ETHICS SECTION

Review Article

Stigmatization of Patients with Chronic Pain: The Extinction of Empathy

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Abstract

Objective. To address how health professionals may inadvertently contribute to the stigmatization of patients with chronic pain.

Setting. Formulation and implementation of the Australian National Pain Strategy.

Design. Review of current concepts of stereotyping and stigma, consideration of their relationship to empathy, and how they might impinge upon the clinical encounter.

Findings. The extinction of empathy, which we refer to as “negative empathy,” can overwhelm health professionals, allowing the entry of negative community stereotypes of chronic pain sufferers and add to their stigmatization. Prevailing dualistic frames of reference encourage this process.

Conclusion. Greater awareness by health professionals of their own potential, often inadvertent, contribution to the stigmatization of their patients with chronic pain may serve as a basis for an expanded model of clinical engagement.

Key Words. Chronic Pain; Stereotyping; Stigma; Empathy

Introduction

Why is pain, something invisible and experienced by everyone—and therefore unlike the kinds of characteristics that usually lead to stigmatization—so often stigmatizing in its chronic form? [1]

The task of removing the stigma from those with chronic painful conditions is given a high priority in Australia’s National Pain Strategy (NPS) [2]. To attain this objective, the NPS outlines important goals, which include changing community attitudes toward people with pain (such as disbelief), as well as targeting health professionals and third-party providers by providing them with educational programs to raise awareness that physical, psychological, and environmental factors may all worsen the pain experience [2].

Given the increased scientific understanding of the neurobiology of nociception and the ready availability of a biocultural framework for evaluating pain, it seems paradoxical that stigmatization of the person with chronic pain persists in Australia. Perhaps Shah and Diwan [3] were correct when they considered that the role of stigma “is a fundamental yet unexplored issue as a barrier to adequate chronic pain treatment.”

In this article, we explore the issue of stigmatization of pain sufferers and suggest that one of the principal reasons for this is the failure of health professionals to appreciate that their own clinical reasoning and behaviour, which are likely to be based on entrenched dualistic thinking, can contribute to this process.

Concerning Stigma

In Judeo-Christian societies, stigmatization harks back to Biblical times when, as it is said: “the Lord set a mark upon Cain” (Genesis 4: 15). Although there is no record of the nature of this mark—and its significance has been
debated—tattoos and brands burnt into the skin (literally, stigmata) were used by societies to single out those who had been disgraced in some way or were of lowly status, such as slaves.

Over the centuries, diverse personal characteristics, such as the lesions of leprosy, the behavior of those with mental illness and even skin color or difference thereof acquired a stigmatic status at particular times and in particular societies.

Sociologist Erving Goffman [4] defined stigmatization as a process by which the reactions of a community to such specific personal characteristics reduce a person’s identity “from a whole and usual person to a tainted, discounted one,” causing that person to be discredited, devalued, rejected, and socially excluded from having a voice [5].

Stigmatization and Chronic Musculoskeletal Pain Syndromes

Examples of medically controversial painful conditions that have been associated with stigmatization of sufferers include railway spine [6] and occupation neurosis [7] in the 19th century, and in the 20th century, repetitive strain injury [8,9], “whiplash” [10], nonspecific low back pain [11], and fibromyalgia syndrome [12,13]. Each of these conditions, for which no identifiable organic pathology could be found to explain the ongoing pain and disability, generated lengthy debates in the medical literature. Each debate resulted in psychogenesis (“in the mind”) becoming the default interpretation. In fact, such dualistic thinking has long characterized Western medicine.

Dualism and the Cartesian Legacy

Dualism refers to any theory that endorses an ultimate distinction of nature between two kinds of things [14]. In the context of chronic pain, the dominant discourse of medicine still pays homage to the body–mind dualism attributed to 17th century philosopher Rene Descartes [15]. Human beings were said by him to consist of a mind or soul (res cogitans), which was distinct from an extended body (res extensa). Descartes regarded the body exactly as he framed the world, as a mechanism, and his idea of a disembodied mind seems to have shaped “the peculiar way in which Western medicine approaches the study and treatment of disease” [16]. This axiomatic formulation (that is, one taken as a self-evident truth) remains influential in Western medical theory [17], by providing physicians with a seemingly universal and objective scientific frame of reference.

When seen through this Cartesian dualistic frame, pain suffers appear to a clinician either as a disordered bodily machine or as a disturbed mind. Because Western medical practice privileges “objective” evidence of bodily lesion over a subjective claim such as being in pain, the absence of evidence of a “disordered machine” defaults to an inference of a “disturbed mind.” When a patient’s pain is framed in this way by the clinician, there is little chance for meaningful negotiation between the two parties.

The scientifically inappropriate imputation of a mental disorder upon the person in pain can be a potent cause of iatrogenic stigmatization, not only because it invokes another stigma—that of the “weak mind”—but also because such mislabeling can lead to inappropriate treatment and thereby promulgate poor treatment outcomes.

The dualistic approach to pain stands in stark contrast to the scientific revelations of neuroplasticity that provide plausible neurobiological explanations for complex sensory and motor phenomena that would once have been dismissed as residing in the mental domain [18,19]. However, until conceptual frames, other than dualism, have been developed to cope with this complexity, the default to “psychological” by clinicians craving the certainty of a demonstrable “lesion” will continue to perpetuate this source of stigmatization.

Stereotyping and Labeling

Although stigma always carries a negative connotation, stereotypes can have positive, negative, or even neutral attributes. According to Bem [20], stereotypes function as “thinking devices” (heuristics) that help to avoid conceptual chaos by packaging the perceived world into a number of clearly defined categories [21]. In this view, they function to reduce confusion.

In the clinical context, stereotypic labels that represent agreed-upon patterns of disease allow health professionals to proceed to a differential diagnosis with relative certainty.

However, the philosopher Alfred North Whitehead [22] warned that a stereotype emanating from an external and often remote authority whose credibility is taken for granted might appear as a self-evident truth and to demand no further justification [20]. The influence of Descartes on current medical thinking is a good example of such a remote authority. But such broad categorization can come at a dangerous cost to society when negative stereotyping of a person or group of persons gives rise to prejudicial attitudes or behavior toward them [23].

Nexus of Stigma, Stereotype, and Labeling

Link and Phelan [24] identified a number of factors contributing to the phenomenon of stigmatization, the principal one being that of “difference” from a commonly accepted norm. Such “difference” becomes emphasized whenever an observer attaches to a person or group a categorical label that implies a negative stereotype.

The labeling process then serves to readily identify these “others” and to reinforce their separation from a socially constituted and accepted personal or group norm, thus separating “us” from “them” by conferring negative attributes on those identified as “them” [25].
As argued by Cronje and Williamson [26], an attempt to compare a patient’s self-report of pain and associated behaviors “against a population-derived expectation of what would be normal... reflects a de facto reliance on an irrational, indefensible, and inhumane folk idea.”

In the clinical context, stereotyping has been taken further by clinicians who have given the label of “heartsink” to patients deemed to be untreatable [27]. Compounding this, recently, the term “maldynia” (bad pain) has been introduced in an attempt to differentiate the pain itself experienced by these patients from pain that is deemed treatable, termed “eudynia” (good pain) [28]. Such expressly negative labeling of both patients and their pain can be attributed to the distress that such patients cause their clinicians arising out of the lack of diagnostic certainty [29].

Another factor in stigmatization, as identified by Link and Phelan [24], is power imbalance, whereby a dominant group becomes motivated to maintain the status quo in relation to those who are stigmatized, an action that can have important ethical, political, economic, and sociocultural repercussions [30,31]. In the clinical context, some (pseudo-)diagnostic labels can induce health professionals to make presumptions about the values, morals, and beliefs of patients that can unduly influence their clinical decision making [8,32]. Thus, stereotypes can function as moral constructions that might determine how patients are to be treated. They can even influence health care policy decisions [30].

In Western societies, physicians tend to be stereotyped as aggressive, intelligent, error-free healers and as scientists “battling at all cost, death, and disease” [21]. Another popular stereotype is that of the physician as “lone decision maker” [21]. Such stereotypes serve not only to reinforce the high status, reputation, and powerful influence of biomedicine in these societies but also reinforce the gulf between physicians and their patients, by privileging the view of the former.

When sufferers of medically unexplained disorders (such as chronic pain syndromes) cannot fit into the conceptual frame of biomedicine and therefore cannot meet health professionals’ expectations of what constitutes an illness, their personal legitimacy is undermined. Indeed, Werner and Malterud [33] suggest that the marginalization of those with these conditions may have become culturally embedded.

The consequences for people thus stigmatized can include loss of status as well as discrimination in a number of areas of their lives, such as access to health care, education, and income support. Most insidious of all is their loss of voice, termed by Habermas [34] as “communicative rationality.” They become literally “the unheard” and are publicly denied access to reciprocal engagement in a legitimate process of making sense of their predicaments.

Thus, at the heart of stigmatization of pain sufferers is a unilateral, imposed, and ostensibly “objective” interpretation of their pain by health professionals that precludes a reciprocal recognition and interpretation of stereotypes between the stigmatizer(s) and the stigmatized “other.” For as long as the stigmatizing group maintains its hold on power, attempts by the stigmatized to redress the situation will go unheard and unacknowledged.

**Empathy**

Could this development of stigmatization of chronic pain sufferers be related to “abnormal” empathy? Empathy denotes the capacity of an observer to sense the emotions and feelings of another human being [35].

Etymologically derived from the Greek empatheia for “in suffering or passion,” empathy implies a shared phenomenology wherein the observer is able to accept and understand the expression of another person’s experience because it reflects that observer’s own experience [35,36].

Edith Stein [37] suggested that empathy functions as a foundation for other acts that allow one to live in the experience of the “other” in an intuitive manner without the necessity of having to share that same experience especially at an emotional level, as is the case for sympathy [38].

Gallese et al. [39] discuss three levels of descriptive analysis for empathy: the phenomenological, the functional, and the neural.

**Phenomenological Level**

At this level, empathy refers to the sensing of experience that “enables us to directly recognize others, not as bodies endowed with a mind, but as persons like us” (p. 35) [39]. Actions, sensations, and emotions experienced by others become meaningful to us because we can sense them in and with others. The lived experience of pain is a good example of this process.

**Functional Level**

Barnes and Thagard [40] proposed a simulation theory of empathy as an analogical mapping process—of, for example, the mental state corresponding to an emotion—from one person’s situation to another. This mapping can be relatively automatic and unconscious, or it can depend on rule-based reasoning, making it more deliberate and theoretical.

Similarly, Gallese et al. [39] suggest that the ability to sense experiences is achieved through a simulatory brain modeling process that is used both to produce the experience and to decode it when the “other” is experiencing it. They refer to this process as simulated representation.
Neuroscientific research supports the existence of this process [38–41].

Neural Level

Evidence from neuroimaging studies accords with the phenomenological descriptions [38] and functional simulation proposals [39, 40], suggesting that the act of observing others who are experiencing pain triggers activation of neural networks that have been implicated in the direct lived experience of pain [42].

Importantly, these networks include those that have been found to accompany the observation of strong negative emotional expressions such as disgust, fear, anger, and sadness [42] as well as those associated with positive emotions such as joy [43].

Negative Empathy—The Mutation of Empathy

Health professionals have regarded empathy as a positive (“good”) attribute to be conveyed by them to their patients [44]. In this sense, empathy embraces both the experiential side (shared mutual phenomenology) and the prosocial behaviors (compassion) that can follow such understanding [45].

However, empatheia can also embrace strong negative emotions, such as those that may accompany a sense of personal danger [46] or hostility or prejudice, which could be directed at another person, especially when the legitimacy of that person’s distress is in doubt and their presentation challenges the observer’s expectations and conceptual framing of the world.

Empathy may then mutate into a projection of negative emotion and judgment toward the other person and even a conscious avoidance of compassion [47]. The term “negative empathy” is used here to refer to the extinction of empathy, a process that can be envisaged as being on a continuum. As many community-based stereotypes contain negative emotional valence [48], “negative empathy” on the part of their health professionals may be a component of the complex process of stigmatization of chronic pain sufferers.

Because clinical relationships are morally charged, those presenting with chronic pain are particularly at risk of being placed in “moral jeopardy” by their clinicians [49]. For example, should they fail to validate the effectiveness claimed by their health professionals, or should they challenge their clinicians’ power to control the relationship, patients may acquire negative labels denoting that their motives are suspect and the legitimacy or reality of their symptoms doubted.

Moreover, clinicians can themselves encounter the same lack of validation should their choice of treatment happen to conflict with the views of regulatory authorities [50]. The prescribing of opioid medications is a case in point [51].

The Remediation of Negative Empathy

Being flexible and changeable phenomena, stereotypes are potentially malleable at the individual level by any number of motivational, situational, and dispositional factors [52]. These include the clinician’s attitude to treating members of different cultural or socioeconomic groups, an appraisal of the context in which illness has occurred, and issues of gender.

The hope that clinicians might be able to banish stigmatization and negative stereotyping of their patients simply by decreeing that they are against such practices seems unrealistic. Perhaps a fundamental change in their collective worldview (paradigm) may be required, beginning with a critical examination of the conceptual frameworks they use.

The examination might commence with the binary terminologies that are readily found in the pain medicine literature: objective/subjective; normal/abnormal; eudynia/maldynia; body (nociception)/mind (somatization). Recognition of how these culturally embedded dualistic frames can work against patients’ best interests would be integral to a program that seeks not to perpetuate them. The stage would then be set for the emergence of theory with greater explanatory power [53].

The establishment of a new paradigm requires a critical review of previous theories and methodologies of interpretation, an exercise that has already commenced [54]. Moreover, the findings from neuroscientific investigations cannot be ignored as they compel clinicians to accept empathy in all its connotations as being of fundamental importance to the understanding and management of patients presenting with complex pain states.

Any new model of clinical engagement is both scientifically and ethically obliged to redress iatrogenic stigmatization and to discard the use of conceptual frames that perpetuate negative stereotypes. There must be no hidden rules of the consultation (such as those governed by power imbalance) that might hinder a rapprochement between clinician and patient.

In proposing what might be termed a social neuroscience paradigm for Pain Medicine, we invoke the concept of the intersubjective or “third space” [54, 55], which allows for many different ways of communication. In this “third space,” the experiences of both patient and clinician are shared and negotiated, neither being an “expert” compared with the other, thereby resisting socially or culturally determined stereotypes.

In fact, the “third space” has always been available to be shared during most clinical engagements, but negotiation becomes difficult and at times impossible when a metaphorical brick wall is built between the participants by the very conceptual frames they choose to employ.
Implications for Pain Medicine

The Australian NPS recommends a number of strategies to destigmatize the predicament of people with pain including, “Comprehensive education and training in pain management...will give health professionals an accurate conceptualization of pain and underpin care” [2]. The imparting to them of up-to-date neurobiological information is obviously important, but in our opinion, such programs need to first focus attention upon what is happening in the intersubjective space where health professionals first engage with their patients. Without a sufficiently negotiated sense-making engagement in this “third space,” any education may all too readily default to an imposition of the beliefs and attitudes of the clinician upon the sufferer.

The practicality of implementing a clinical engagement process such as the one we propose is far from straightforward, as shown by the difficulties encountered by those with similar aspirations for various chronic health-related arenas badged under chronic disease management [56]. It is now understood that the practices of social systems may need to be changed in order to promote health benefits at a population level [57,58].

Nevertheless, in our opinion, there is an urgency for Pain Medicine globally to construct a more ethical basis for its discourse with people in pain, one that utilizes insights from the burgeoning volume of neuroscientific research to an informed scientific methodology. This process will, in itself, tax the resources of the specialty that may not only parallel but be the envy of other medical domains. It is an applied ethical challenge, but it is also a most propitious time to commence it.

Pain Medicine is already committed to a radical reformulation of its clinical modus operandi. If pain clinicians and researchers reframe their conceptual models to incorporate neurobiological insights into the nature of empathy in the clinical encounter, they may be better placed to recognize stigmatization of their patients and to assist them toward achieving societal validation and inclusion.

References


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