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## Understanding stigma and chronic pain: a state of the art review

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### 1.

### Introduction

Chronic nonmalignant pain makes individuals prone to stigmatizing reactions of others. Stigmatizing responses are devaluing and discrediting responses of observers toward individuals who possess a particular characteristic that deviates from societal norms [16]. In the context of chronic nonmalignant pain, an absence of clear tissue damage deviates from the widely held biomedical model, which presumes that clear physiological pathology underlies the pain experience [22]. As well, most people understand pain through acute pain experience, which resolves relatively rapidly over time, leading to uncertainty about pain that does not diminish [48,63]. These and other processes must be understood to explain the substantial evidence that individuals with chronic pain commonly suffer from stigmatization by others [32].

The stigma associated with chronic pain are not well understood, with research lacking accounts of determinants, including underlying mechanisms in stigmatizing persons and details concerning vulnerabilities and the impact on stigmatized persons. Furthermore, prevention strategies for teaching how to deal with others' stigmatizing reactions and programs aimed at minimizing stigmatizing behaviors of observers are scarce. This topical review briefly describes the current understanding of stigma attached to chronic pain and has the intent to provide some thought provoking ideas and highlight future directions that will inspire both researchers and clinicians.

## **2. Stigma and chronic pain**

### **2.1. Stigma perceived by the patient**

Abundant evidence highlights the ubiquity of stigma in the lives of individuals with chronic pain [1,21,25,26,32,34,52,54,55,62,73,74,76]. Qualitative evidence indicates they feel not believed by romantic partners [32], relatives [52] and friends [73]. They believe practitioners think their pain is exaggerated [55] or imagined [76]. They feel blamed [62], misled [74] and even report being dismissed by healthcare providers [21]. Stigma is also experienced in the

work environment where patients perceive hostility from their colleagues [30,50] and they report a lack of satisfying work rehabilitation [21,62]. Besides numerous qualitative studies, a few questionnaire studies suggest perceived stigmatization in patient groups, such as patients with chronic facial pain [41], patients with fibromyalgia and rheumatoid arthritis [38,44], and patients with somatoform pain disorder [24].

## **2.2. Stigma in the eye of the beholder: public stigma**

Observers tend to react with uncertainty and confusion to patients whose pain is not clearly medically understood. Consistent with the perception of stigma from various parties described above, individuals in the general population [6,18,20,68], medical students [7], nursing students [30], nurses [71], internal medicine physicians [69], physiotherapists and general practitioners [19] attribute lower pain to patients when their pain does not have a clear basis in tissue pathology. Further, people in the general population and healthcare practitioners are less inclined to help [71], feel less sympathy [18–20], dislike patients more and suspect deception when there is no clear medical explanation for the pain [18,19]. Also, nurses attribute lower pain to patients when the pain is chronic compared to acute [71] and the discrepancy between nurses' and patients' pain ratings are larger with patients with chronic pain than with patients with acute pain [72]. Thus, observers typically discount pain reports, take patients less seriously and express doubt about credibility [45,48] when the pain cannot be 'justified' by clear medical evidence and/or when the pain is chronic in nature.

## **2.3. Impact of stigma on the wellbeing of pain patients**

Although thorough research into the consequences of both perceived stigma and public stigma on the wellbeing of pain patients is lacking, preliminary evidence shows that the discounting responses of others are related to poorer physical and psychological wellbeing [38]. Patients have reported that stigmatizing reactions from others challenge maintenance of their sense of

self-esteem and dignity [76]. We suggest several processes that might account for this relationship.

First, people are not passive recipients of the stigmatizing reactions of others. There is variability in the impact of stigmatizing attitudes and reactions of others (i.e., *public stigma*) on personal wellbeing—some people display resilience and are not affected [16]. According to the stage model of *self-stigma* [11], others' stigmatizing behavior will be detrimental only when the stigmatized individual is aware of, agrees with and applies the stigmatizing attitudes to the self [10,11]. Qualitative research suggests that the lack of a clear diagnosis for the pain makes patients skeptical about the nature and reality of their own symptoms and, in consequence, question the credibility of their own pain [52,73].

Second, perceived unfairness might be another mechanism [33] whereby external inequities, such as stigmatizing reactions of others, influence patient wellbeing. Perceptions of unfairness reflect judgments that one's position is inferior to that of a similar other in a specific situation [51]. Perceived injustice has been related to lower wellbeing (e.g., depression), poorer rehabilitation outcomes and prolonged work disability in individuals with chronic pain due to injury [66,67] and depression and anxiety in individuals with fibromyalgia [60]. Finally, stigmatizing responses of others might also impact on the patient's wellbeing through medical decisions, such as an inadequate prescription of pain medication or through structural social processes, such as limited access to health care or fitness facilities.

#### **2.4. Underlying mechanisms for observer stigmatizing responses**

We propose some potential mechanisms underlying the stigmatizing responses of observers towards individuals with chronic pain. Stigmatizing behavior can be conceptualized as a special case of a range of possible reactions to people who are in pain [14]. Acute pain displays most likely to yield visceral reactions of empathy and sympathy include involuntary,

automatic expression, e.g., nociceptive reflexive withdrawal, facial expression or nonverbal vocalizations. Chronic pain expression is less likely to be reflexive or automatic; rather, it typically is either voluntary, conscious expression, e.g., verbal report, or actions ambiguous as to whether they are automatic or voluntarily controlled [49]. Purposive behavior tends to indicate higher level executive processing and planning, or personal intent to influence the situation motivated by appraisal of the social context [14,27]. When taken in contexts of commonplace and sometimes institutionalized beliefs that dissembling of chronic pain is commonplace, the absence of automatic pain behavior could lead to questions about credibility and would distance the person expressing pain from the observer. In line with this reasoning are the findings of Martel and colleagues that patients displaying protective pain behaviors are viewed as less likable than patients displaying other forms of pain behavior [46]. Patients reporting higher levels of pain severity [70] or particularly severe impact of pain on life quality relative to physical pathology appear particularly vulnerable to stigmatization.

As well, reactions to people in pain are not determined solely by input from the person in pain (“bottom up” sources), but “top-down” factors, such as personal beliefs, attitudes and relationships with the person in pain also affect judgments [28]. Tendencies to devalue individuals with chronic pain would be consistent with explanations of stigmatizing behavior based on evolutionary biology [40,53,61]. Consistent with hierarchical social structures in ancestral species and early hominins, people value others to the extent to which they are perceived as contributing to their personal well-being and the good of the community. In the context of chronic pain, the absence of a clear medical explanation for the pain or failure to fit with a narrow biomedical perspective based on acute pain (in contrast to more comprehensive models incorporating CNS and brain neuroplasticity) may lead to suspiciousness about the genuineness of the pain complaints [12,13,18,19] and may lead to devaluation of the other person. Sensitivity towards cues for social deception may protect observers from being

exploited by others [35]. In particular, the absence of a clear medical explanation for the pain might function as a threat for the observer regarding availability of reciprocity (i.e., the social exchange) to be expected from individuals in pain [35].

There is a substantial literature demonstrating that individuals stigmatize individuals from the “out group” [58]. “In group” people include those similar to the observer, e.g., kin, friends, age peers, whereas “out group” people likely include those with different skin colors, ideological persuasions, etc. In the context of pain, observers feel less empathy and less altruistic motivation towards members of social out-groups than members of in-groups [29,47] and the pain complaints of “out group” members tend to be discounted [65].

A further construct useful in understanding stigmatization arises from theories addressing attribution of causality—to what extent is the person judged personally responsible for their plight [23]. Perceived responsibility for the stigmatized behavior increases the rejection [15]. This is consistent with findings that observers attribute lower pain to patients who are considered responsible for their pain condition [17,68].

A final useful explanatory approach arises from the considerable research which indicates that healthcare practitioners often feel uncertain or unprepared to manage patients with chronic pain [56,63,64]. According to Blascovich and colleagues [3], increased uncertainty and a lack of familiarity with ‘stigmatized’ individuals comes at the cost of appropriate social interactions, which, in turn, might estrange clinicians from patients and prevent changes in observers’ attitude and familiarity with chronic pain patients.

### **3. Future directions**

Prevalence of adverse personal, social and economic consequences of stigmatizing behavior demands greater research understanding and innovative intervention strategies. While qualitative studies have identified an impact of stigma on chronic pain sufferers, theory-driven research is needed to extend understanding of the impact of perceived and public stigma, for

example, on depression, anxiety and activity limitation. As well, studies are needed that address mechanisms whereby stigma impact on the wellbeing of patients, for example, through self-stigmatization or perceived unfairness. More generally, a theoretical framework is needed to investigate stigma in general [31,42] and especially stigma with regard to chronic pain. A primary methodological problem has been heavy restriction of investigations of chronic pain stigma to self-reports; this is unlikely to fully capture the actual stigmatizing behavior of observers [16] or its impact. We note also the absence of studies of the impact of stigma on vulnerable patient groups, such as children, people with cognitive impairment and elderly adults. Finally, research focusing on stigma in caregivers of patients with pain is to our knowledge nonexistent.

The literature describes intervention strategies that address stigma at different levels: a) intrapersonal (e.g., teaching people with chronic pain how to deal with the stigmatizing responses of others through education or defusing cognitive and emotional distress engendered by prejudice), b) interpersonal (e.g., creating environments in which others respond in a less prejudiced manner, e.g., through enhanced intergroup contact) and c) structural (e.g., policy interventions) [9]. Evidence addressing the effectiveness of these strategies is, to our knowledge, largely lacking.

Given that professional healthcare providers have insufficient knowledge about the nature of chronic nonmalignant pain [75], or report feeling less effective and uncertain when treating patients with chronic pain [63], the first step would be to enhance knowledge of chronic pain through pain education [5,8,39,57]. Extending the narrow biomedical perspective on acute pain to the comprehensive biopsychosocial model would compel consideration of a broader range of determinants of pain related disability [2,5]. The focus on the biology of pain should be extended from concentration on narrow sensory specificity concepts of tissue pathology and nociceptive afferent systems to greater consideration of peripheral and central



neuroplasticity [59] and descending inhibitory control [4], which provide an understanding of the biological substrates of the cognitive/affective processes associated with the transition from acute to chronic pain [37] and self-regulatory processes [50]. Including the broad domain of multidisciplinary pain management strategies in the curriculum of medical and other health care students would make healthcare practitioners more confident about treatment of chronic pain and might decrease the social threat value of chronic nonmalignant pain [43].

Interventions are available that empower individuals to become more resilient towards the stigmatizing reactions of others [10]. Acceptance and Commitment therapy (ACT) aims at enhancing psychological flexibility, i.e., the ability to adapt to fluctuating situational demands, to reconfigure mental resources and to shift perspective and balance competing desires, needs and life domains [36]. Self-management strategies emphasize active participation in the multiple personal and social tasks involved in long term conditions [50]. In general, interventions that aim to increase effective management of medical encounters are needed, with a particular focus on coaching both patient and healthcare practitioner [39].

To conclude, abundant research indicates that individuals with chronic nonmalignant pain suffer devalued social status, but thorough, systematic research is lacking. This appears due to an absence of a clear theoretical framework, which would permit study of the sources of stigmatizing behaviors, the underlying mechanisms and their impact on the wellbeing of the stigmatized. Achieving this would contribute to development of interventions that target observers' stigmatizing reactions and enhance resilience and empowerment of those stigmatized.

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