventions that prioritize self-efficacy as an outcome measure.

Loss of independence and fears of reliance on others

The process by which chronic pain disrupts emotional well-being involves impairment in both physical and social functioning. It has been proposed that disrupted social relationships may be an even more salient factor in creating emotional distress than physical impairment (9). Consistent with this finding, participants in our study described pain as a lonely experience that made them less able to connect with their social networks and to maintain healthy interpersonal relationships. Not wanting to be viewed as self-pitying, many hoped to endure chronic pain while complaining as little as possible. Importantly, though, participants could not realistically fulfill their desire to cope with pain on their own. They needed to depend on others for emotional and functional support. Many saw this as a loss of independence, and some described feeling vulnerable or guilty having to depend on other people. This aligns with existing literature describing pain as a type of trauma that can provoke social anxiety and social role avoidance (34).

For some participants, the desire for independence, combined paradoxically with the practical necessity of social dependence, may have further decreased an already low sense of self-efficacy. Participants often felt defeated in their efforts to maintain a sense of independence while living with chronic pain. They thus felt little capacity to effect change in their pain levels, their social relationships, or other aspects of their lives. Some tried to set manageable goals and complete small tasks during the day in order to salvage some sense of control, consistent with behavioral pacing strategies routinely discussed in cognitive behavioral therapy (35).

This conflict between diminished sense of capability, loss of independence, and desire for self-efficacy offers an enriched picture of the daily emotional burden chronic pain begets. This finding also highlights discordance between what participants in our study considered the salient aspects of their experience and those typically emphasized in psychosocial models of pain (36). Given how chronic back pain pervades their social experience and brings up issues around dependence on others and self-worth, patients may experience efforts at encouraging them to develop self-efficacy as ignoring some of the unique obstacles they experience with regard to forced reliance on others for physical and social functioning.

Participants frequently expressed empathy for others dealing with the invisible, subjective experience of chronic back pain. Some described people in their lives who were also affected by chronic pain and who provided solace in that shared experience. This idea of drawing comfort from group affiliation is resonant with findings and practice in other conditions, including psychotic disorders and substance use. In pilot studies, peer support strategies that acknowledge the central role of relationships and support in self-management have been effective in reducing the psychological and social burden of chronic pain (37). To our knowledge, support groups in which the group interaction itself is therapeutic (as opposed to group interventions, where the provider-patient interaction is the focus) constitute an underutilized practice for supporting individuals with chronic pain. Interventions like this that foster mutual social support could allow patients to feel they contribute valuably to others in the group, and theoretically could thus increase self-efficacy while being mindful of the obstacles to practical independence that patients encounter in their daily interactions and relationships.

Fragmented treatment experience with multiple ineffective modalities

Most participants had tried multiple approaches to chronic back pain management, and these had largely proven ineffective. Most of them recounted experiencing back pain over a period of many years and seeing numerous different providers. It has been shown that when multiple providers are involved in a patient's care, poor communication, low patient satisfaction, and worse outcomes can result (38). Consistent with this, participants described their fragmented treatment experience as tiring and frustrating. In the case of chronic back pain, the difficulties associated with the fragmented treatment experience may be self-perpetuating. For pain that is refractory to existing medical and interventional treatment, providers may be unable to offer satisfactory therapies, and patients may then seek care from multiple different providers in an attempt to find relief. This can compound frustrations of both patients, who have baseline decreased self-efficacy and are being forced to navigate a treatment system that requires them to continuously advocate for themselves, and providers, who may encounter their own frustrations when they are unable to treat the condition effectively.

Concerns about drawbacks of pain medication

Pain medications were discussed more than any other aspect of the chronic pain treatment experience. Overall dissatisfaction with opioids and other neurologically active medications was almost universally expressed. Participants' concerns about complications of long-term opioid use were not misplaced: chronic opioid exposure is associated with risk of misuse, addiction, and overdose in a dose-dependent fashion (39). Even participants who used opioids regularly tended to see the effectiveness of these medications as limited. Consistent with these participants' experiences, there is no evidence in the literature that long-term opioids effectively improve chronic pain and function (40).

Self-efficacy & self-advocacy: tensions in provider-patient relationships

Participants described negative experiences where clinical providers failed to listen to them or to validate their psychosocial concerns. Because pain is a subjective experience, there is evidence that providers may develop a tendency to see others' pain through their own lens, thus losing some of the empathy essential to a trusting patient-provider relationship (2, 25). As participants in this study mentioned, when providers are inflexible in their thinking about chronic pain, this can make patients feel invalidated and engender mistrust in providers. Participants appreciated providers who created safe spaces for discussion about how pain impacted patients' lives, listened to psychosocial concerns, were responsive to patient input, and validated patients' needs in a non-judgmental fashion. Effective provider support took a variety of forms: supporting alternative treatment and coping methods, allowing patients to drive the direction of treatment, or conversely, choosing treatment directions for patients who felt most comfortable with the provider devising the treatment plan.

Implications for future research and clinical practice

This study affirms the necessity for clinicians to recognize the significant emotional burden chronic pain imposes on patients' sense of self-efficacy in their daily lives and their social relationships. Although self-efficacy is positively associated with quality of life and prognosis in those with chronic pain, our study suggests that any efforts to promote self-efficacy will need to acknowledge patients' diminished sense of functional capability, and to recognize that pressure to be more self-efficacious could exacerbate underlying concerns about needing to rely on others. Our findings emphasize a need for a balanced treatment approach in which individuals are not only empowered to support themselves, but also especially encouraged to accept support when needed while still cultivating a sense that they contribute valuably to their social relationships.

More generally, our work underscores the importance of utilizing a fully biopsychosocial approach in the management of all patients with chronic pain. In settings that disproportionately focus interventions on passive pharmaceutical and procedural interventions, a crucial opportunity for improvement of patient quality of life is often missed. Multimodal approaches that take the complex biopsychosocial situation of patients with chronic pain into account have the opportunity not only to decrease pain symptoms, but to help patients understand the changes they can make to improve the quality of their own lives in the long term.

Interdisciplinary treatment is well established in the literature as the most effective approach to chronic pain management, leading to improved mood, pain, and function

(41-43). Unfortunately, none of the participants in our study mentioned experiencing any coordinated interdisciplinary treatment for their pain, and many had unmet psychosocial needs related to their pain. Among all pain-related treatments, interdisciplinary pain rehabilitation programs are the only approach consistently shown to be associated with return to work, reduction in hospitalizations, and meaningful, sustained improvement in pain and function (41). These interdisciplinary rehab programs vary in their exact structure, but typically involve providers from multiple backgrounds (e.g. pain medicine, addiction medicine, psychology, physical therapy, occupational therapy, social work) working together on a common treatment plan for every patient (44). Cognitive behavioral therapy and other behavioral interventions are central to these interdisciplinary programs (45). In particular, chronic pain interventions that focus on increasing self-efficacy and encouraging self-care have received attention as promising approaches (13, 46, 47).

If these types of interventions are made accessible to more patients, and if the providers implementing them take into account the potentially fraught baseline low level of self-efficacy of patients and empathize with their psychosocial experiences, there is great potential for positive change in the treatment experience for chronic back pain.

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