

The Trajectory of Chronic Non-Cancer Pain in Six Patients: A Roller-Coaster Ride

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Abstract

The diagnosis of chronic non-cancer pain (CNCP) is based entirely on patient self-report unlike conditions such as diabetes or multiple sclerosis. Objective tests, the sine qua non of the medical model, are not widely known outside of specialty clinics. Canadian family physicians are poorly trained to deal with this common and debilitating condition.

Using a novel graphic representation of the major themes raised during primary care visits, Dubin and Van Vlack (Pain Res. Manage., in press) discussed factors including mood disorders, financial concerns, conflicts with employers and insurers, and independent life events which affected healthcare utilization in six pain patients followed in Dr. Dubin's general practice for 6 to 22 years. A locally-developed education/exercise CNCP self-management program seemed to improve patient function and reduce healthcare utilization in those whose major conflicts were behind them.

Physicians, insurers, lawyers and employers may be contributing to patients' pain and disability by adopting a disbelieving and confrontational approach to CNCP sufferers. Terms such as "functional", "malingering", "drug-seeking", and "sickness or pain behaviours" allow professionals to separate themselves from and "blame" their clients. At the same time, patients may be forced to use ever-more exaggerated verbal and non-verbal cues to communicate their distress to others.

This paper will present the chronic pain trajectory as a roller-coaster ride which engulfs the patient, family, employers, insurers and medical care-givers alike. Avoiding this destructive path requires a shift from the medico-legal models (purely scientific, allowing only objective findings) to ones that incorporate both patient empowerment and an expanded understanding of the pain experience. Professional training in chronic pain should be multi-disciplinary, and should include input from the Humanities and Social Sciences.

Key Words: chronic pain, healthcare utilization, self-management, exercise, conflict, pain behaviours, stress

The past, being more or less imagined, or more or less organized after the event, acts on the future with a power comparable to that of the present itself. Paul Valery.¹

But if the only external sign of the felt-experience of pain (for which there is no alteration in the blood count, no shadow on the X-ray, no pattern on the CAT scan) is the patient's verbal report (however itself inadequate), then to bypass the voice is to bypass the bodily event, to bypass the patient, to bypass the person in pain. Thus the reality of a patient's X-rayable cancer may be believed in but the accompanying pain disbelieved and the pain medication underprescribed.....to have great pain is to have certainty, to hear that another person has pain is to have doubt. Ellen Scarry.²

1. Introduction

Twenty percent of Canadian adults live with chronic non cancer pain (CNCNCP). Access to specialty pain clinics is limited both by geography and wait lists that exceed one to two years. While veterinary students receive 87 hours of lectures on pain during their 4 years, medical students get only 16 hours! Though family physicians are poorly trained in chronic pain treatment, they manage the majority of chronic pain sufferers.^{3,4,5}

Pain arising from the back, neck and joints is the most common reason that patients visit their doctors. Musculoskeletal disorders are the major cause of long term disability, reduced function, and healthcare utilization. Chronic pain causes significant psychosocial dysfunction and societal costs. These patients require more time per visit and suffer more mood disruption than other patients. It is little wonder that family physicians find them challenging to manage.^{6,7,8}

Evidenced-based medicine is the current mantra. Yet in chronic pain, the only “evidence” is the patient’s self-report, or history. The absence of recognizable organic pathology may lead healthcare providers, employers, insurers, and even family members, to disbelieve or downplay the pain patient’s suffering. Lacking a clear understanding of the cause of their symptoms, patients themselves may develop increased disease-related anxiety with subsequent increased healthcare visits.^{9, 10, 11, 12}

As a family physician, I struggled ineffectually to prevent my patients from entering the maelstrom of chronic pain. The treatments that I and others were recommending: physiotherapy, medications, MRI’s, consultants and rehabilitation professionals were failing to improve their lives. When one of my patients, a man who had suffered from chronic back pain for over a decade, wept in my office because he could no longer be intimate with his wife, I realized that my medical model had failed.

With the help of physiotherapists, an occupational therapist, fitness consultants, pain physicians, and a pain psychologist, I spear-headed the development of a local exercise/education self-management program for chronic pain patients, which we named Y-PEP (for **YMCA Pain Exercise/Education Program**).¹³ On reviewing the files of my patients who had completed this program, I recognized that the major correlate of healthcare utilization in my chronic pain patients was stress: from depression, from financial losses, from insurance or legal claim conflicts, and independent life events. My graphic exposition of these selected patients’ 6-22 year histories in my clinic is neither randomized, nor controlled, but contains the richness of years of longitudinal information from a primary care practice.¹⁴

The purpose of this paper is to illustrate through these case histories both the roller coaster trajectory of chronic pain and those factors which, in my opinion, make patients sicker. My hope is that, by reviewing the past (i.e. these case histories), I can find a future path that will allow everyone: patients, families, healthcare providers and insurers, to avoid stepping aboard the chronic pain roller coaster.

2. Case Histories

I reviewed patients' complete medical files, recording the number of healthcare visits made annually for reasons either relating to pain or other conditions. Visit themes of depression, conflict with employers/insurers/ lawyers or others, and financial concerns were also noted. Graphs of these data are presented for four patients whose histories follow below. Two patients' case histories are included without graphs due to their relatively brief time in my practice (6-9 years). All patients agreed to share their stories with the public and the Research Ethics Board of Queen's University approved the Y-PEP studies.

A. Martin, 46 (Figure 1)

Martin came to Canada from a war torn country in 1990, learned English, and worked in a restaurant, successfully achieving a managerial position of which he was very proud. Though he had mild lower back pain for many years as well as recurrent prostatitis, he functioned normally and was happily married with two children. An occupational injury in 1998 led to 4 years of intensive rehabilitation efforts while he faithfully attempted to remain at work despite developing hypertension and morbid obesity. His boss fired him however, on seeing him take pain killers. A severe depression ensued along with major financial stressors, followed by a brief psychiatric admission when Martin's home burned down while he was at my office! His pain visits rose dramatically until after his home was rebuilt, his worker's compensation pension was granted, and he abandoned his dream of returning to work. Martin's pain visits fell after he attended Y-PEP in 2006. His pain was well controlled until mid 2009 (not shown on graph) when he had a major flare; the psychosocial correlate: his sister was found to have metastatic breast cancer. Since her successful therapy, his pain control and distress have improved, though he admits to isolating himself from family and friends and spends much time alone and in prayer.

B. Luis, age 53 (Figure 2)

Luis emigrated from the same country as Martin where he had received death threats for his work in human rights. In Canada he got a job in patient care but suffered a back injury in 1994. He too worked very hard to get better. In 1997, he became severely depressed due to lack of progress in his recovery. When his dog attacked a neighbour in 1998, he was admitted briefly to a psychiatric ward. Other diagnoses included hypertension, non-cardiac chest pain, diabetes and post-traumatic stress syndrome. Luis persevered and retrained as an addictions counsellor but re-injured his back while attempting to catch a client who collapsed at the Detoxification Centre. He again went through intensive

rehabilitation therapy. A minor car accident in 2001 caused further pain. Finally in 2004 as he tried to retrain once more, he failed a course at school and accepted a pension from the Workmen's Safety and Insurance Board (WSIB), after which his pain visits fell. In 2009, Luis spear-headed a chronic pain patient's support group along with several other patients of mine, and he is currently doing very well.

C. Dixie, age 35 (Figure 3)

Dixie had been my patient since 1988 when she was made a teenaged ward of the Children's Aid Society because of parental abuse. In her early years she had back, pelvic, wrist, and abdominal pain and was diagnosed with fibromyalgia. A pregnancy in 1992 was followed by post-partum depression. Dixie worked at a manual job where a back injury in 1999 led to rehabilitation treatments through Workmen's Compensation (WSIB). She eventually refused to "fight" with her employer and the WSIB over their return-to-work expectations and chose to stop receiving insurance benefits. She was supported by her spouse. Upon completing Y-PEP in 2006, she continued to exercise regularly, reduced her medication and took a full time job at a call centre after four years of unemployment. She also decided to leave her spouse. Unfortunately a minor car accident in 2007 and the subsequent pain, financial losses and conflicts with the auto insurance company caused a complete reversal of the gains she had made in 2007. Until recently she was involved in a lawsuit regarding her car accident, her pain levels, medication doses escalated and she was forced to live with her ex-husband who assisted with housework and finances. (Her insurance benefits have been withheld at times leaving her with no money for food or medications.) Her lawsuit has recently settled and her pain and pain-related visits have also fallen.

D. "P", age 48 (Figure 4)

"P" was referred to me on discharge from a psychiatric hospital in 1989 where he had been admitted for months with severe depression. He suffered physical and verbal abuse as a child, was illiterate, and was abusing alcohol, cocaine and IV drugs. He had an ankle injury in 1992 requiring multiple surgeries, lower back pain and chronic abdominal pain due to hepatitis C. He was not a candidate for interferon treatment of his hepatitis because of his depressions. From 1998 to 2002 his pain increased when he was fired from a part time job, was abusing alcohol and was in conflict with his wife. "P" attained

abstinence in 2003, and his health care visits declined. His disability pension and drug plan provide financial stability and access to pain medications. After attending Y-PEP in 2006, and after 8 years of unemployment, he returned to a part time job which he continues to enjoy to this day.

E. Dennis, age 37 (Figure 5)

Dennis was referred to me in 2007, 3 years after a car accident which left him completely disabled from his job as a truck driver. He had been off work briefly a few years earlier due to an occupational shoulder injury but had completely recovered. In 2004, he was rear-ended by a fast-moving car while turning into his driveway. The car accident, witnessed by his wife and son, sent his vehicle flying across the lawn. He suffered a vertebral fracture and also a resurgence of severe shoulder pain at the site of the earlier injury.

Dennis is married, with one child, and has had no previous psychosocial problems. His only previous medical problem was hypertension. An ordinary Canadian, he enjoyed all-terrain-vehicles, snowmobiles, hunting and fishing, and puttering around in his garage. During and after Y-PEP he remained completely disabled, with severe depression and pain that was unresponsive to medication. Deep muscle injections and nerve blocks by a pain specialist provided his only pain relief.

Litigation involving Dennis' accident went on until late 2008 and involved multiple lawyers and consultations by professionals from the "other side" attempting to prove that he was exaggerating his disability. Both his wife and child experienced anxiety related to this process. Insurance benefits were withheld and the family eventually lost their home to creditors.

Dennis' lawsuit was settled in his favour at the end of 2008. Three days later he suffered a minor thrombotic stroke from which he has fortunately recovered. His pain visits fell dramatically and the family was able to purchase a new home. However in late 2009 while another legal hearing for further damages was pending, Dennis has again developed severe pain.

F. "A", age 53 (no Figure)

“A” had a 30 year history of chronic back and pelvic pain due to endometriosis as well as chronic depression. She had been abused as a child, had a history of substance abuse, and continues to smoke marijuana daily for pain relief. She lives on her husband’s disability pension and hence has some degree of financial stability as well as a drug plan. Since attending Y-PEP her visits have fallen to regular preventive care, and she expresses much more life satisfaction.

3. Discussion

The chronic pain trajectory was like a roller-coaster with increases in medical visits at the time of injuries and later during “crises” when pressure from insurers, legal battles, failed return-to-work attempts or other personal troubles occurred. “Pain” was the “presenting problem” that brought patients to the office, and this was the issue that I, at the time, believed I was to deal with. Other major themes during medical visits including socio-economic and employment problems as well as mood and sleep disruption did not appear so important until I carried out this retrospective review. These themes did not recede until the previously mentioned conflicts were resolved.

We doctors are trained to rule out “red flags” such as tumours and infections and may not recognize the life stressors that could be causing increased pain. We then order more tests, consultations, and stronger medications (with an inevitable increase in often debilitating side effects). By failing to provide accurate explanations to patients about the nature and course of chronic pain, we may contribute to patient anxiety and increased healthcare visits. By ignoring the psychosocial conflicts we may perpetuate patient suffering and disability.

Dr. Grant Russell, in a PHD thesis on the family practice care of patients with occupational injuries, performed qualitative interviews with injured workers and their physicians in both Canada and Australia.¹⁵ Physicians resented the administrative time involved, felt pressure from insurers to return patients to their work whether they were ready or not, and were uncomfortable speaking to employers due to confidentiality concerns.

The patients described their experience with Workmen’s Compensation as cumbersome, intimidating, frustrating, demeaning, causing feelings of powerlessness and anger. There were delays in claim processing resulting in

inability to pay for medication for severe acute pain. Patients found the compensation process confusing, and felt disempowered. Injured workers expressed feelings of “not being heard” by the insurer, and two types of reactions were noted: antagonism and anger, or passive “uncaring” withdrawal.

Frustration, disempowerment, anger, and stress may increase pain levels in their own right.¹⁶ These negative emotions can lead to depression which is a well known correlate of increased pain. Insurers may be ramping up patients’ pain and depression by withholding benefits and creating major financial crises (e.g. Dixie, Dennis). Lawyers and experts for the “other side” in litigation can accomplish the same by attacking the patient’s veracity and reality (Dennis). Patients with compensation and litigation issues are known to be more functionally impaired and suffer more pain and depression.^{17, 18}

Physicians have traditionally considered non-dermatomal sensory loss patterns to indicate “functional” or in other words, non-organic (i.e. due to psychiatric) reasons. However, patients identified as “management problems” by WSIB in Ontario had a higher prevalence of non-dermatomal sensory loss which was associated with altered functional MRI brain activation patterns.¹⁹ Chronic pain is an inflammatory state, and it is conceivable that the stresses in dealing with insurers and lawyers could increase pain perception through inflammatory mechanisms leading to maladaptive “neuroplasticity.”²⁰

A recent study using PET scans of patients, many of whom, like mine, had been exposed to serious emotional trauma, revealed metabolic changes in emotion and pain processing areas of the brain. Perhaps at last, the term “somatization”, like “psychogenic” and “hysterical”, now has a physiological explanation.^{21, 22, 23}

Pain specialists believe that “catastrophizing”, a character trait or appraisal process that is ‘associated with a tendency to magnify pain threat, worry excessively about pain or hold an unduly pessimistic view to the ability to deal with pain,’²⁴ predisposes patients to negative therapeutic outcomes. This may be true in some instances. I am not the only physician who has recognized patients with a “style of being” such that we know they will do badly after an injury.¹⁵ However, Walker et al, in a qualitative study of British chronic back pain patients identified themes of loss of physical and mental abilities, occupational and social activities, financial hardship and changes in interpersonal relationships. All of these eventually lead to loss of self worth, future and hope. They stated that:

[T]he stories told by our participants suggest that the negative material and social consequences of back pain may be sufficient to generate feelings of worthlessness and hopelessness even where no latent personal vulnerability existed prior to the onset of pain.²⁴

Labels such as “catastrophizer”, “functional”, “drug-seeking”, “malinger”, and “sickness or pain behaviours” can be useful clinical concepts, but can also serve to separate the professional from the patient and could be interpreted as blaming. Family physicians often have the advantage of knowing their patients before misfortune befalls them. Despite having experienced catastrophic events in their lives (childhood abuse: Dixie, “P” and “A”, civil war and emigration: Luis and Martin, and an accident witnessed by the entire family, loss of their home and stroke: Dennis) my patients had behaved quite normally within the limits of their personalities before their injuries. Luis and Martin made repeated and energetic attempts to return to their jobs and their optimism only began to fade as they began to fail and had to give up their dreams of working productively. “P” and “A” had conquered addiction and lived on disability pensions for many years. Yet “P” chose to return to part time work. Dixie had adopted an independent fitness-oriented life when a car accident knocked her back to an even greater level of pain, disability and dependence on others. Dennis was a completely normal Canadian man until his car accident catapulted him into severe pain, depression and disability.

My patients’ pain experience was one of recurrent losses in many spheres combined with powerlessness at the hands of insurers and lawyers. Their process of grieving was complicated by financial constraints and independent life misfortunes. Reaching a state of acceptance²⁵ could really only occur once financial security of some sort was achieved, and reconciliation to their losses had occurred.

The concept of a “chronic pain trajectory” is not new,^{9, 26} but this is the first study to graphically depict this journey over several decades. Family physicians who recognize “pain behaviours”²⁷ as manifestations of neurobiological phenomena could explore the

underlying psychosocial problems that drive worsening pain, depression and function. Family practice care that is characterized by listening, understanding and shared management was the greatest factor in reducing global disability in occupationally injured patients¹⁵ and should be the standard of practice everywhere. Physicians may improve their patients' outcomes by keeping an open mind when symptoms arise for which pathophysiological explanation are as yet unavailable. Factitious illness, in my experience, is uncommon.²⁸

That legal and insurance claims worsen pain is not a new discovery. Many multidisciplinary pain programs refuse to accept patients who are involved in ongoing claims (which begs the question: how ethical is it to refuse care to the most severely affected clients with the greatest suffering?) However, the insurance and legal industries should also recognize their role in patients' pain and disability. Experts from the social sciences and humanities will have to become involved to effect major changes to these systems so that "invisibly" disabled people are believed and given material security. Strong-arm tactics, like withholding benefits or imputing malingering despite medical opinions to the contrary, should be recognized as damaging to the patient. Health professionals require more education in pain medicine, but so do lawyers and claim managers. The treatment of chronic pain is a basic human right,²⁹ and institutions that prolong or worsen peoples' suffering should be revamped and their members re-educated.

In 2003, Blyth et al, from Sydney, suggested that 'there is a need to establish to what extent the compensation process per se contributes to these outcomes [pain-related disability]'.³⁰ In 2010, in Sydney, I would like to suggest that this is an idea whose time has come.

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