
Navigating the health care system: perceptions of patients with chronic pain

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Abstract

A new framework is needed for patients with chronic pain and their primary care physicians that acknowledges the individual's experiences and provides evidence-informed education and better linkages to community-based resources. This study describes the experience of 19 chronic-pain sufferers who seek relief via the health care system. Their experiences were recorded through in-depth semistructured interviews and analyzed through qualitative methods. The participants reported early optimism, then disillusionment, and finally acceptance of living with chronic pain. Both individuals with chronic pain and their health care professionals need evidence-informed resources and information on best practices to assist them to manage pain. Empathetic communication between health care professionals and individuals with chronic pain is crucial because insensitive communication negatively affects the individual, reduces treatment compliance and increases health care utilization.

Key words: *chronic pain, empathetic communication, health care system, patients' perspectives, patient education, qualitative research, coming to terms*

Introduction

Pain is a complex phenomenon with physical, psychological, social and spiritual aspects. Chronic pain has a major effect on individuals and their families, on health care costs and on productivity. Individuals with chronic pain are frequent users of health care services,^{1,2} with most seeking to relieve their symptoms, primarily if the pain interferes with their day-to-day activities, or to determine if the pain indicates a serious pathology.^{3,4} Of the range of health care professionals, the primary care physician plays an important role in assisting patients to manage their pain and is a key source of information. Yet pain, particularly chronic pain, often remains unrelieved and the reasons why are not well understood.

Researchers have found that individuals' perceptions and management of their pain is influenced by their experiences with treatment regimes,⁵ their interactions with health care providers⁶⁻⁹ and their beliefs about the nature and causes of pain.^{4,10-13} The meanings of both pain¹⁴ and pain management regimes^{13,15,16} differ between patients and health care professionals. These differences in perceptions affect the patterns of help-seeking and adherence with treatment regimes.

People with pain often become socially isolated.¹⁷ They may be labelled as "malingers" and even "drug seekers" and seek recognition and acceptance from health care professionals as well as the broader society.¹⁸ As chronic pain can be frustrating and difficult to treat, patients

are often expected to accept their pain and to learn to manage it themselves.^{13,19-22} Chronic pain sufferers comment that health care providers vary in attitude, knowledge and understanding of the social and emotional impact of pain,^{8,11,23,24} expect adherence to the medical model of care⁸ and may not determine the patient's preferred management strategies.²³ At the health care systems level, pain management services are not coordinated²⁵ and evidence-based resources to assist both individuals and health care professionals are minimal. If health care professionals do not meet patient expectations, they either withdraw from care or "shop around" to find providers whose model of care coincides with their own.^{4,12} For chronic pain sufferers, interacting with the health care system can be complicated and stressful, and the outcome unsatisfactory. These circumstances promote the cycle of high use of health care services and unrelieved pain.

The purpose of this paper is to describe the perspectives of people with chronic pain as they seek relief via the health care system.

Methods

Description of the participants

Most participants were recruited through a mailing to a chronic pain support group, and two were recruited via snowball sampling.²⁶ Participants were eligible if they had back pain, neck pain or migraine headache, were between 40 and 65 years old and had experienced pain for a minimum of six months. Participants with

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back or neck pain or migraine headache were chosen because, according to Canadian population studies,^{27,28} these are the most common types of chronic pain. Pain here can have a marked effect on individuals: back pain can contribute to pain in the lower extremities and neck pain to pain in the upper extremities; migraine headache is an example of severe, episodic and unpredictable chronic pain. While chronic pain is defined as pain that exists for a minimum of three to six months, we chose six months as the minimum for this study so as to include those who would have had to manage their pain longer. As one ages, one is more likely to have chronic pain, and chronic pain sufferers, on average, have endured their pain for 10 years.^{27,28} The age range was set at 40 to 65 years to achieve homogeneity within a broad sample and to include those who may have had to become unemployed due to chronic pain and/or found it necessary to re-train or re-educate themselves for other careers.

Of the 19 individuals recruited, 15 had suffered chronic pain for more than ten years and four for less, with the duration of their pain ranging from 4 to 52 years; 12 were single, widowed or separated while seven were married; 13 were women. Participants represented various levels of education and types of employment. Two worked full-time, six worked part-time or were retired, and one was a full-time student; ten stated they were unable to work because of their chronic pain. All 19 participants had government-administered health care insurance that funded some of their health care needs including physician's visits; nine had third party insurance such as Worker's Compensation Boards, automobile insurance and supplementary health insurance.

Data collection and analysis

Ethics approval was obtained from the participating university and all participants provided informed consent.

Data were gathered with the help of a semistructured interview guide and included questions about how participants managed their pain, who helped them manage it and how they sought assistance for their

pain. Approximately half the interviews were done over the telephone and the remainder were face-to-face. Interviews ranged from 30 to 90 minutes. Participants were interviewed until data saturation was achieved, i.e. until no further information emerged from the interviews.²⁹ Six participants were re-interviewed to verify and expand upon the themes that were being found in the data.

Data analysis began with the first interviews. Data were analyzed by searching for themes. Preliminary codes that captured the participants' descriptions of their experiences were assigned.^{26,29} Second-level codes or categories were developed from these preliminary codes. Using constant comparative methods,³⁰ categories were examined for similarities and differences. Two researchers (A. D., K. G.) developed and verified the major conceptual categories. A third (J. M.), who was not involved in the data collection, assisted with the data analysis. An audit trail was established through a reflective journal and field notes.²⁹ Data diagrams were used to conceptualize the data as a whole.

Results

Coming to terms

The major category that evolved from the data, "Coming to terms," best described the participants' search for a cure or for better pain management. Attitudes changed from initial optimism to disillusionment and then to a level of acceptance of the realities of their pain and the limitations of the available health care. This time-consuming process often involved repeated interactions with different health care providers. Three subcategories evolved from the data: "Working with the system," "Changing perspectives" and "Becoming realistic."

Working with the system

Participants approached their primary care physician as a gatekeeper to the health care system, with the expectation that their pain would be relieved and the cause diagnosed. For most participants, this expectation was not met; thus began their struggle to seek a cause, find some relief or adjust to their pain.

Seeking a cause

The participants initially anticipated the cause of the pain would be determined. Given the nature of chronic pain, success could sometimes depend upon the persistence of the patient and/or physician though often a cause could not be found; in such cases, the participants often felt devastated as they believed this invalidated their pain. Other researchers have also found that a diagnosis legitimizes a sufferer's pain^{13,16,19,31} and reduces the perceived stigma associated with an invisible condition.³² It also establishes their credibility, not only to the physician, but also to family, employers, co-workers and friends.

I cannot believe that the MRI didn't show what's going on with me. I cannot believe with medicine today that something doesn't stand out like a sore thumb and say, "Oh goodness, no wonder the woman is like this."

Interacting with the primary care physician

Many participants indicated that having a supportive physician who provided guidance, sympathy and treatment options helped them manage their pain. A supportive relationship was characterized by the physician's willingness to listen to and believe them and to consider their perspective in treatment decisions. Even if the treatments did not relieve the pain, participants continued to visit their physicians if the relationship was supportive.

My physician [helps me manage my pain], I've been seeing him...[for some time] and [my pain] was difficult. ... I didn't know where the pain was coming from. Some days were worse. He tried different medications.

Many participants reported positive interactions with their physicians, but others found that their physicians were dismissive and hurried and did not provide information or solutions that relieved their pain. When they sought care for other health concerns, they considered that their physicians too quickly attributed these to their chronic pain.

When you go to the physician and say you have something else or you're not feeling well, they don't hear what you're saying because you've already talked to them about pain every visit for the last few years.

Whatever the relationship, participants depended upon their physicians to prescribe medications, provide information and refer them to medical specialists and other health care professionals. As this relationship was so vital, the participants developed various techniques to attract the physician's attention and maintain support. For instance, they learned not to overburden the physician with numerous complaints but only reported on "one pain" or on their major pain problem to stop him or her from "tuning out."

I got to learn that you didn't mention too much of your pain to the physician, you only mentioned a certain little bit that really concerned you.

Our findings support those of other researchers who argue that patients believe that they are primarily responsible for maintaining the relationship with their health care provider and use various strategies to preserve this important relationship.^{7,9}

Chronic pain can also limit patients' access to diagnostic procedures as well as referrals to other health care professionals and medical specialists, particularly when third party insurers are involved. Certain diagnoses, such as failed surgeries or fibromyalgia, or involvement in litigation labelled patients as "risky," and some physicians were hesitant to take them under their care.

My [primary care physician] was moving ... and I was trying to find a new GP and it's like finding a needle in a haystack. Nobody wants this. I know it's not me personally but there's too many [health care problems] going on. I'm a complex patient.

Changing perspectives

When their pain was not relieved and/or a cause or diagnosis not established, many

participants became disenchanted with their health care providers and the health care system; they began to view their pain and their health care differently and search for alternatives. This change in perspective was also influenced by conflicting messages about treatment and by their experiences and beliefs about the effectiveness of medications, causing them to feel anxious about finding help.

Conflicting messages about treatment

Participants reported receiving confusing or conflicting information from different physicians and health care providers. For some, this affected their willingness to seek further treatment. Even having a diagnosis did not always explain the pain or give direction for satisfactory treatment, leaving participants sceptical and concerned about where to get assistance.

[S]o they said there was no correlation, it didn't fit ... I thought, "Oh well, they must be right, of course."... The physicians were gods to me at that point, and I went for MRIs, I went for all kinds of things, and the more physicians you see, the more opinions you get ... So you're left totally confused as to what direction you should take or what is really going on with you. I sort of opted to just do it myself, go home and do the natural thing and let my body heal, but it didn't, it never did.

I'm doing what seems to work but I don't know if it's the best thing. Nobody has ever discussed that with me. I've been given prescriptions for painkillers and told to take them as needed, and some physicians seem to [sic]—like the rehab physician—think you should take as little as possible.

Concerns about medications

While intending to provide relief, medications were sometimes a major source of concern and even conflict between the participants and their primary care physicians, particularly if there were troublesome side effects, or if the participant's knowledge, beliefs or experiences were at variance with those of the physician.

I dropped the anti-seizure medication ... because I'd broken out really bad [sic] on my hand—severe blistering. My physician kept trying to convince me it was dermatitis ... After 3 months of trying cortisone, steroids ... I couldn't wash my dishes under warm water, I would go through the roof. I decided to personally try to reduce my dose to 300 mg a day.... My skin improved.

Many participants did not understand how to manage their medications or the role they played in their treatment. Some reported that pain medications worked for a while and then stopped; several reported that they became "allergic" to medications or that they were afraid of becoming addicted. Antidepressants were a common source of concern and best represent physicians' and patients' differing perspectives. Many participants were ambivalent about the helpfulness of antidepressants and either restricted their use or wanted alternative methods for dealing with their mood and their pain.

I refused to go on 150 mg of [antidepressant]. It was like a tug of war. He thought I was sabotaging myself and didn't understand why I was spending so much money to go to physiotherapists ... I don't care what they say about it not being addictive—it's a bunch of bull.

Side effects were not the only concern regarding prescriptive medications. Some of those participants who were prescribed opioids believed that their physician labelled them as "drug-seeking" and they felt mistrusted. Additionally, opioids can contribute to feelings of dependency, inequity and vulnerability among chronic pain sufferers.

I just couldn't do that revolving door right now. Going for pain medication and trying to save them, drag them out as long as I possibly could, so I had something for pain because it's humiliating going back for more. When you take your last, it's horrible.... It's

so humiliating more than anything. The idea that the physician doesn't trust you and believe you.

While patients are reluctant to take opioids and other pain-relieving medications,^{10,23,33} there has been little research regarding reservations about taking antidepressants for pain.³⁴ Piguet found that patients did not associate antidepressants with pain relief and felt the physician did not believe that they were in pain.³⁴ Our participants commented that medications and their side effects were the "double-edged sword" of pain treatment and a major factor in their change in perspective on the health care system. Their comments also illustrate that their interactions with prescribers influence their feelings about themselves as pain sufferers; likewise, prescribers' pain management practices influence their patients' beliefs about medications.¹⁰

Searching for alternatives

The participants became disillusioned with conventional health care when they felt invalidated, when there were unresolved differences about treatment decisions and when there was a lack of shared decision making. To address their pain and dissatisfaction, they tried other options: changing primary care physicians, seeing other health care professionals or seeking further information. Complementary and Alternative Medicine (CAM) was an option and an adjunct to prescription medications for many, particularly if patients were afraid of addiction or otherwise concerned about conventional medications. Some participants were enthusiastic about CAM practitioners because they devoted more time to them and managed their health in a holistic manner.

Oh, and I saw a naturopath one time. It was like nothing I had ever experienced. He asked me everything about mental, physical, spiritual health. It was a two-hour appointment ... I saw him occasionally when I was fed up with the medical system, and he usually came through with something helpful.

As with conventional medicine, CAM did not work for everyone, and some approaches were expensive. Some participants reported that CAM medications seemed to work for only a while and that some had side effects.

In my specific case, I tried all kinds of alternative treatment but a lot of them didn't work because it's very individual.

Patients' disillusionment with CAM for pain management is not widely reported in the literature.³⁵ However, more pain sufferers are turning to CAM, and there are varying reports of efficacy when CAM is used alone or in conjunction with conventional therapies.³⁶

Becoming realistic

Often many interventions or combinations of interventions, such as exercise, pain-relieving medications or CAM, appeared to work, but only temporarily. The participants, weary of having their hopes repeatedly raised and dashed with only short-term relief, became reluctant to seek care. This phase involved acknowledging the system's limitations, accepting the reality of the pain and seeking information to assist them to manage.

Acknowledging the system's limitations

Participants described a transition when they were able to move from searching for a cure and being dependent on the medical system to the realization that the pain was ongoing. They did not expect a quick cure, but they kept their options open while functioning within their limitations.

I went through the gamut of homeopaths, naturopaths, pain clinics ... it all works for a short time. The hardest part of the situation is to accept that my life is full of pain, and I have to make the best of it and go on. I wouldn't say I'm not willing to try new things. I'm more sceptical of it.

For some participants, becoming realistic meant they learned to find a balance between interventions. During this stage, many began to reduce their use of prescription medications and incorporate their

knowledge of other treatment methods into a regime that helped them.

In the middle of the night ... I will use Reiki. Then ... I will use hypnosis to go back to sleep. I did the pain course. I'm hoping it will help me.

Accepting the reality of the pain

Current pain practice generally encourages acceptance of chronic pain, as opposed to an ongoing search for a cure. However, health care professionals should be cautious when discussing acceptance as a goal for patients living with a chronic condition.²² The numerous definitions of acceptance^{37,38} indicate that terms and their meanings need to be carefully communicated between patient and physician.

Most participants did not respond positively when health care professionals told them that they must accept the situation and "live with the pain." Such comments were viewed as an excuse for not determining the cause and placing the onus on the patient to accept the situation. Acceptance was equated with physicians not trying to find a solution.

You can't just accept your pain because if you just accept it, you won't have a life. You have to find ways of easing the pain or you won't be able to function. But people accept it because they're frustrated with medical advice or lack of it.

Conversely, others reported a different view of acceptance and indicated that accepting chronic pain meant that their search and hope for relief had ended. For these individuals, becoming realistic meant learning to endure the pain. Acceptance was helpful in dealing with their situation.

I've searched for 20 years and then gave up searching ... I have tried everything—relaxation, biofeedback, magnet therapy. I'm at the point where it takes too much [*sic*] energy than I've got and I don't use my energy trying anymore.

Seeking information

People with chronic pain want clear explanations about the diagnosis and treatment, and supportive reassurance and advice about pain management.^{3,16,19,39,40} Many participants described obtaining information through formal and informal sources. Support groups provided access to experts and allowed them to share ideas and experiences with their peers. This type of support empowered them to make more informed choices and was an important adjunct to the care offered by their physicians.

My support group meetings are important; when I went to the first meeting, they had a pharmacist there and suddenly all my stomach problems were resolved because I discovered [my stomach problem was due to] my pain medication. [I get] information from various support groups ... I've met people through these and learned a lot.

Participants who used group support and educated themselves about pain management generally spoke in more positive terms about their situations and interactions with health care providers. However, not all participants were members of these organizations. Some stated they did not find these “pity parties” helpful and chose to manage pain on their own.

Discussion

Coming to terms with the pain was a process of working with the system, changing perspectives and adjusting to the reality of pain. This complex process involved a series of difficult personal transitions. As the participants learned that their chronic pain was not going away, they also learned that their physicians were not able to provide all the answers and solutions, and that available treatments had side effects and limitations. However, a trusting and supportive relationship with a physician who believed their complaints and helped them to become less dependent on the health care system and more reliant upon themselves was important; non-supportive encounters, on the other hand, could lead to a personal disconnection with the health

care system, or a withdrawal. Because of their numerous and, at times, prolonged encounters with the health care system, participants who were involved with third party insurers were particularly prone to withdrawing and becoming discouraged about finding relief. This disconnection has many ramifications, the most important being that pain sufferers do not obtain the treatment that they require for other comorbid conditions. Their perceived need to be responsible for managing their interaction with their health care providers increases the many troublesome burdens associated with chronic pain. Patients need a combined approach to pain management—and the support to try these various approaches—that incorporates different strategies that can work alone or in combination with medications.

Conclusion

Even if the cause of the pain is not diagnosed, patients need confirmation that their chronic pain is “real” and want to feel empowered through access to consistent and reliable information on best practices. This suggests that there is a lack of accessible evidence-based resources to help patients and health care professionals, that existing resources are underutilized and that communication between health care providers and patients needs to improve.

The emphasis on “acceptance” as the patient’s responsibility can create an additional barrier between patients and physicians. An important finding was the degree to which the perception of contradictory diagnosis and treatment advice played in building scepticism and dissatisfaction, which resulted in high utilization of or withdrawal from the health care provider and the health care system.

Practice implications

Both health care professionals and patients need a better framework to address chronic pain. The study participants were seeking better information about types of medications, non-pharmaceutical options and CAM. Further research on the efficacy of CAM and conventional therapies for pain management could reduce the economic burden of this vulnerable population.

The participants frequently commented that they were not heard and that they were not being provided with consistent information about best practices; health care professionals should be aware of the differing expectations between patients and practitioners and provide support, focusing on how they can best assist the person to deal with the realities and ambiguities of chronic pain. Further research is needed on how to improve communication between health professionals and patients. At the health care systems level, services need to be coordinated to provide improved access.

With the prevalence of chronic pain in the population and its socio-economic burden, there is an urgent need to reduce the gap between current research and health care practice and to provide evidence-based resources to chronic pain sufferers and their families. There is a need to synthesize and mobilize our current knowledge base to support health care professional training and consumer education.

Limitations to the study

Most of the participants were recruited from the member database of a chronic pain education and support organization; they represent those who are willing and able to join these associations. The participants were relatively well educated and may be less vulnerable and have more options than pain sufferers from a lower socio-economic position.

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