

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/335552326>

Exploring the Meanings of Pain: My Pain Story

Chapter · September 2019

DOI: 10.1007/978-3-030-24154-4_1

CITATIONS

2

READS

383

1 author:



Jolitta Belton

11 PUBLICATIONS 60 CITATIONS

SEE PROFILE

Chapter 1

Exploring the Meanings of Pain: My Pain Story



Joletta Belton

Abstract First-person narratives of the lived experience of pain, and the meanings of that experience, are uncommon, especially from persons who are not also clinicians or researchers. Yet such narratives could be particularly useful in understanding pain. First-person accounts, stories of pain, can lend unique insights into the lived experience of pain, how individuals make meaning of it, how they come to those meanings, and how those meanings can change over time. Such narratives could lead to new areas of inquiry and explorations of new possible treatment paths. This chapter provides such a narrative, offering a glimpse into one person's lived experience of pain and its meanings. It demonstrates how our individual narratives, our stories, help us make sense of our experiences, including pain. It demonstrates how our narratives can change over time as new information and understandings lead to new meanings, and how such changing narratives and meanings can be a part of a therapeutic process that can lead to better outcomes for patients and clinicians alike.

Clinical Implications: This chapter provides a first-person account of the lived experience of pain and recovery. It explores the meanings of pain, how they came to be, and how those meanings change over the course of time, from early onset of pain through worsening, unexplained pain to recovery from pain.

Keywords Lived experience · Pain · Chronic pain · Narrative · First-person phenomenology · Meanings of pain · Patient experience · Recovery · Healing

1 Introduction

What are the meanings of pain? It is a question that has been asked by researchers and clinicians, philosophers and poets, for centuries. A question that is no doubt asked by many of the millions of people who live with pain. It is an incredibly

J. Belton (✉)
Endless Possibilities Initiative, Fraser, CO, USA
e-mail: Jo@epicolorado.org; <http://www.mycuppajo.com/>

© Springer Nature Switzerland AG 2019
S. van Rysewyk (ed.), *Meanings of Pain*,
https://doi.org/10.1007/978-3-030-24154-4_1

1

difficult question to answer. The meanings of pain are deeply personal, yet also shared. They change over time, within individuals and within cultures [1]. Just as the meanings of pain are ever-changing, the experience of pain is ever-changing, too. Perhaps that is one and the same thing. Pain changes from day-to-day, moment-to-moment, year-to-year. It has a different character in different contexts, yet also stays the same, one of pain's many paradoxes [2]. Pain is certainly not just a sensation, not just a symptom, not any one "thing" to be objectified at all [3]. Pain is *lived* rather than known, *experienced* rather than felt or thought about. We *have* pain, taking ownership of it in unique ways. We rarely, if ever, say we have joy, have love, have fear. Pain takes ownership of us as well. It disrupts our lives [4], destabilizes our worlds [2], threatens our identities, our futures. . .our very existence [5–7]. Pain is the unmaking of the world [8].

This chapter reflects what my pain has meant to me over the years, my own changing meanings. From the early days, when I first felt a twinge in my hip stepping off a fire engine on a routine call at work, to the ongoing worsening pain that unexpectedly ensued, to seeking care and failing treatments, and to an eventual path to recovery. It's a story of darkness and despair, of not being understood and not understanding, as well as one of light and hope, of connection and making sense of things.

To be clear, when I say "my pain" I mean very specifically the pain I felt in my right hip for many years, not the many pains that came before, the pains that came during, or the pains that have come since. I've never referred to the other pain I've experienced as "my pain." That in itself is interesting. I don't know exactly when it became "my pain." I suspect it did so when it didn't resolve as all the other pains have, when it became *chronic*. There was no distinct demarcation between acute and chronic pain, though. It was the same pain, just continuing on for longer than it *should* have [6]. This pain, *my pain*, was different. I suspect some of the difference lies within the meanings associated with it, the meanings I explore in this chapter.

I could not explore these meanings without help. There are references and quotations throughout this chapter from researchers, clinicians, writers, and fellow humans who've lived with pain whose words and work have helped me give voice to what has oftentimes been inexpressible. There are many more whose works and guidance have influenced me in immeasurable ways and have helped me to make sense of things but are not referenced here. To all of them I extend my deepest gratitude.

2 My Pain Story

My pain started during a routine call, a medical aid in the middle of the night. My crew and I had transported a patient to the hospital and were about to pull away when I realized I'd left my clipboard in the emergency room. I'd stepped off fire engines thousands of times over the course of my career as a firefighter paramedic without incident but, this one time, I missed the step and felt a twinge in my hip. Just a

twinge. Little did I know that the missed step would land me on a path of ongoing, worsening pain that didn't make sense. That this small twinge would lead to a downward spiral into a darkening abyss of despair, hopelessness, and loss. Of pain and suffering, of isolation and withdrawal from the people, places, and experiences that mattered to me. That made me *me*.

I was lost. If you'd asked me to define myself before this pain set in, I would have answered: "I'm a firefighter." To me that encapsulated all that I was. Strong, fit, capable. A badass. A hero. A firefighter.

And then, one day, I wasn't.

The pain eventually led to my medical retirement. With the loss of my identity, I also lost my purpose and self-worth, my way of being in the world and of relating to the world. I lost my social roles, my hobbies, my meaningful activities. I was no longer a runner, a weightlifter, a medic, an athlete. No longer a firefighter. No longer *me*. The world disappeared, my horizon of meaningfulness diminished until nothing, but the pain remained [7, p. 116]. Pain became everything. I became pain.

That story, my story, is not found in my medical record. When I look through my years of paperwork, reports by numerous physicians, clinicians, and claims adjusters, my experience is nowhere to be found. In its place are lists of symptoms and limitations, iterations of a hip injury history, myriad (and sometimes conflicting) labels and diagnoses, and a litany of failed treatments. My pain is nowhere in there. My losses, my grief. My suffering glossed over or missing altogether.

My record says things like "pleasant thin female," "still has discomfort with sitting." It doesn't say "distressed and worried human being who hasn't been able to sit for over 2 years, which has wholly altered her life and her person." No sitting meant no driving a car, no meeting friends for coffee or dinners out, no socializing or visiting family, no trips to the grocery store, no watching a movie on the couch with my husband. No work. No play. No life.

It is noted in the pages of my medical record that I was forced to medically retire from my career, but there are no notes on how medical retirement meant losing the identity that had defined me. How with it I lost my sense of worth and purpose. How I lost my friends, financial security, and future. How I had lost a drastic amount of weight and was no longer recognizable to myself, my family, my friends. I was not "pleasantly thin," I was *terrifyingly* thin. Firefighters I had trained and worked alongside for years were shocked when they saw me, they thought I was dying. Their shock, the shock of all of this experience for me, is not in my paperwork. What pain meant to me, what it meant for my life, for my future, was not documented.

My medical history tells the story of a pained and troublesome hip that didn't play by the biomedical rules. A hip that didn't respond to treatments as expected. It only tells the story of a hip. I write this story to right that story.

3 Meanings When Nothing Made Sense

Pain as Assault on the Self [6] “The whole life and personal identity of the person in pain becomes strangely alien and foreign” [7, p. 121]. Pain changes everything. Especially pain that goes on beyond when it should have ended and for which there is no explanation, no reason. It changes us. We are not ourselves. By far the most profound aspect of my pain experience was losing my sense of who I was, my sense of worth and purpose, of *thereness*. I lost my identity, my place in the world. The person looking back at me in the mirror was unrecognizable, unknowable. Small, frail, weak. Broken. An imposter [4]. A stranger I could not accept as *me* [6].

The real me had been hijacked by a foreign invader named pain. The enemy. My body the traitor that had betrayed me [9]. My hip, my whole leg, no longer felt like mine. It felt *other*. Alien [7]. My body, my identity, my life all became so strange and foreign. A landscape I could not navigate, for which I had no map, no direction, no guiding light to show me the way forward. I withdrew from the world, becoming disconnected from all the things that mattered to me. The people, places, and experiences that had given me a sense of purpose and worth, that had made my life meaningful. I was like a hurt animal, withdrawing into the shell of my former self to seek some sort of protection and safety, to try and make sense of all that seemed so insensible.

David Biro [10, p. 18] wrote that “pain is an all-consuming internal experience that threatens to destroy everything but itself—family, friends, language, the world, one’s thoughts, and ultimately even one’s self.” It is not the integrity of our tissues that is threatened by pain, it is our integrity as persons, our continued existence, our very being, that is threatened [5].

Searching for Answers When the twinge didn’t go away, when it persisted, when it morphed into ongoing pain that never let up, the need for a diagnosis, for an answer, became more and more urgent. This pain that did not get better, this threat to my very being and way of life, needed an explanation. Perhaps more pressing, it needed a solution. I wanted the pain, which I vaguely conceived of as some sort of injury, some mechanistic problem, some parts of the machine not working right, to be found and fixed [11]. It seemed so simple. Just a matter of finding the fault and fixing it. Just a matter of getting the machine back up and running.

Turned out it wasn’t so simple. Despite all sorts of faults being found over the years, the pain was never fixed. The faults found differed between professions and clinicians, and clinicians within professions, based on the particular lens of education, training, and biases through which they viewed my hip and my pain. All sorts of fixes were tried: medications, physical therapy, injections, surgery, chiropractic care, acupuncture. . .but I failed them all.

Those years were a roller coaster ride of relief and high hopes when I would be told *this* is the reason you have pain and *this* treatment will fix it, followed by the depths of despair when treatment after treatment didn’t work. When my pain persisted, or worse, got worse. Despite my diligence, my adherence to every plan, despite my motivation to recover and get back to work, get back to my life, get back

to being me, I failed to get better. And to be certain, it was *I* who failed. *We* fail treatments, they do not fail us [11].

It was devastating. All those years, all those treatments, all those failures. And I still I had no explanation for my pain. No solution. No way forward.

Shame After years of searching for answers and failing treatments, the only conclusion to be drawn was that there was nothing *really* wrong with my hip. The damage had been repaired by surgery, my anatomy was fixed. There were no more faults to be found and corrected, we'd run out of plausible possibilities. If there was nothing *really* wrong with my hip, then naturally there had to be something really wrong with *me*. In the absence of a disordered spine, it must be a disordered mind [4, p. 231].

My self-blame rose exponentially.

And I was ashamed. So ashamed. Ashamed of my pain. Ashamed of my failures. Ashamed I didn't get better when I *should* have. Ashamed I wasn't handling it all better. Ashamed of the person I'd become, this broken, useless, *weak* person. I was ashamed I had let my fellow firefighters down. Ashamed I'd let my family and friends down. Ashamed I'd let my health professionals down, too. People I liked very much, people I trusted. People I wanted to tell their treatments were working, even when they weren't.

I was especially ashamed I'd let my husband down. Ashamed I was no longer the person he fell in love with, no longer the person he married. Ashamed I was no longer even present, as I was wholly focused on the pain. Pain that demanded all of my attention, used up all of my resources, and consumed all of my thoughts until there was no room for anything else.

Pain Is in Everything [7] "The pain of a small and particular thing. . .can totalize itself. The specific pain diffuses like a malignant mist throughout the experienced world" [2, p. 255]. Pain is lived. Experienced. Not just felt or sensed or thought about. Lived. When it sticks around long enough, pain imbues every aspect of our being, coloring every thought, every emotion, every moment, every story. Pain is in everything, a total experience [7, p. 117]. It becomes the mist through which we see the world, the medium in which we live out our lives.

Every decision in my life became centered around pain. Believing that pain meant damage meant that every painful step, every painful moment, meant more damage, more harm. That meant nothing could be done without forethought, no matter how minute the task. What used to be thoughtless and easeful now required extensive planning and effort. Every movement, every posture, from sitting to standing to walking to getting out of bed. So much work to just lie down, sit, take a step. In anticipation of pain and making things worse, doing more harm, I was constantly bracing, tensing, guarding, protecting, which only increased my pain. When the pain increased, so, too, my vigilance and focus on the pain, which only served to increase my worry and anxiety, which of course only increased the bracing, tension, guarding, and protection that increased my pain. . .and so on and so on and so on.

Worry “Pain is an ideal habitat for worry to flourish” [12, p. 234]. My worry certainly flourished, fertilized by years of unclear diagnoses and failed treatments. It was also fertilized by the language of healthcare. Words like “dysfunctional,” “weak,” “unstable,” “imbalanced,” “torn,” “out-of-alignment,” “degenerating,” “injured,” “failed.” Words repeated so often they became my own, a part of my belief system about myself, about what I could and could not do. I still remember all of the NOs in my workers’ compensation paperwork: no running, no lifting, no squatting, no climbing, no awkward positions, no sitting for more than 20 min. . . no no no. Words that came to define me, not just my pain.

After failing all the treatments all I was left with were these labels, these limitations, and nothing to do about them. I was worried I was never going to get better, that things would never change. I was worried about the future, that all it held in store was pain and suffering. I was worried about my relationship with my husband, our financial security, our future together. I was worried I was never going to be able to fix this pain that had caused all this worry. Worried that this was as good as it was going to get.

Ending the Search [9] Three years after the twinge, two years after surgery, I was declared permanent and stationary. A medico-legal decree that my condition had plateaued and there was nothing more to be done. A decree that I was never going to get better. That this was, in fact, as good as it was going to get.

“There’s nothing more we can do.” A statement so freely said with no acknowledgement whatsoever of what that means to those of us receiving the sentence. And a sentence it is. We often hear those words when we’re at our lowest point. When we’ve desperately searched for answers yet still don’t understand our pain. When we’ve failed every treatment. When we are no longer ourselves and the future seems so dark and despairing. When we don’t feel heard, seen, or understood. When it seems no one is listening, and we wonder if they ever were [13]. When we have lost so much and are suffering so greatly.

“At first it was a heavy sense of loss and sorrow, wherein I could distinguish little else. By imperceptible degrees, it became a hopeless consciousness of all that I had lost—love, friendship, interest; of all that had been shattered. . . the whole airy castle of my life; of all that I remained—a ruined blank and waste, lying wide around me, unbroken to the dark horizon.” David Copperfield, Charles Dickens.

After years of searching for the biomedical fix to my pain and failing miserably, after hitting rock bottom, my life a ruined blank and waste, there was nothing more to be done. The only choice left to me was to withdraw from the healthcare system altogether [14]. As dismal as that seemed, it actually led me to a different path forward.

4 Changing Meanings, Making Sense

Reconceptualizing Pain “When will this pain go away and real life recommence?” [2, p. 6] During those worst years of my pain, those years of searching in vain for answers, of losing my identity, of shame and blame and worry, my life had been on hold [15]. The pained life I was living was somehow not my *real* life, just as I was not the *real* me. My real life would only recommence once my pain was sorted out, fixed, gone.

It never occurred to me during that time that I *was* living my real life. That it *was* the real me. What a terrible thing to think at the time. It being my real life, the real me, only became possible when my pain came to mean something different. Only then was it acceptable.

My way forward was through science and stories that helped me make sense of my experiences and enabled me to reconceptualize my pain and myself with pain. Three years to the day of the twinge I medically retired from the fire department, having worked in a civilian position after my failed surgery prevented me from going back to work as a firefighter. In the months prior to my retirement (much earlier than I’d ever expected or wanted), I started graduate school to earn my Master of Science in human movement, hoping to discover the structural or biomechanical explanation for my pain, and what to do about it, that everyone else had missed. I was still searching for *the* fix, so I chose pain science as my research focus. It should come as no surprise that my search did not turn out how I expected and instead challenged the notion that there was a singular cause, a singular fix, to be found for my pain at all.

Rather than the fix what I found was validation. Legitimacy. Understanding. When I learned that pain is a complex, emergent experience underpinned by biology and influenced by myriad psychological, social, and cultural factors, I finally felt like my pain was validated. Finally felt like my pain was *real*. With real, credible, scientific explanations for it. My pain was not just “all in my head,” not exaggerated, not made-up, not my fault. I was not crazy, not a malinger. Not just weak of mind, body, or character. It was an immense relief. A burden was lifted. I wasn’t to blame for my pain. At the same time I felt I could take responsibility for how I moved forward, that I had the capacity and ability to do so.

When I learned just how relevant our thoughts, emotions, beliefs, and expectations are to our experience of pain, how influential our relationships, cultures, environments, the language we use and hear, the stories we tell about ourselves to ourselves and to others [16], I finally felt like I could *do* something. We are ever-changing beings, after all. Adaptable, resilient. Bioplastic [17]. Our biology constantly changing in response to our environment, our internal and external contexts, our new and repeated experiences, until our very last breath [16–18]. I felt empowered for the first time in a long time. Not so helpless and hopeless. There was realistic hope for change.

Embracing Uncertainty I also came to recognize the inherent uncertainty in understanding pain in all its complexity. One might expect that to be disheartening, but instead it lifted some of the weight of blame and shame of all my failed

treatments off my shoulders, and off the shoulders of others. It lightened the load. We don't know all there is to know, and that is ok. It is better to embrace uncertainty than give people false hope that their pain is X and Y will fix it. When the explanations do not explain, and the fixes do not fix, the meanings of our pain become ever more threatening, carry ever more weight, bear even more consequences.

Honesty can still be hopeful. There is always something that can be done. We can always tell a better story. A story that makes biographical and biological sense and tells a better account of reality than the current one [19]. A story that helps us reconcile our pained selves with our real selves, so we are whole once again. Ourselves again.

Other Ways of Knowing “Art and science are alike in their quest to reveal the world” [20, p. 41]. The seeds planted by the science of pain had to be fertilized with things outside the realm of the scientific literature, too. To rediscover my place in the world, to feel I belonged in that world, I needed writers, poets, and songwriters, people who've long been trying to tell the truth of the human experience, to help me make sense of things. Many of my truths were found on the pages of nineteenth century literature and in the stories of Stephen King. I saw my pain, my suffering, myself, in song lyrics, poems, and movies. Countless stories helped me to see I was not alone, not aberrant, not an outlier. That I was connected to our collective human experience [11, 21]. Placing my pain, myself, into the larger context of humanity helped ease my suffering. Reading literature, something I had abandoned in my years of pain, opened the door to creative thinking again. To curiosity and reflection. To possibility.

Through science I began to make sense of my pain. Through stories I began to make sense of my life, of myself, with pain.

Mitigating Threat Understanding that pain was not a damage meter, that it was not a direct reflection of the state of my tissues [16], meant pain was no longer such a threat to my future, to my being, to my very existence. My life no longer had to be on hold until I was rid of it. When the meanings of pain became less threatening, less sinister, less despairing, the sensations I felt in my hip—the thunks, clunks, and shifts, the tightness and weirdness—no longer meant there was *something really wrong in there*. They were just sensations in my hip. Sensations I could interpret differently. I could notice the sensations without fear, without so much worry, without having to attend to my hip so vigilantly. They were just weird, different. I also didn't have to pretend they weren't there, didn't have to pretend that pain wasn't there. Pain was no longer the enemy, my body no longer a traitor. I could respect pain without fearing it. I could acknowledge my pain and still get on with living.

Reconnecting No longer laden with a sense of impending destruction, with the threats abated, I was no longer at war with my pain and my body, which meant I finally had the capacity to focus on things other than the pain. When pain wasn't so threatening, I could make space for it, which meant there was room for everything

else. For all of the things that mattered to me. The people, places, and experiences that gave my life meaning, that made me feel like me.

Reconnecting with nature was one of those things, and something else I had withdrawn from in my pain. While literature opened the door onto the world again, venturing back outside made it literal. No longer so worried that I was doing harm to myself with each painful step, I could more easefully exist in the world. I didn't have to plan every movement, every moment. I was free. No longer a prisoner in my home, no longer so wholly inside my hip and my head, no longer a prisoner of pain, I saw the world again, as though for the first time. I started taking pictures, literally seeing the world through a different lens and with a fresh perspective. It was a revelation. The world was still out there, in all its mystery and wonder, despite my absence from it for so long. I felt insignificant in the best possible way. A part of something much larger than myself, much larger than my pain.

"I came one evening before sunset, down into a valley, where I was to rest. . . I think some long-unwonted sense of beauty and tranquility, some softening influence awakened by its peace, moved faintly in my breast. I remember pausing once, with a kind of sorrow that was not all oppressive, not quite despairing. I remember almost hoping that some better change was possible within me." David Copperfield, Charles Dickens.

5 New Meanings, Sense Made

Myself Again Some better change was possible within me. Things did change. My life changed, my pain changed. I changed. I found myself again. Perhaps I found myself for the first time. I regained my sense of worth, of value. I became whole once again, no longer broken, frail, weak. No longer disregarded. I was whole. Strong, adaptable, resilient. Kind and caring, loved and loving. I was *me*.

It took a long time for me to realize I hadn't been who I was because I had been a firefighter. That I had been a firefighter because of who I was. The more I (re)discovered and (re)engaged with my values, the less worry and attention I paid to my pain. The more I engaged with the things that gave my life purpose and meaning, the bigger my life became, and the smaller the pain relative to that bigger life. The pain wasn't gone, it was just no longer the center of everything. And that was everything.

Acceptance I could finally accept pain as a part of my story, a part of my human experience, a part of me. I could finally accept what had happened, accept my pain, accept all the changes that had taken place, all the suffering that was endured, all the darkness and the chaos, because it didn't mean accepting it as my future, too. There was so much more to my life, to me, than pain. So much more to my story. And there was so much yet to be written.

A Better Story We are the stories we tell ourselves, and our selves are also "being formed in what is told" [22, p. 55]. Our stories shape our understanding of our experiences. They reflect what we've gone through and help us create what is yet to

come. For a long time, I told a dark and dismal story. A story of pain, loss, and despair. Of brokenness. And that was the story I lived. But stories can change. The story I tell of my pain now is much different than the story I told seven years ago, or four, or just last year. It is a changing narrative, which affords the possibility of telling a better story in each retelling [21].

Removed from the chaos, removed from the constant threat of pain, I now see my experience as a quest [22]. One that led me down a path of pain and suffering, but also down a path of learning, discovery, and growth, of light, hope, and possibility. A path that led to a better understanding of myself and of others. Of being kinder and more compassionate. Of being more grateful for what I have rather than focusing so much on what I've lost. It was also a path that forced me to be more creative, to find the ways of engaging with my values that work within my limitations, while also gently challenging those boundaries from time to time to be sure I am not limiting myself unnecessarily. I did not know I was on this quest along the way, I can only see it now that I've gotten to this point along the path [22].

Patience and Persistence None of this happened overnight. It was a gradual process over the course of years. It took time for cognitive shifts to become behavioral shifts to become biological shifts. It wasn't linear. There was no step-by-step process. And there were setbacks. As I came to new understandings, new ways of thinking and being, I came to experience moments of *not-being-in-pain* [2]. When you are in pain for many years, not-being-in-pain, even for just a few moments, is a revelation (if a bit of an untrusted one). What was surprising was that no matter how brief the not-being-in-pain lasted, when the pain came back it would often derail me. It would bring back the old fears, old worries, and the oh-too-familiar despair. It was as though I utterly forgot what the years of being in ongoing, debilitating pain had been like. And once back in pain, or during a flare-up, it would be as though I'd never had any moments of not-being-in-pain. I'd once again feel I was sentenced to a lifetime of pain and suffering and misery.

This happened repeatedly, even with all that I had come to know, come to understand, come to believe. I had to keep coming back to what I knew, keep telling myself a new and better story about my pain, keep repeating a more therapeutic narrative rather than reverting back to the old, familiar, confining story of pain, disability, and lost identity I lived for so many years [3]. Over time, with a bit of courage and a whole lot of patience and persistence, the new and better story won out.

Clinicians and Meaning Making “One need not attain full physical recovery in order to heal” [2, p. 15]. When I was in the depths of my pain, nothing made sense, there was no meaning, no end to my suffering in sight. It was chaos, there was no cohesive story to be told [22]. We seek care to make sense of the things, to bring order to the chaos, to end our suffering. We seek care because we are not equipped to handle what we are going through on our own. Howard Brody [21, p. 85] wrote that when we seek treatment we are really saying:

“Something is happening to me that seems abnormal, and either I cannot think of a story that will explain it, or the only story I can think of is very frightening. Can

you help me to tell a better story, one that will cause me less distress, about this experience?” Or, if you prefer, “my story is broken; can you help me fix it?”

Tell Me Your Story A couple years ago I started having pain in my left hip, my “good” hip. Without realizing it, I’d gradually begun to limit my life again, not doing things some of the things I loved doing, planning my movements, holding rigid postures. I started reverting back to the pained me, but it was a slow reversion, so I could readily rationalize it all. It so happened that about seven months into this new pain I was a patient demo for physical therapist and researcher, Peter O’Sullivan, at the 2017 San Diego Pain Summit. At the start of the demonstration he asked me to tell him my story, to start wherever I’d like. Surprisingly, to myself at least, I didn’t start with what was going on in my left hip. Instead I went all the way back to seven years before when I’d stepped off the fire engine and felt the twinge, despite my right hip not even bothering at the time.

I teared up, realizing in the telling of my story how afraid I was of going back to that time. Back to the beginning of this long and often treacherous path through ongoing, worsening pain that had ended the career that had defined me and had taken so much. I had rebuilt my life. I was volunteering as an adaptive snowboard coach for people with disabilities, running a non-profit I co-founded to empower people living with pain to live well, writing my blog, traveling, spending time with family and friends. I could drive again, sit on furniture, go out for dinner or a coffee, the simple things I vowed never to take for granted ever again. And I was terrified, deep in my biology if not my consciousness, that I was going to lose it all again. That pain would become everything once more.

It was a profound moment. I hadn’t given voice to those worries, those fears, before I was asked to tell my story. Not even to myself. Even with all that I knew, even with years of having lived with pain and studied pain and worked through pain, I still needed help making sense of this new pain, this new challenge. I still needed help connecting the dots and putting this experience into a more comprehensive context, so I could come to my own conclusions and new understandings and tell a better story about this pain. One that made biographical and biological sense and put things in perspective.

Stories in the Clinical Encounter Stories are always told in the clinical encounter, whether we think they are or not. The stories told are often of a biomedical sort, the health care professional seen as the expert and the “only voice that counts” [11, p. 227]. The story tends to be one of faults that have been found with their litany of labels, accompanied by myriad diagnoses or, perhaps worse, ruled-out diagnoses. We are told everything that is wrong with us, or that there is nothing *really* wrong with us at all. We’re told what’s to be done, or that nothing can be done, and then the story ends.

It’s often not a very good story. Not a very helpful or healing story. These biomedical stories are told to us about us, but we are nowhere to be found in their telling. Too often, the character most egregiously missing in these stories is the person in pain. It is the story of an elbow [23] or of a hip. We are depersonalized

and thus dehumanized, our stories too often treated as superfluous, a waste of precious time, rather than as a valuable form of knowledge that could, and should, inform the treatment plan and path forward [21, 24].

We are not machines to be fixed, not problems to be solved. We are human beings in need of compassion and understanding, guidance and support. We need help to make sense of what is happening and to determine how best to move forward with what we learn from one another. Our stories can lead to greater understanding of not just *our* pain, but to a greater understanding of pain. Within the shared humanity between patient and clinician, with all the inherent uncertainty and all of our human fallibility and vulnerability, there can be crafted therapeutic narratives that provide credible explanations for the patient's pain as well as realistic paths forward for them. It is their story, after all. The story they will live outside the clinic walls.

Love and Be Loved The other profound moment along my journey occurred the year after my medical retirement. I interviewed neuroscientist and physical therapist Lorimer Moseley while in graduate school for a project. I grilled him for 45 minutes on pain science, still believing my answer, *the* answer, would be in there somewhere. That I would discover just what I needed to do to be rid of this pain that had so altered myself and my life. At the end of the interview I asked him what the one thing he'd want people in chronic pain to know or to do. His response was to love and be loved.

To love and be loved.

I was floored. There are few moments in our lives that truly change the course of things, and that was one of those moments for me. It was in that moment I saw a different possible future. It was what helped me to reframe the problem to be solved [12]. It was the light I needed to guide the way, the nudge I needed to reconceptualize my pain and see a different path forward. A path not so focused on being rid of pain and was instead focused on getting back to the things that mattered to me, that meant something, that made my life worth living. It was what helped shift my perspective, what opened the door onto better possible futures and future selves, what made my recovery possible.

The two most profound things said to me by clinicians were "tell me your story" and "love and be loved." Not what most would expect and not what I knew I needed to hear until I heard them. Even more important for this discussion, though, is that in both of these instances they listened to my story and we had a conversation. I felt heard, believed, and validated, which confirmed my worth as a human being and that what I said was of value. That I was of value. That cannot be overstated. When we are in the depths of our pain, when we feel invisible and disregarded, when we do not like who we've become, it can be really hard to see our worth, our value. Our own humanity.

6 Conclusion

I started this chapter saying my pain story started with a step off a fire engine. Truth is, my pain story started long before that. We each come to every experience of pain with a lifetime of learning, memories, and beliefs. A lifetime of knowledge, societal and cultural influences, and experiences. A lifetime of illnesses, injuries and recoveries, thoughts, emotions, and expectations. We each come to every episode of pain with biological and philosophical foundations uniquely our own. With pasts and plans for the future that affect our present. With a sense of who we are and who we will continue to be.

Pain disrupts all of that. Disrupts all that seems so certain and true. All that we thought we knew.

My medical record tells the story of a hip with pain, but my hip did not feel pain. My hip did not make meaning of pain. My tissues, while certainly playing a role in my experience, did not have any experience at all. I did. Just me. Yet while it was only I who felt the pain, it wasn't just I who felt its effects. Pain affected those around me, too. My employers and co-workers, my friends and family, even strangers on the street I may have been curt and unkind to when my pain was overwhelming. Pain most affected my husband and dog as our lives together were completely upended. Pain changed everything. It changed me. The changes were unasked for and unwanted, the person I'd become unwelcome. It was not the present my past was supposed to lead up to [22, p. 55] and none of it made any sense.

Gratefully, it was in making sense of my experience, through science and stories, through the help of many guides within and without the health care system, that the threat was abated, that my suffering ended, that life resumed. That I was *me* again. A changed me but still me. A self I could accept, a self I wanted to be. My experience of pain and all that it wrought can now be placed in a wider context, a broader narrative. I can now tell a better story. A more cohesive story, with a cohesive self [25] at its center.

I've found my place in the world again.

As much as I've written about my pain over the years, I've learned so much in writing this chapter. It forced me to explore the meanings of my pain over time, which meant having to go back to those dark years and remember as best I could. It forced me to highlight meanings I thought were most salient, and the changing meanings that were most relevant. It made me think about my recovery as well. What got me to where I am today, what might have gotten me here sooner. Lous Hesusius [26] wrote in her book, *Experiencing Chronic Pain in Society*, that all she ever wanted was someone to listen. It seems a sensible place to start to revolutionize our understanding of pain and our approaches to pain research and treatment. Listen. Hear us. Hear our stories.

When we feel listened to, heard, validated, and understood, it makes all the rest of it possible. It allows us to explore what our experience means and discover new possibilities. When we are in the depths of pain and our personhood is sustained by the personhood of others, we have a chance to recover from our suffering [5]. When

we hear words that promote healing [21], that emphasize our strengths, courage, and persistence, our resilience and adaptability, we have a better chance at better outcomes. When we share power with our health care team, when we jointly construct narratives that make biological and biographical sense, we can tell, we can live, better stories. Stories where we are an agent in our own rescue [27]. Stories where we are the heroes of our tale.

When we can fix our broken stories we can heal, even if we are not cured.

References

1. Bourke J. *The story of pain: from prayer to painkillers*. Oxford: Oxford University Press; 2014. 396 p.
2. Leder D. The experiential paradoxes of pain. *J Med Philos*. 2016;41(5):444–60.
3. Morris DB. Narrative and pain: toward an integrative approach. In: Moore RJ, editor. *Handbook of pain and palliative care*. New York: Springer; 2013. p. 733–51.
4. Bunzli S, Smith A, Schütze R, O’Sullivan P. The lived experience of pain-related fear in people with chronic low back pain. In: van Rysewyk S, editor. *Meanings of pain*. Cham: Springer; 2016. p. 227–50.
5. Cassel EJ. The nature of suffering and the goals of medicine. *N Engl J Med*. 1982;306(11):639–45.
6. Smith JA, Osborn M. Pain as an assault on the self: an interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychol Health*. 2007;22(5):517–34.
7. Svenaeus F. The phenomenology of chronic pain: embodiment and alienation. *Cont Philos Rev*. 2015;48:107–22.
8. Scarry E. *The body in pain: the making and the unmaking of the world*. New York: Oxford University Press; 1985. 400 p.
9. Toye F, Seers K, Hannink E, Barker K. A mega-ethnography of eleven qualitative evidence syntheses exploring the experience of living with chronic non-malignant pain. *BMC Med Res Methodol*. 2017;17:116.
10. Biro D. *Listening to pain: finding words, compassion, and relief*. New York: WW Norton; 2011. 256 p.
11. Loftus S. Pain and its metaphors: a dialogical approach. *J Med Humanit*. 2011;32:213–30.
12. Eccleston C, Crombez G. Worry and chronic pain: a misdirected problem solving model. *Pain*. 2007;132(3):233–6.
13. Thacker MA, Moseley GL. First person neuroscience and the understanding of pain. *Med J Aust*. 2012;196(6):410–1.
14. McGowan L, Luker K, Creed F, Chew-Graham CA. How do you explain a pain that can’t be seen? The narratives of women with chronic pelvic pain and their disengagement with the diagnostic cycle. *Br J Health Psychol*. 2007;12(2):261–74.
15. Bunzli S, Watkins R, Smith A, Schütze R, O’Sullivan P. Lives on hold: a qualitative synthesis exploring the experience of chronic low-back pain. *Clin J Pain*. 2013;29(10):907–16.
16. Butler DS, Moseley GL. *Explain pain*. 2nd ed. Adelaide: NOI Publications; 2013. 133 p.
17. Moseley GL, Butler DS. *The explain pain handbook: protectometer*. Adelaide: NOI Publications; 2015. 49 p.
18. Doidge N. *The brain that changes itself: stories of personal triumph from the frontiers of brain science*. New York: Penguin Books; 2007. 427 p.
19. Launer J. *Narrative-based practice in health and social care: conversations inviting change*. 2nd ed. Abingdon: Routledge; 2018. 164 p.

20. Banville J. Beauty, charm, and strangeness: science as metaphor. *Science*. 1998;281(5373):40–1.
21. Brody H. “My story is broken; can you help me fix it?” Medical ethics and the joint construction of narrative. *Lit Med*. 1994;13(1):79–92.
22. Frank F. *The wounded storyteller: body, illness, and ethics*. 2nd ed. Chicago: The University of Chicago Press; 2013. 279 p.
23. van Rysewyk S. A call for study on the meanings of pain. In: van Rysewyk S, editor. *Meanings of pain*. Cham: Springer; 2016. p. 1–22.
24. Charon R. Narrative and medicine. *N Engl J Med*. 2004;350(9):862–4.
25. Thompson BL. Making sense: regaining self-coherence. In: van Rysewyk S, editor. *Meanings of pain*. Cham: Springer; 2016. p. 309–24.
26. Heshusius L. *Experiencing chronic pain in society*. Arroyo Grande: CreateSpace Independent Publishing Platform; 2017. 272 p.
27. van der Kolk B. *The body keeps the score: mind, brain and body in the transformation of trauma*. New York: Penguin Books; 2014. 445 p.