

Part One
Context

1

The Lived Experience of Chronic Pain: Evidence of People's Voices

Cary Brown

1.1 Introduction

Box 1: Key points

- People in pain are all around us—they speak through literature, in scholarly writing, through visual art and, increasingly, in electronic form on the internet.
- Too often the individual in pain remains unacknowledged, isolated in a downward spiral of suffering.
- Common themes of experiential accounts emphasize doubt, invisibility, and unpredictability.
- Confronting lived experiences of pain and these themes directly in health education may promote compassion in health care providers that can affirm the individual and increasingly overcome alienation and its negative effects.

Modern health care responds to an ever-expanding set of scientific evidence about treatments, drugs and program delivery models and yet the number of people who live in chronic pain continues to grow. This is an alarming puzzle.

Perhaps we are using the wrong tools to address the problem of pain [1, 2]. Perhaps we have just not heard the voices of people in pain, or understood and appropriately responded to them. In her classical work, *The Body in Pain*, Elaine Scarry [3] tells us that

“to have pain is to have certainty; to hear about pain is to have doubt” and that “the doubt of other persons . . . amplifies the suffering of those already in pain”

Perhaps it is just difficult for the person in pain to speak. Philosopher David Morris [2] said that

“ . . . pain not only hurts but more often than not frustrates, baffles, and resists us.”

In *On Being Ill*, Virginia Woolf [4] commented:

“the merest schoolgirl when she falls in love has Shakespeare and Keats to speak for her, let a sufferer try to describe the pain in his head and language at once runs dry”

Nor is this just an academic or literary message (Box 2).

Box 2: Brenda's story



“I have been known to . . . Storm out [of the office], be . . . what's the word, a difficult patient because I'm frustrated. You know, if you feel you're not being listened to, it's frustrating, really frustrating.”

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'Brenda' (a pseudonym) has made her story available through an online repository of patient narratives [5]. Her's is one of dozens of stories about chronic pain and other health conditions. To provide the pain sufferer's own words, to convey the lived experience of pain as a reality in daily life, I will weave Brenda's story through this chapter.

The first section tells how to better access accounts of the experience of living with chronic pain and offers samples which identify some persistent themes. The second section explores the legitimacy of evidence offered through lived experience and the techniques that researchers in the social sciences use to understand meanings, values and beliefs. The third section identifies barriers and discusses the consequences of not hearing the voices of people with pain. To conclude I note some promising initiatives that can serve as models for policy development.

1.2

The Perspective of People with Pain

Box 3: Brenda's story

Brenda is 52 years old and worked for a number of years as a medical receptionist prior to being involved in a car accident where she was badly injured and was unable to return to work. She experiences back pain and has had multiple interventions including: Facet joint injections, physiotherapy and TENS. Her current medication is: dihydrocodeine, co-proxamol, buprenorphine (Temgesic) for flare-ups, and diazepam for muscle spasms. Brenda lives with her dog who she credits with keeping her motivated and active.

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1.2.1

Unfiltered Voices

There are many places where we can learn about the chaos of lives in pain without the filter of a third-party. Autobiographies are an example. Oliver Sacks, a physician, experienced prolonged pain as a result of a climbing accident that left him bed-ridden for many months [6]. He emphasized the isolation of people suffering from migraine pain

“If migraine patients have a common and legitimate second complaint besides their migraines, it is that they have not been listened to by physicians. Looked at, investigated, drugged, charged, but not listened to.”

Arthur Frank wrote about his experience of living with cancer [7]

“In writing about the incoherence of pain, one risks becoming incoherent all over again. Language easily goes wrong. I could write that at night in pain I came to know illness face to face.

But this metaphor distorts that experience . . . at night I faced only myself”

Lucy Grealy was diagnosed at age nine with Ewing’s sarcoma and wrote about the physical and psychic pain that marked her life from that point forward as she endured over 30 surgical procedures to reconstruct her jaw [8]

“This presented a curious reversal of fear for me, because I already understood that with other types of pain the fear of not knowing about it usually brought about more suffering than the thing itself. This was different, this was dread. It wasn’t some unknown black thing hovering and threatening in the shadows; it had already revealed itself to me and, knowing that I knew I couldn’t escape, took its time stalking me. This was everything I ever needed to know about fate.”

Not being listened to, ‘language gone wrong’, fear of the known—these are all common themes that emerge from the stories of people with pain. Because ‘Brenda’ used to work for a doctor and understands the time pressure doctors are under, she works to overcome these problems . . .

Box 4: Brenda’s story



“So if I go to a GP and I’m not being understood or I’m not being . . . thinking “Okay here comes another one” you know, or whatever, whatever they don’t know about chronic pain, I’ll try and be different and say “Well actually it . . .” you know, and go overboard to try and make them understand a little more of what my situation is like”.

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1.2.2

Literary Routes to the Lived Experience of Pain

Literature is a powerful way to convey the lived experience of pain. Victor Hugo [9] pointed out the idiosyncratic nature of pain

“Pain is as diverse as man. One suffers as one can.”

At the end of the nineteenth century, Leo Tolstoy [10] wrote

“The gnawing, unmitigated, agonizing pain, never ceasing for an instant, the consciousness of life inexorably waning but not yet extinguished, the approach of that ever dreaded and hateful Death which was the only reality, and always the same falsity.”

This stark image of pain from *The Death of Ivan Ilyich*, written in 1886, is strikingly congruent with what Lucy Grealy says about pain and dread despite being 100 years and a universe of medical technology apart.

Contemporary non-fiction also makes people’s description of the pain experience available. Marni Jackson’s recent journalistic work *Pain: The Fifth Vital Sign* [11] is intended to make diverse information about the complexity of pain accessible to a wide audience. Jackson frequently uses her own and others’ voices to illustrate what it is like to live with pain.

1.2.3

Lived Experience of Pain in Scholarly Publications

Professional journals (e.g. *BMC Medical Ethics* at www.biomedcentral.com/bmcmedethics) are increasingly available in open-access, on-line formats. Because the financial burden of subscribing to these journals is removed, everyone (clinicians, policy makers and the general public) can examine emerging issues and share in understanding the pain experiences these forums provide. Some health-care journals regularly contain first-person accounts from people with a range of life-altering medical conditions (like chronic pain) to illustrate points within a medically focused discussion. For example, in a *British Medical Journal* (BMJ) article, Chloe talks about her doctor’s disbelief about her arthritis [12]

“I made an appointment with my (now ex) GP, who when I informed her that I had been diagnosed as having RA said “Nonsense you probably just have flu.” I finally persuaded her to order blood tests, which reconfirmed the diagnosis. However she flatly refused to allow me to keep the rheumatology appointment and insisted that I attend a hospital with an over one year waiting list, even for “urgent” first appointments.”

Other healthcare journals include qualitative research reports that depend on quotations from study participants to illustrate the researcher's conclusions. For example, in the journal *Work*, a young student musician's words illustrate his reaction to his physician [13]

“. . . figured if I had pain and it was something that's going to affect my career, not only in school, but my performing career, that it should be taken a little more seriously [by the physician I went to].

1.2.4

The Visual Arts

People hear differently. What is clear to one, may not be clear to another. This is well illustrated by the simple children's game of 'whispers' where a message is started by one child and whispered around the circle until it returns to the originator. What started off as 'see the dog run away fast' may come back as a nonsensical statement, about 'cooking wild duck on an outdoor potato hat'. Hearing about other people's pain may be rather like that; the message is garbled because people hear in different ways. This makes it important that as many alternative media as possible are used to convey the message. People who don't read Tolstoy or Victor Hugo may find pain messages accessible through a range of electronic media available on personal computers. For example, a 'Google' search of the internet locates many 'pain art' projects.

Of particular interest are two projects that show how we can directly access people's pain expression through visual art. Debra Padfield's *Perceptions of Pain* (<http://ije.oxfordjournals.org/cgi/content/full/32/5/704>) started when people from a pain clinic worked with an artist to create images of their pain. The resulting exhibition was published as a book with the assistance of *Novartis Pharma AG* and is now owned by *Napp Educational Foundation*, in Cambridge, UK. Selected images from the project (see Figure 1.1) are available through a research project for healthcare providers in primary care to use with patients attending doctors' appointments. Perhaps when words fail, as they often do for people with pain, images can be used to give pain a presence accessible to others. The images in *Perceptions of Pain* were created in an effort to express the multilayered experience of living with chronic pain. As one participant said [14]

“. . . when I first saw the images that Deborah and I produced together I felt a shiver of recognition mixed with feelings of anger and sadness. But for the first time I was able to point at something and say 'that's my pain'."

The *PAIN Exhibit* (www.painexhibit.com) is an online collection of works created to express pain experience. The artists are international and the work is often accompanied by commentary to increase the likelihood that the viewer will accu-



Figure 1.1 Pain expression through visual art: *Jubilee clip* from Debra Padfield's *Perceptions of Pain* (with kind permission from Dewi Lewis Publishing).

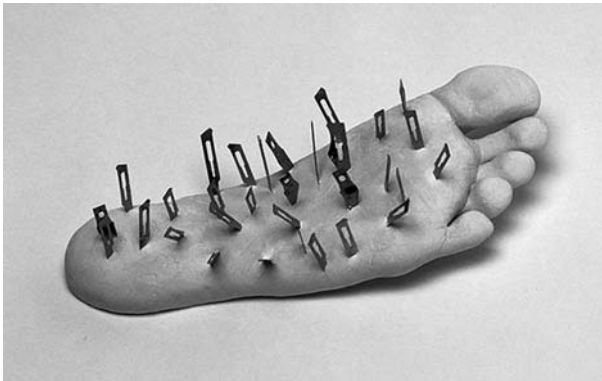


Figure 1.2 Pain expression through visual art: *CP11* by Mark R. Collen (with kind permission from the artist).

rately decode the experiential evidence. Mark R. Collen began the collection in 2001 as a response to the years of under-treatment he endured (see Figures 1.2 and 1.3). Collen was motivated to exhibit his and over 500 other works of pain-related art because they are “far more effective at communicating the pain experience than words”. (www.painexhibit.com/aboutexhibit.html). The exhibit is categorized into sub-themes (for example ‘normalcy’, ‘suffering’ and ‘hope’) so that viewers can more readily access works related to the evidence they are seeking. The *PAIN Exhibit* has been used widely in North American and Europe for teach-



Figure 1.3 Pain expression through visual art: *CPIII-Trapped in Hell* by Mark R. Collen (with kind permission from the artist).

ing healthcare providers. To date, the work has received attention in both the popular press and academic journals.

1.2.5

Pain Voices in Electronic Media

Electronic media allow people with pain and their significant others to share experiences and information across continents and time-zones via the internet. Brenda is an example. Brenda's story and more than a hundred others are freely accessible from the DIPEX website (www.DIPEX.org). This very rich resource contains audio-video clips of people talking about living with a chronic condition. The viewer can select by type of health condition and/or by type of life issue (family, employment, sexuality etc.) and then watch short clips. One can see the guarded postures, the grimaces and the smiles; all the non-verbal communication of ordinary people talking about dealing with extraordinary challenges. These clips are all the more powerful for pointing to what is not talked about. Here are Brenda's experiences with facet joint injections.

Box 5: Brenda's story

“But I spoke to a woman, a nurse at the pain clinic and she said that I was on the right track. Some people, unfortunately, don’t exercise, don’t watch their diet and expect the injections to do everything for them without, without you know adding to it, you know being their own doctor as it were and that’s unfortunate.”

Credits: DIPEX[®] – <http://www.dipex.org/DesktopDefault.aspx>

Being able to see Brenda as she talks about the experience tells us even more. Brenda becomes a real person, sincere, with a sense of humor, and a conviction that she has an important story to tell. These types of resources—graphic and compelling—communicate a richness that is inaccessible through textbooks, lectures or simulated patient exercises. They can be invaluable teaching tools.

1.3 Quality

How do we know that patients’ voices and art work can be considered as good quality evidence about the experience of pain? Sackett, a foundational thinker in evidence-based medicine, does suggest that [15]

“Evidence based medicine is not restricted to randomized trials and meta-analyses. It involves tracking down the best external evidence with which to answer our clinical questions . . .”

We have located exemplars of the patients’ voices. But how do we know that these voices are ‘*best evidence*’? Perhaps the patient is speaking of a highly individual experience, or has some secondary or hidden agenda or bias behind the recounting of the story. Even evidence from experimental studies that appear to be carefully designed and rigorously controlled are sometimes found to have serious flaws. What are the indicators of quality in the type of experiential evidence discussed here?

First, we look for *transparency* [16]. Is the source credible? Have contributors explicitly stated their perspective and background? For example, the patient narratives used to illustrate points in the previously cited BMJ article [12] are very transparent. We know where they come from and a context has been provided. Mark Collen's *PAIN Exhibit* provides the background of the project and tells us exactly why the project was started. We know that this evidence is presented from the perspective of someone who has experienced on-going pain. Collen has made the biases explicit. Similarly, Deborah Padfield provides information about herself and the commercial interests (Novartis Pharma in this case) that sponsored the work. Arthur Frank, Lucy Grealy and Oliver Sacks' publishers all provide bibliographic information to help the reader understand the context and bias of the authors. Given that there is no 'bias-free' evidence; an indicator of quality is how transparent the author is about their bias.

A second criteria of quality is the *credibility* of the sources presenting the evidence [16]. Journals like *BMJ* and *Work* that bring us the patients' voices are credible in that they are peer-reviewed and are regarded as being 'high-quality' by their readers. Narrative evidence presented in books from large publishing houses like Harpers, who published Grealy's work, have more credibility than those that are self-published. Morris [2], Scarry [3], Good [17] and Frank [6], all present their academic credentials as demonstration of their credibility. In the case of Brenda's story, the DIPEX site [4] is supported by the National Health Services (NHS) in the United Kingdom and is a registered charity. DIPEX makes available information about its structure and board on the website. DIPEX was also voted by two leading national newspapers in the UK as being among the top health websites providing evidence that the resource is well respected by credible reviewers.

Trustworthiness of experiential evidence is also related to what qualitative researchers call *triangulation* [16]. This means that consistent themes emerge from across the range of resources being reviewed. Where there is more consistency, there is stronger evidence that what the author is articulating is a theme that is universal, not isolated or idiosyncratic. When we look at the evidence presented through the voices of people with pain there are definite consistencies. *Disbelief, feeling 'voiceless' and unheard*, and *the desire to have others legitimize pain* are all themes that emerge consistently from stories about living with chronic pain. These themes are evidence that despite all of the advances in medical technology and the availability of apparently effective interventions, people with pain are still suffering, in part from our neglect and refusal to acknowledge the genuineness of their suffering.

1.4 Barriers to Accessing the Evidence

That healthcare providers and policy makers do not hear the patients' voice is not a problem unique to chronic pain. However, not being heard is even more likely for people with chronic pain because, unlike a fracture, or arthritis, or most other health problems, chronic pain is invisible.

Why don't healthcare professionals and policy makers listen? Historically, the answer is largely embedded in Descartes's idea that the body and the mind were two separate parts of what make us human. When this idea was presented in the mid-seventeenth century, it revolutionized thinking about the body. Many important advances in anatomy and physiology are a result of this perspective. From that point forward 'scientific' thinking about pain focused on understanding the biological/organic components of pain. Over the next 400 years critical advances in our understanding of the biological processes involved in pain and its treatment were achieved. Unfortunately, similar attention was not paid to the psychological processes and we marginalized this type of study as less important and valid. It is only recently that healthcare providers have recognized the importance of viewing health and illness as part of a complex system composed of biological, psychological and social elements, all of which interact and influence illness and disease [18, 19].

Research now suggests that ignoring the psycho-social aspects of chronic pain increases the likelihood that the patient's pain experience will become progressively more complex and resistant to intervention. The interaction between patients who can't express themselves and healthcare providers who do not understand what the person with pain is trying to express results in misunderstanding, negative affective responses and, frequently, mistrust and disbelief [20]. Without effective and accepted pain expression the person with pain cannot communicate his or her experience. Without awareness of the patient's experience a reliable assessment of interdependent bio-psychosocial function cannot be achieved and consequent interventions may be ineffective, wasteful and potentially harmful.

1.5

Consequences of Unvoiced Pain

Box 6: Brenda's story



"I just felt less than human almost. I did, I felt like a cow or something I just felt less than human almost."

Credits: DIPEx[®] – <http://www.dipex.org/DesktopDefault.aspx>

There are negative consequences when patients feel they are doubted by their physician and when physicians express distrust of their patients [21].

Physicians, frustrated when treatment isn't working, can begin to blame the patient and the patient can become angry and withdrawn, understanding that the physician doubts their honesty [22, 23]. Existing social stereotypes about people with pain can act as critical barriers to accepting patients' accounts as indicators of legitimate ill health, particularly when the patient does not respond in an anticipated manner [24]. People with pain, and the myriad of stakeholders they interact with may come from different linguistic groups [25]. They may not feel the need/comfort/ability to share their opinions overtly, may not be allowed to speak for themselves [26], and may be suffering the effects of past miscommunications [27]. Taken together, these barriers to effective communication of the pain experience can be overwhelming.

1.6 Dealing with the Evidence

What strategies will help healthcare providers and policy makers appreciate the role of lived experience in effective programming for chronic pain? We have identified diverse sources for gaining access to the patient's voice. What remains is knowledge translation—*“developing healthcare workers' and policy makers' receptivity to and awareness of lived experience”*. Knowledge translation strategies make explicit the benefits of the evidence available through qualitative inquiry. For example, the University of Alberta's Arts and Humanities in Health and Medicine (AHHM) Program (www.med.ualberta.ca/education/ahhm.cfm) offers healthcare providers a broader socio-cultural perspective on issues of illness and wellbeing. The newly revised *Core Curriculum for Professional Education in Pain* produced by the International Association for the Study of Pain (www.iasp-pain.org), and the expanding range of publications in journals like the *BMJ* that stress the value of listening to the patient's narrative as a critical component of healthcare for people with chronic, complex conditions [28] can also help. A report released by the University of British Columbia, *Where's the patient's voice in health professional education?* [30] is another useful source of background information and strategies.

1.7 Summary

Box 7: Brenda's story



“It just felt awful because I think there are benefit cheats, you know. There are people that are on benefits that could be working and aren't, they see themselves, you know, easy bit of money or something. I don't know, I'm not them and I don't want to talk about them really, but well it just really hurt my feelings and the thing that was in my favour was that, you know, I said to them “Look I want to work” or something’.

Credits: DIPEX[©] – <http://www.dipex.org/DesktopDefault.aspx>

Three themes arise from the literature with regularity. The first theme is *doubt*. People with pain experience the doubt of healthcare providers, family, colleagues and policy makers on a regular basis. This doubt exists because people with chronic pain do not respond to biomedical interventions in the expected manner (i.e. ‘getting better’!). Tragically, after repeated encounters with social and health providers that seem to mistrust the person’s pain account; pain sufferers begin to doubt their own experience, losing confidence in their ability to manage their health and cope with the life-changing events of chronic illness.

The second theme is *invisibility*. People with chronic pain often have no outward medical signs that legitimize their claim and communicate their situation to others. Unlike someone using a wheelchair or with a paralysis, people with pain cannot rely on others’ observation as a way to communicate the pain experience. A range of communication tools are that much more important because observable physical signs are absent and cannot ‘communicate’ for the individual.

The third theme is that people with chronic pain lead an *unpredictable* life. Chronic pain results in significant social, financial, functional and psychological losses. These losses leave people with chronic pain lacking control over many aspects of their lives. Often attempts to regain control (for example assertive demands for assistance) are perceived by others as negative behaviors. Limited predictability and limited agreement about the best route forward are characteris-

tics of complex health conditions like chronic pain [29]. For people living with chronic pain this uncertainty is experienced as a confusing 'yo-yo' of attitudes, advice and undesired reactions.

The literature is rich with examples of the consequences of these core themes; the iatrogenic effects of disbelief and communication breakdown, the impact of social marginalization and role loss, fear and avoidant behaviors related to physical activity because of the unpredictable nature of pain. Embedded within each of these consequences are multiple layers of contextual influences. Chronic pain is truly more than the sum of its parts. Each problem is dynamically intermeshed with many other confounding and interacting factors.

Currently we have many of the tools needed to locate and to listen to the patient's voice. We can access the pain experience through our own patients and through on-line resources like DIPEX, and a range of art projects and literature. We have the IASP core curriculum in pain for healthcare providers; we have access to many on-line, public domain educational resources. We have examples of successful initiatives to build upon.

The core themes of the pain experience (doubt, invisibility and unpredictability) are conceptual, not tangible objects. Biomedical healthcare is highly effective, but not for problems that are relational and existential. Gordon and Dahl [1] suggest that continuing to examine what are actually systems' and interactional problems with clinical tools is akin to trying to break the sound barrier by tinkering with a Model-T Ford car. We already have many of the pieces of the pain experience. Our challenge is to appreciate their therapeutic value. 'Brenda's' voice has been with us throughout this chapter and the final word rightly belongs to her.

Box 8: Brenda's story



“So I’ll make an extra effort to, to give them an idea of what it’s like to, you know, walk in my shoes.”

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