“It’s not all in my head. The pain I feel is real”: How Moral Judgment Marginalizes Women with Fibromyalgia in Canadian Health Care

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Fibromyalgia (FM) is a chronic pain condition that affects 440,000 Canadians, most of whom are women. Many physicians, although not all, are sceptical of FM’s legitimacy and discredit women with FM. This moral judgment takes the following forms: disbelief of women’s pain reports, blaming women with FM for adding to their pain by catastrophizing, dismissing new symptoms by assuming that they are related to FM, accusing women of not wanting to get better, and seeing them as a frustrating waste of time. Moral judgment marginalizes these women, impeding their healthcare needs from being met. In this article, I illustrate this kind of moral judgment by drawing on my own and other women’s experiences of FM, as well as physicians’ attitudes and advice to other physicians about FM. I profile three practices that could

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mitigate moral judgment of women with FM: listening, validation, and empathy.

Fibromyalgia (FM) is a chronic pain condition affecting 440,000 Canadians, of whom 352,000 are women (Statistics Canada, 2010), and most are middle-aged. The status of FM is contested in biomedicine: debate continues over whether its medically unexplained symptoms constitute a legitimate disease. As a result, many women with the condition report being marginalized in health care: their pain experiences are disbelieved, they are told that their pain results from psychological problems, and some are accused of faking pain to gain sympathy or disability benefits. Individuals with many other pain conditions share this experience.

Health professionals may construct people with medically unexplained long-term pain as moral deviants (Kotarba & Seidel, 1984). In observing pain management seminars, Kotarba found that, in informal discussions, professionals referred to such people using “terms like ‘crock,’ ‘maligner’ [someone who fakes illness for personal gain], or ‘pain in the ass’” (1983, p.76). He also found that professionals considered this pain to be in the individuals’ minds rather than their bodies. Because medically unexplained pain is considered psychogenic, Kotarba and Seidel argued that pain-management programs target people with pain, rather than pain itself. Through what these authors consider to be overwhelmingly a deviance-management process, such programs aim to change the attitudes and behaviour of people with pain, to teach them to live with it. However, few such people are willing to accept intractable suffering, so most do not comply; therefore, “the pain patient is by definition a problem patient” (1984, p.1394). The label of moral deviance discredits not just the behaviour of people with long-term pain, but their very character. This discrediting of character is the essence of moral judgment.

This article will demonstrate how moral judgment by physicians impedes Canadian women with FM from having their healthcare needs met. I will begin with a discussion of biomedical skepticism about women’s chronic pain, particularly when it is not considered legitimate. I will then demonstrate how women with FM are marginalized in Western healthcare because of physicians’ attitudes toward them. To illustrate how women with FM are morally judged, I will take an auto-ethnographic approach, exploring personal experiences to gain insight into a social phenomenon (Taber, 2010). I will reflect on how I was morally judged by physicians when I had FM and will explore these personal experiences within a wider social context (Chouinard, 2010). I will also explore how other women experienced moral judgment, based
on their postings on the website of a Canada-wide self-help organization, FM-CFS Canada. I initially collected these stories as part of a critical discourse analysis of how Web-based information portrays FM (Oldfield, forthcoming). In this article, I will identify and illustrate five forms that moral judgment can take. Then I will explore physicians’ attitudes toward women with FM and their advice to others treating women with the condition, based on quotations that I collected from research articles about physicians’ perceptions of FM. It is important to note that not all physicians make moral judgments about women with FM. Postings on the FM-CFS Canada website testify to the benefits of finding sympathetic physicians, but unfortunately many physicians are not supportive. I will conclude by profiling three physician practices that could mitigate the moral judgment of women with FM and thus improve their healthcare: listening to the women’s life stories, validating their pain experiences, and empathizing with them.

Background

Gender Differences in Pain & Biomedical Skepticism about Women’s Chronic Pain: Chronic illness is associated with longevity (Doyal, 1995). Because women tend to live longer than men in similar economic circumstances, they have higher rates of chronic illness (Doyal, 1995) and pain related to chronic conditions (Unruh, 1996). In contrast, men are more likely to experience pain from injuries and life-threatening diseases (Unruh, 1996). Not surprisingly then, chronic pain is more prevalent among women than men, and women have higher rates of pain-related impairment (IASP, 2007). This impairment may affect the lives of women in different ways than the lives of men, and may have a greater emotional impact on women. For example, whereas men may perceive pain as threatening their jobs, employed women with family responsibilities such as housework, childcare, and eldercare may perceive pain as threatening not only their jobs, but also their families. Additionally, when employed men find that pain interferes with their work, they may have more time to recuperate at home when they are not responsible for housework, childcare, and eldercare (Unruh, 1996).

The paradox that women live longer than men but have more non-life-threatening illness often leads to physician skepticism about the seriousness of women’s pain (Doyal, 1995). This skepticism may also be rooted in the successful history of Western biomedicine in treating acute infectious diseases: biomedicine is much less able to manage chronic illness and pain, and physicians may struggle to treat non-life-threatening conditions that have no identifiable bodily cause. They may also expect women to be better able to endure pain than men, a general perception in society (Bendelow, 1993). This perception may also lead to expectations among physicians that women’s pain does not need to be
taken as seriously as men’s (Sev’er, Sibbald & D’Arville, 2009) and therefore that women who cannot endure pain have poor coping skills. These physician perceptions can also lead to frequently inadequate pain treatment: for example, prescribing antidepressants rather than opioid analgesics (Unruh, 1996).

**Gendered Contested Conditions:** A number of conditions have contested moral legitimacy because they have no biomedically-agreed-upon bodily cause (Moss & Teghtsoonian, 2008; Zavestoski et al., 2004). Without an identified bodily cause, these conditions are labelled “functional diagnoses” (Aronowitz, 1992: 156): syndromes assumed to be imagined or a result of mental illness (Barker, 2008). This aspersion discredits the moral character of individuals with contested conditions; to regain moral legitimacy in the face of aspersion, these individuals emphasize that the causes of their symptoms are in the physical body, not the mind (Conrad & Stults, 2008). They criticize biomedicine’s reluctance to accept the legitimacy of their bodily experiences and strive for medical recognition, because their moral legitimacy is contested not only by biomedical professionals but also by family, friends, and employers (Wolfe, 2009) who see medical knowledge as the ultimate arbiter of socially legitimate disease (Aronowitz, 1992).

Most people with contested conditions are women (Barker, 2005). In part, this stems from hysteria, a diagnosis that 19th century physicians applied to women’s reports of pain, fatigue, and distress (Greenhalgh, 2001). Scull traced the history of hysteria even further back, to 18th century England, where hysteria (from the Latin for ‘womb’) was thought to originate in women’s reproductive systems. Some men were also diagnosed with hysteria, and were described as “weak, effeminate creatures bereft of the qualities generally seen as appropriately masculine” (2009, p.55). The perception of hysteria transformed from a condition originating in the body to a condition of the mind at the turn of the 20th century. Freud proposed that hysteria was the somatic conversion of psychological distress and that this distress originated in repressed memories that needed to be brought to consciousness through his new technique of psychoanalysis (in Scull, 2009). Later, during World War I, some soldiers were diagnosed with a new form of hysteria: shell shock. Army commanders, seeking to prevent more soldiers from using this reason to avoid returning to the battlefield, labeled shell-shocked soldiers as cowards who were shirking their patriotic duty (Scull, 2009). In this way, hysteria became associated with malingering.

By the late 20th century, diagnoses of hysteria had evolved into a proliferation of female-dominated pain syndromes (Greenhalgh, 2001), including FM. Barker identified rheumatology as the biomedical specialty that popularized this condition: in the 1980s, a group of North American “diagnostic entrepreneurs” (2005, p. 23) proposed
‘fibromyalgia syndrome’ as an explanation for the medically unexplainable, long-term, widespread pain that rheumatologists were encountering among their patients. Concomitantly, women diagnosed with the condition established a network of self-help support groups. The network allied itself with rheumatology researchers searching for a bodily cause for FM as well as with specialists and general practitioners who believed that FM is a medically legitimate disease. This alliance, which is still active, came about because rheumatologists organized and labeled women’s distress in the same way that women understood it: as a disease of the body, not the mind (Barker, 2005).

Despite its origins in rheumatology, FM’s status as a legitimate disease is hotly debated within the field. Rheumatologists Gordon (2003), Hadler (2003), and Hazemeijer and Rasker (2003) argued that FM is a socially constructed or iatrogenic (doctor-created) syndrome. In 2009 Wolfe, another rheumatologist and one of fibromyalgia’s “diagnostic entrepreneurs” (Barker, 2005, p. 23), decried the promotion of FM as a disease by health professionals, drug manufacturers, and lawyers who handle claims for disability benefits. Anthropologist Greenhalgh (2001) argued that the medicalization of women’s long-term pain is an excuse to keep its roots in sexist oppression unexposed. Sociologist Barker (2005) concurred, warning of the dangers involved when women seek medical explanations for their distressing experiences, because doing so diverts attention from the non-medical reasons for their distress. Despite arguing that FM is socially constructed, these questioners of FM’s legitimacy as a disease still acknowledged that women’s pain is not imaginary.

Some men are diagnosed with FM, but they appear to experience it differently; for example, men’s pain is more likely to be believed (Sev’er, Sibbald & D’Arville, 2009). In a search of qualitative studies on FM, I was only able to locate one English-language study of men with fibromyalgia: the authors reported that, unlike Swedish and North American women with FM, who frequently reported disbelief from others, Swedish men with FM were more likely to be believed (Paulson et al., 2001, 2002). However, these men also reported feeling that their masculinity was questioned, and feeling that, if they disclosed their condition to anyone outside their families, they would be judged as “whiners” (Paulson et al., 2002, p. 244). Even though they had been diagnosed with FM, they considered it a ‘feminine’ ailment (Paulson et al., 2001, p. 57).

The marginalization of women with fibromyalgia in Western healthcare: Fibromyalgia is a very low-status condition. A Norwegian survey asked senior doctors, general practitioners, and senior medical students to rank 38 diseases in terms of prestige, and FM was ranked last by all three groups (Album & Westin, 2008). Canadian physicians may
also consider FM low-status. Although rheumatologists carved out a
diagnostic niche for FM in the 1980s (Barker, 2005), a recent survey
reported that 71% of rheumatologists in Canada’s most populous
province, Ontario, no longer want to “retain ownership” of FM (Ghazan-
Shahi, Towheed, & Hopman, 2012). Instead, 89% of respondents wanted
family physicians to be responsible for treating the syndrome.
Rheumatologists Shir and Fitzcharles (2009) argued that this transfer
would give individuals with FM more access to treatment for the wide
range of symptoms they experience in addition to pain. However,
another recent Canadian survey (Hayes et al., 2010) found that family
physicians felt unprepared to take over FM treatment from specialists.
The same survey revealed that half of all participating family physicians
and specialists felt unable to meet the psychological needs of women
with FM.

Women with FM are marginalized in Canadian healthcare,
perhaps because the condition has such low status and people
experiencing pain are considered morally deviant. Among Canadians
with the condition, 31% report unmet healthcare needs (Statistics
Canada, 2010). This proportion is double that for people with cancer
(16%) and heart disease (13%)—both uncontested conditions (National
ME/FM Action Network, 2011), and rated high in prestige by physicians
in Album and Westin’s 2008 study noted above. People with
uncontested, high-prestige diseases are more likely to have their
healthcare needs met.

Fibromyalgia self-help organizations respond to marginalization
by advocating that FM is a disease with a bodily cause. Individual
women with FM also strive to have their pain experiences legitimized.
Cheri’s story, posted on the website of a Canadian FM self-help
organization, FM-CFS Canada, captures how women with the condition
are morally judged:

The most frustrating aspects of the illness are the stigma and lack
of understanding I’m faced with every day. We don’t ‘look’ sick.
The illness is not in our head, it is not due to mental illness, and it
is not hypochondria. We don’t want to feel this way. We aren’t
faking. We aren’t lazy (Cheri, Personal Testimonial, FM-CFS
Canada website, 2011).

Other women described their experiences of moral judgment in
testimonials posted on the same website. The next sections draw on these
experiences, along with my own, to illustrate five forms of moral
judgment: not believing the pain that women report, blaming women for
exacerbating their pain, assuming that any new symptoms are caused by
FM, accusing women of not being motivated to get better, and regarding women with the condition as a frustrating waste of physicians’ time.

**Disbelief: It’s All in Your Mind**

I begin with my own story: I had it better than women with FM who struggle for years to find a diagnosis for their pain. After decades of depression, anxiety, and anger, I had a car accident on Christmas Eve, 1993. My whiplash injury seemed minor, but the pain had still not gone away by February. My family doctor told me I had FM. I said “What’s that?” She answered, “You’re a researcher. Research it!” She tried me on the drugs that were recommended at the time, tricylic antidepressants and muscle relaxants whose effectiveness I can’t recall, and she willingly referred me to any rehabilitation programs and specialists I could find. Although my doctor believed that my symptoms were real, many women in the FM self-help network have been told that their pain is not real.

Many women with FM report negative encounters with physicians. Studies of FM illness experiences from Scandinavia, the United Kingdom, and North America have demonstrated that women’s pain is often doubted, dismissed, or labeled as imaginary or the result of psychological disturbance (e.g., Asbring & Narvanen, 2002, 2004; Barker, 2005, 2008; Sim & Madden, 2008). Sheryl Ann, who posted her story on the FM-CFS Canada website, described how others, not only physicians, disbelieve that she is in pain all the time: “I am good looking on the outside and that actually goes in my disfavour with this health malady most of the time. People are just judgmental period. They look at me and they just can’t believe that I have this malady that has me tired and in pain 24-7” (FM-CFS Canada website, 2011).

Women with FM may encounter disbelief for two main reasons: the invisibility of pain and the social hierarchy of pain. First, pain is invisible; it can only be observed through outward signs such as a ‘pained’ facial expression, crying, or the use of a mobility aid. For example, when I was losing the use of my legs, it was painful to stand in a crowded bus. I took to carrying a cane to make my pain visible, and that helped get me a seat. Making my pain visible by using a mobility aid legitimized the pain.

The social hierarchy of pain is the second reason for FM pain being disbelieved (Bendelow, 2006). Within this hierarchy, pain caused by medically explainable physical pathology is more valid and more respected than pain considered to be caused by the mind. When no bodily cause—such as tissue damage visible to biomedically trained eyes (Jackson, 2000) or detectable by scientific instruments (Barker, 2005), or a disease identified by laboratory tests—can be found, FM pain is not considered as valid as pain with a bodily cause. Physician Janneke
Gradstein (2005) described how her fellow medical students compared FM pain to ‘real’ pain: “[When I was in medical school] a fourth-year student was describing his elective in the Pain Clinic to a classmate. He said it was an interesting and useful experience because he had the opportunity to treat patients that were ‘in a lot of pain…real pain, not ‘fibromyalgia pain’” (2005: 662). Not only did the medical students dismiss FM pain as ‘not real’, they also morally judged the people who reported the pain. They appeared to imply that women with FM are ‘crocks,’ a term that Kotarba (1983) encountered in his observations of pain-management seminars. Rosenberg (1992) pointed out that finding a specific underlying mechanism is key to establishing an illness’s moral legitimacy, and therefore only people with legitimate illnesses are entitled to sympathy. When no specific pathology explains pain, physicians often label the pain psychogenic, a common practice in the case of FM. The survey of Ontario rheumatologists revealed that 55% of respondents believed that FM is primarily a psychosomatic illness, and 31% considered referring people with FM to psychiatrists (Ghazan-Shahi, Towheed & Hopman, 2012). When physicians label FM pain as psychosomatic, it is unlikely that they will believe women’s pain reports.

Not being believed has serious consequences for women with FM. When their reports of pain are challenged, dismissed, or downplayed (Barker, 2005), they feel rejected and belittled (Werner, Isaksen & Malterud, 2004). Such moral judgment may establish mutual animosity between doctors and patients (Kotarba & Seidel, 1984; Radomsky, 1995). Women may leave their doctors and search for more sympathetic ones via online self-help groups (Barker, 2008). Women with FM also encounter disbelief in their social world, when families and friends similarly believe that pain is only ‘real’ if it has a bodily cause. The emotional consequences of disbelief and the attendant loss of social support can be devastating. As Pat posted on the FM-CFS Canada website:

There are no organizations to help people like me because…I don’t look sick….there are no friends to help out as they all abandoned us because….they didn’t believe there was anything wrong with me. Sometimes the emotional aspects of FM hurt more than the pain itself (FM-CFS Canada website, 2011).

**Being Blamed for Making Your Pain Worse: They’re Catastrophizers**

The second way in which women with FM are morally judged is being blamed for exacerbating their pain. Kotarba and Seidel (1984) argued that pain-management professionals blame people in pain for magnifying their own suffering. I encountered this form of moral judgment when I attended the World Congress of the International
Association for the Study of Pain in 2010. Fibromyalgia was a hot topic in the Congress sessions. I frequently heard the word ‘catastrophizer,’ a term used to describe people who worsen their pain by exaggerating it. This label reminded me of a phrase I had encountered in the biomedical literature about FM that I read in the 1990s, the ‘fibromyalgia personality.’

The idea of the ‘fibromyalgia personality’ lives on today. One of the physicians in Hayes et al.’s study said: “You immediately know they have FM, often even before they say anything, just from the way they’re behaving, and their personality” (2010, p.389). Part of this supposed personality is being a ‘catastrophizer,’ described as “individuals who had a tendency to magnify or exaggerate the threat value or seriousness of the pain sensations” (Sullivan et al., 2001, p.53). ‘Catastrophizing’ is described as an “exaggerated negative orientation toward the threat of actual or anticipated pain” (Van Damme, Crombez & Eccleston, 2004, p.70) and “involving elements of magnification, helplessness, and pessimism” (Edwards et al., 2004, p.335–336). Catastrophizing is considered to intensify FM pain and the depression associated with it (Hassett et al., 2000).

Labeling women with FM as ‘catastrophizers’ is a moral judgment, because the label locates the women’s pain in their minds rather than their bodies. Applying the label ‘catastrophizer’ to women with FM may be inappropriate, because in pain research, the concept of catastrophizing is based on experiments in which participants were exposed to extreme heat or cold for a few minutes at a time (e.g., Sullivan, Tripp & Santor, 2000; Van Damme et al., 2004). While this research can illuminate catastrophizing during acute pain, such experiences may not be generalizable to chronic pain. As Edwards et al. (2004) noted, participants in laboratory experiments know that they will only experience pain for a short period and that they can control when to stop it. In daily life, long-term pain can be unpredictable and therefore more threatening. It also has different meanings for each individual, depending on many factors such as life histories, interactions with the social world, and the social meanings of pain in various cultures (Morris, 1991; Vrancken, 1989).

Turner and Aaron (2001) distinguished between ‘catastrophizer’ and ‘catastrophizing.’ The former refers to a personal trait of the person with pain and can thus be used to label that person as morally deviant (Kotarba & Seidel, 1984). The latter labels a behaviour specific to a situation, such as extreme pain, that could occur to any “psychologically healthy” person (Turner & Aaron, 2001, p.68). The second term thus takes into account external factors that may contribute to catastrophizing. Because anyone can catastrophize depending on their situation, labeling the behaviour may be less morally judgmental than
labeling the person. However, pain-management programs focus on treating the person in pain, not the pain itself (Kotarba and Seidel, 1984). Therefore, the character of the person in long-term pain is still discredited.

What appears to be ‘catastrophizing’ may actually be an attempt to be believed, as well as a response to being morally judged. Schoofs et al. (2004) investigated how social and healthcare supports affect quality of life among women with FM. Their participants explained why they exaggerate their symptoms: in an effort to have their illness experiences taken seriously. One participant referred to how it feels to be blamed for your own suffering: “You’re crazy or you’re a hypochondriac or you’re just fat and that’s the root of your problems” (Schoofs et al., 2004, p.371).

Being blamed for their own suffering not only discredits women with FM, it harms their relationships with physicians who, although well-meaning, may not look beyond the individual woman to find the social causes of her suffering (Ryan, 1976). As evidenced in pain-management programs (Kotarba & Seidel, 1984), the individual is expected to change, not society (Ryan, 1976). Life’s ‘lesions’ (Finkler, 1994), social conditions such as poverty and abuse that may painfully scar the ‘lived-body’ (Leder, 1990) are not considered. Physician Camerlain and her coauthor Myhal (2009) argued that ascribing responsibility for FM symptoms to personality traits is like negative racial profiling: “Does profiling also exist in health care? Does prejudice deprive some patients of compassion, the opportunity to build a positive therapeutic relationship with their health care providers and, ultimately, of proper treatment?” (2009, p. 238). When women with FM are labeled ‘catastrophizers’ and blamed for magnifying their own pain, is it possible for them to have their healthcare needs met?

**Fibromyalgia Patients are not Motivated to Get Better**

In the third form of moral judgment, women with FM are accused of not wanting to get well. This accusation played a role in the history of hysteria, as did disbelief. Scull (2009) described the frustration of 18th century English physicians with the ineffectiveness of hysteria remedies they prescribed. This frustration spilled over into anger at their patients. Perceiving them as determined to remain invalids, these physicians suspected a willful retreat into illness. Today, this form of moral judgment is still evident in how some physicians perceive women with FM. Hayes et al.’s study asked physicians about their attitudes. One specialist commented: “They say they want to get better, but they don’t help themselves get better” (2010, p. 388). Another physician speculated about why women with FM are ‘unmotivated:’ “There are patients who really adopt their illness and they want to live with it, they want to keep it up” (2010, p.389).
Linked to the idea that women with FM want to remain invalids is the idea of ‘secondary gains,’ a biomedical explanation for the persistence of chronic pain. According to this explanation, patients are blamed for not wanting to let go of their pain because they gain from it (Moon, 2003). Secondary gains are defined as attention or approval (Morris, 1991), money in the form of disability payments (Kleinman, 1988; Morris, 1991), and freedom from social responsibilities (Goffman, 1963) such as employment. This idea of secondary gains underlies physician Gradstein’s initial moral judgment of women with FM:

I heard about fibromyalgia years before medical school. A friend complained of suffering from it when we were teenagers, while her parents were getting divorced. She did not seem sick to me, and I assumed the diagnosis was an attempt—conscious or not—to focus her parent’s energy on her rather than on each other. In my mind fibromyalgia became synonymous with seeking attention (2005, p.661).

In this story, FM is framed as a strategy the teenager devised to manipulate her parents into giving her attention, a secondary gain. Another suspected secondary gain is malingering, which Kotarba and Seidel (1984) defined as exaggerating the intensity of one’s pain, or even inventing it, for material rewards. People with pain may also be accused of malingering when others perceive a misuse of the illness as a way to gain release from social responsibilities (Aronowitz, 1992). Both suspicions discredit the moral character of people with pain. Accusing women with invisible symptoms of malingering is not new: Scull reported that, among 19th century American physicians, “complaints that hysterical women were deceitful, manipulative, selfish creatures permeated many medical discussions of the problem they represented...[they were viewed as] cynical malingers” (2009, p.93).

Malingering deserves particular attention because it underlies the difficulties women with FM may face in securing government disability benefits (Lightman et al., 2009). Women must prove that they are impaired by a medically legitimate condition. This proof requires documentation by the woman’s family doctor, who may be unwilling to provide it because the doctor may suspect the woman of malingering. This suspicion is surprisingly common: in Hayes et al.’s survey, almost a quarter of general practitioners (23%) agreed with the statement “Fibromyalgia patients are malingers” (2010, p.388). Suspicion of malingering also underlies the efforts of some private disability insurers to prove that claimants are lying about their pain disability and are therefore ineligible for benefits. These insurers have been known to hire
detectives to follow claimants with long-term pain, documenting their ability to do daily tasks also used in the workplace (Moon, 2003).

In sum, women with FM may be accused of wanting to remain in the sick role, using pain for secondary gain, and even malingering. Can women who are morally judged in these ways receive the healthcare they need and deserve?

*It’s your Fibromyalgia: Get Used to It*

The fourth way in which women with FM are morally judged is being told that they cannot be helped and therefore must learn to live with their pain, to accept it, and adapt to it. The latter may be an example of the deviance-management process that Kotarba and Seidel (1984) describe. Physicians may also assume that every new symptom these women report results from FM and so dismiss their concerns, telling women that nothing can be done and so they must learn to live with their condition. One woman with FM shared her frustration with this attitude: “I should be healthy, I should be working...they need to help you out, make you better, not just say, ‘This is it, you’re stuck with this for your life’” (Hayes et al., 2010, p.389). She did not get the healthcare she needed.

When physicians assume that every newly reported symptom results from the condition they may miss other diagnoses, with serious consequences. My own experience illustrates this: “It’s your fibromyalgia. Get used to it,” said my family doctor when I told her in October 1997 that the world was so loud I had to wear earplugs all the time and that the light, even indoors, was so bright that I had to wear sunglasses all the time. By the following spring, my life had dramatically worsened. My legs were so painful that I could barely walk, and I could no longer climb the stairs in my own apartment, let alone get into the subway. I had stopped working and rarely left home. With little appetite, I lost 20 pounds. It turned out that my extreme sensitivity to light and sound six months before were early warnings of a severe depression. By spring, I was at the bottom of a deep pit of despair.

I did not receive the healthcare I needed to address the depression and the pain in my legs. Because I was now a ‘problem patient,’ the warning signs of depression were ignored and the leg pain was attributed to FM. It turned out, however, that something else had caused the leg pain: In Spring 1998, after neither my family doctor, the rheumatologist I consulted, nor a physiotherapist, could find the cause of pain in my legs that severely impaired me, I dropped in to a foot-and-leg clinic one day. The specialist took a look at my shoes and noticed that their linings were worn through to the leather. I had put heel supports inside the shoes—backwards. That caused me to walk with my feet tilted inward, straining the outer muscles of both thighs. The doctor removed
the inserts and gave me a pair of arch supports to put in the shoes, so that I could walk properly. If I had not walked into that clinic and had simply accepted the other doctors’ assumptions that nothing could be done, that I had to accept and adapt to my FM, who knows whether I could have ever returned to work, to my former life. Moral judgment prevented me from getting the healthcare I needed.

Fibromyalgia Patients are too Frustrating: They Aren’t Worth my Time

Scull (2009) described how 18th-century English physicians perceived their hysterical patients as chronic complainers. With hysteria’s great-great-grandchild, fibromyalgia, little has changed. Hayes et al.’s survey revealed that 76% of general practitioners and 64% of specialists agreed with the statement “Fibromyalgia patients are time consuming, frustrating” (2010, p.388). Note that the survey asked physicians not about their frustration with ‘fibromyalgia,’ but with ‘fibromyalgia patients.’ As Kotaba and Seidel (1984) pointed out, the person with pain is targeted for intervention, not the pain itself. Two other items on Hayes et al.’s survey reflected the assumption that people with pain are the problem: “Fibromyalgia patients are not proactive” and “Fibromyalgia patients are malingerers,” while the other questionnaire items, many of which referred to physicians’ abilities, contained neutral words.

Rheumatologists may blame women with FM for wasting their time, as illustrated by my own experience. A rheumatologist I consulted told me how annoyed she was with FM patients who wouldn’t get better. “You’re a worrywart,” she said, then motioned me to the door as she added, “Excuse me, I have to give an injection to an old lady whose spine is crumbling.” It was clear to me that I was wasting her time, which was better spent on patients with ‘real’ diseases like osteoporosis.

Why are physicians frustrated with FM patients? A key reason may be doctors’ inability to help them using currently available treatments. Drugs for FM may or may not be effective, and nondrug treatments take time and much effort (Barker, 2005). Gradstein reflected on why her colleagues in medical school felt frustrated:

Most of the other conditions that we came across in rheumatology were so clear-cut: a joint was hurt, usually by deposits, inflammation, and especially the pain. Patients were grateful and could get on with being productive members of society, and doctors felt useful and fulfilled. This was not the case with the fibromyalgia patients we saw. They complained of pain that could not be explained. They were taking treatments that did not work. They seemed to want far more than we could give them (2005, p.661).
Here, the “far more” may refer to the psychological support that half of the physicians in Hayes et al.’s survey indicated they were unable to give to women with FM. Barker (2005) noted that many rheumatologists express frustration with women’s psychological distress and with resistance from women dissatisfied with their care. These dissatisfied women may have been subjected to previous moral judgments from other physicians (Radomsky, 1995), and so may fear being judged again.

With all of these sources of frustration, it is not surprising that rheumatologists no longer want to be responsible for FM (Ghazan-Shahi, Towheed & Hopman, 2012). According to one woman with FM: “I’ve seen maybe six rheumatologists...They don’t want to be bothered with you” (Hayes et al., 2010, p.389). Michelle Skop-Dror, a PhD candidate researching healthcare for women with FM, suggested: “Perhaps rheumatologists feel that they have too many patients with FM who are eating into their time... it is easier to offload the patients and say ‘It is not our problem anymore,’ instead of working with them. It is like FM is an orphaned disorder that nobody wants” (M. Skop-Dror, personal communication, May 2012). If FM is an ‘orphaned disorder,’ can the healthcare needs of women with the condition be adequately met? On top of all this moral judgment, the guilt and self-blame that can come from being marginalized compounds the suffering of women with FM (Greenhalgh, 2001).

Not All Physicians Morally Judge Women with Fibromyalgia

To be sure, some physicians sympathize with and offer great support to their FM patients. One question for future research, given that FM is seen as a gendered condition, is whether female and male physicians differ in their level of supportiveness. Women who post on the FM-CFS Canada website say they are ‘lucky’ to have sympathetic doctors. According to Rochelle:

I happened to speak to my sister who has Fibromyalgia, and asked her what her symptoms were – they described my condition completely. From there I asked my family Dr. for testing for Fibromyalgia. My family Dr. had little knowledge, only knowing that there was some form of testing that could be done for ‘tender points’ by a Rheumatologist. I tested positive for 18 out of the 18 tender points, and was lucky to connect with other Doctors that I knew who treated my type of condition (CFS-FM Canada website, 2011).
‘Lucky’ is a word that frequently appears on this website—as though the women are surprised when they receive the healthcare they need.

I eventually found the healthcare I needed, although I had to piece together much of it on my own: in Summer 1998, a different doctor put me on anti-depressants. I began to feel better, sleep through the night, and, by doing stretching and strengthening exercises under the guidance of a new physiotherapist I found, I was able to walk without pain by the end of the summer. I continued increasing my physical activity into the fall. By Winter 1999, I was stronger and fitter than I had been before the FM diagnosis. After five years of impairment, I was significantly better. I decided to rid my life of nasty people, consider whatever aches and pains I had as part of normal middle age, and pursue a low-stress life. Like the women with FM in Schaefer’s (1995) study, I reframed my aches and pains as part of normal aging. Later in 1999, I visited the doctor who had diagnosed me with FM to pick up my medical records. She apologized for ignoring the warning signs of my depression. I admired her humility in admitting error to a patient. Over the following decade, I worked on healing the scars left by my life’s lesions. My pain slowly went away. And so FM had a silver lining for me. It transformed my life for the better.

Mitigating the Moral Judgment of Women with Fibromyalgia in Healthcare

What can physicians and other health professionals do to lessen the moral judgment that marginalizes many women with FM? The remainder of this article contains recommendations from women with the condition and from physicians who have reflected on their relationships with patients who have FM. The recommendations fall into three areas: listening to the life stories of women with fibromyalgia, validating their pain experiences, and empathizing with them.

First, looking only at women’s individual psychology obscures ‘life’s lesions’ (Finkler, 1995), oppressive social conditions that may have left painful scars. If physicians and other health professionals listen to women with FM tell the stories of their lives, they may learn more about the circumstances that contribute to their pain. Family doctor Nellie Radomsky (1995) advised physicians to do this. In her initial meetings with new female patients with long-term pain, she asks about their family lives. She reported that not only does this help her learn more about her patients, she has come to admire how these women are able to move toward healing once they have told her their life stories. She added that many women have told her that no other health professionals have asked them to talk about their lives.
Egeli et al. investigated patients’ views on improving care for people with FM; the findings highlighted the importance of physicians listening to women. Listening was the most frequent recommendation from participants, who said they generally felt “ignored, rushed, belittled, and that care was inadequate” (2008, p.366). Along with being morally judged, their healthcare needs were not being met. Other women with FM have advised health professionals to “listen to patients and learn from them” and to “find out what helps” each individual woman (Schoofs et al., 2004, p.372).

Family physician Baraa Alghalyni also stressed the benefits of learning about the life circumstances of her patients with FM by listening to them:

> Poverty is a huge barrier for some of my patients. There are cultural barriers, too. I have a patient who recently immigrated to Canada; she tells me she is always tired, headachy, and achy all over. She’s expected to stay home, cook, and care for her children. Her husband works 2 shifts and, when he’s home, has no time to talk to her. How can I motivate her to go to a gym or even go for a walk in a shopping mall before the stores open? (Alghalyni & Oldfield, 2008, p.1577).

Alghalyni considers FM a “bona fide medical condition” (Alghalyni & Oldfield, 2008, p.1577); instead of morally judging the patient, she learned about the difficulties faced by her patient as an immigrant woman and how these may affect her motivation to carry out instructions to exercise more. Alghalyni tries to understand why it is difficult for the woman to follow her doctor’s advice, instead of assuming that she does not want to get better.

The second way to mitigate moral judgment is to validate the pain experiences of women with FM. Participants in Egeli et al.’s study defined validation as “taking the patient seriously” (Egeli et al., 2008, p.366). Participants in Schoofs et al.’s (2004) study also wanted health professionals to believe their reports of pain; the authors concluded that perceived support from health professionals improves the quality of life among women with FM. Feeling validated, instead of morally judged, may contribute to this perceived support. Alghalyni echoed women’s calls for validation in her advice to other physicians: “When [fibromyalgia] patients complain, we shouldn’t dismiss their complaints as psychosomatic. We should validate our patients” (Alghalyni & Oldfield, 2008, p.1577). The reassurance that validation provides is vital for people with long-term pain, who may have been morally judged in the past and consequently mistrust physicians. In her chapter ‘Flying Bricks,’ Radomsky described women with FM who were very angry
when they arrived at her office. Instead of considering them a frustrating waste of her time, she was able to help them by listening to their life stories and validating them. Through this validation, Radomsky’s relationships with the women improved over time.

Physicians can validate women’s pain experiences even when they do not believe that FM is a bona fide disease. Rheumatologist Frederick Wolfe offered a way for physicians to avoid morally judging women and to simultaneously give them hope, advising: “One way might be to say to the patient something like this. ‘You have a kind of pain problem that we commonly see but that doctors do not understand well. There is a lot we can do to help you’ (Wolfe, 2009, p.676).

The third way to mitigate moral judgment is empathy, which can involve the first two ways (listening to women with FM and validating their pain experiences). Participants in Egeli et al.’s (2008) study used other words to express a similar idea: “sympathy,” “understanding,” and “compassion” (2008, p.366). Any of these supportive practices may mitigate the emotional distress that results from being discredited and help rebuild trust in the doctor–patient relationship. Gradstein reflected on how she began to feel empathy for women with FM, calling it her ‘reconceptualization of the illness:’

While reading the accounts of these patients [in Raymond & Brown, 2000], I also began to feel empathy for them. This was something I had consciously avoided doing up to this point, because of my biases concerning fibromyalgia. The concerns that study participants raised, such as the importance of continuing to work and be involved in the community without overdoing it, the difficulties of coping with a chronic illness, and the necessity of dealing appropriately with stress to avoid exacerbations, were all issues that I could relate to on a personal level. These people were facing the same challenges that I saw in my own life and in the lives of my friends and family…This embryonic empathy…made me feel more hopeful in my ability to participate effectively in the care of these patients (Gradstein, 2005, p.662–663).

Gradstein’s empathy increased as she came to realize that women with FM had concerns similar to her own. Empathy helped this physician feel better able to care for women with FM.

Empathy can contribute to compassionate care, as well as helping to alleviate physicians’ frustrations related to their inability to meet the psychological needs for women with FM. Although physicians who must see many patients in a day may have limited time, a few words of validation and empathy, followed by referral to a professional who has more time to listen to women’s life stories, might help them.
Physician Monique Camerlain and her coauthor Geneviève Myhal encouraged physicians to shift to compassionate care: “Let us not let cynicism, skepticism and prejudice stand as barriers to care and empathy for patients with fibromyalgia. As with all patients, let us do our best to meet their needs and expectations and to relieve their pain and suffering” (Camerlain & Myhal, 2009, p.238).

REFERENCES


Oldfield: MARGINALIZING WOMEN WITH FIBROMYALGIA


