

“Today is a Four”: How Students Talk About their Chronic Pain

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ABSTRACT

According to critical embodiment theory, people notice the acts and functions of their bodies only when their bodies are not normalized, which causes them to perceive a difference between normalized bodies and their own. People with chronic pain likewise perceive a disconnect between themselves and people without chronic pain. This study examines, through semi-structured interviews with university students who have chronic pain, how participants conceive of their pain in different ways. This study confirms that participants considered themselves different from those without chronic pain, although nearly all participants identified one or more individual out-group “allies.” Further, participants conceived of their pain differently, as evidenced by the various established and unestablished frameworks they used to communicate their pain. Because these concepts of pain are grounded in bodily experiences, it is impossible to fully “translate” pain to others.

Keywords: disability studies, chronic pain, community, communication

that make life feel burdened, uncomfortable, and all too often desperate. (Kleinman 1988, 44)

In short, chronic pain goes beyond a mere physical burden. The ways in which people from the same culture relate to chronic pain may be understood as based in a shared worldview (Hall 1997, Miles 2010). In many Western cultures, chronic pain is at once stigmatized and marginalizing, as those with chronic pain feel a divide between themselves and their family, friends, and colleagues without chronic pain (Kleinman 1988).

Much empirical scientific evidence, considered so valid in Western world systems (Jordan 1993, Prakash 1999), argues against the validity of the mind-body dualism. Despite this, according to Johnson (2007, 2), the concept persists:

We postulate a 'higher' self (the rational part) that must seek to control the 'lower' self (body, desire, emotion). We assume that each of us has an inner core (a 'true self' or a 'soul') that transcends our bodily, situated self. We buy into the notion of thinking as a pure, conceptual, body-transcending activity, even if we realize that no thinking occurs without a brain.

People believe in mind-body dualism because when the body senses something external, the brain typically focuses on the external experience rather than the body's act of experiencing. For instance, a driver who focused on how the image of another moving vehicle traveled through the rods and cones of her eyes, through the optic nerve, and into the brain would, of course, be unable to focus on driving safely.

It is not until the body undergoes trauma, disrupting this body schema by preventing sensation from occurring as it should, that a person becomes aware of this bodily processing (Johnson 2007, 5-6). For example, most people are not consciously aware of the functions of their internal organs after they eat lunch, and they can immediately return to work without thinking about their intestines. Yet someone with Crohn's Disease or Irritable

When I asked one of my participants, Joshua, if he was in pain at that very moment, he immediately responded, "Well, today is a four." Stunned, I repeated, "Today is a four?" I asked all my participants the same question, after asking them their average high and average low pain, but none had spontaneously answered using the 1-10 pain scale. Most began by saying that they were surprised that their pain was not as bad as it could be before going on to describe the nature and location of their pains. Instead, Joshua explained, "Basically, the hill from my house to here wasn't fun, and every time I stand up it isn't too fun, but like... Let me put it this way, if you told me right now, 'Walk around campus a couple of times,' I could do it, but if you told me like, 'Hey, run a mile,' I'd be like, 'That's not happening.'" He was the only one of my participants to describe their chronic pain in such stark terms.

The International Association for the Study of Pain notes vaguely that chronic pain "persists past the normal time of healing," which may manifest as "less than one month, or more often, more than six months" (Merskey and Bogduk 1994, xi). In fact, after onset it may last for decades or even the rest of a person's life. Chronic pain is frequently a product of chronic illness, though the two do not necessarily go together. Moving beyond clinical definitions, people with chronic pain and illnesses face

coming to grips with the mundaneness of worries over whether one can negotiate a curb, tolerate flowers without wheezing, make it to a bathroom quickly enough, eat breakfast without vomiting, keep the level of back pain low enough to get through the workday, sleep through the night, attempt sexual intercourse, make plans for a vacation, or just plain face up to the myriad of difficulties

Bowel Syndrome is intimately familiar with their digestive processes, and may continue to think about these processes for the rest of the afternoon. Merleau-Ponty (2002) similarly posited that bodies are “habitual” when they perform actions without drawing attention to the performance of those actions. A person who walks with an apparently unhindered gait into an elevator will not draw the same amount of attention as a person in a wheelchair entering the elevator. Furthermore, a stranger already in that elevator will not perceive the event in the same way as the wheelchair user, who repeats this situation on a regular basis. And if the apparently able-bodied individual has chronic pain, they might be consciously aware of every step they take, while the stranger might immediately forget the event.

In other words, both internal and external characteristics can draw one’s own and others’ attention to the body in different ways. Ahmed (2007) studied this using the external characteristic of race, or more specifically, whiteness. She explained, “White bodies are habitual insofar as they ‘trail behind’ actions: they do not get ‘stressed’ in their encounters with objects or others, as their whiteness ‘goes unnoticed’” (156). In contrast, a Black person walking into a predominantly white space will immediately notice and be noticed. As a result, white people are more easily able to dismiss the impact of race on a situation than Black people. Both whiteness and ability remain normalized through institutionalized inequality and social prejudice. The disabled or pained body draws the attention of the body’s owner and others who are able to detect the impairment. Because of the disabled or pained person’s hyperawareness of their body and the differences between their body and the normalized body, the disabled or pained person is more likely to perceive a corresponding social divide between the owners of different bodies than the owner of a normalized body would be.

Mainstream medical anthropologists and sociologists tend to study communities from an outsider’s perspective, which can disempower the communities being studied when researchers treat participants as strange or irrational through the lens of Western medicine (McRuer 2006). Some scholars, such as Das

(1997), Jordan (1993), and Kleinman (1988), have tried to address this by incorporating different subjectivities into their narrative accounts of the people they study. These researchers try to better understand participants’ thoughts and behavior by not only examining participants’ worldviews but also interrogating their own. The growing field of critical embodiment studies, which includes scholars like Ahmed (2007), Johnson (2015), and Merleau-Ponty (2002), crucially takes into account both researcher and participant subjectivities.

I analyze chronic pain through critical embodiment theory rather than mainstream medical anthropology. Specifically, I have used the lens of linguistic anthropology to analyze participants’ embodied understandings of their own bodies. This paper examines how students with chronic pain conceived of a difference between themselves and people with normalized bodies, and how they expressed that perceived difference through speech acts. It then delves into the ways participants conceived of their own pain through established and unestablished frameworks.

Methods

In line with critical embodiment theory, this study depends on reflexivity, in that my status as someone with chronic pain caused by rheumatoid arthritis (RA), an autoimmune disease, was a crucial factor in shaping the access I had to participants. In fact, Patricia explicitly told me as much: “But the reason I felt comfortable talking to you about it—and originally, even though we’re not very close, is because I know you have RA. And I know you get it.” An outsider might have designed this study differently, and might not have even asked the same two research questions. Yet being an insider poses its own challenges. To avoid imposing my personal values and perceptions upon participants’ experiences, I employed member-checking throughout my interviews by verifying my interpretations of what they told me. I continually questioned my own assumptions about which concepts, values, and practices are shared and which are not.

For this study, I recruited five students among my acquaintances and their

acquaintances who self-identified as having chronic pain. After obtaining informed consent, which included disclosing to them that I experience chronic pain, I conducted a one-hour semi-structured interview with each participant in order to discuss participants' experiences and perceptions of chronic pain. I then conducted two group conversations using the same participants so that I could see firsthand how people with chronic pain interacted with each other in discussing both their pain and how they related to people without chronic pain. Because my research focused on the disconnect between people with chronic pain and those without it, I wanted to give my participants the option of connecting with other people who had chronic pain so that they might derive additional benefit from my research. I invited my participants to select one or both scheduled group conversations based on their availability rather than specifying which participants should be in each group.

While I emphasized that the group conversation was entirely optional, all five participants expressed interest and selected at least one session. The first focus group went as planned, with myself and three of the people I had interviewed responding to "I" statement prompts about our pain and then discussing our answers. However, two participants were unable to attend the second focus group at the last minute, leaving two of the participants from the first focus group. Rather than rehash old responses, I encouraged the two participants to have an unguided conversation about topics relating to the themes in my project, and I provided limited contributions to the conversation. With participants' permission, I audio recorded every interview from both stages of the study to conduct linguistic analyses on participants' exact words.

I have represented participants' speech as accurately as possible and preserved every "um" and "like," following the conventions of linguistic anthropology. Yet I have broken with convention by representing these quotes ethnographically, in their conversational context, rather than with line-by-line numbering. My representation of quotes thus seeks to ground the reader's experience of them in the ethnographic moment by inviting

the reader to delve deeper into the quote-as-text, including focusing on participants' readiness or hesitation to disclose their thoughts to me, and to recognize participants' speech patterns as unique traits that distinguish individuals from each other. At times, I have also made myself present in these accounts, both because of my position as a member of the community and because of my active role in these ethnographic moments.

Disclosing pain

The identification of sameness and difference are fundamental in building identity, as they enable individuals to imagine themselves as members of a group distinct from others (Bucholtz and Hall 2005). The boundaries between "us" and "them" need not be reciprocally agreed upon, and the members of a given group may not even agree exactly where those boundaries lie. Furthermore, as Anderson (1991) famously wrote, members of a group do not have to see and know each other to believe in the existence of the group, or "imagined community." People typically consider themselves to be members of multiple types of groups, although one group may supersede the others to be the focal point of identity construction (Derrida 1998, Bhabha 2004).

Individuals are socialized through language into new roles and identities throughout their lives, even after childhood (Ahearn 2011, 60-64). In this way, Krummel described how her doctors' use of technical jargon in letters referring her to other doctors socialized her into an identity of having multiple sclerosis:

I consider this letter my first notification of MS because the correspondence marks the beginning of my new and very different life. I am now receiving (or acquiring, as the case may be) letters that introduce the MS language to me: demyelination [...] and diplopia [...]. Doctors write to each other about me and use the words "multiple sclerosis." I am not particularly disturbed by being referred to in the third person; I realize that I have internalized

Miriamne Ara Krummel as
"patient." (Krummel 2001, 67)

Through medicalized encounters, those with chronic pain or chronic illness come to understand their current state of being or diagnosed condition. This understanding, combined with the awareness of their own bodily functions and acts, is followed by a sense of difference from their own past bodies or from the normalized bodies.

All five participants described feeling a divide between themselves and people without chronic pain, such as their colleagues, friends, family members, and medical practitioners. Participants often conflated these groups into a vague, anonymous "they" with statements such as, "They don't understand." At times, participants explicitly referred to "those who get it" versus "those who don't," and the participants in the focus group validated each other's understandings of this divide. For example, Carol said,

I had a lot of friends beforehand, before I really got sick, who hadn't really gone through anything serious? So when I was going, you know, I had six months of recovery, and when I was telling them these things, they just didn't get it. One of my—former roommates—um. I was having a lot of blood clot issues, and so I was on blood thinners, and I'd get my blood levels checked two to three times a week, and they were never consistent, and that was very dangerous, and I'd be crying to her on the phone, going like, "my blood levels aren't where they're going to be, holy crap—what's gonna happen?" and she would just be like, "that sucks," but then she would tell me her miscellaneous problems of like, she spilled coffee on her shorts that day and it ruined her day, and I'm just thinking like, "blood clot could be going to my lungs."

Marge responded to her, "Sometimes I like listening to it as like, a watching TV thing. Like 'oh, look at all these people's problems, it's so nice.'"

Carol, who had begun experiencing chronic pain more recently than the other participants, reacted differently to this disparity compared to Marge, who from a young age had dealt with health complications unrelated to her current pain. However, both agreed on the existence and nature of the divide: people who encounter potentially life-threatening problems on a regular basis, and can understand each other's plights, versus people who do not encounter these problems regularly and prioritize seemingly unimportant ones and are unable to understand or be understood by the former. Nonetheless, friendships and romantic relationships were not impossible with "those who don't" because participants' identities as individuals with chronic pain had not superseded all of their other identities.

In fact, four of the five participants also identified one or more allies, or individuals without chronic pain to whom participants reported confiding their pain. These allies were typically roommates or significant others and directly witnessed participants' pain more than other people because of their relative proximity. In some cases, participants claimed that these allies were especially sympathetic because they had their own mental health conditions or had witnessed a family member's chronic pain or illness. However, witnessing did not equate to understanding, because allies could not truly grasp the experience of living with chronic pain. For instance, Marge was very close with her roommate and sometimes confided in her, especially because the two dealt with mental health conditions. However, Marge also claimed that her roommate could only understand her up to a certain point:

You know, when my roommate comes home, this was mostly last semester, and she was like... "I can't do this, I have a concussion!" Like—she had a concussion, had a very serious one, and she was sleeping all the time, and she was like, "I can't, I can't not do this, I have to do all these things, the—these things, dot dot dot dot," and I was like, "You literal—your body can't. I hate to be the one to break it to you? But like." This is what I discovered, that like, no able-bodied person, like—this is

temporary. She's had her share of mental health issues, but like. But like, the concussion was the one thing that was like. Physically limiting for her. For the first time, and I was like... "You're gonna hate me for this, but congrats, you literally cannot. That's it. Period. Done. There are things you cannot do." And no one likes to hear that.

While allies could provide valuable emotional support, they were still only allies. Marge, like other participants, at times explicitly linked allies to "those who don't get it," or in this case, able-bodied people. Marge and Carol both struggled to relate to these "others." Even though both had experienced similar difficulties as their roommate or friend had, respectively, Marge and Carol considered some difficulties trivial, to the point of being normalized or even, in Marge's case, entertaining, since Marge had already come to terms with what her body could not do.

Participants all claimed that their bodies "decided" when participants needed to disclose pain to others, especially casual acquaintances and colleagues. Participants avoided disclosing their chronic pain when they did not feel it was necessary, but during moments of crisis, they either had to explain to companions what was happening to them or had to request a rest in order to prevent future pain. However, participants did not perceive a significant overall loss of agency because they still felt in control of how and to what extent they explained their chronic pain to their companions. In fact, two participants, Carol and Oletta, described feeling empowered by this disclosure. Carol explained:

I always feel like they're gonna judge me very quickly, and so yeah, I am pretty cautious about telling new people... You know, 'I can't keep up with you' and stuff. But... I think I'm becoming a little bit indifferent about it now, and I'm more of looking out for myself, so if I have to tell, just a new acquaintance I'm hanging out with, like, "we need to slow down." I feel... Um. I guess less embarrassed by it

and more looking out for myself— cuz I used to really try to keep up with people, and uh, it was only backfiring.

Oletta and Carol both claimed that at the beginning of their experience with chronic pain, they had tried to keep up with other people and, as a result, had pushed their bodies past their physical limits. Both also told me that they now realized their limits and respected them by telling companions that they needed to rest "now," before they breached their limits. Oletta and Carol were not only accustomed to disclosing pain, they were also proud of their ability to do so because it meant to them that they valued personal physical comfort over social conformity.

During interviews, participants reported being acutely aware of the difference between themselves, as people with chronic pain, and people with normalized bodies (although it is difficult to know how often or in what circumstances this awareness comes to the surface in their everyday lives). Because people with normalized bodies seldom noticed the acts and functions of their own bodies, they conversely did not perceive this difference to the same extent. Participants, however, were socialized into identities of chronic pain, and in some cases disability, through medicalized language. The acceptance of these identities only crystallized the perceived difference in embodied experience. However, as participants came to accept these identities, they also became more accustomed to or even empowered by disclosing their pain to people with normalized bodies. Thus the identities of chronic pain and disability did not necessarily disempower participants, even though the physical conditions of pain and disability restricted them.

Conceptualizing pain through established frameworks

If the mind is embodied, then meaning is grounded in bodily experiences—even reason and imagination are tied to the body (Johnson 2007, 11-13). Thus the ways in which people conceive of pain are grounded in bodily experiences of pain. There can be no one-size-fits-all pain assessment because individuals'

experiences are so different. Nevertheless, health practitioners, loved ones, and online communities of people with chronic pain demand standard ways of relating pain. How does one translate the untranslatable? According to Das (1997), pain “is not that inexpressible something that destroys communication or marks an exit from one’s existence in language. Instead, it makes a claim asking for acknowledgement, which may be given or denied” (70). Pain is an internal, personal experience, but it is possible to “touch” someone else’s pain by recognizing it.

Once a person has conceptualized their own pain, seeking to make meaning of their experiences, they may choose to share that pain with others. Two people with chronic pain might not necessarily relate to one another’s exact sensation of pain, but they could share the general experiences of living with pain. In contrast, two of my participants claimed that when talking to people who did not have chronic pain, they could only translate their pain through the framework of ability. These two participants claimed that such people do not know or care what chronic pain feels like, and only want to know how it impacts them personally: will the other person be able to go to the party with them, or help them build a bookshelf, for example. This difference—

between the individual and those with chronic pain versus those without chronic pain—can best be described as the difference between experiencing, empathizing, and sympathizing.

During the individual interviews, I investigated how participants related to three established frameworks of pain, the 1-10 pain scale (see Figure 1), the McGill pain questionnaire (Melzac 1975, 1987), and the Spoon Theory (ButYouDontLookSick.com 2016). The 1-10 pain scale is frequently employed in clinical settings, including the emergency room, and all participants were familiar with it. I asked participants if they used the 1-10 scale to describe their pain, then asked them to respond to two different representations of the 1-10 pain scale. The first 1-10 pain scale included an activity tolerance scale, and the second included examples or equivalents of pain relevant to each level. Both scales featured the facial grimace scale, which uses icons of faces with different expressions from happy to agonized, although only the second scale used a green-yellow-red color scheme coordinated to the faces’ levels of pain. Participants generally responded negatively to these faces. For example, Joshua remarked, “Can I even remember being the green guy?” Marge scoffed, “Freakin’ happy faces. Just feels like super inadequate,” and Patricia laughed and

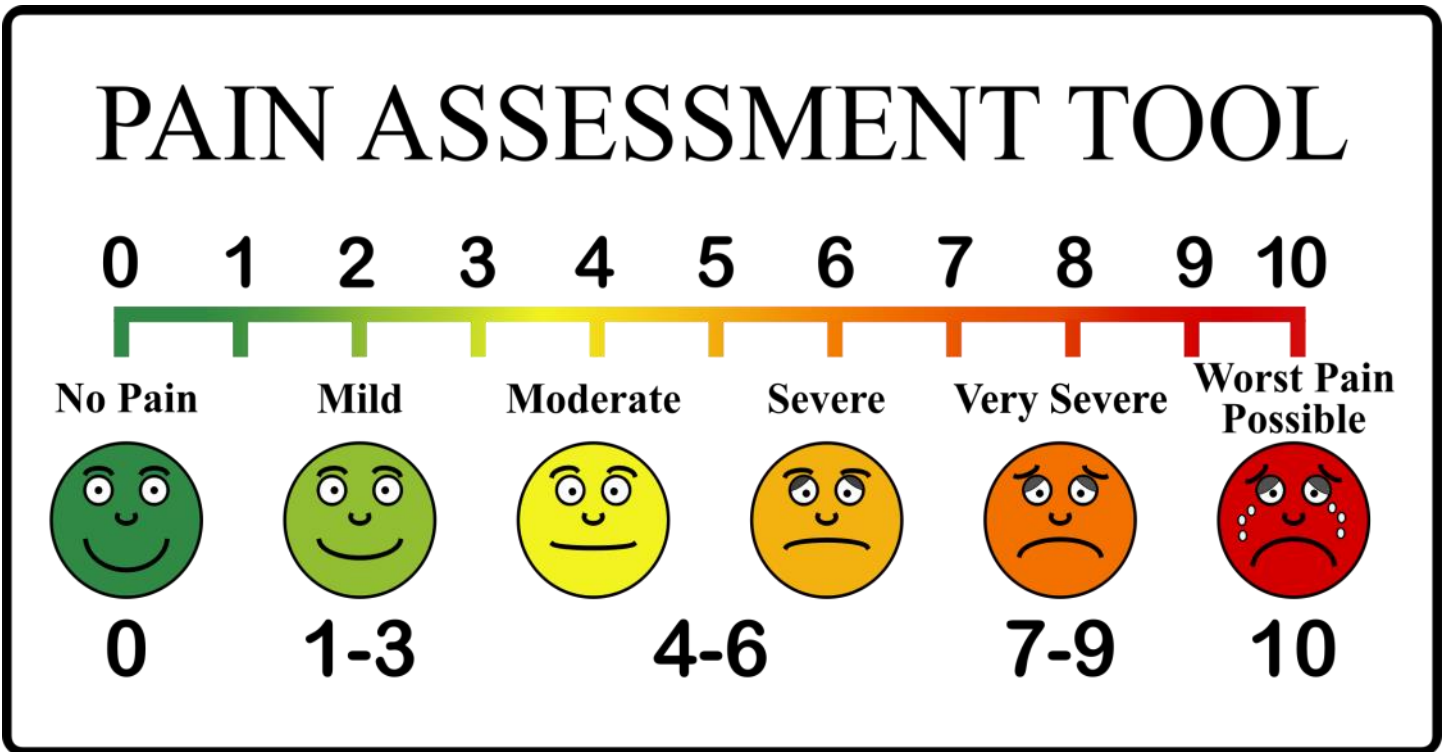


Figure 1: A typical 1-10 pain scale. Source: <https://openclipart.org/detail/238112/pain-scale-fixed>

admitted, “I think the faces are infantilizing.”

I next asked participants for their thoughts on the first representation’s activity tolerance scale, which participants viewed more favorably than the facial grimace scale alone. For example, Oletta was generally receptive to the activity tolerance scale, and most of her comments were positive. However, she had a few objections; at one point, she laughed and said, “Bedrest required, LOL. If we’re being honest, if I don’t wanna like, hate myself for the rest of the week, I need bedrest around here,” and pointed to a lower number on the activity tolerance scale. Oletta thus conceived of this part of the activity tolerance scale in a preventative manner, even if she considered most of the other levels accurate to her own experience. Patricia, on the other hand, appreciated the scale the most. She told me, “I also like the one, the activity tolerance scale? Um... Because that—that’s something that I’ve used to describe my pain to people who don’t experience chronic pain, because then they don’t have to actually understand my pain, they just have to understand what I can do at that moment with them. Um... So that’s useful to me.” Patricia directly related to the activity tolerance scale because, as both she and Joshua explained, people without chronic pain do not understand or care about the pain itself. Patricia and Joshua claimed that such people only want to know what Patricia and Joshua can and cannot do at any given moment.

I then showed participants the second 1-10 pain scale, which ranked pain levels by giving examples or equivalents of pain for each number and accompanying facial expression. When Oletta began to read the examples on the second scale, she initially accepted them, but soon objected. She read aloud:

Hurts just a little bit, broken fingers—broken fingers hurts just a little bit? I’ve never had a broken finger, but that freaks me out. [...] Whoa, that does not sound right. This is honestly—if someone showed me this scale of pain, I’d be super confused. Natural childbirth is only 7 to 8? Okay, once again. Okay, cracked head open—okay that makes sense. Knocked

unconscious—but if you’re unconscious, how can you feel it?

To Oletta, the examples were senseless or disturbing at best and misleading at worst. She clearly did not relate to this scale at all. Patricia, however, was the opposite. She said,

I like the bottom one? Where it talks about [Kate: broken bones?] Yeah, where it talks about broken bones. And it’s like yeah, like I agree, like. A broken finger is like a 2. Like, it sucks but I’m gonna forget about it. Um... And yeah, I would agree, like a 7 or an 8 is...like natural childbirth. Like that’s how I described my broken femur. Um. I have cracked my head open though and I don’t think it’s as bad as a 9 or 10. I think the femur was the worst thing. Um, but I feel like that particular pain scale, the one on the bottom? Is, um...a lot more realistic to people with chronic pain...than a lot of other pain scales. Like I like seeing that.

Patricia, unlike Oletta, had broken multiple bones multiple times. As a result, describing pain in terms of the bones broken made sense to her. Patricia’s and Oletta’s bodily experiences of pain directly impacted how they were able to relate to the second 1-10 pain scale.

I also asked my participants to respond to a version of the McGill pain assessment, which asks users to select adjectives, with pre-assigned numeric values, to describe their current pain (for instance, throbbing, pricking, gnawing, searing, aching, or radiating). The physician is then able to add the values together to determine the “total” value of the person’s pain. Three participants had not encountered the McGill before. Participants who responded positively to the McGill were generally those who had responded negatively to the 1-10 pain scale, and vice versa. For example, Marge initially said, “Oh, brightness, dullness, that’s interesting. That’s a lot more comprehensive. This looks like it was made by someone who actually like, understands what that means.” She concluded that she would like to use the assessment herself but reflected that

the results would probably be depressing because of her high level of pain. Oletta had seen a different version of the McGill and told me that she appreciated the other version, which included a diagram of the body that allowed her to circle the different parts where she experienced pain for different reasons. (Marge said that a doctor had once given her a body diagram and she circled the entire body, demanding, "Well, what did you expect?")

But while she and Oletta linked the McGill questionnaire to a better understanding of pain, Joshua and Carol rejected it as being too time- and labor-intensive for someone with high amounts of pain. Joshua, for instance, said,

This is something that I distinctly remember, actually. Because I remember not being able to figure it out. And, um, now I'll just say, I mean. No offense to the lovely people at McGill, but how do you expect someone in pain to do all of this? The face thing is better because you can just point, it doesn't take long. [...] It almost seems a little too complicated, this seems like a very, give you a very accurate idea? Of how someone's feeling. Like almost definitely. But. I just don't understand how you could expect someone who has...a lot of pain going on...to...answer this.

To Patricia, Carol, and Joshua, the quantitative immediacy of the 1-10 pain scale made it more useful than the qualitative descriptiveness of the McGill that Oletta and Marge preferred. While Joshua allowed that the McGill could provide a more accurate description of pain, he and Carol considered it highly inaccessible to the very people whose pain it sought to describe. And while Patricia found the descriptive adjectives useful to her personally, she said that only people with chronic pain would be able to make sense of them, meaning that the McGill would be inadequate as a standardized way of conveying pain.

I also asked participants about the Spoon Theory. The Spoon Theory is widely used in online chronic pain and chronic illness

communities. Created by Christine Miserandino (ButYouDontLookSick.com 2016), the Spoon Theory has become a popular way to describe chronic pain and chronic illness, specifically to healthy and abled individuals. On her website, Miserandino recounted an explanation to her best friend of her own experience with lupus. Miserandino picked up several spoons from a table, saying that she began every day with a set number of metaphorical spoons. Every activity, from getting dressed to cooking to cleaning, cost one spoon, until she reached a point where she had no more spoons and could either choose to end her day without completing all her desired tasks or take from tomorrow's reserve of spoons. People who use the Spoon Theory will often refer to "running out of spoons" or tell others that they "send spoons" rather than saying "get well."

Four participants knew of the Spoon Theory, and again, those who related to the McGill also related to the Spoon Theory, and those who related to the 1-10 scale did not relate to the Spoon Theory. Even though Oletta disliked the quantification of the 1-10 scale, she claimed to like the Spoon Theory's means of quantifying the depletion of her body's energy and stamina:

I would say it's useful for me because I know that I have so many things coinciding inside like, my body? So it's like—it's easier than like, I think if I had one, like one thing that was causing issues, I wouldn't necessarily have to like. Use like a qua—something to quantify it, like a spoon. But since I have so many different things, like it takes into account my mental health, my physical health...

Oletta found the Spoon Theory helpful because of its inclusiveness. She and Marge also enjoyed the social aspect of the Spoon Theory, which allowed them to be immediately understood by "those who get it" and created a sense of community among fellow users. Oletta, for example, explained that she includes #spoonie in some tweets so that people within the community, even if they do not know her well, understand her while "those who do not get it" miss the reference.

On the other hand, Patricia and Joshua disdained the Spoon Theory, calling it frivolous. For example, Patricia said:

I...I've heard of it. I know what it is. I'm glad that people feel empowered to use it, and that they like it, I think it's stupid. Um... And I think it's because...I'm just a stubborn asshole, like it's not anything wrong with the theory, I just...I either like, need to lay in a bed and die, or I will do something, I will figure out a way to do it.

While Patricia recognized the community value of the Spoon Theory, because she experienced pain in a binary manner, she did not conceptualize pain as a quantity of spoons that allowed her to complete certain activities but not others. Yet she liked the activity tolerance scale on the 1-10 pain scale, which served much the same purpose. Patricia's claim to be a "stubborn asshole" may have pushed her to disavow the popularly-used Spoon Theory even if she liked being able to tell people the activities she could or could not complete so that they would not need to try to understand her pain. Joshua was similarly blunt in his disregard of the Spoon Theory, even though he too conceptualized pain in terms of what he was and was not able to do.

Carol, with her relatively recent advent of chronic pain, admitted that she did not know many others with chronic pain and thus did not feel like part of a chronic pain community. She was the only participant who had not heard of the Spoon Theory. When I first described it to her, she told me that it felt extremely limiting, and as a student of economics, "Now I'm just thinking of like, really definitely cost-benefit things that I can get." She sounded almost horrified at such a concept of pain involving weighing the risk of pain with the reward of the activity. However, when she saw how Oletta and Marge used the Spoon Theory to both describe their pain and situate themselves within a chronic pain community, she said that she had not understood the Spoon Theory from how I explained it, and she now liked it.

Of the three major established frameworks of pain, no one framework resonated with all participants, nor did all participants come to a consensus about any one framework. Participants judged each framework on how useful it was to them, based on how their bodily experiences of pain shaped their concepts of pain, and how readily it conveyed pain to others. In a few cases, participants found a framework to be personally useful but interpersonally useless. While all frameworks included similar elements, participants nevertheless responded very differently to the context in which each framework employed those elements. Participants' embodied concepts of pain, and in some cases, their personality, impacted the ways in which they related to these contextually-situated elements. The 1-10 pain scale, McGill pain questionnaire, and Spoon Theory were each described as quantitative at times, but the McGill and Spoon Theory were perceived to be more qualitative than the 1-10 scale, and all participants preferred one perceived group over the other.

Conceptualizing pain through unestablished frameworks

In addition to the established frameworks of pain that participants used, they also conceived of their pain in other, non-standardized ways. For example, Joshua and Patricia conceived of their pain in terms of activities they could and could not do, ostensibly because people without chronic pain only cared about physical ability in the moment. Likewise, Oletta told me that she sometimes framed her pain in terms of what she needed, claiming that she tells her doctor that she needs a medication or that she tells her friends that she needs to sit down. To uncover how participants conceived of their pain outside of established frameworks, I asked them during their individual interviews if they could describe their current pain to me and if they imagined anything while in pain. Many of my focus group prompts also targeted how participants conceived of their pain, such as "My chronic pain is a lack/surplus of..." and "If I were a superhero, my power would be.../my name would be..." Participants' answers revealed the wide variety of ways in which they conceptualized their pain.

Multiple participants claimed to imagine pain as the color red, and explicitly cited medication advertisements that represent pain as red spots on the body to be the reason for this visual conceptualization. Oletta, Patricia, and Joshua also visualized pain relief. Oletta was very embarrassed about her visualization, telling me multiple times that it was “weird” before saying that “sometimes my back muscles are like in a lot of pain, I’ll like just imagine myself, like—this is so gross, but like, just like, cutting like my muscles out. It’s a really gross like, depicter, but like, I’ll imagine like that, just for some reason in my mind, it like, thinks that that’s a solution, even though I know, like that would obviously be super painful.” She returned to this visualization several more times, once adding that she imagines being able to scrape “junk” off of her back muscles, reminding me of the surgical removal of cancer.

Joshua was less abashed when he told me, “I always imagined that I could just, like. Pull something out, ya know? Like maybe... It’s a little centipede in there, that’s causing all the pain, and if I just reached in hard enough, I could just grab it and just pull it right out, ya know?” He then modified his description, adopting Oletta’s ashamed tone:

Do you know what it is, and this is really embarrassing, but ya know what, everyone in their—ya know. When they come home, they’re. In the privacy of their own home, you know, sometimes you got a booger, and you pull it out, right? You know you got a really, really really big one, it’s making it hard for you to breathe? And like you can feel it, and so you just go into the bathroom, and just—pull the sucker out, and wash your hands, you know, it’s all good. And that’s such a satisfying feeling, right? Same thing. I just imagine, I’m just gonna grab it, and I’m just gonna pu-u-l-l it out, it’s gonna feel so nice when it’s outta there, it’s gonna be great.

Both he and Oletta seemed to derive much satisfaction from these visualizations, even though both qualified that the visualizations

were “weird,” “gross,” and “embarrassing.” Even though Oletta prioritized physical comfort over social conformity when she told friends that she was in pain, her pain visualization still operated within a framework of what was and was not normal and socially acceptable. Additionally, Oletta and Joshua imagined pain as a tangible and unpleasant thing—cancer-like “junk,” a centipede, or a booger. By visualizing pain as something physical and bounded, they could better imagine removing it from their bodies. As Oletta pointed out, even though such visualizations could never become reality—pain cannot simply be cut from the body when the entire body is chronically in pain—imagining such scenes is a form of relief in and of itself.

Patricia’s visualization was heavily grounded in her own long experience as a ballet dancer, a childhood activity that she knew she and I shared. She said that for her, visualization was “a big part of. How you think about your posture, and your. Um... Your stretching? When you’re doing ballet? So, when I’m trying to stretch out my back, I’ll think of like a rubber band. Or the thing that my teacher drilled into me when I was little, which was like, ‘Imagine that there is a string, connecting your head to the top of the ceiling, bluh bluh bluh bluh bluh.’” However, as she pointed out, she did not visualize pain itself, but merely the relief of it. Since her visualization did not involve the removal of a tangible and unpleasant thing, she did not derive any satisfaction from the visualization itself. Instead, she used it as a tool to help her decrease pain, as dancers use such visualizations as tools to improve their posture or flexibility. Patricia also pointed out that, as a ballet dancer, she had been taught that pain is beauty because dancers must push themselves to the breaking point to create art. As a result, she dealt with her chronic pain in the same way, as a constructive pain that resulted from necessarily pushing herself. She told me that the absence of a tangible imagined pain said more about the way she emotionally processed pain than anything else, and she confessed to me that pain is the one thing she believes she does not process.

For the focus group, I included the prompt, “If I were a superhero, my power would be.../my name would be...” because I had hoped to

encourage participants to think of their pain in a more empowering lens, framing what they had been able to overcome as superpowers. Yet after I read the prompt aloud and gave my own personal example, the next speaker, Oletta, interpreted the prompt as superpowers we would like to have in order to overcome our pain. Carol and Marge followed her example and answered the question in the same way. Rather than try to “correct” participants’ answers by guiding them to answer within my intended parameters, I allowed them to continue with the answers apparently more relevant to them. As an anthropologist, my ideas of agency and empowerment did not always align with participants’ interpretations of their own experiences, demonstrating the importance of member checking.

Because of the inadequacy of established frameworks of pain such as the 1-10 pain scale, McGill questionnaire, and Spoon Theory in capturing and conveying pain, participants conceived of their pain in other ways. These conceptualizations were also grounded in participants’ bodily experiences including but not limited to pain. While visualizing pain as a tangible thing that could be removed from the body provided minor relief to some participants, they also felt ashamed at what they described as “weird” and “gross” visualizations that broke with social conventions of polite conversation. Other past experiences, such as being a dancer, also influenced how participants perceived and responded to their pain. The imposition of any one framework, whether one newly created by the researcher or one previously established and widely used, is not necessarily useful to participants if it does not resonate with their embodied experiences of pain.

Conclusion

When I showed Patricia the second 1-10 pain scale with its examples, we found that we were at an impasse. Having broken multiple bones at multiple times, she affirmed that the scale’s classifications of bone breaks made sense to her. I admitted that I had never broken a bone—earning myself a look of jealousy—and therefore could not relate to the examples. The only example that I had personally experienced,

“Rheumatoid Arthritis hands swollen 2-3x normal size,” seemed grossly understated to me, which I told Patricia. She reflected, “I don’t understand...like how RA feels. And like you don’t—like it’s different kinds of pain. So even though we can both sit down and say like, ‘I’m in pain, all the time, it sucks.’ Like... I don’t—like—is it more or less than what’s described on there? I don’t know, you know?” Embodied pain is specific to every individual.

Different sources of pain can cause it to be throbbing, pricking, gnawing, searing, aching, radiating, or any of the dozens of other words provided by the McGill pain questionnaire. Pricking pain cannot be translated to aching pain; they are two fundamentally different experiences. Those in pain struggle to relate their pain to others, and it is only the mere presence of pain that they can share:

Where is my pain—in touching you to point out the location of that pain—has my pointing finger—there it is—found your body, which my pain (our pain) can inhabit, at least for that moment when I close my eyes and touch your hand? And if the language for the inexpressibility of pain is always falling short of my need for its plentitude, then is this not the sense of disappointment that human beings have with themselves and the language that is given to them? (Das 1997, 70)

People can witness each other’s pain but can never fully understand it. Yet this untranslatability lies not in the words that do or do not exist to describe pain. Instead, it lies in the irreconcilability of the different ways in which people conceive of pain based on their bodily experiences. Pain originates in the body and is perceived by the mind, but because the mind is so grounded in the body, pain cannot be understood outside of this embodied context.

People with normalized bodies are by definition not hyperaware of the acts and functions of their bodies, and therefore have comparatively limited concepts of pain compared to people who have chronic pain.

The group of “those who do not get it” thus encompasses those who do not understand the physical and emotional toll of chronic pain. While allies can comfort people with chronic pain, the latter know that allies cannot understand this physical and emotional toll. And although others with chronic pain may generally empathize with the constant presence of pain, they do not experience that pain within their own bodies.

Even for those who have chronic pain, the 1-10 pain scale without an activity tolerance scale may not be commensurate between two people—one person’s “four” may not be the same as another person’s “four.” An individual’s conception of where and why one level ends and another begins resides solely in their mind. It is not unreasonable to expect that these conceptions can change over time within an individual, as most people with chronic pain were once those without. Despite any names or numbers that we may assign to it, pain cannot be adequately conveyed outside of the body, as an individual’s pain is relative only to itself. Ultimately, I suggest that it is the shared understanding of the physical and emotional toll, rather than a shared embodied concept of pain, that people with chronic pain seek in communities and support networks of chronic pain and illness.

References

- Ahearn, Laura. 2011. *Living Language: An Introduction to Linguistic Anthropology*. Hoboken, NJ: Wiley-Blackwell.
- Ahmed, Sara. 2007. "A Phenomenology of Whiteness." *Feminist Theory* 8(2):149-168.
- Anderson, Benedict. 1991. *Imagined Communities*. New York: Verso.
- Bhabha, Homi. 2004. "DissemiNation: Time, Narrative and the Margins of the Modern Nation." In *The Location of Culture*, 199-244, 2nd ed. New York: Routledge.
- Bucholtz, Mary and Kira Hall. 2005. "Language and Identity." In *A Companion to Linguistic Anthropology*, edited by Alessandro Duranti, 369-94. Hoboken, NJ: Wiley-Blackwell.
- ButYouDontLookSick.com. 2016. "The Spoon Theory written by Christine Miserandino." Accessed September 19. <http://www.butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/>
- Das, Veena. "Language and Body: Transactions in the Construction of Pain." In *Social Suffering*, edited by Arthur Kleinman, Veena Das, and Margaret Lock, 67-91. Berkeley: University of California Press.
- Derrida, Jacques. 1998. *Monolingualism of the Other: Or, the Prosthesis of Origin*. Trans. Patrick Mensah. Stanford: Stanford University Press.
- Hall, Stuart. 1997. "The Work of Representation." In *Representation: Cultural Representations and Signifying Practices*, 15-62. London: Sage Publications.
- Johnson, Mark. 2007. *The Meaning of the Body: Aesthetics of Human Understanding*. Chicago: The University of Chicago Press.
- Johnson, Rae. 2015. "Grasping and Transforming the Embodied Experience of Oppression." *International Body Psychotherapy Journal: The Art and Science of Somatic Praxis* 14(1): 80-95.
- Jordan, Brigitte. 1993. *Birth in Four Cultures: A Crosscultural Investigation of Childbirth in Yucatán, Holland, Sweden, and the United States, 4th ed.* Prospect Heights, Illinois: Waveland Press.
- Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books.
- Krummel, Miriamne Ara. 2001. "Am I MS?" In *Embodied Rhetorics: Disability in Language and Culture*, edited by James C. Wilson and Cynthia Lewiecki-Wilson, 61-77. Carbondale, IL: Southern Illinois University Press.

- McRuer, Robert, ed. 2006. *Crip Theory: Cultural Signs of Queerness and Disability*. New York: NYU Press.
- Melzack, Ronald. 1975. "The McGill Pain Questionnaire: Major Properties and Scoring Methods," *Pain* 1:277-99.
- Melzack, Ronald. 1987. "The Short-Form McGill Pain Questionnaire," *Pain* 30:191-197.
- Merleau-Ponty, Maurice. 2002. *The Phenomenology of Perception*. Trans. Colin Smith. London: Routledge.
- Merskey, Harold and Nikolai Bogduk, eds. 1994. *Classification of Chronic Pain: Descriptions of Chronic Pain Syndromes and Definitions of Pain Terms, 2nd ed.* Seattle: IASP Press.
- Miles, Ann. 2010. "Ecuadorian Women's Narratives of Lupus, Suffering, and Vulnerability." In *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness*, edited by Lenore Manderson, Carolyn Smith-Morris, 113-30. New Brunswick: Rutgers University Press.
- Prakash, Gyan. 1999. *Another Reason: Science and the Imagination of Modern India*. Princeton: Princeton University Press.



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