

All in
Your
Head

Making Sense of
Pediatric Pain



Mara Buchbinder

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for Simon Joseph

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The dissertation on which this book is based was dedicated to my beloved grandfather, Simeon Joseph Bogin, who passed away weeks after I filed, a few months short of his hundredth birthday. I dedicate this book to his namesake, Simon Joseph Summers, who arrived a few years later and has thus far honored his great-grandfather’s memory in

every possible way. Thank you, Simon, for filling our home with your boundless curiosity and effervescent laughter, and for giving me a reason to close my laptop and put this project to rest. I hope that you will never know the pain of which these pages tell.

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Acronyms and Initialisms

ACE	angiotensin-converting enzyme
ADD	attention deficit disorder
ADHD	attention deficit/hyperactivity disorder
ASL	American Sign Language
BPD	borderline personality disorder
CAM	complementary and alternative medical (therapies)
CBT	cognitive behavioral therapy
CRPS	chronic regional pain syndrome
DSM	<i>Diagnostic and Statistical Manual of Mental Disorders</i>
EEG	electroencephalogram
EKG	electrocardiogram
FDA	Food and Drug Administration
GATE	Gifted and Talented Education program (California)
GI	gastroenterology
HMO	health maintenance organization
IASP	International Association for the Study of Pain
IBS	irritable bowel syndrome
IT	information technology
MRI	magnetic resonance imaging

OCD	obsessive compulsive disorder
PDD	pervasive developmental disorder
PDD-NOS	pervasive developmental disorder not otherwise specified
RSD	reflex sympathetic dystrophy
SSRI	selective serotonin reuptake inhibitor

Transcription Conventions

- [indicates overlapping speech
- : indicates phonological elongation
- indicates a noticeable and abrupt termination of a word or sound
- , indicates a continuing intonation (not necessarily a grammatical comma)
- . indicates a completing intonation (not necessarily a grammatical period)
- (.) indicates a brief pause
- = indicates that one turn runs into another with no interval
- (xxx) indicates indecipherable content
- (()) indicates nonverbal action

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Introduction

The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry.

—Virginia Woolf, *On Being Ill*

In what sense are my sensations *private*?—Well, only I can know whether I am really in pain; another person can only surmise it.—In one way this is wrong, and in another nonsense.

—Ludwig Wittgenstein, *Philosophical Investigation*

Marian Grindall wiped a tear from her cheek.¹ “I always feel like I’m just right on the edge of tears,” she said apologetically. Silently, I cursed myself for again forgetting to bring tissues. I was sitting with Marian and her husband, Tom, at their kitchen table on a quiet Sunday morning in February. Abundant sunlight streamed in through French doors, glinting off modern silver appliances and softening their weary faces. I listened intently as they explained to me how their seventeen-year-old daughter, Cassandra, their only child, had come down with a mysterious illness in September that had left her bedridden for months with painful headaches and a dizzying nausea. No one had been able to diagnose her problem, and the lengthy illness and futile search for an explanation had taken a toll on the family. Cassandra shut herself in her bedroom for hours on end, which troubled her parents greatly. “When she wants something, she knocks on the wall,” Marian said. “It’s just a battle to even get her to get up out of bed so I can change her sheets.”

Two months later, a team of clinicians sat around a table in a drab, mauve-painted conference room discussing Cassandra's case. Ted Bridgewater, an acupuncturist, had treated her twice, and was very concerned. Usually, patients relax once the acupuncture needles have been inserted, he said, but Cassandra had remained rigid for the duration of the treatment. Moreover, her tongue was swollen, indicating "stuck dampness," and this was not a good sign.² "Part of the problem is that she hasn't bought into us," Ted surmised. Rebecca Hunter, a child and family therapist, was also deeply worried. Her main concern was that Cassandra was convinced that the only way she would get better was if she hid out in her bedroom for three or four weeks. She had cut off all contact with her friends, who served as a reminder that her life was moving on without her. "It's extreme," Rebecca said. "She may end up needing inpatient treatment." Dr. Novak, Cassandra's physician, was alarmed by this suggestion, and resolved to revisit her chart after the meeting so that they could put her case at the top of the list for the next meeting.

Cassandra's case highlights a curious paradox about pain: while it has long been viewed as the quintessential private experience, pain is configured, explained, understood, and even experienced in ways that are deeply relational. Across the humanities and social sciences, scholars have argued that chronic pain is inexpressible, imperceptible, and alienating, and thus essentially unknowable by others. This portrait of pain is poignantly reflected in the image of Cassandra alone in her bedroom, where she remained isolated for weeks on end, cut off from her family and friends. At the same time, however, glimpses of another view of pain emerge in the foregoing scenes. A middle-aged couple tells their daughter's story to a curious anthropologist, and in the telling, convey their own internalization of their daughter's long-term suffering. A group of clinicians meets to discuss a patient's treatment, conveying their care and concern. Without denying that pain is a fundamentally private experience, these two scenes reveal that pain, in some important senses, is also profoundly social.

Phenomenological approaches to pain have flourished in recent years, because pain has been cast as a private experience that shatters language and evades representation.³ And yet, despite the obvious epistemological constraints on apprehending another's internal states, language is what translates pain from the solitary and unknowable to a phenomenon that is richly and excruciatingly described in literature, medicine, and everyday life. *All in Your Head: Making Sense of Pediat-*

ric Pain builds on phenomenological accounts to capture the life-altering dimensions of chronic pain, but situates pain in an intersubjective context to emphasize the relational, everyday means by which it is understood and managed. Through careful attention to the language of pain—including narratives, conversations, models, and metaphors—and detailed analysis of how pain sufferers make meaning through interactions with others, this book reveals that, however private pain may be, making sense of it is deeply social.

In the pages that follow, I draw on ethnographic research that I conducted from 2008 to 2009 in a Southern-California-based multidisciplinary pediatric pain clinic, which I call the West Clinic, to explore how clinicians, adolescent patients, and their families make sense of puzzling symptoms and work to alleviate pain. It is important to state from the outset that this book does not address the embodied experience of pain—what pain *feels* like to those who suffer it—or at least does not do so directly. Several exemplary ethnographies have charted the lived experience of pain in heartrending detail, and I refer interested readers to these works.⁴ My primary goal for this book has been somewhat different: to trace the ways in which chronic pain transcends the individual body through its treatment in the social arena. A related goal for this work has been to attend closely to practitioners' discourse and clinical experiences, which are necessarily orthogonal to the phenomenology of pain, and have received relatively less attention than patient perspectives in the social scientific literature.⁵

Where adult chronic pain patients have inspired long-standing debates about whether American society ought to bear the collective burden of lost work and productivity, there are no general expectations in the contemporary United States that children and adolescents make substantial economic contributions to society. Greater, here, is the moral burden of grappling with children's suffering. Middle-class Americans by and large presume that children are innocent, dependent, and vulnerable, and view children's health as an index of societal well-being.⁶ While the situation is somewhat more complicated for adolescents, for reasons that I explore in this book, they, too, are presumed to require special safeguards and protections. During my fieldwork, parents constantly told me that they felt horrible about being unable to relieve their children's suffering and wished they could bear their children's pain.

It is precisely this vulnerability that makes pediatric pain a rich case for exploring the social embedding of pain. This book focuses specifically on chronic pain during adolescence, a time of great social upheaval