

The Bottom of the Funnel

But the greatest thing by far is to have a command of metaphor. This alone cannot be imparted by another; it is the mark of genius, for to make good metaphors implies an eye for resemblances.

—Aristotle, *Poetics*

If an electrical engineer could look at your neurological wiring, he would see where the problem is.

—Dr. Novak

Suppose that a physician had decided that your pain was *all in your head*. What, exactly, would that mean? When we label pain as “all in your head” beyond merely specifying a physical location where pain is thought to reside, we also draw on the head as a prevailing metaphor for psychological phenomena. In the U.S. context, this metaphor is persuasive because it draws on widely held cultural models proposing that illnesses are *either* mental *or* physical. Because the mind is the province of the imagination, “all in your head” may also suggest that the pain is made up or “unreal,” the invention of a self-defeating mind, or, worse, the fabrication of a malingerer. “All in your head” is thus a powerful metaphor for illness because of the multiple meanings that it crystallizes and collapses.

In this chapter, I examine the metaphors that clinicians use to explain pain to adolescents and families. In her book *Illness as Metaphor* (1978), the literary critic Susan Sontag famously rejects the notion that serious illness can be understood in terms of metaphor.¹ For Sontag, metaphors stigmatize cancer sufferers by cloaking a terrible disease in an aesthetic veil. Sontag pleaded for society to strip diseases of this symbolic content

and understand them purely in terms of their biomedical meanings.² What Sontag's point misses, however, and what I seek to illustrate here, is that metaphors—*aesthetic or otherwise*—are endemic to biomedical practice itself and foundational to the ways in which practitioners understand and explain bodily processes.³

Here, I highlight in particular the pragmatic function that metaphors serve within clinical explanations. Drawing on interviews I conducted with clinicians on the West Clinic team, as well as other pediatric pain practitioners, I examine a set of metaphors used to present chronic pain as a problem of neural circuitry. Characterizing pain in this way addresses two persistent dilemmas that plague contemporary biomedical understandings of chronic pain: an ambivalent stance toward the role of individual psychology and the elusiveness of concrete causes. Metaphors for neural circuitry reconfigure the relationship between material explanations and biomedical legitimacy by replacing the fruitless search for mechanical dysfunction with a more diffuse model of nerve-signaling difficulties. Neural metaphors thus work to transform intractable pain from an abstract, senseless phenomenon to one that is meaningful, clear, and concrete. In doing so, they bolster the credibility of adolescent chronic pain sufferers, whose legitimacy and moral standing are routinely called into question when biomedical explanations fail.

THE LONG ROAD THERE

Before turning to these metaphors, it is important to say a few words about how families make their way to pediatric pain clinics. Chronic pain patients, including children and adolescents, are often referred to specialized treatment centers months or even years into their diagnostic journey, having seen multiple specialists and undergone scores of inconclusive tests, only to be told that there is nothing wrong, or, worse, that the pain is all in their heads. As Mark Siegel put it the first time we met: "In the past sixty-two weeks I've seen eleven doctors, nine of whom think I'm insane." Dr. Novak referred to the West Clinic as "the bottom of the funnel" because, as Nina Herrera, the clinical coordinator, explained it, "They've been to every pediatric subspecialty clinic; every test has been negative; everything's been cleared."

Most West Clinic patients found their way to the clinic after consulting at least three specialists—typically, gastroenterologists, neurologists, orthopedists, and rheumatologists. To families on a prolonged diagnostic odyssey, testing seems to offer a beacon of hope, a pathway out of

uncertainty, yet in the case of chronic pain, it repeatedly fails to produce the desired result.⁴ One mother referred to this thwarted quest as a journey through the “Bermuda Triangle” of pain, a metaphor that captures the aimlessness and sense of abandonment that many families experience as they search for help. Some disappear into the medical system, feeling rudderless and bewildered.

Mark Siegel’s pathway to the West Clinic exemplifies the circuitous routes that many families take before finding their way to pediatric pain clinics. Mark lived in an affluent community with his mother, Julie, a pharmaceutical sales representative, his father Micah, who worked in marketing, and his younger brother, Noah. Mark’s pain began after a boogie-boarding accident in August 2007, when he was thirteen, that cracked the growth plate in his left elbow. When the pain did not let up, Julie took Mark to an orthopedist, who diagnosed the fracture and put the arm in a cast. This was the third break to Mark’s left arm: when he was six, he had fallen jumping off a jungle gym at school and broken the ulna and radius, and six months later, he had tripped and broken the same arm again. This history was significant because chronic regional pain syndrome (CRPS), the diagnosis that Mark eventually received, often occurs at the site of repeat injuries.

From the beginning of the latest injury, Mark was extremely uncomfortable. During the first nine weeks, the orthopedist changed the cast several times due to swelling, until he finally removed it for good. After that, Mark received physical therapy three times a week for ten weeks, but he remained highly sensitive to pain, and his physical therapist came to suspect that the arm had not entirely healed. However, when Mark returned to the orthopedist for further X-rays, no fractures were identified. The orthopedist encouraged the Siegels to “toughen up” on Mark, speculating that the pain would fade as he became more active. By February, his arm had still not improved, and he was complaining of pain more often. Julie brought him to two physiatrists, who recommended laser therapy, which Mark underwent twice weekly for five months to no avail.

Mark returned to his pediatrician, who referred him to a neurologist, Dr. Carmine, who finally diagnosed Mark with CRPS. Dr. Carmine ordered an MRI to make sure that Mark had not sustained any nerve damage and prescribed Neurontin, a drug initially developed to treat seizure disorders that is now widely used “off-label” to relieve neuropathic pain.⁵ On Neurontin, Mark felt “loopy” but got no relief. Lyrica, another neuropathic pain agent originally developed for treatment of epilepsy, likewise offered no relief. Nearly a year after Mark’s injury, he returned

to Dr. Carmine for a third time. Now, because the medication trials had failed, she decided that he might be an appropriate candidate for a sympathetic nerve block.⁶ The first nerve block was unsuccessful, and although the radiologist had suggested that it might require several attempts, Mark was reluctant to have a needle inserted into his neck again.

Meanwhile, during his recovery from the nerve block, Mark's blood pressure soared up to 168/82.⁷ Julie brought him back to the pediatrician, who sent them to a cardiologist. The cardiologist ordered an EKG, which was normal, and an echocardiogram, which showed thickening on the left side of Mark's heart. The cardiologist then referred Mark to a nephrologist to rule out renal artery stenosis, a possible cause of high blood pressure in children.⁸ Mark underwent several weeks of testing, but everything came back negative. However, because his blood pressure remained worryingly high, he started taking a low dose of Enalapril, an ACE inhibitor, to lower his blood pressure. Julie and Mark were both convinced that his high blood pressure was related to his pain. Reflecting on this time, Mark said, "At the year mark it made me angry because my doctors have been idiots up to that point, not knowing what the heck is wrong with me. That a city with one million people doesn't have a doctor that can treat this is beyond me." Nevertheless, he believed that his best hope for recovery lay with medical doctors—he had tried alternative treatments such as acupuncture, herbs, and moxa with no success.⁹

When I met the Siegel family several days before Mark's first West Clinic appointment, they had begun to research pain programs and physicians in other parts of the country, afraid that they might have exhausted treatment options in their area. They told me about future plans to travel to a clinic in Northern California and to the Mayo Clinic in Minnesota, which they had put on hold when they found out about the West Clinic. In my experience, such travel was not unusual; several families traveled from out of state and stayed several weeks to have their child treated in the West Clinic. Julie reported that Mark was quite involved in the research process: "He gets on the computer himself, looking for pain specialists, and he's like, 'I gotta find someone that'll get me out of this pain.'"

In the face of Mark's increasing discouragement, Julie stressed the importance of his treatment. She said, "And he knows we keep trying and we keep calling doctors and we keep- you know, we're not giving up. And that's what we do, is we reassure him that we're not giving up. We're gonna try to get him—find him someone to get him the help he needs." For the Siegels, a big component of "not giving up" was finan-

cial: Julie reported that they had spent \$4,300 between August and October alone. Yet Julie's investment was more than just monetary. She spent countless hours on the phone with physicians and pharmaceutical industry colleagues trying to get the best care for Mark. "I'm on the phone with doctors every day! Seeing what I can do. I'm on the Internet. I have not given up," she told me.

For Mark and his family, the West Clinic represented, if not the absolute "end of the road," certainly one of the last stops on a winding journey that included a narrowing range of possible destinations. However, while Dr. Novak's funnel metaphor might create the impression that all children and adolescents with chronic pain will eventually make it to a place like the West Clinic if they spin around long enough, this is not quite accurate. As with most health-care resources in the United States, access to tertiary care medical services such as specialized pediatric pain clinics is stratified according to families' insurance status and ability to pay. The story of fifteen-year-old Crystal Martinez, the first patient that I enrolled in my study, is quite telling in this regard. Although I recruited Crystal after her first appointment in the West Clinic was scheduled, she never actually became a clinic patient, because her Medi-Cal health insurance would not cover her treatment.¹⁰

Crystal's mother, Lucinda, a Guatemalan immigrant and single mother, was exceptionally devoted to providing her two U.S.-born daughters with the best available educational, extracurricular, and travel opportunities. The three lived in a two-bedroom apartment with Lucinda's sister and nephew in a part of town known for high crime rates, where the buildings were more weathered than in the Siegel family's community. A year and a half before we met, Crystal had come home from a school trip to Guatemala with body aches and a fever. When the fever spiked on the third day after her arrival back, Lucinda rushed her to the local children's hospital, where she was diagnosed with dengue fever and salmonella. After several months, Crystal had seen an infectious disease specialist and made two subsequent emergency room visits, but the body aches and abdominal pain remained. "They were not helping her," Lucinda recalled. "Whenever we go there it was the same thing. You know, Tylenol or [other] painkillers. I think they give her something really strong for the pain. But I don't want to give her that, because then she will get addicted to it."

At this point, Crystal's pediatrician referred her to a gastroenterologist in the same children's hospital, but the first available appointment

was three months away. In the meantime, the family for whom Lucinda had worked since Crystal was six months old, as a nanny and then a housekeeper, suggested that Lucinda take Crystal to the emergency room at a different hospital across town and request that she see a gastroenterologist. Once there, Crystal was referred to a pediatric gastroenterologist, who eventually referred her to the West Clinic, located in the same hospital, when she ran out of treatment ideas.

The gastroenterologist prescribed Xifaxan, a short-course antibiotic that was not covered by Crystal's insurance, for which Lucinda paid \$255 out of pocket. "We talked to [the gastroenterologist] about sending some forms but then in those days she went on vacation," Lucinda explained. "And the, uh, doctor that was . . . covering for her, ah, they didn't got the forms, and [when] they did got the forms, they send it to the insurance, they got lost. So whatever happens it just took a while. At the end, I never got any response from anybody, insurance or the doctor, so I just went in and paid for myself." I found Lucinda's experience particularly vexing because I had taken Xifaxan myself about eight months prior, and my own doctor, knowing that I was in graduate school, had told me that if my insurance would not pay for it, she would give me free samples. Lucinda was not offered these, and as a struggling single mother, the cost hit her hard.

Beyond the importance of financial resources, Lucinda and Crystal's experience also highlights the important role of what the sociologist Janet Shim calls *cultural health capital*, tacit or deliberate cognitive, behavioral, or sociocultural resources that predispose patients to optimal health-care encounters.¹¹ The suggestion by Lucinda's employers that she take Crystal to a different, more prominent hospital marked a critical turning point in Crystal's therapeutic trajectory. For working-class, non-native-English-speaking immigrants like Lucinda, the cultural health capital necessary to identify appropriate doctors and therapeutic pathways beyond ordinary pediatric care can be far out of reach. Prior to this point, Lucinda told me that, unaware of how to go about finding a suitable doctor in the United States, she had looked for a doctor for Crystal by dialing telephone numbers that she found in the Yellow Pages under "gastroenterologist."

Lucinda recalled this strategy as the most frustrating aspect of Crystal's medical journey:

Find a doctor. Find a GI. That was so upsetting. I even went to the Yellow Pages and looked myself and tried to see a GI. And they said, "Sorry we can't take you because we only take from eighteen and up. Sorry we can't take

you.” This is so frustrating. We find one that was gonna take us but it was, the appointment was for two months, and the visit is between 400 and up or 200 and up. Expensive. Which, I, like I said, you know, I don’t mind the money you know, if it is helping her or is gonna help her, I will pay for the visit. ‘Cause they say, “What plan do you have?” “Well I have this HMO, whatever.” And they say, “Oh no, we don’t take that.” I say, you know, “It doesn’t matter. I pay for the visit.” And, it’s start from—I think they said from 250 and up.

Despite Lucinda’s resourcefulness, her willingness to incur substantial debts to secure medical care for her daughter, and her employers’ willingness to help her financially, it was the relational currency of the latter’s cultural health capital that proved instrumental in opening the door to better treatment for Crystal. Lucinda said of the wife, “She’s the one who calls [the hospital], she’s the one who calls here and helps me make phone calls. To help me get in anywhere.”

Unfortunately, Lucinda learned just days before Crystal’s first scheduled appointment in the West Clinic that her insurance would not, after all, cover the visit.¹² The West Clinic office visit would cost from \$250 to \$400, so they would need to postpone it. The West Clinic attempted to obtain authorization for Crystal’s visit, but the insurance representative instructed Crystal see someone within the company’s network first. When they updated me on this turn of events, Lucinda and the West Clinic receptionist formulated it somewhat differently. When I called Lucinda to check in with her, she told me that Crystal’s appointment “had been canceled.” I noticed this passive language choice because I had received an e-mail from the receptionist the day before indicating that the family “had decided to cancel.” This subtle shift in agency highlights how, for many families faced with children’s health-care needs, the notion of medical “choice” may be little more than illusion. If the choice really was Lucinda’s, she was choosing between two undesirable options: keep the long-awaited appointment and take on a debt that she could ill afford, or forego it and attempt to find good care elsewhere.

Four months later, Crystal did obtain an appointment with a pain specialist at another pediatric pain clinic in the area, albeit one less renowned than the West Clinic. In this sense, Crystal’s case was not a complete failure of pediatric pain treatment. Yet as I stayed in touch with Lucinda and continued to follow Crystal’s therapeutic trajectory, it was clear to me that she received far less support and did not fare as well as many of the patients in my study, partially as a result of her family’s limited financial means. Several months after Crystal’s first pain

clinic appointment, she suffered another treatment setback when the state determined that Lucinda no longer qualified for Medi-Cal and Crystal lost her insurance.

Crystal's experience demonstrates how, despite state and federal efforts that pay lip service to ensuring access to health care for all U.S. children, tertiary care pediatric services may nevertheless be construed as luxury goods that are not distributed equally. Patients like Mark were thus far more likely to make it through the West Clinic's doors than patients like Crystal. One reason for this differential access is the different levels of cultural health capital available to their families. Consider, for example, the ways in which the two families approached the task of identifying medical providers. While Julie queried her pharmaceutical industry colleagues, and Mark himself did Internet research, Lucinda adopted the less efficient strategy of looking in the Yellow Pages, until she received helpful assistance from her employer. These divergent pathways suggest that, if the West Clinic and others like it constitute "the bottom of the funnel," the funnel itself does not provide an opening that all families enter and pass through equally. As is typical in U.S. biomedicine, some never quite make it to the mouth of the funnel, while others remain permanently lodged in the neck, unable to get to the bottom.

CLINICAL CHALLENGES AT THE BOTTOM OF THE FUNNEL

For families fortunate enough to secure a consultation in a pediatric pain clinic, the challenges are not yet over. Many adopt a cautious stance in their first visits, steeling themselves for yet another disappointment, however hopeful they might be. Families are especially likely to be guarded if they have been treated dismissively in the past. "If the family feels like they've been told that the pain condition has been all in their child's head," the psychologist Hillary Traynor told me, "they develop a real mistrust for working with care providers and even avoid that."¹³ Dr. Joseph Stanley, the physician-director of a pediatric pain clinic in the midwestern United States, was more emphatic: "They're *always* skeptical and they're *always*, you know, 'We don't know what to expect. Every other doctor's told us that we're whacked in the head.' You know, or, 'People didn't believe us.' Or, 'No one's been able to help us.' They've all been through the medical wringer already, so they all come with baggage of one sort or another. And very few of them expect that we're gonna be able to help."

Referrals to numerous physician specialists, a seemingly endless stream of diagnostic testing, the tremendous burden of medical uncertainty, and insinuations that chronic pain is “all in your head” combine to put a great deal of pressure on pediatric pain clinicians to handle family interactions with great care and sensitivity. If pediatric pain clinics represent the bottom of the funnel, by the time families arrive, they have already been “through the medical wringer,” as Dr. Stanley put it: spun around, siphoned through a narrowing range of treatment options, and spit out the bottom with nowhere else to go.

How do pediatric pain practitioners respond to this pressure? How do they explain chronic pain in such a way that patients feel validated? Metaphors provide a powerful resource for handling several interrelated challenges that confront clinicians at “the bottom of the funnel.” First, although the biopsychosocial model of pain eschews simplistic views of psychological causality, psychological factors remain important to the patient’s experience and pain management possibilities. Yet questions about symptoms of anxiety and depression can easily send the message that clinicians conceptualize chronic pain as a psychological phenomenon, and thus not a *real* biomedical problem—particularly when families are predisposed, based on past experience, to view such questions suspiciously. The dilemma for pediatric pain clinicians, then, is how to convey to families that while they may inquire about a patient’s emotions and mental state, which form an important part of the landscape of life with long-term pain, this does not (or does not necessarily) mean that they think that the pain is “all in your head.” Dr. Novak addressed this directly with a favorite joke: “You may be crazy, but that has nothing to do with this.”

A second challenge for pediatric pain clinicians is to manage expectations for a concrete diagnosis. “They come to our pain program expecting, not necessarily a miracle, but they want a diagnosis—a lot of them want a diagnosis, a clear-cut diagnosis that can be treated,” Nina Herrera said. The assumption underlying repeated efforts at diagnostic testing is that the appropriate test—be it imaging, laboratory, or something else—can help to pinpoint a specific causal mechanism. The historian of medicine Charles Rosenberg has traced the emergence, over the course of the twentieth century, of a theory of disease specificity that conceptualizes diseases as concrete, isolatable entities that can exist, in his words, “outside the unique manifestations of illness in particular men and women.”¹⁴ It is precisely this understanding of disease that perpetuates the diagnostic odyssey: this logic suggests that there is

something there to be diagnosed, and that eventually the correct test will identify it.

Chronic pain syndromes, however, often resist such specification. In addition to pain, the adolescents I met in the West Clinic frequently reported diffuse symptoms such as nausea, fatigue, insomnia, and even pseudo-seizures, as well as sensitivities to heat, cold, and sound. Consequently, their illnesses were not always clearly and indisputably linked to a specific organ or disease entity, but might be characterized instead with catch-all labels such as “central pain syndrome,” a term used to express sensitization of the pain-signaling system, or generic categories such as myofascial or neuropathic pain.¹⁵ Not surprisingly, this diagnostic fluidity sometimes left families unsatisfied. “They would be almost happier if you said, ‘Your child has diabetes and needs daily insulin shots,’” said Deborah Vuolo, a psychologist working at a pediatric pain clinic in the northwestern United States. “Because it’s concrete, and the problem with chronic pain is it’s not concrete.” Several patients and parents told me that it would almost be easier if the diagnosis had been cancer, because then there would be a clear treatment. What families feared most was, not a serious, devastating illness, but rather the complete absence of a concrete biomedical explanation—confirmation that the pain might really be “all in your head.”

In what follows, I illustrate how the pervasive use of neurobiological metaphors in pediatric pain medicine works to address these interpersonal and explanatory challenges by finding an alternative vocabulary for pain that is “in the head,” yet not psychological—in the sense of being “unreal” or made up. More specifically, I show how metaphors that conceptualize pain in terms of neural circuitry provide a compelling alternative to the doctrine of disease specificity by replacing the search for structural dysfunction in a particular organ with a more diffuse model of nerve-signaling difficulties. This model also helps to explain why other specialists have failed to grasp the problem: they tend to locate pain in a discrete body part, such as the stomach, head, or back, instead of in the nervous system. In laying out this alternative model of pain, pediatric pain clinicians provide a persuasive rationale for a novel mode of treatment based on “reprogramming” the neural circuitry. At the same time, neurobiological metaphors evoke tropes of techno-scientism and realism that are especially salient for middle-class Americans. In contemporary U.S. popular culture, neurobiology is widely and uncritically accepted as an agent of legitimacy that explains a wide range of symptoms and behaviors, and alleviates individuals

from responsibility and blame.¹⁶ By developing elaborate metaphors to visualize and concretize a phenomenon that is notoriously difficult to represent, practitioners work to transform chronic pain from a perplexing set of loosely connected symptoms to a “real” illness condition.

It is important to keep in mind that neurobiological metaphors can serve to legitimize health-care providers as well as patients. At one pain convention that I attended, an audience member asked a well-known pediatric pain psychologist how he got families to accept his rehabilitation model of pediatric pain management. The psychologist responded that he always spends a lot of time explaining physiological pain mechanisms. “Your credibility goes up a lot if you do this, particularly if you emphasize the neural mechanisms,” he explained. Striking here is the psychologist’s suggestion that his own legitimacy, and not just the legitimacy of his patients’ pain, was at stake in neurobiological explanations.

Metaphors are also common in pediatric pain medicine for another reason: they help translate complex concepts into terms that children and adolescents can more easily comprehend. Metaphors buttress clinical communication by capturing young patients’ attention and helping them understand and remember complicated scientific ideas. Particularly in a domain such as pain medicine, in which there is so much complexity and uncertainty, metaphors draw on children’s imaginative capacities to employ meaning creatively when it is otherwise underdetermined.¹⁷ Explanatory metaphors for pain thus perform vital rhetorical work designed to counteract the evidentiary crises that surround pain.

CLINICAL METAPHORS

When Dr. Novak describes her clinic as “the bottom of the funnel,” she does not literally mean, of course, that the clinic is located at the bottom of a funnel. Instead, she suggests that the experience of pain treatment shares some of the funnel’s properties and conventional meanings. The funnel metaphor not only suggests that patients and families are channeled along a constricting range of treatment options as the diagnostic odyssey progresses, but also highlights the lack of agency and control that they feel along this journey. Here, the metaphor works as a figure of speech that helps to provide conceptual clarity in virtue of its poetic properties.

Cognitive scientists, linguists, philosophers, and anthropologists have long observed, however, that metaphor is more than a poetic flourish; it is a critical mode of thought and action that pervades our everyday life.

In their classic text *Metaphors We Live By*, George Lakoff, a cognitive linguist, and Mark Johnson, a philosopher, argue that metaphor is a basic mechanism of the human mind that tacitly shapes how we think and act in ways that often go unnoticed.¹⁸ At the most basic level, then, a metaphor is a form of representation that helps us to categorize the world around us.

Medical anthropologists have examined the role of metaphor in illness and healing from a number of different angles: by developing critical perspectives on the metaphorization of diseases;¹⁹ by illustrating how bodily symptoms can express broader sociopolitical disorder;²⁰ and by identifying metaphors that serve as central organizing tropes in particular medical systems.²¹ Anthropologists have devoted relatively less attention, however, to the functions of metaphor within clinical discourse. As linguistic forms, metaphors perform an important communicative function by encoding implicit assumptions about body and mind and lending concreteness to the inchoate, abstract, or elusive. In doing so, they produce “semantic movement” from abstract concepts to “more concrete, ostensive, and easily graspable” ones.²² In clinical interactions, physicians, patients, and patients’ families wield metaphors to help present a particular stance on a problem and persuade other parties of their perspective.²³ Such tactics are often successful because metaphors, beyond merely mapping analogical relations, transform the content of what they represent.²⁴ Furthermore, by endowing illness meanings with semantic flexibility, metaphors provide a convenient means of addressing the gap between available models of disease and treatment, on the one hand, and the experience of illness, in all its particularity, on the other.²⁵

Given their utility in dealing with ambiguity and uncertainty, it is not surprising that metaphors pervade clinical discourse about pain. Metaphors are especially useful when ordinary language is stretched to capacity to perform its denotative function. This is why it might seem simpler to say that one’s pain feels like sitting on a bed of nails rather than attempt to describe its qualities more objectively. Yet while many anthropologists have documented metaphors for pain in lay discourse,²⁶ few of these accounts have examined the metaphors that clinicians use as part of their explanatory armamentarium. It is to this task that I now turn.

The Software Model

Early one September morning, I sat with Dr. Harvey Bergmann in his office before his staff meeting. Dr. Bergmann, the physician director of

a prominent pediatric pain program in the eastern United States, had invited me to sit in on the staff meeting and had agreed to be interviewed beforehand. The modest size and appearance of the cramped office, cluttered with piles of books and papers, reminded me of Dr. Novak's office, perhaps reflecting the humble status of pediatric pain in the medical hierarchy. Like many of the physicians I spoke with, Dr. Bergmann had trained in developmental pediatrics, a subspecialty devoted to caring for children with developmental, behavioral, and learning issues. He had also completed a year-long fellowship in psychosomatics, where he worked with a child psychiatrist to treat children with medical conditions and co-morbid psychological disorders. "This was a very long time ago," he said. In that era, he explained, there had been "very much a dichotomous kind of approach to many problems. It was either medical or psychological."

After accepting a faculty position and launching his career at an urban children's teaching hospital, Dr. Bergmann was often called in to assess the mental status and psychological functioning of patients with sickle cell disease. At the time, many clinicians believed that sickle-cell patients were all addicted to their pain medications, because they would ask for more drugs every few hours. "What really got me going with this was a thirteen, fourteen-year-old girl who was admitted to the hospital screaming in pain," he recalled. "And the question was: Was she addicted? Because she was requesting pain medications. And when I actually looked at her chart, she had had like five different pain medications, all of them inadequately dosed. She was watching the clock because she knew [that] every three or four hours she was entitled to new medication. Never treated adequately. So we changed her medication doses and she stopped complaining."

Nearly thirty years later, this incident still stuck with Dr. Bergmann. It had piqued his interest in pediatric pain and inspired the direction of his emerging research and clinical interests. In the intervening years, he developed an exemplary pediatric pain program, one of the first of its kind in the United States. More recently, he had shifted into the advocacy domain, working both locally and globally to, in his words, "create change in the culture of the institution." From Dr. Bergmann's perspective, it was not enough to rely on the "good graces" of individual physicians who understood the complexities of pain treatment; meaningful change had to come from the top down as well as the bottom up. Yet the cornerstone of his professional career remained his clinical practice, where he ran multidisciplinary inpatient and outpatient services for

children and adolescents with chronic pain, as well as a consultation service for hospitalized patients with acute pain problems.

I was eager to ask Dr. Bergmann how he might explain pain to a new chronic pain patient, something I asked all the clinicians I spoke with. “So that’s an interesting question, and I bet you’ll hear amazing similarities, but everybody using different metaphors,” he said. Dr. Bergmann motioned me toward his computer monitor, where slides for an upcoming grand rounds lecture on functional pain syndromes were already open on the screen. Flipping through the slides, he said:

Because [other] people don’t believe they’re in pain, and they’ve been through lots of different people who disbelieve them, we tend to [tell them something like], “Your nerves have become hyper-aroused or overstimulated in some way, shape, or form.” Rich Grostaurk talks about the habit of firing, the neuro-firing. Other people talk about the example people have heard of, phantom limb. But the model we use is that the nerves are overexcited for whatever reason. And we’ll often use the software-hardware model. I don’t know if you’ve heard [of] that model, too. So that’s why everybody’s looked inside of you, they haven’t found anything wrong, it’s because the software is the problem. And so what we want to do is figure out a way to reprogram that. And what makes the software—what got it going? Well any number of things. A family history of this kind of problem might make you more vulnerable. We know that stress is responsible for all kinds of hormone production, and those stimulate the nerves. And yada, yada, yada, yada. And they’re just firing, firing. So we get away from the psychosomatic. We get away from the dichotomous descriptions.

According to Dr. Bergmann, attributing chronic pain to neural arousal or hyperstimulation legitimizes it by establishing that it is caused by a concrete physiological problem. To illustrate this, Dr. Bergmann employed the central metaphor: “Chronic pain is malfunctioning software.” This metaphor and its corollary—“Chronic pain is NOT malfunctioning hardware” in turn enable several key propositions that have important practical consequences for patients’ understanding. First, other physicians have failed to correctly identify the pain because they are trained to address “hardware” problems—that is, problems with individual organs. Chronic pain results instead from problems with neural circuitry, which is here represented as “software.” Consequently, other physicians (and their battery of diagnostic tests) have failed to explain the pain, not because it is “unreal,” but rather because they lack the appropriate expertise. Second, the software metaphor provides a clear way of conceptualizing treatment as “reprogramming.” This model of treatment offers an optimistic prospect of recovery because software problems are generally easier to fix than

hardware ones. Finally, the software metaphor exposes a range of potential causes for pain—from genetic predisposition to social stress—that provide viable alternatives to psychosomatic models.

I remarked that it must have been interesting for Dr. Bergmann to have seen the evolution of such explanatory models of pain, given his background in psychosomatics. He nodded in agreement. Had he been dissatisfied with the model available at the time, I wondered? “Well it made no sense,” he said. “And also, the psychiatrists were lunatics. I hate to say it, but they were lunatics. You know, they would think that if you couldn’t find a physical cause, there was a psych cause that was in there and we’ll keep beating you. ‘I think I see a little this or that,’ you know, they’ll make some crap up. You know, and they had this metaphor, you know, peeing. ‘You’re enuretic because you’re peeing on your mother,’ all this insane stuff. And I knew that they were nuts then. But there weren’t good models then.” Approaching the end of his slides, Dr. Bergmann summed up the appeal of his model: “So that’s the model that we tend to use. And families respond to that very nicely because they don’t feel blamed. They feel that, aha! This person understands the problem. . . . Most doctors say, ‘Well I don’t know what this is. But it’s not this.’ We say, ‘We *know* what this is. We know what this is. We see this all the time, it looks differently in different kids, but we see this all of the time.’ And that’s giving people a reassurance that this is not a unique [phenomenon], that they’re not the only one with this problem..”

“You’ve got pain!”

My conversation with Dr. Bergmann was not the first time that I had heard a computer metaphor to describe chronic pain. Dr. Petrosian, Dr. Novak’s junior colleague in the West Clinic, was especially fond of using the analogy of the Internet service provider AOL’s well-known greeting: “You’ve got mail!” Invariably, when explaining pain to new patients, Dr. Petrosian would ask what e-mail server they used. If a patient said she used AOL, he might respond, “I use Gmail and Yahoo. You want to know why I don’t use AOL? I check them when I need to. I don’t like be told constantly, ‘You’ve got mail!’” Here, Dr. Petrosian would mimic the grating voice that periodically notifies an AOL customer when a new message arrives in the inbox. He then would go on to explain how the neural networks that transmit pain signals start to develop patterns, firing irritating messages that say, in effect, “You’ve

got pain!” over and over again, just like the AOL voice. “So we need to switch you to a new e-mail service provider,” Dr. Petrosian would conclude, before laying out his treatment plan.²⁷ In this way, Dr. Petrosian’s computer metaphors laid the groundwork for a particular kind of treatment: he often told patients that they needed to take their problem to the IT (information technology) people—meaning physical therapists, hypnotherapists, and psychologists.²⁸

The AOL metaphor vividly depicts chronic pain as resulting from malfunctioning nerve-signaling circuits. When Dr. Novak spoke about neuropathic pain, she emphasized that it was a nerve-signaling rather than a nerve-damage problem. Thus, when a parent asked about surgical treatment options, she would often respond that you could cut the nerve, but the pain circuit would still remain in the brain, as in the phenomenon of phantom limb pain. As Meg Pratt, a West Clinic physical therapist, put it: “Amputate the foot, the person still has pain in their foot. It’s not attached to their body anymore, so how can that be? How can they still have pain—feel pain—in their foot when their foot’s no longer attached to their body? Because it’s registered up in the brain.” Dr. Novak also regularly told her patients that the nerve-signaling problem was the sort of problem that only an electrical engineer would be set up to fix. “That’s why no one has found the cause,” she once said. “It’s not structural, not metabolic, not immunologic. The reason the tests did not turn up anything was that the diseases weren’t there. And subspecialists don’t get training in the neural networks of pain.”

The importance of the distinction between nerve-signaling problems and nerve damage became clear to me one day that I observed a new patient’s appointment with Dr. Petrosian. The patient, Phillip, was a ten-year-old boy who had developed CRPS in his right foot after a football-related injury. Dr. Petrosian explained that the pain was nerve-based, and as a result, the foot would not need to be put in a cast. Phillip looked at Dr. Petrosian with a puzzled expression on his face and asked, “So I broke my nerve?” Everyone in the examination room laughed, and Dr. Petrosian made a second attempt to explain the pain, this time using a football metaphor. Phillip had disowned his foot, Dr. Petrosian said, and he needed to retrain his brain to tell his foot what to do: “If you’re tackling, you need to tell yourself to keep your feet moving. It’s the same with this.”

It is quite likely that Dr. Petrosian’s second explanation was more successful than the first, because it drew upon a cultural schema that had personal resonance for Phillip.²⁹ Yet Phillip’s confusion also highlights

the dominant status of the body-as-machine metaphor in contemporary biomedicine. According to the anthropologist Cheryl Mattingly, this metaphor, which constructs the body as “potentially fixable,” “operates virtually unnoticed in many clinical encounters.”³⁰ It is only in moments when intersubjective understanding breaks down that the tacit assumptions underlying it are made explicit. In this case, Phillip’s mistaken assumption that his nerve must be “broken” relates to a pervasive understanding of medical problems as occurring when the machine-body breaks, and of medical treatment as a matter of repairing a structural defect. In other words, the machine-body conventionally presupposes a mechanical fix.³¹

The computer-body suggests a very different kind of treatment, however. While a computer is also a machine, it is a specific kind of machine programmed to perform routinized functions. Rather than a mechanical repair, then, the computer metaphors described above conceptualize treatment as a recalibration of internal circuits and signals. Dr. Bergmann’s software metaphor and Dr. Petrosian’s clever deployment of AOL’s signature line help to circumvent the doctrine of disease specificity by offering a different model of the body, in which pain is caused by underlying circuitry problems rather than “broken” parts.

In her work on views of immunity in American culture, the anthropologist Emily Martin tracks a parallel shift in metaphors for the body from the early twentieth-century view of the body as a fortress that must be protected from external penetration (e.g., by germs) to views popularized by the AIDS epidemic in the late 1980s that characterized it as a complex, flexible communicative system.³² As Martin points out, the former model conceptualizes the body as a mechanical system composed of parts that can break down, whereas in the latter, body “parts” do not comprise the whole in a straightforward way. Rather, the body is constituted by a constant, fluctuating series of interactions that resist simple mechanical localization. Similar to the computer metaphors for pain, one of Martin’s informants goes so far as to characterize the immune system as a “metabolic computer” that keeps the rest of the body in balance.³³

One of the consequences of conceptualizing the body as a complex system is the paradox, as Martin puts it, “of feeling responsible for everything and powerless at the same time.”³⁴ Like popular views of the immune system, the computer metaphors described above relay a paradoxical form of agency. As we will see further in the next chapter, a treatment approach based on “reprogramming” pain circuits, rather

than structural repair, entails specific responsibilities for patients as well as their doctors. This differentiates pain management from the mechanical fixes sought in many areas of U.S. biomedicine, which tends to configure patients more passively. In this respect, computer metaphors for chronic pain also highlight the relational dimensions of pain treatment, demonstrating that therapeutic efficacy hinges on the patient's position within, and connectivity to, a particular social network.³⁵

Alarm Metaphors

Thus far, I have suggested that metaphors for circuits and signals help to lay out a causal mechanism that attributes pain to a nerve-signaling problem and addresses why diagnostic testing typically fails to locate a cause. Yet another important function of metaphor, as I hinted at earlier, is its capacity to make abstract concepts concrete. Depicting chronic pain as the relentless voice saying, "You've got mail!" animates and concretizes a phenomenon that ordinarily resists such visualization. Another way of establishing that pain is real and not "all in your head" is thus to provide a set of metaphoric images that represent it as a material entity.

Consider the metaphor of pain as a burglar alarm that I heard from Dr. Sterling, the psychiatrist in the West Clinic, who explained:

So here I am building a house and I take out my hammer, and I'm going to go to hammer a nail. And I miss the nail and I whack my finger. And I go, "Ouch, that hurts," right? But I've got to build a house, so, you know, I go back and I hit the nail and the next time I miss and I hit my finger again. And at some point, I don't actually have to hit my finger, but my brain says, Alan, you should probably put your finger away. And I can almost feel the pain, right. So there's a learning component to this. So that's the first thing I say. So there's pain information that goes from your finger, goes through the spinal column, and up to—there's a computer in the brain, which is monitoring everything we do, and memories and messages and all that stuff. And it says, uh, Alan move your finger, you're about to get whacked . . . So I think of it as an internal homeland security system. Like a burglar alarm.

In this account, Dr. Sterling uses metaphoric language to explain how the pain signaling system, when it becomes sensitized, may report pain that is not truly there. First, he provides an analogy for the conditioning associated with chronic pain: if you hit your finger with a hammer enough times, eventually the hammer alone can come to produce the pain response. He then offers two metaphors—an internal homeland security system and a burglar alarm—that bring these invisible neurosensory processes to life by anchoring abstract concepts in con-

crete visual images. The burglar alarm, a computerized monitoring system that warns of possible dangers, provides an apt conceptual metaphor for the nerve-signaling system, which monitors the body's sensory input. Like a burglar alarm, the primary function of the nerve-signaling system is to defend the body from harmful intruders, although "false alarms" are always possible.

Dr. Stanley described a similar situation using the metaphor of a smoke alarm. "There's supposed to be a set point, so your body knows when something's going wrong. And it's supposed to be like a smoke alarm," he explained. "And you know, much like your smoke alarm, you don't want it to go off all the time like it can when the battery's dead. And you don't want it to wait 'til your whole house burns down and your arm falls off to go off, either. You want there to be a set point so you know when your body is suffering from damage. But that set point can push out of balance." Much like the burglar alarm, the smoke-alarm metaphor suggests that chronic pain results from an overly sensitive set point that detects smoke when it is not really a danger. The concept of a "set point" concretizes the abstract notion of "pain as warning signal." The solution is to recalibrate the set point so that it detects pain at a more appropriate threshold. Dr. Stanley continued:

You may still have a structural component. But that's not going to explain all of the pain that you're suffering from. There is this neuro-physiologic hypersensitivity piece on top of that. And that's really what in pain clinic we're focusing on treating. So we're not treating the underlying arthritis or treating the underlying structural defect in your shoulder. We're treating this neuro-physiologic hypersensitivity piece and you're gonna use a different way to get at that. So we're gonna use your body to get at it with the use of medication. We're gonna use your brain, the conscious part of your brain, to be able to be more in control of your nervous system as well and exert that control in a more constructive way.

The smoke-alarm metaphor thus paves the way for a particular kind of treatment that relies on the brain to control the nervous system. Although structural problems might also contribute to pain, they were not the focus of Dr. Stanley's treatment.

In this way, clinical metaphors enable specific possibilities for therapeutic action that map onto preexisting treatment ideologies. Because clinical explanations are necessarily "bound up with the practitioner's therapeutic imperative to act and his compelling need to rationalize his actions,"³⁶ causal metaphors for illness and disease can in some ways seem like post hoc justifications for a particular course of treatment.

This is not to say, however, that the practitioner's pragmatic motives here are purely self-interested. An important consequence of such justifications is the reassurance that intractable pain is treatable. For families who have been told that pain is "all in your head" and that nothing else can be done, the added value of an explanatory metaphor that concretizes the causes of pain and pathways for its treatment is the sense of relief that comes from feeling heard and understood.

In this respect, Chris Girard's recollection of his daughter's first appointment with Dr. Petrosian is instructive: "He nailed it, though, the first time we met you guys. He said several things that made sense which made it easier for us either, one, to understand, or two, explain it to people. And what she's going through now, you know, is the AOL account." His wife Shellie broke in, "You know, 'You've got mail'? That was big." Even though Dr. Petrosian had not been able to do very much for their daughter's debilitating pain symptoms, Chris and Shellie Girard recalled their introduction to him with obvious satisfaction, because he had explained her pain in a meaningful way. From this perspective, we might say that metaphors have an instrumental efficacy independent of therapeutic success.

MEANING, CAUSE, AND THERAPEUTIC EFFICACY

However confident practitioners may sound when they explain chronic pain, the fact remains that the causes of chronic pain are often a mystery. As Hillary Traynor told me, "Sometimes we don't know exactly what causes chronic pain, but there can be illness or something physiologically going on that may cause kind of an overarousal of nerve pathways that may stay heightened after the illness is over, for reasons that we don't completely understand yet." Note that this response is full of mitigation and epistemic uncertainty: "we don't know *exactly*," "*may* cause," "*may* stay heightened," "don't *completely* understand." Such language underscores that chronic pain can be a baffling experience for patients and clinicians alike.

A central claim of this chapter has been that metaphors provide a rhetorical resource for clinicians to grapple with precisely this sort of causal ambiguity. Metaphors of circuits and signals are a powerful force in the West Clinic and pediatric pain medicine more generally. They help to address the uncertainties that pervade unexplained pain by providing a coherent causal framework that both materializes pain by representing it as a concrete entity and offers reassurance to patients and

families that it is physiological and not psychological. Through concrete visualization practices, metaphors work to overcome the epistemological limits of the biomedical body, in which “to be ‘real’ is to ‘show up’ visually.”³⁷ In other words, metaphors for the body can help to locate pain spatially when diagnostic technologies fall short. This rhetorical shift has moral implications, too. The ability to identify a concrete organic etiology—that is, to determine that pain is “real” as opposed to mental, emotional, and “all in your head”—helps to establish that a person is not crazy. Therefore, metaphors may help to validate accounts of suffering that have previously been met with suspicion.

Pediatric pain clinicians routinely turn to metaphors that substitute the metaphor of the body as a computer for the long-standing biomedical trope of the body as a machine. Depicting the body as an integrated network of signals and circuits enables clinicians to circumvent the doctrine of disease specificity and supplant the search for organ dysfunction with a model of nerve-signaling sensitivity. This also constructs bodily imaginaries that reflect broader cultural values surrounding labor and economy, as Emily Martin’s work has also shown.³⁸ Computer metaphors that imagine one’s body as hypersensitive suggest that, in our contemporary preoccupation with connectivity and flexibility, the pendulum may have swung too far, making us *too* responsive to changes in our environment. Yet far better to be hypersensitive, suggests this metaphor’s implicit moral logic, than completely oblivious to potential environmental assaults, especially because in suggesting that one’s nervous system is working too hard, this neural responsiveness evokes the cultural values of productivity and labor. Moreover, imagining the body as a complex system that can be recalibrated by IT experts draws on cultural ideals of techno-scientific enhancement and perfectibility.

The metaphors for chronic pain described here thus consolidate two intertwining temporal trajectories: a retrospective trajectory that explains pain in terms of its cause and a prospective trajectory that explains it in terms of its treatments. It is not simply the case, then, that clinicians first determine a cause and then settle on the appropriate treatment. Instead, metaphors for chronic pain reveal how the available treatment modalities prefigure certain causal explanations precisely because clinicians characterize pain in a way that renders it amenable to the therapeutic interventions that they can offer. For this reason, the meaning of pain is very much intertwined with therapeutic efficacy.³⁹

Metaphors are intertwined with therapeutic efficacy in yet another way, however. In her ethnography of an inpatient pain-treatment center

in Boston, Jean Jackson describes how metaphors for pain can be directly employed to great therapeutic effect.⁴⁰ In the treatment center Jackson studied, patients were encouraged to objectify pain by developing a visual image of it and then picture it entering and leaving the body. In imagining their pain as sea serpents, crabs, and medieval weapons, patients established a sense of control over pain: “The interaction between the pain image and the narrator frequently involved confrontation and struggle, requiring the pain sufferer to move from passivity to activity—even at times to risk danger and perhaps even more pain.”⁴¹ In this way, metaphors can become a powerful and productive therapeutic resource, illustrating that not just things like medicines but also words and images can have a healing effect on the body.

Although there is an abundant scholarly literature on metaphors for illness, mind, and body, underrepresented in this work are fine-grained accounts of what explanatory metaphors can accomplish in clinical discourse. As this chapter has shown, metaphors, as rhetorics of medicine, have the potential to reframe lay understandings of illness and harness positive, new, and valued meanings. Their persuasive power hinges on their semiotic properties as well as the social dynamics of the clinic. As I will explore further in the next chapter, patients buy into clinicians’ metaphors in part because of physicians’ authority.

If metaphors are a key element of clinical rhetoric, though, *how* do they persuade? Lakoff and Johnson distinguish between conventional metaphors that “structure the ordinary conceptual system of our culture” and a more imaginative variety “capable of giving us a new understanding of our experience.”⁴² That is, rather than merely describing our experience, they *transform* as they represent.

To illustrate this point, Lakoff and Johnson provide the example of a foreign university student they once taught who understood the American idiom “the solution to my problems” in strange yet evocative terms. The student had visualized this expression in terms of a chemical metaphor: a bubbling vat of liquid in which were suspended his “problems,” in liquid or solid form. Depending on what catalyst one added to the solution, specific problems might dissolve or precipitate out. For Lakoff and Johnson, this metaphor offered a new, distinctive worldview, in which problems would never disappear entirely: “To live by the CHEMICAL metaphor would mean that your problems have a different kind of reality for you. A temporary solution would be an accomplishment rather than a failure. . . . The way you would understand your everyday life and the way you would act in it would be different if you lived by the CHEMICAL metaphor.”⁴³

The point for Lakoff and Johnson is not that words alone change our reality, but rather, that changes to our conceptual systems—to the *metaphors we live by*—can have this world-changing effect. For Chris Girard and his family, who had consulted seven specialists at multiple hospitals after a soccer injury left their daughter homebound with crushing leg pain, Dr. Petrosian’s AOL metaphor facilitated a fresh perspective on pain that offered a renewed sense of hope for therapeutic possibilities. The Girard family’s experience illustrates that changes to conceptual systems for making sense of pain constitute one of the most important therapeutic resources that families encounter at the bottom of the funnel, at this point in their diagnostic journey. Metaphors are thus critical clinical tools that perform essential rhetorical, interpretive, and therapeutic work. In this respect, clinical metaphors for pain offer a “synthesis of interpretation and creation”⁴⁴ that opens up vastly different perspectives onto reality. In the next chapter, I explore such world-changing metaphors in action by looking at a series of clinical interactions as they unfolded.