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## Chronic pain: An invisible disease in Western biomedicine



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Chronic pain operates in an uneasy harmony with modern biomedicine. Biomedicine usually follows the pattern of diagnosing the problem, treating the problem with drugs or other Western treatment

modalities, and curing the problem as quickly as possible. The idea of an ambiguous and incurable problem does not fit within these standards. Therefore, biomedicine does not give legitimacy to chronic pain, and it has largely been rendered invisible.

Arthur Kleinman and colleagues were among the first to bring attention to the “uncertain status of chronic pain in biomedicine.”<sup>1</sup> This idea is expanded upon by Marja-Liisa Honkasalo and Jean Jackson in their discussions of chronic pain as a liminal, stigmatized state.<sup>2,3</sup> This framework is useful in studying ethnographic research on chronic pain conducted in the United States, Finland, and Micronesia, and helps show that chronic pain is made visible—made real—through the narratives of those who experience it as well as its impact on the social worlds of chronic pain sufferers.

### The biomedical delegitimization of chronic pain

Some argue that all types of pain can be understood from a neurophysiological standpoint.<sup>4</sup> However, to

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utilize this biomedical perspective is to ignore the “social, psychological, and cultural factors...that also need to be considered.”<sup>4</sup> These social, psychological, and cultural factors can be helpful in distinguishing acute and chronic pain. While acute pain is usually seen and acknowledged by others in the community, the opposite is often true for chronic pain, which has diminished public visibility over time, even as the individual’s suffering continues.

Chronic pain is something that “alienates the person from the environment, rather than increasing their connection to other people.”<sup>4</sup> Chronic pain is more private, and more stifled within the sufferer.

The biomedical framework operates under the methodology of identifying symptoms, treating them, and ultimately have the symptoms disappear. Within this context, pain is often seen as a symptom that can be treated and mitigated by over-the-counter analgesics. Acute pain, is accepted within the biomedical context because it serves a biological purpose: to “[protect] us from further harm.”<sup>5</sup> The alienating, longitudinal, and hard-to-treat nature of chronic pain makes this concept uniquely difficult to understand within the context of biomedicine.

Kleinman describes the status of chronic pain in biomedicine as “baffling to clinicians...[because] its course and outcomes do not conform to any known biochemical and mechanical processes.”<sup>1</sup> Honkasalo contends that accepting the idea of chronic pain as a disease within the biomedical framework is in itself ambiguous, because it lacks the “visible signs necessary for diagnosis.”<sup>2</sup> Commenting more broadly, writer and pain researcher David Morris describes today’s chronic pain epidemic as one rendered invisible by modern biomedicine. Not only does it appear to serve no biological purpose, it is simply “commonplace and nonfatal...failing to convey the macabre glamor of deformity, contagion, and imminent death.”<sup>5</sup>

The ambiguous origins and the unmarked lengths of time in which chronic pain afflicts individuals make it hard to define in the biomedical context. Through his ethnographic work, medical anthropologist, Byron Good comments that chronic pain is much more likely to be accepted if a biomedical origin can be identified.<sup>6</sup> Without it, chronic pain lacks legitimacy. The delegitimization of chronic pain as an acceptable, real concept also delegitimizes those who suffer from it. Honkasalo describes biomedicine as providing a “moral code”<sup>2</sup> that chronic pain simply fails to meet.

Kleinman criticized the notion of considering chronic pain within a biomedical framework to begin with. They

point out that, “The experience of chronic pain is fundamentally intersubjective...profoundly [affecting] the lives of the family, intimate friends, co-workers, and even at times the caregiver...[which] in turn shape the experiential world of the sufferer.”<sup>1</sup> Thus, while biomedicine fails to legitimize chronic pain, it may also fail to be a meaningful framework through which to analyze chronic pain.

It can be useful to conceptualize how chronic pain sufferers are at odds with the traditional role of the sick patient. Jackson brings to light the temporal condition of Parson’s definition of the sick role, noting that “it is legitimate only for a period of time.”<sup>3</sup> Because chronic pain sufferers fall outside the traditional definition of the sick role through their ambiguous and longitudinal pain, they are further delegitimized in the eyes of outside observers. Often, chronic pain patients are seen more as pains to their loved ones and their physicians rather than patients—this is something that patients recognize.<sup>3,5</sup> As one patient comments, “after a while, no one believes you, not even [your] wife.”<sup>3</sup>

While chronic pain has largely been made invisible in biomedicine, it is still very present and visible to the sufferer.

### Chronic pain as a liminal, stigmatized state

Part of what makes chronic pain so difficult to be understood from a biomedical context is its spatial and temporal ambiguity—where the origin of pain is, and how long it will last. Honkasalo and Jackson consider chronic pain a liminal state.<sup>2,3</sup> In other words, chronic pain can be viewed as an in-between of statuses, a “process of transition.”<sup>2</sup>

However, because it is unknown how long one will stay in this in-between—how long the chronic pain will persist—the liminal nature of chronic pain can redefine one’s social world. Honkasalo goes so far to describe the stability—or lack thereof—of people with chronic pain as an “interstructural state.”<sup>2</sup> This is characterized by “chronic ambiguity” across multiple domains, which destabilizes the social world of the sufferer.

Jackson elaborates on this contending that the liminality of chronic pain also results in its stigmatization and therefore an othering of those who suffer from it.<sup>3</sup> However, Jackson also contends that this stigmatization is distinct from the classic definition put forward by Goffman, in which stigma leaves an indelible mark on a person.<sup>7</sup> To Jackson, the “lack of a visible mark...[creates] the conditions for stigmatization.”<sup>3</sup> These conditions include questionability regarding the reality of chronic

pain; perceptions that the sufferer's complaints are immature and unwarranted; and the idea that chronic pain is largely, if not purely, psychogenic. Many of Jackson's interlocutors express annoyance at the invisibility of their pain, wishing it could be made visible through something like a cast or a pacemaker.<sup>3</sup>

The concept of chronic pain as a liminal state which destabilizes the everyday life and causes stigmatization of the sufferer reshapes his/her social world. Honkasalo writes that chronic pain results in a reorganization of the world—the pain affects space, time, and direction. This is illustrated through the experiences of chronic pain sufferers across cultures, from the U.S., to Finland, to Micronesia.

### Similarities and sociocultural differences

Good explores the story of one of his interlocutors, Brian, whom he met through a study on chronic pain in the U.S. He highlights Brian's early childhood narrative as a potential instigator of his later chronic pain, detailing his brief abandonment by his parents when he was only two-years-old—an event he does not remember but claims irreversibly damaged him—as well as the anxiety, depression, and chronic pain that plagued him since adolescence. The early changes in Brian's social world, adversely impacted his sense of self, and according to Good, can be held partially responsible for his chronic pain. This pain “shapes his world to itself” in a way that “[threatens] the objective structure of the everyday world in which Brian participates,”<sup>6</sup> explains Good.

Brian's chronic pain makes him feel like he is not in control of his own body, that there is a “demon, a monster...lurking around banging on the insides of [his] body, ripping it apart.”<sup>6</sup> This stark description shows how Brian has imposed a more tangible origin to his chronic pain in an attempt to create a biomedical justification for his illness. Brian latches onto the biomedical diagnosis of temporomandibular joint disorder as a means to explain his chronic pain, though this diagnosis in and of itself, is not completely fruitful in solving the pain.

Going along with the idea of not feeling in control of his own body, Brian comments that his pain experience distorts his understanding of time. Good describes Brian's experiences powerfully, noting that for Brian, “time caves in. Past and present lose their order. Pain slows personal time, while outer time speeds by and is lost.”<sup>6</sup> The idea of chronic pain altering one's sense of temporality and causing someone to lose grounding in their life is troubling and shows the extent to which pain can warp one's social world.

Honkasalo explores the relationship between chronic

pain and an individual's social world in Finland.<sup>2</sup> Like Brian, the Finnish also conceptualize chronic pain as something that is outside of their body, an intruder of sorts. However, the cultural context of the pain experience in Finland is significant because it impacts the way chronic pain is experienced and dealt with by those who suffer from it. Honkasalo introduces the Finnish proverb, “The one who complains becomes a prisoner of his own complaints,” to describe the unacceptability of complaining in Finnish culture.<sup>2</sup> It is preferable to suffer in silence.

Honkasalo also notes that the Finnish often feel shame and weakness as a result of chronic pain. These feelings stem from Finnish values of honesty and autonomy: physicians may cast doubt on a patient's honesty, and chronic pain can often result in the sacrifice of personal independence. This makes “[people] feel smaller, meaning that they lose social identities and spaces...[and] removes one's robes of identity—one's social roles and positions,”<sup>2</sup> explains Honkasalo.

One of Honkasalo's interlocutors, Matt, claims that he has incorporated his chronic pain into his sense of self and his new social identity. Another, Annika, refuses to incorporate chronic pain into her identity, but acknowledges that her pain makes her feel like she is walking the line between being ill and being healthy.

C. Jason Throop explores the chronic pain experiences of residents of the island of Yap in Micronesia. Similar to the Finnish and the Americans, the Yapese also express their pain as something that is separate from them, describing their pain as something that “exists” or “came to [them].”<sup>8</sup> However, social and cultural aspects of Yapese life—especially with regard to their notions of suffering and morality—uniquely shape their pain experience. Pain in Yapese culture can be understood as either “an unwanted dysphoric experience in terms of ‘mere-suffering’ or as a virtue...in the context of ‘suffering-for.’”<sup>8</sup>

For the Yap, having a directionality and purpose to one's suffering can transform it from ‘mere-suffering’ to ‘suffering-for’, which paints the suffering as noble and virtuous, two highly regarded qualities. Throop experiences this in his conversations with his interlocutors, who claim that they were able to reinterpret their pain with regard to “core cultural understandings of what it means to be a good person and to lead a good life.”<sup>8</sup> In fact, it seems that achieving this meaning behind suffering and chronic pain is something that the Yapese should strive towards.

In this way, Throop's findings differ from those of Good's and Honkasalo's. The Yapese seem to have a “morally valenced” opinion on pain and suffering,<sup>8</sup>

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making meaningful suffering a virtuous and moral thing. In contrast, the American patient describes his chronic pain as something that is demonic and outside of his control, and the Finnish describe their chronic pain as at odds with their cultural values.

In all of these scenarios, chronic pain puts sufferers in a liminal state that can certainly subject them to stigmatization. Chronic pain also reshapes the social world that the sufferer exists in. However, the social world one lives in also impacts the way one experiences chronic pain. Because one's social world is uniquely shaped by the cultures and conditions one grows up in, there will also be sociocultural specificity to one's chronic pain experience.

### A liminal state

An affliction that does not fit neatly into the mold established by biomedicine, those with chronic pain can be thought of to be in a liminal state—one characterized by temporal and spatial ambiguity, and which distorts the social world of the sufferer. The liminal and ambiguous nature of chronic pain often results in stigmatization of the suffering individual, resulting in reduced visibility and increased otherization.

Ethnographic work across the U.S., Finland, and the Yap island of Micronesia reveals similarities and differences between how the experience of chronic pain alters the social world and how the social world affects the experience of chronic pain. From the desire to ascribe a biomedical origin to one's chronic pain in the U.S., to the Finnish values of honesty, autonomy, and silent suffering, to the Yapese moral ideal of suffering-for rather than mere-suffering, it is evident that the interplay between sociocultural background and chronic pain has significant effects on the individual experience of chronic pain sufferers.

Chronic pain simultaneously reshapes the social world of those affected by it through making pain their central reality and mutating their sense of self; however, the social world of chronic pain sufferers also affects the experience of chronic pain. The bidirectionality of this relationship alters the lived experience of the sufferer.

It is evident that even though chronic pain has largely been made invisible in the biomedical context, that does not make it any less real to the sufferer and those in his/her social world.

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