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The Resurrection of "Female Hysteria" in Present-Day ERISA Disability Law

Cassie Springer-Sullivan†

I. INTRODUCTION

The Berkeley Women's Law Journal was my home during my three years at Boalt. It was comprised of dynamic, activist people who both welcomed me and challenged me. I was proud to contribute to the journal, and to serve as its Editor in Chief during my final year at Boalt. BWLJ also forever changed the way I will think about "women's issues." Through its mandate, BWLJ has imbedded in me a firm conviction that women who also must combat other forms of oppression are those who are most often underrepresented, underserved, and overlooked. This mentality, and my desire to do something about it, impacted my career choice and my life goals. I am most proud of myself and feel as though I am serving BWLJ's mandate well when I am helping disabled women fight the biggest battles of their lives.

I primarily work with disabled people who are being denied disability benefits by their long-term disability insurance carriers. Although I represent women and men with many different disabilities, I have been surprised to find that many of the disabled women who come to my firm seeking legal representation suffer from illnesses that are typically labeled "women's illnesses," such as fibromyalgia and lupus. As explained below, I believe that this is because disability insurers often presume (incorrectly, in my experience) that women suffering from these types of illnesses are magnifying their symptoms or just have a low pain tolerance. When I represent these women, I am reminded of BWLJ's mandate, and I feel satisfaction that I am representing and serving women who are also facing oppression due to their disabilities.

At this time of celebration and remembrance of the impact that BWLJ has

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made over the years, I sincerely hope that others continue to be inspired by BWLJ's mandate and its commitment to social justice as much as it inspired and continues to inspire me.

II. WOMEN AND FIBROMYALGIA

Approximately four to seven million people in the United States, the vast majority of whom are women, suffer from a chronic, often debilitating condition called fibromyalgia, also known as fibromyalgia syndrome or FMS.1 Fibromyalgia is recognized as a legitimate medical condition by the American College of Rheumatology, the American Medical Association, the World Health Organization, and the National Institutes of Health.2 Perhaps the saddest part of this illness is not the relentless pain and fatigue experienced by those who have it, but that its sufferers are often not believed. Instead, people with fibromyalgia are often labeled as malingerers, accused of exaggerating or making up their symptoms altogether, and frequently denied long-term disability benefits as a result. Does disbelief of an illness that more often strikes women than men sound familiar? It should: Fibromyalgia seems to be the modern-day version of what medical skeptics have called “female hysteria” for hundreds of years. Although many doctors and courts recognize the legitimacy of this illness, in my work representing disabled people who are pursuing their claims for long-term disability benefits, I have observed that many doctors and insurers still lag far behind and lean towards a presumption of disbelief, and some insurers are even writing their policies to exclude benefits for people with fibromyalgia.

I represent people who are making a claim for insured long-term disability benefits under the Employee Retirement Income Security Act (“ERISA”). I have represented at least six people who have been diagnosed with fibromyalgia, and they all have one thing in common: They are women who were successful, hard-workers, but who were struck with a debilitating condition that dramatically changed their lives. Each of these women does not want to be disabled. Rather, each wants to find a cure for her illness, struggles each day just to cope with the tasks of daily living, and wants more than anything to return to work.

I have worked with these women to understand their stories,3 and how fibromyalgia has affected their lives. One woman described to me how she is in so much pain that it usually takes her three hours just to fall asleep at night, and she is often awakened in the middle of the night two or three times due to jolts of pain. Her goal is to accomplish one thing during each day, such as going to the pharmacy or the doctor. Sometimes, she is in too much pain to even accomplish

3. The following accounts of these women’s cases arise from conversations and information gathered that are covered by attorney-client privilege. The author has notes concerning these women’s cases on file with her.
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this. As a result of this pain and fatigue, her relationships with many friends have deteriorated. She has tried everything imaginable to get better, including dietary restrictions, physical therapy, and acupuncture, but none have helped in a significant way. She remains unable to return to a job that she loved.

Another woman, who prior to the disease’s onset had been a rising star in her field, tried to work part-time from home so that she could remain productive and active, with the hope that she would someday get better and be able to return to work. However, she would often fall asleep during work calls because she would be too fatigued to focus. Pushing herself kept making her sicker, and she eventually had to be placed in a position with less responsibility since she was not able to keep up with deadlines. The change was dramatic, and a source of embarrassment for her.

The stories like this continue. In my experience, women disabled by fibromyalgia do not want to be sick. They want to return to work and do everything they can to try to do so. However, their physical limitations prevent them from leading the energetic lives that they used to lead. Their limitations are a source of shame to them. Moreover, their inability to continue working becomes a financial strain, especially when their long-term disability insurers refuse to pay benefits. It is my belief that although courts have made some headway into recognizing the legitimacy of fibromyalgia, insurers fight these claims because of a misguided notion that women with fibromyalgia are making up their symptoms.

III. FIBROMYALGIA: SYMPTOMS AND MANIFESTATIONS

Fibromyalgia is an illness most commonly characterized by widespread pain, fatigue, and sleep disturbance. People with fibromyalgia describe experiencing deep muscle pain, pain and stiffness in the mornings or with repetitive motion or exertion, sleeping without feeling refreshed, decreased headache, irritable bowel, ringing in the ears, numbness, light-headedness, and cognitive dysfunction or brain fog. The symptoms may be worsened by lack of sleep, poor sleep, and exertion, among other things.

In 1990, the American College of Rheumatology published diagnostic criteria for fibromyalgia, which includes experiencing pain in at least eleven of eighteen “tender points” located on specific parts of the body when the examiner applies four kilograms of force. Thereafter, more statistical information about people with fibromyalgia became available, although doctors are still working to better understand this condition. The average age at onset of fibromyalgia is twenty-five to forty-five years, and there is a family history of fibromyalgia in

4. BERNE, supra note 1, at 26.
5. Id. at 29-30.
6. Id. at 32.
7. Id. at 33.
about thirty percent of patients, suggesting a genetic component.\textsuperscript{8} Although some people are able to work with fibromyalgia,\textsuperscript{9} approximately thirty percent of those diagnosed with the illness are disabled by it.\textsuperscript{10} In addition, while fibromyalgia is not fatal, there is currently no cure for fibromyalgia, and it is considered a chronic condition, although its causation is not known.\textsuperscript{11}

\section*{IV. FIBROMYALGIA AS MODERN-DAY HYSTERIA}

Eighteenth-century theorists believed that the womb was the cause of women's illnesses, "for through the evil quality thereof, the heart, the liver, and the brain are affected."\textsuperscript{12} These supposed womb-based illnesses became known as "the hysterical passion,"\textsuperscript{13} and the woman hysteric was born. In the 1800s, when doctors, rather than midwives or herbalists, began to treat patients, the "hysterical" woman became a commonplace label when the doctor was unable to understand or diagnose the problem.\textsuperscript{14} Women with multiple sclerosis were initially labeled as hysterics, as were women with fever-induced delirium.\textsuperscript{16} Even today, people who are ultimately diagnosed with lupus may be accused of exaggeration when they first present their symptoms.\textsuperscript{17} This is likely linked to the fact that many of the initial symptoms of lupus - fatigue, achiness, and stiffness\textsuperscript{18} – are the same symptoms that doctors for centuries past have noted in "hysterical women."\textsuperscript{19} Notably, these same symptoms, especially pain and fatigue, are the hallmark of fibromyalgia.

The root of the "hysteric" label seems firmly bound in misogyny and an unwillingness to believe that ill women were anything other than "the whining woman behind the female patient."\textsuperscript{20} Indeed, doctors in the late nineteenth century discredited women's complaints of chronic fatigue because they believed that women who did not work had nothing to be tired over.\textsuperscript{21} It

\begin{itemize}
  \item \textsuperscript{8} \textit{Id}. at 28.; \textsc{Starlanyl}, supra note 2, at 7.
  \item \textsuperscript{9} \textsc{Berne}, supra note 1, at 47.
  \item \textsuperscript{10} \textsc{Starlanyl}, supra note 2, at 6.
  \item \textsuperscript{11} \textsc{Berne}, supra note 1, at 47.
  \item \textsuperscript{12} \textsc{Edward Shorter, From Paralysis To Fatigue: A History Of Psychosomatic Illness In The Modern Era} 18 (1992) ("in hysteria, the uterus is the affected organ and ... it plays the principal role").
  \item \textsuperscript{13} \textit{Id}. at 16.
  \item \textsuperscript{14} \textit{Id}. at 12-14.
  \item \textsuperscript{15} \textit{Id}. at 12, 14.
  \item \textsuperscript{17} \textit{Id}. at 3-4.
  \item \textsuperscript{18} \textsuperscript{12} \textit{Shorter, supra note 12, at 10-12.}
  \item \textsuperscript{19} \textit{Id}. at 126 (noting the historical description of "hysterical paraplegia as, 'women with a low, whining, bleating voice that is by itself a tell-tale of the kind of will-less ataxia which seems to cripple the mind no less than the body'").
  \item \textsuperscript{20} \textit{Id}. at 282 (noting one doctor's description of the "New England Invalid," as a woman who "is an invalid with nothing to do, and who requires a household to help her do it. She has had no hardships, she has studied moderately at school, and perhaps has had a fall or an acute sickness, but she does not convalesce beyond a certain point, and is, or thinks she is, as
apparently did not enter consideration that a physical ailment, even if it was an ailment not yet understood by medicine, could be causing the fatigue and pain.

What is remarkable, however, is that this type of labeling continues today, largely with regard to medical conditions from which more women suffer than men. Rather than being called hysteria, however, these conditions are called "somatic" or "psychosomatic," meaning "any illness in which physical symptoms, produced by the action of the unconscious mind, are defined by the individual as evidence of organic disease and for which medical help is sought."22 Despite a developed set of diagnostic criteria to identify those suffering from fibromyalgia, it is sometimes characterized by the medical community, courts, and insurers of long-term disability plans as having a psychological component, and sometimes as even being a psychosomatic illness. Of course, those who advocate the legitimacy of fibromyalgia take issue with this label because "[t]here is now clinical evidence that FMS represents a distinct rheumatic disorder and should not be regarded as a somatic illness secondary to psychiatric disorder."23

V. FIBROMYALGIA AND THE COURTS

On the whole, courts have taken a progressive approach in analyzing whether people diagnosed with fibromyalgia are disabled under the terms of long-term disability policies governed by ERISA. In 1997, the Ninth Circuit issued one of the first decisions to address comprehensively fibromyalgia and its symptoms.24 In Lang v. Long-Term Disability Plan, the claimant was initially diagnosed with depression, but later diagnosed with fibromyalgia.25 The insurer initially applied a mental illness limitation to her claim,26 which is a common limitation found in long-term disability policies, usually restricting the payment of benefits to two years for mental illnesses. Once diagnosed with fibromyalgia, Ms. Lang asked the insurer to re-assess its decision to pay benefits under the mental illness limitation because fibromyalgia is a physical illness.27 The insurer refused, stating that Ms. Lang "had failed to establish that her fibromyalgia, 'separate from psychological factors, [was] disabling in and of itself.'"28 The court disagreed, stating that fibromyalgia is "an affliction with a physical source, but which is often accompanied by depression," and awarded Ms. Lang her

22. Id. at 95 ("Hysteria is the old-fashioned term for somatization").
23. STARLANYL, supra note 2, at 9.
25. Id. at 796.
26. Id.
27. Id. at 796-97.
28. Id. at 797 (alteration in original).
disability benefits. In rendering this determination, the Ninth Circuit paved the way for this illness to be legally legitimized as a medical disability that was not the product of exaggeration or mental fantasy. Nonetheless, insurers and doctors employed by insurers still sometimes try to claim that fibromyalgia is a somatoform disorder rather than a physical ailment. Courts largely reject this analysis.

Most recently, insurers have responded to the courts’ refusal to characterize fibromyalgia as a mental illness by instead rewriting disability insurance policies to exclude or limit benefits for conditions that are based on “self-reported” symptoms such as pain and fatigue, and to require “objective evidence” of a disability. One example of such a self-reported symptom limitation specifically lists “headaches, pain, fatigue, stiffness, soreness, ringing in ears, dizziness, numbness and loss of energy” as symptoms that are considered self-reported. Notably, these are many of the symptoms experienced by people with fibromyalgia. Some policies also specifically list fibromyalgia as a limited payment diagnosis.

Why would insurers include such provisions when fibromyalgia is a medically accepted diagnosis and even recognized by the courts to be physical in nature? Most likely, insurers start with an assumption that people with these symptoms are faking or exaggerating their symptoms, such as the female hysteric was believed to do, and therefore should not be entitled to a full course of disability benefits because they are assumed to be frauds. This baseline assumption presents a conundrum, however, as nearly all conditions are characterized by some type of “self-reported” symptom. For example, a cancer patient may experience pain that can be disabling, and few would question the

29. Id. at 799-800.
30. See Maronde v. Sumco USA Group Long-Term Disability Plan, 322 F. Supp. 2d 1132, 1137 (D. Or. 2004) (describing that insurer attempted to pay the claimant, who was diagnosed with chronic fatigue syndrome and fibromyalgia, under a mental illness limitation provision because the insurer’s doctors believed that the claimant had no physical limitations, but that she merely believed she was disabled by her diagnoses).
31. See id. at 1140-41.
32. See Welch v. Unum Life Ins. Co. of Am., 382 F.3d 1078, 1079, 1084 (10th Cir. 2004) (holding insurer’s amendment of plan to include a 24 month limitation on illnesses “which are primarily based on self-reported symptoms” could be applied retroactively to a woman disabled by fibromyalgia).
33. See Stup v. Unum Life Ins. Co. of Am., 290 F.3d 301, 306 (4th Cir. 2004) (rejecting insurer’s attempt to terminate disability benefits where insurer agreed with diagnoses of fibromyalgia and lupus, yet claiming that no objective evidence was present that demonstrated claimant could not work in a sedentary occupation); Gilbertson v. Allied Signal, Inc., 328 F.3d 625, 628 (10th Cir. 2003) (describing that insurer denied the claimant’s application for long-term disability benefits because she did not submit objective evidence of how her fibromyalgia symptoms were disabling).
34. Welch, 382 F.3d at 1081.
35. BERNE, supra note 2, at 29-30.
validity of this pain, even though it is self-reported, because cancer is known to be painful. Someone with AIDS may experience nausea, fatigue, and pain that may be disabling; these too are self-reported, but cannot reasonably be called into question because these are known symptoms of this illness. Thus, it is illogical that someone with fibromyalgia should be denied disability benefits because she experiences pain, fatigue, etc., since these symptoms are known to result from this illness. However, this is exactly what insurers are doing under these self-reported symptom limitations, and courts are starting to agree.

In *Jordan v. Northrop Grumman Corp. Welfare Benefit Plan*, the Ninth Circuit acknowledged its previous holding that fibromyalgia is a physical rather than a mental disorder, but stated that “[t]he symptoms of fibromyalgia consist of the patient’s reports of pain and nothing else” and upheld the insurer’s decision to deny benefits because the claimant’s doctors did not adequately explain why fibromyalgia disabled Ms. Jordan. However, the insurer’s and court’s analysis seems rooted in the same presumption that has pervaded how insurers handle these claims: Women who report pain and fatigue are faking it, and they are, essentially, hysterics. The insurer’s doctor in *Jordan* wondered “about a nervous / mental dx [diagnosis] such as depression / anxiety,” despite the fact that three doctors had diagnosed the illness as fibromyalgia. Moreover, the court prefaced its analysis with this statement: “[o]bjective physical signs, laboratory results, and x-ray results are generally negative, and ‘[b]ecause the majority of patients appear tense and anxious and have no recognizable basis for symptoms, the syndrome is often considered psychogenic’” It seems unlikely that either the insurer or the court was inclined to find Ms. Jordan or her three physicians credible, given these statements.

VI. CONCLUSION

Has recognition of the legitimacy of fibromyalgia come full circle? Are the courts and insurers back to believing that fibromyalgia cannot be disabling because “self-reported” symptoms cannot be believed when offered by a woman who claims pain and fatigue, and that she is a hysteric? One recent case gives us hope that this is not true. In *Hawkins v. First Union Corp. Long-Term Disability Plan*, the Seventh Circuit found the claimant disabled by fibromyalgia where he

“pain can be an early warning sign of the side effects of the cancer or the cancer treatment”) (last visited Mar. 30, 2005).

37. See EMEDICINEHEALTH, HIV/AIDS SYMPTOMS, available at http://www.emedicinehealth.com/articles/15476-3.asp (listing common AIDS symptoms as “Cough and shortness of breath; Seizures and lack of coordination; Difficult or painful swallowing; Mental symptoms such as confusion and forgetfulness; Severe and persistent diarrhea; Fever; Vision loss; Nausea, abdominal cramps, and vomiting; Weight loss and extreme fatigue; Severe headaches with neck stiffness; Coma”) (last visited Mar. 30, 2005).

38. 370 F.3d 869, 877, 880-81 (9th Cir. 2004).

39. Id. at 874.

40. Id. at 872-73, quoting CECIL TEXTBOOK OF MEDICINE 208 (Paul Besson, et al., eds., 15th ed. 1979).
presented pain and fatigue as his primary disabling symptoms.\textsuperscript{41} The court wrote:

\begin{quote}
    Pain often and in the case of fibromyalgia cannot be detected by laboratory tests. The disease itself can be diagnosed more or less objectively by the 18-point test... but the amount of pain and fatigue that a particular case of it produces cannot be. It is "subjective" — and Dr. Chou seems to believe, erroneously because it would mean that fibromyalgia could never be shown to be totally disabling, which the plan does not argue, that because it is subjective Hawkins is not disabled.\textsuperscript{42}
\end{quote}

Thus, there is hope that courts will continue to acknowledge that people with fibromyalgia are not hysterics, that it is a legitimate illness, and that women who experience pain, fatigue, and other symptoms are not automatically liars out to defraud doctors, insurance companies, and courts. Whether insurers will accept a fibromyalgia diagnosis without a court order to do so, however, is a different question.

\textsuperscript{41} 326 F.3d 914, 919 (7th Cir. 2003). Also note, however, that this case differs from the others in that the plaintiff in Hawkins v. First Union Corp. is a man, not a woman.

\textsuperscript{42} Id. (emphasis added).