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OXFORD

Special Article

Why Are Women with Fibromyalgia so Stigmatized?

ABSTRACT

Introduction. Many female pain sufferers with medically unexplained pain are at risk of being stigmatized in our Western society. Fibromyalgia is offered as the exemplar condition. **Aim.** To understand why these women are being stigmatized. **Methods.** A review of the recent literature was conducted with a focus on the perceptions of women with a diagnosis of fibromyalgia who have been stigmatized. **Results.** Three intertwined themes emerged as contributing to their stigmatization: moralizing attitudes, disbelief as to the reality of pain, and pain's invisibility. **Conclusion.** Given how embedded the factors responsible for the stigmatization of women with fibromyalgia in Western society are, the realistic prospects for addressing this issue are poor.

Key Words: Medically Unexplained Pain; Stigma; Fibromyalgia

Introduction

Stigma Attends Chronic Pain

Medically controversial painful conditions, those in which no pathology could be found to explain ongoing pain and disability, have generated lengthy debates in the medical literature. Such conditions include railway spine [1] and occupation neurosis [2] in the 19th century, and in the 20th century, repetitive strain injury [3], "whiplash" [4], nonspecific low back pain [5], and fibromyalgia syndrome [6]. Each debate has resulted in psychogenesis ("in the mind") becoming the default interpretation.

Recently, in commenting on the report of the Institute of Medicine, "Relieving Pain In America" [7], Carr [8] provided important clues to current stigmatizing attitudes when he provided three testimonies that, in his opinion, "eloquently convey the stigma experienced by nearly every patient with chronic pain."

> It has been hell. First, you have to find someone who believes you. (Testimony #135)
> Doctors don't recognize pain they cannot see or diagnose as a specific issue. (Testimony #314)
> The stigma is one of the biggest barriers. I have been treated like a lowlife by medical people when I disclose that I have chronic pain and use opioids for it. (Testimony #383)

These quotes exemplify three major themes that characterize the stigmatization of those experiencing pain: 1) the influence of moralizing attitudes, 2) frank disbelief as to the reality of their pain, 3) which, in turn, reflects pain's invisibility.

What Is Stigmatization?

Derived from the Greek, stigma originally referred to a visible bodily mark made by a pointed instrument, such as a stick. The mark was either cut or burned into the skin of criminals, slaves, or traitors in order to identify them as blemished or morally polluted persons, who were to be avoided or shunned [9].

In modern societies, the word has been applied to other personal attributes that are generally considered to be shameful or discrediting. Sociologist Erving Goffman [10] 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." The person being stigmatized is said to differ from others by possessing an undesirable attribute.

Where Has this Stigma Come from?

The etymology of "pain" conveys negative connotations of punishment and guilt. In Greek mythology, *Poine* (*Poena* in Latin) was the personified spirit of retribution, vengeance, and punishment and was seen as the penalty for the crimes of murder and manslaughter [11]. However, the language used by the ancient Greeks could convey other important meanings for "pain." They distinguished between the feeling of pain, called *ponos*, and associated pathos or wretchedness (called *lupê*). But *ponos* could also be used to signify illness, poverty, and low social status, whereas *lupê* could signify distress and sometimes grief [12]. This complex etymology raises questions about which specific attribute or attributes might be possessed by those with chronic pain, which can lead to them being stigmatized.

Despite the presumed moral neutrality of medical science, the concept of something being bad or wrong (Latin: *mal*) [13] is portrayed in language employed by contemporary pain theorists and researchers, that is, maldynia [14], maladaptive response [15], and maladaptive pain [16].

Apart from these etymological considerations, sociocultural beliefs and attitudes about pain can also play a prominent role in stigmatization. For example, Goldberg [17] drew upon the 19th century example of the highly contested medical condition known as "railway spine," where the very subjectivity of the persistent pain of those involved in railway accidents clashed with the spirit of objectivism, which demanded that incontrovertible evidence of injury be produced in order for them to receive monetary compensation [1].

Fibromyalgia Is a Stigmatizing Diagnosis

In 1990, North American rheumatologists constructed fibromyalgia as a distinct clinical entity [18] to counteract the potentially stigmatizing labels of "psychosomatic rheumatism" [19] and its progeny "psychogenic rheumatism" [20]. Both labels implied underlying psychological disturbance [21]. Apart from anxiety, which was seen as being a less common manifestation of FM, but still more frequent in patients than in controls, significant mood disorders were not reported as affecting those who made up the original cohort [18]. To emphasize that most were women, the location of the tender points required to make the diagnosis of FM were placed on a cartoon depicting the Three Graces of ancient Greek mythology [18].[1]

Nevertheless, even after the 1990 classification criteria were widely promulgated, a clinical diagnosis of fibromyalgia could raise seeds of doubt and guilt, within both the medical and the wider community. Those awarded the diagnostic label were predominantly women [22], who were more likely to harbor psychological disorders [23]. They were therefore placed in the invidious position of having to convince others (including their health care professionals) of the reality of their pain [11,14–16,24].

Stigmatizing Themes

This section explores each of the three contemporary themes that appear to have contributed to the stigmatization of women with fibromyalgia.

Moralizing Attitudes

The following testimony speaks of the perceived lowered moral status of the sufferer [8]:

> The stigma is one of the biggest barriers. I have been treated like a lowlife by medical people when I disclose that I have chronic pain and use opioids for it. (Testimony #383)

In their analysis of the diagnostic experiences of patients with fibromyalgia, Mengshoel et al. [24] identified moral issues encountered by some sufferers, including their alleged laziness and work-shyness, as well as a failure to recover their health, even after what was believed to be "medically correct" treatment. Asbring and Närvänen [25] noted that physicians used moralizing terms when characterizing such patients as "illness focused, demanding, and medicalizing."

Source of Moralization Applied to Females

The allusions to "hell" in Testimony #135 and to "low repute" in Testimony #383 are traceable to the teachings of Aurelius Augustinus (354–430 CE; known as St. Augustine), said to be the founder of the Western spirit [11]. His views were strongly influenced by the teachings of Plotinus (203–270 CE).

1 Figure 3. The Three Graces, after Baron Jean-Baptiste Regnault, 1793.

Augustine [26] affirmed that the evils of mankind were attributable to the Biblical Fall in the Garden of Eden, the so-called "original sin." He thus imposed a difficult heritage upon Christianity, which was that of a basic character flaw in man's nature:

> A religion which teaches men and women to regard their humanity as chronically flawed and can alienate them from themselves. Nowhere is this alienation more evident in his denigration of sexuality in general and women in particular. [26]

The Problem of Guilt

Serbic and Pincus [27] found that guilt is a common experience in patients with chronic low back pain, who can become acutely aware of deeply rooted cultural expectations that are morally laden, causing them to feel guilty for being unable to meet these expectations [28–30].

Such expectations can include accessing a plausible explanation for their pain, together with a socially acceptable medical diagnosis; accepting that their identity may have changed; meeting the physical and emotional demands made by family and work; countering unfair judgments made by colleagues; and being restored to full health following what was considered to have been appropriate medical treatment [29].

Misogyny

Augustine's opinion on women reinforced that of the Christian theologian Tertullian (160–220 CE), who castigated women as "evil temptresses, an eternal danger to mankind" [31]. He wrote in these harsh terms:

> Do you not know that you are each an Eve? The sentence of God on this sex of yours lives in this age: the guilt must of necessity live too. You are the devil's gateway, you are the unsealer of that forbidden tree, you are the first deserter of the divine law.... You so carelessly destroyed man, God's image. On account of your desert, even the son of God had to die. [31]

Medical Responses

As members of a spiritual community, Christian physicians were obliged to defer to the church in matters of the soul, and as a result, the Church's moralizing themes began to influence the practice of Western medicine [32,33]. These themes not only lauded a morally acceptable way of life but also judged alternative lifestyles and values to be immoral.

However, in the early 20th century, a further shift in medical thinking occurred. Sigmund Freud (1856–1939), the Austrian neurologist and founder of psychoanalysis, set out to confront humans with the "sorry truth of their inner selves" [34], as did St. Augustine some 1,500 years before him. Freud's central conclusions—that human beings are driven by instinctual drives, especially sexuality and aggression, which exist in tension with morality and conscious thought—have been so internalized in Western thinking that they are often taken to be common sense [34]. It is therefore understandable why many pain sufferers might have feelings of guilt.

The linking of pain with guilt appears to have been an inevitable consequence of Western society following the Judeo-Christian theological tradition and is attributable to these moralizing doctrines that came to the fore in medieval times and can readily be understood as a reaction to people who have done wrong in the eyes of the Church. The influence of the doctrines also explains why sinners might wish to be punished for their behavior and to then seek salvation [35]. But the deeper implication of these doctrines for the Western tradition derives from "its emphasis on guilt and sin, struggle and strain in the religion of God in the West ever since Augustine," culminating in "the very negative conception of human nature" [36].

Gradually, ethical values became increasingly determined by the individual rather than by society in general, and behavior was judged on how well people adhered to correct procedures and obeyed the letter of the law [37]. Kalberg [38] described this process as "a *methodological-rational* organization of life." But the powerful ideas underpinning Augustinian morality did not disappear [39].

Disbelief as to the Reality of Their Pain

Disbelief is clearly expressed in the following example supplied by Carr [8]: "Doctors don't recognize pain they cannot see or diagnose as a specific issue" (Testimony #314).

In their recent metasynthesis, Mengshoel et al. [24] analyzed the negative health-related experiences encountered by patients (mainly female) with fibromyalgia, which comprised expressions of disbelief as to the validity of the diagnosis itself, being seen as the medicalization of psychosocial problems, and the failure of patients to try hard enough to combat their illness, and their "taking a free ride."

In the rheumatology literature, Ehrlich [40] believed that the clinical phenomena of fibromyalgia could be sourced to the sufferers' inability to cope adequately with personal social problems. He opined that "denial of the strong psychogenic component reflects our culture's discomfiture with the influence of the mind on the body; many consider such an attribution pejorative."

The Invisibility of Pain

Because pain is invisible to observers, there have always been suspicions that people experiencing pain may be malingering or feigning disease.

Malingering

The accusation of malingering by pain sufferers has a long history. Galen distinguished patients with "real" pain from those who were faking pain (i.e., malingering) on the grounds that the latter group made every effort to avoid treatment they perceived to be in any way unpleasant and/or risky [41].

Avicenna (980–1037 CE), an influential Arabic physician, was aware that pain might persist long after the original noxious stimulus was no longer in evidence. He classed such pain as "not true pain" and cautioned doctors not to offer treatment because the cause no longer existed [42].

The issue of malingering also concerned doctors during the 19th and early 20th centuries [43,44]. Many of them adopted a moralistic approach to malingerers in the military services and considered them "reprehensible, corrupt and detestable" due to their bad influence upon their fellow soldiers.

Since then, the term "malingering" has broadened to include people who are loath to work for a living, avoid arrest, evade criminal prosecution, receive medication for dubious reasons, and gain admission to hospital for shelter [45].

"Malingering" therefore contains elements of cheating, immoral behavior, and transgressing other societal boundaries. Women with fibromyalgia are therefore potentially vulnerable to such accusations.

Armentor [46] commented that some women with fibromyalgia were under the impression that others (including their medical practitioners) might see them as faking their symptoms. Both Mengshoel et al. [24] and Juuso et al. [47] documented similar perceptions reported by female sufferers.

Those presenting with fibromyalgia (and other medically unexplained painful conditions) report experiencing these pressures to conform and thus become "worthy" patients in the eyes of their ethically motivated clinicians [48].

Kurzban and Leary [49] suggest that the perception that another person is receiving undeserved benefits, financial or otherwise, might be seen as "blemishes of character" [10] and thus contribute to stigmatization. This perception could result in societies inflicting sanctions upon such people to coerce them toward the "right" way of life, in which any benefits obtained are deserved [24,49].

Discussion

Since the time of Hippocrates, medicine has always upheld the clinical encounter as being pivotal to its "internal morality" [50]. As Pellegrino [50] argues, the encounter depicts "the confrontation of doctors and patients whose lived worlds intersect in the moment of clinical truth. . .upon which the actions of individual doctors as well as the whole health care system converge - that moment when some human being in distress seeks help from a physician within the context of a system of care."

On the other hand, the "external morality" of medicine derives from the social constructions of goals, purposes, and values that reflect the social and political contexts in which medicine is practiced [50]. These are ends to which the physician is obliged to serve in order to function effectively within society, but they can erode the first principle of medical ethics, as paraphrased in the motto that underpins the Hippocratic tradition [51]: "If you can do no good, at least do no harm."

How any particular patient is seen in the eyes of a clinician may depend upon a variety of factors operating in societies where financial benefits are made available to those in need of them. For example, clinicians might display sympathy toward their patients "based on their perceptions of whether the illness was acquired through praiseworthy or contemptible means" [52]. The evidence assembled in this paper suggests that women with fibromyalgia have been seen in a negative light by many clinicians.

As Scheurich [53] observes:

> Clinicians struggle with animosity towards patients when the moral attitude contaminates the clinical attitude, that is, when clinicians feel justified in holding patients responsible for some aspect of their illness.

When a cluster of diverse medically unexplained clinical phenomena were badged as fibromyalgia, the condition was initially portrayed as being almost exclusively a women's disorder [18,28]. The belief in female preponderance soon became widespread, which can be attributed to public statements of unconsciously biased medical experts, which appeared in the content of medical textbooks, the pronouncements of respected governmental and nongovernmental organizations, extensive pharmaceutical advertising, and the lobbying of patient support groups [54]. This belief made it more likely that physicians would diagnose fibromyalgia more often in women than men. Recently, selection and confirmation bias have been identified as relevant to a

diagnosis of fibromyalgia, confirming that the condition has both social and medical dimensions [54].

The apparent low prevalence of mood disorders reported in the original fibromyalgia cohort [18], which is at variance with that reported in the later literature [23], suggests that the same biases were in operation. In the former case, it seems likely that it was done by clinicians in an attempt to shield sufferers from accusations of psychogenesis.

Conclusions

Many women with fibromyalgia find themselves stigmatized through no fault of their own. This can be attributed to the powerful and deeply embedded narratives of punishment and guilt in Western society arising out of its Judeo-Christian heritage, with its moralizing prescriptions for how to live one's life. These themes are embodied in the etymology of the word "pain" but in current discourse to the virtual exclusion of other connotations found in the ancient Greek tradition.

Countering the negative cultural beliefs and attitudes about women with fibromyalgia will require the formulation and implementation of multiple strategies targeted at many levels in the community. However, whether this stigma can ever be removed remains an open question.

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OXFORD

Commentary

Commentary: Pain, Stigma, and the Politics of Self-Management

In his 2016 "President's Message" to the American Academy of Pain Medicine, Carr suggested that "the depth and complexity of [pain patients'] experiences are not easily captured by purely quantitative data" [1]. Quintner follows the implied charge, that is, to use multiple methodological approaches to understanding pain stigma, in his article "Why Are Women with Fibromyalgia so Stigmatized?" [2]. His approach to pain stigma, rooted in a historical narrative, deepens our understanding of how this problem, especially for women suffering from pain, is deeply systemic insofar as it is embedded in the very cultural structures of language, religion, philosophy, and literature.

As a scholar of religion, my work (see, e.g., *Peace, Love, Yoga: The Politics of Global Spirituality,* forthcoming) [3] analyzes what I call *neoliberal spirituality* in order to further our understanding of religion in contemporary society. In the present editorial, I hope to bridge that work with some themes in the literature on pain stigma, building on Quintner's analysis by bringing into consideration the present cultural moment, more specifically, the context of neoliberal capitalism. I argue that many of the factors responsible for the ongoing stigmatization of those suffering from pain, especially women, and arguments for self-management interventions are as embedded in the contemporary dominant ideology and structures of neoliberal capitalism as they are in the historical sources Quintner discusses.

Following Brown [4], I use neoliberalism to refer to not just a set of late capitalist, free market economic policies, but also a governing rationality that disseminates market values and metrics to every sphere of life, formulating everything, everywhere, in terms of capital investment and appreciation, including and especially living beings. Neoliberal governmentality—which holds the individual fully responsible for their conditions—can be seen at play in discourses of self-sufficiency, which reify the individual, construed as an automaton, ideally self-optimizing, self-sustaining, productive, and entrepreneurial.

My work on neoliberal spirituality teases out the deep elective affinity between self-care industries, such as yoga and mindfulness, and the dynamics of neoliberal capitalism. Most significantly, I highlight the tendency to wed the goal of material "prosperity" to "self-care" in the quest for freedom (from oppression, pain, suffering), rooted in some form of ancient or exotic wisdom. Huge swathes of consumers in global cities all over the world spend their money on self-care commodities, hence the emergence of large transnational corporations, indeed entire industries, producing self-care products and practices. Increasingly, the medical system reflects the growth and mainstreaming of those industries; we see increasing attention in medical contexts to what are called self-management programs, which can include tai chi, yoga, mindfulness, or other self-care interventions, in hospitals, doctors' offices, and labs.