

Chronic Pain in Women: Neglect, Dismissal and Discrimination

ANALYSIS AND POLICY RECOMMENDATIONS

MAY 2010



 Produced by
campaign to
end chronic pain in women
www.EndWomensPain.org

Including Organizational Members of the:


Overlapping Conditions Alliance

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PREFACE

Members of the Overlapping Conditions Alliance (OCA) produced this white paper to promote awareness and research of neglected and poorly understood chronic pain conditions that affect millions of American women. The paper includes detailed policy recommendations to further these goals.

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ABOUT THE CAMPAIGN TO END CHRONIC PAIN IN WOMEN



The Campaign aims to improve the quality of women's lives by raising awareness of chronic pain conditions that disproportionately impact women, as well as the neglect, dismissal and discrimination faced by women suffering from chronic pain. This Campaign will alert policy makers, health care professionals and the general public to the lack of scientific research conducted on these conditions, as well as the poor quality of education health care providers receive on chronic pain. It will focus on implementation of the recently passed health care reform law to ensure it includes a long-overdue focus and emphasis on women's pain conditions. Equity demands no less. As documented in this groundbreaking report, the recommended policy solutions could save billions in wasted health care costs each year.

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Produced by M2 Health Care Consulting for the Campaign to End Chronic Pain in Women with financial support from Pfizer and through the extensive volunteer contributions of member organizations of the Overlapping Conditions Alliance.



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EXECUTIVE SUMMARY

As many as 50 million American women live with one or more neglected chronic pain conditions.* For the majority, our health care system offers frustratingly little help. In fact, they face neglect, dismissal and discrimination. The federal government and private sector have severely shortchanged research funding on these conditions and, as a result, they are poorly understood. Health care professionals receive inadequate training in the diagnosis and treatment of these conditions, and effective evidence-based treatments are lacking. In addition, a growing body of evidence shows a discriminatory pattern in the medical care provided to women who suffer from chronic pain. Studies have shown that:

- Women report pain that is more frequent, severe and of longer duration than men, but are nonetheless treated for pain less aggressively;
- Women's pain reports are often taken less seriously by health care professionals than men's; and
- Health care professionals are more likely to dismiss women's pain reports as "emotional, psychogenic, hysterical or oversensitive" and therefore "not real," leading to more frequent mental health diagnoses.^{1,2}

Chronic pain conditions exact a heavy personal toll on millions of women, as well as a staggering financial burden.

Our failure to effectively deal with just six of these conditions—chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular (TMJ) disorders and vulvodynia—adds as much as \$80 billion a year in direct and indirect costs to Americans' annual health care bills.* The good news is that there are solutions; for example, targeted research funding could help to determine the causes of, and effective treatments for, these conditions, and improved medical education efforts would enable health care professionals to better recognize and diagnose them. While these solutions would greatly improve women's quality of life and cut billions of dollars in unnecessary wasteful care, thus helping "bend the curve" of health care costs, they have been largely overlooked in the current heated health care reform debate. This report provides policy makers with a detailed set of recommendations necessary to transform these solutions from a possibility into a reality. One section of the Patient Protection and Affordable Health Care Act, the new health care reform law, contains a series of much needed improvements in general pain care policy. The Campaign to End Chronic Pain in Women's goal is to ensure that implementation of this law includes appropriate focus and emphasis on women's pain conditions. Equity demands no less.

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

BACKGROUND

Chronic pain—defined as pain persisting more than six months—is all too common. It is estimated to affect 25 percent of Americans and account for more than 20 percent of all physician office visits.³ Unfortunately, women bear the brunt of chronic pain conditions. All six conditions discussed in this report—chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular (TMJ) disorders and vulvodynia—either solely affect women, or target women at least four times more often than men. As many as 50 million American women live with one or more of these neglected and poorly understood chronic pain conditions.*

The financial toll exacted by these six chronic pain conditions is staggering—as much as \$80 billion a year in direct and indirect costs.* In addition, much of this care is unnecessary and wasteful, as women often must visit multiple health professionals before obtaining a diagnosis. Also, many women receive costly and sometimes harmful treatments that may not be effective or based on quality scientific research.

Despite the millions of American women who suffer from these conditions and the billions in costs to our health care system, research into these conditions has been glaringly shortchanged to date. **The National Institutes of Health (NIH) invested only \$65 million last year in research into these six conditions—just about two-tenths of one percent of its**

total budget. That is an average of just \$1.33 for every affected woman and represents less than one-tenth of one percent of the annual estimated cost of these conditions. Also, what little research that has been conducted has lacked sufficient coordination, interdisciplinary collaboration and direction. As a result, the underlying causes of these conditions are unknown, diagnostic protocols are lacking and there are very few, if any, scientifically proven treatments. Health professionals are therefore left without adequate knowledge to appropriately diagnose and treat these chronic pain conditions.

Those afflicted are routinely misdiagnosed, shuffled from office to office, inappropriately treated and left without answers or hope, needlessly suffering. They are often left to experiment with a myriad of therapies, most with unknown benefits, until they find a treatment or combination of treatments to relieve some of their pain.

It typically takes several months to years and multiple consultations for a woman suffering from one or more of these conditions to obtain an accurate diagnosis.

For example:

- Forty percent of women with chronic vulvar pain remain undiagnosed after three medical consultations.⁴
- Fewer than 20 percent of chronic

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

fatigue syndrome patients in the United States have been properly diagnosed.^{5,6}

- For those with temporomandibular disorders, there is an average four-year span from symptom onset to diagnosis.⁷
- Fifty percent of women with endometriosis see at least five health care professionals before receiving a diagnosis and/or referral.^{8,9}

This delay in diagnosis and initiation of appropriate treatment has multiple costs. It can cause a woman's symptoms to worsen and may predispose her to developing chronic pain in other areas of her body, greatly impacting the quality of her life. It also adds billions in unnecessary health care costs.

A growing body of literature also documents a pattern of discrimination in the care and treatment of women with chronic pain conditions. Studies have shown that:

- women report pain that is more frequent, more severe and of longer duration than men, but are nonetheless treated for pain less aggressively;
- health care professionals often take women's pain reports less seriously than men's;

- health care professionals are more likely to dismiss women's pain reports as "emotional, psychogenic, hysterical or oversensitive" and therefore "not real," leading to more frequent mental health diagnoses rather than treatment for pain.^{10,11}

This report details the human and financial tolls associated with chronic pain disorders that solely or disproportionately affect women and the neglect, dismissal and discrimination faced by women in pain. It puts forward a detailed set of policy solutions designed to both improve health care for these millions of American women and substantially lower health care costs by reducing unnecessary and sometimes harmful medical care.

"After examining me and doing an ultrasound, my doctors said the only problem I had was in my head..."

*Rosemarie
Suffers from endometriosis*

CHRONIC PAIN IN WOMEN: AN OVERVIEW OF KEY CONDITIONS

As many as 50 million women suffer from at least one of these chronic pain disorders: chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular disorders and vulvodynia.* All cause(s) of each are not known at this time, and most are diagnosed by a process of exclusion. Women with these conditions are frequently misdiagnosed or undiagnosed. The conditions are painful and often debilitating. They affect every facet of sufferers' lives, making daily life very difficult. The following provides a summary of each condition, including its prevalence and economic impact.

Chronic Fatigue Syndrome

Chronic fatigue syndrome (CFS) is defined as severe, incapacitating fatigue of at least six months duration that is not improved by bed rest and that may be worsened by physical or mental activity. This disabling fatigue is accompanied by disruptive sleep, problems with concentration and short-term memory, joint and muscle pain, tender lymph nodes, sore throat and headache. A hallmark of the illness is postexertional malaise—a worsening of symptoms following even very modest physical or mental exertion that can persist for days or weeks.¹²

The US Centers for Disease Control and Prevention (CDC) estimates that up to 4 million Americans have CFS.¹³ Further, more than 80 percent of people identified in community studies of CFS

have not been diagnosed and are not receiving appropriate medical care for their CFS.¹⁴ Studies conducted to pinpoint the number of CFS sufferers in this population have been difficult due to a lack of standardization of case definitions and criteria among research groups. A research study conducted at DePaul University revealed that each year, CFS costs the US economy between \$17 and \$24 billion.¹⁵ CFS affects people of all ages, races, ethnicities, and socioeconomic groups. Though CFS is more common among adults aged 40 to 59, children can develop the illness in adolescence.¹⁶ Research also shows that the illness affects women at a rate three to four times higher than in men.

Endometriosis

Endometriosis is a chronic hormonal and immune system disease. The name comes from the word *endometrium*, which is the tissue that lines the inside of the uterus and builds up and sheds each month during the menstrual cycle. In endometriosis, this tissue is found outside of the uterus, causing pain, infertility and other problems. The most common symptoms are pain before and during periods, pain during or after sexual activity, fatigue, infertility and heavy bleeding. Other symptoms may include painful bowel movements with periods, painful urination, diarrhea and/or constipation and other intestinal upsets with periods. Many women also experience a range of immune disorders,

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

including allergies, asthma, eczema and certain autoimmune diseases. The true prevalence of the condition is unknown because surgical confirmation is necessary to diagnose the condition. It is estimated that 2 to 10 percent of women and girls in the US have endometriosis; the number is most likely at least 6.3 million, or 4 percent.¹⁷

Most women experience significant delays in diagnosis, especially for those who present with pain rather than infertility. Girls as young as age 8 have been diagnosed with the disease. From 1990 to 1998, endometriosis was the third most common diagnosis included on hospital discharge summaries of women aged 15 to 44.¹⁸ Endometriosis is the leading cause of chronic pelvic pain in women.¹⁹ Costs arising from endometriosis in women of reproductive age were estimated to be \$22 billion in 2002.²⁰

Fibromyalgia

Fibromyalgia is a chronic condition characterized by widespread soft tissue pain as well as accompanying comorbidities, such as disturbed sleep, fatigue and cognitive difficulties.^{21,22} It is estimated that fibromyalgia occurs in two percent of the general population in the US.²³ Studies reporting direct medical costs demonstrated that patients with fibromyalgia cost employers approximately \$6,000 a year in 1998 dollars.²⁴ Extrapolating from that figure, without accounting for inflation, fibromyalgia costs the US health care

system more than \$20 billion annually. Men and children may present with the disorder; however, women are more frequently diagnosed with fibromyalgia compared to men, at a rate of 9 to 1.²⁵ Diagnosis is most likely to occur between ages 20 to 50.²⁶

Interstitial Cystitis/Painful Bladder Syndrome

Interstitial cystitis (IC), also known as Painful Bladder Syndrome (PBS), is characterized by pain, pressure or discomfort of the bladder in the absence of infection or other pathology. Sufferers also typically experience urinary frequency and urgency. Based on the National Health and Nutrition Examination Survey III, the NIH estimates that 1.2 million women and 82,000 men in the United States have IC/PBS.²⁷ However, it is thought that IC may be underdiagnosed in men because the symptoms of IC are very similar to and overlap with symptoms of chronic prostatitis/chronic pelvic pain syndrome.²⁸ Because so much time is spent obtaining a diagnosis, interstitial cystitis is often diagnosed later in a woman's life—after age 40, even though 30 percent of women begin reporting symptoms before age 30. The prevalence of IC in young women is not well-defined; however, in one group of IC patients, 27 percent were between the ages of 19 to 34.²⁹ In 2000, annual national expenditures for interstitial cystitis were \$66 million.³⁰

Temporomandibular (TMJ) Disorders

Temporomandibular disorders is a collective term used to describe a number of related disorders involving the temporomandibular joint, masticatory muscles and related structures. Jaw pain and dysfunction affect a repertoire of facial movements critical in speaking, singing and making facial expressions, as well as governing the vital functions of biting, chewing and swallowing food. The severity of TMJ disorders ranges from a clicking, popping joint to total oral disability, necessitating a feeding tube for nutritional sustenance; pain ranges from mild discomfort to severe and unrelenting. A 1996 NIH-sponsored Technology Assessment Conference on the Management of TMJ Disorders concluded that there was no consensus on what pain in the jaw signifies; what the condition should be called; and who should treat it. Conference members determined that it was impossible to know what treatments are effective due to the lack of clinical trials and that many people were being harmed by treatments.³¹ Today, we understand that this is a highly complex disease involving genetic and hormonal influences as well as a myriad of complex biologic factors.

Approximately 35 million Americans suffer from TMJ disorders.³² Overall, the prevalence is higher in women than men; 90 percent of patients seeking treatment are women of childbearing age.^{33,34} One study found that TMJ disorders resulted in 17.8 million lost work days per year for every 100 million working

adult Americans.³⁵ Additionally, a study sponsored by the Agency for Healthcare Research and Quality shows TMJ disorders cost \$32 billion per year.³⁶

Vulvodynia

Vulvodynia is characterized by chronic pain in the vulva (area surrounding the vaginal opening) in the absence of infection or other known disease. The most common symptom is “burning,” with women describing the pain as “acid being poured on their skin” or as “constant knife-like pain.” Vulvodynia is not limited to a particular age group. A major study of adult women found that the incidence of symptom onset is highest between the ages of 18 and 25, but a recent study of adolescents aged 12 to 19 years suggests that it may be prevalent among younger females as well.^{37,38} According to an NIH-funded Harvard study, almost 16 percent of US women suffer from vulvodynia at some point during their lives, with more than 90 percent reporting ongoing pain for many years.³⁹ Pain from vulvodynia poses a significant physical, emotional and social burden. According to an NIH-funded study at Robert Wood Johnson Medical School, 60 percent of women suffering from vulvodynia report that it compromises their ability to enjoy life.⁴⁰ Like many of the other conditions discussed, vulvodynia is a diagnosis of exclusion, therefore seeking a diagnosis is usually a long and arduous process.⁴¹ Sixty percent of women consult *at least three doctors* in seeking a diagnosis. Forty percent of those who seek

professional help remain undiagnosed after three medical consultations.⁴² The National Vulvodynia Association is currently funding the first study to ascertain the direct and indirect costs of the disorder.

Chronic Pain in Women: Overlapping Nature of these Conditions

Up to 50 million American women suffer from at least one of these chronic pain disorders. Current research indicates that these conditions frequently coexist,

or “overlap.”⁴³⁻⁵² While studies have not yet identified the exact rates of overlap, we know that some women suffer from two conditions, while others have three or more. In some cases, women suffer from one condition for many years before developing a second or third condition; in other cases, those afflicted experience symptoms of several conditions simultaneously. For example, researchers have found “chronic TMD [temporomandibular] pain is often comorbid with other painful conditions, which are also more prevalent in women, such as fibromyalgia, irritable bowel

SUMMARY OF COMMON PAIN CONDITIONS

DISORDER	DESCRIPTION / SYMPTOMS
Chronic Fatigue Syndrome	Chronic, debilitating fatigue and other characteristic symptoms. Symptoms: Chronic exhaustion. Sleep difficulties. Problems with concentration and short-term memory. Flu-like symptoms. Pain in joints and muscles. Tender lymph nodes. Sore throat. Headache. Postexertional malaise after physical or mental effort.
Endometriosis	Chronic pelvic pain due to growth of endometrial tissue outside of the uterus. Symptoms: Pelvic pain before and/or during menstruation. Pain during/after sexual activity. Fatigue. Infertility. Heavy bleeding. Intestinal upset, painful bowel movements and/or low back pain with periods.
Fibromyalgia	Fibromyalgia is a chronic condition characterized by widespread soft tissue pain, as well as accompanying comorbidities such as disturbed sleep, fatigue and cognitive difficulties.
Interstitial Cystitis	Pelvic pain, pressure, or discomfort related to the bladder typically associated with urinary frequency and urgency, in the absence of infection or other pathology. Symptoms: Pressure, pain or tenderness in the bladder and/or pelvis. Chronic pelvic pain. Urinary frequency and urgency. Pain during/after sex. Increased pain as bladder fills.
Temporomandibular Disorders (TMJ)	Group of conditions that cause chronic pain and dysfunction in the jaw joint and muscles that control jaw movement. Symptoms: Dull aching pain in the face, jaw, neck, or shoulders. Jaw muscle stiffness. Limited movement or jaw “locking.” Painful clicking, popping or grating in the jaw joint when opening or closing the mouth. A change in the way the upper and lower teeth fit together or bite that feels “off.”
Vulvodynia	Chronic vulvar pain without an identifiable cause. Symptoms: Pain or discomfort with sexual intercourse, tampon insertion or sitting. Burning or other painful sensations in the vulva (area surrounding the vaginal opening). Redness/swelling of the vulvar tissue.

syndrome, and vulvar vestibulitis” (a subtype of vulvodynia).⁵³ Similarly, in the case of endometriosis, in “about 20 percent of women with the disorder, it co-occurs with other chronic pain conditions, such as irritable bowel syndrome, interstitial cystitis/painful bladder syndrome, vulvodynia, temporomandibular disorders, migraine, fibromyalgia, and/or with autoimmune disorders such as systemic lupus erythematosus, rheumatoid arthritis, chronic fatigue syndrome, and Sjogren’s syndrome.”⁵⁴

Each of these conditions is poorly understood. Research on each condition is in its infancy, and even less science has been conducted to understand their coexistence, or “overlap.” As a result, we do not have a clear understanding of how or why they are connected. Various theories have implicated central nervous system pain processing dysfunction, as well as genetic, hormonal, inflammatory, immunological and environmental factors. There are many questions that will only be answered through an expanded and better-coordinated scientific research effort.

DISPROPORTIONATELY AFFECTING WOMEN

PREVALENCE (US POP)	PREVALENCE IN WOMEN	SYMPTOM ONSET	MISDIAGNOSED-UNDIAGNOSED	ECONOMIC COST (US, ANNUAL)
1 to 4 million, depending on definition used	Four times more common in women	Highest between 40-59	More than 80% have not been diagnosed	\$17-24 billion (direct & indirect)
6.3 million	Affects women (extremely rare in men)	66% before the age 20	50% of women with endometriosis see at least five providers before receiving a diagnosis and/or referral	\$22 billion (direct & indirect)
6 million	Nine times more common in women	Between 20-50	Has not been studied	\$20 billion (direct & indirect)
1 million	80% women	Between 28-67	38% misdiagnoses rate	\$66 million (direct & indirect)
35 million	90% of severest cases are women in childbearing years	Between teens and 50	4 years from symptom onset to diagnosis	\$32 billion (direct & indirect for orofacial pain)
6 million	Only affects women	Highest between 18-25/teens	40% remain undiagnosed after 3 medical consults	Has not been studied

CHRONIC PAIN IN WOMEN: EVIDENCE AND IMPACT OF NEGLECT, DISMISSAL AND DISCRIMINATION

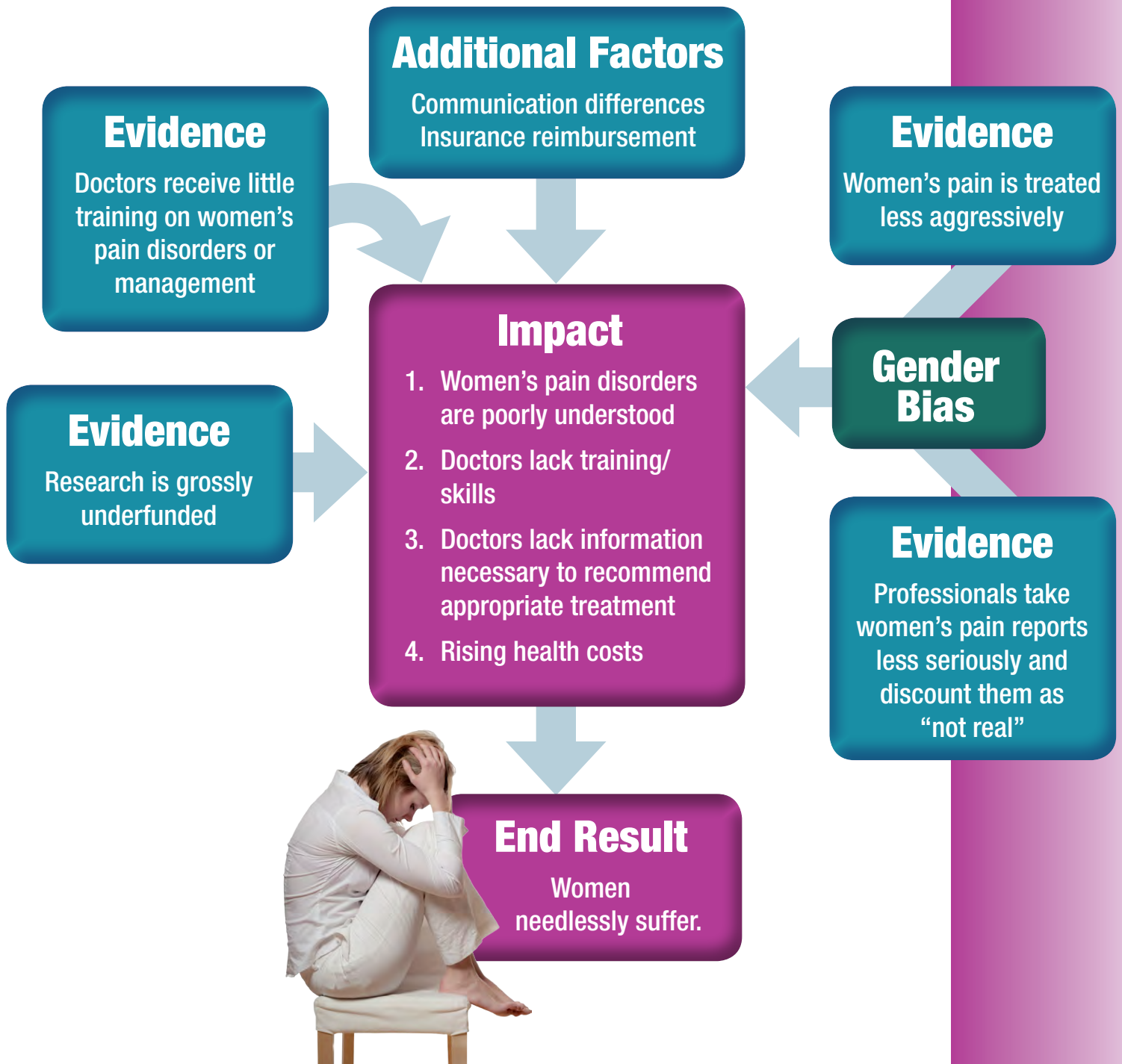
This section highlights both the evidence and impact of the neglect, dismissal and discrimination faced by women with chronic pain. As demonstrated in Figure 1, a growing body of evidence demonstrates:

- One's gender affects pain assessment and treatment. In other words, women's pain is treated less aggressively than men's, and health care professionals are more likely to take women's pain reports less seriously and discounted as "emotional, psychogenic, hysterical or oversensitive" and therefore "not real";⁵⁵
- Chronic pain research, particularly that focused on conditions solely or predominantly affecting women, is grossly underfunded by the federal government; and
- Doctors and health care providers receive little or no training on pain management and pain conditions that solely or predominantly affect women.

In addition to contributing to our nation's rising health care bill, this "perfect storm" ultimately results in the needless suffering of millions of American women because:

- The basic mechanisms and efficacy of treatments prescribed for these chronic pain conditions are poorly understood;
- Medical professionals lack the knowledge and training necessary to appropriately diagnose and treat these pain disorders; and
- Clinicians lack evidence-based data on which to base treatment recommendations.

Figure 1: “The Perfect Storm of Women’s Pain Policy” – How discrimination impacts women with chronic pain.



RESEARCH DISPARITIES

In the most recent fiscal year, the National Institutes of Health (NIH), the nation’s medical research agency, received \$30.5 billion in taxpayer funds to fulfill its mission to improve the health of the nation. The NIH supports research that extends “healthy life,” reduces the “burden of illness and disability,” and studies the causes, diagnosis, prevention and cure of human diseases.^{56,57}

However, considering that up to 50 million American women are affected by the six conditions examined in this report and the associated costs to our nation approach \$80 billion per year,* funding for research on these conditions has been severely shortchanged.⁵⁸

Despite repeated Congressional requests to allocate more research dollars for these conditions, NIH spent just \$65 million in 2009 on all of them combined—just about two-tenths of one percent of its total budget. **That is an average of just \$1.33 for every affected woman and represents less than one-tenth of one percent of the annual estimated costs of these conditions.** In fact, as shown in Table 2, no pain condition ranks in the top 50 research/disease areas funded by the NIH. Funding for all chronic pain conditions combined barely makes the top 75, ranking 74th in research areas funded over the past several years.

Table 2: Estimates of Funding for Various Research, Condition and Disease Categories⁵⁹

Rank	Research/Disease Areas	FY2005 (in millions)	FY2006 (in millions)	FY2007 (in millions)	FY2007 (in millions)	FY2008 (in millions)	FY2009 (in millions)	FY2010 (in millions)
1	Clinical Research	\$8,719	\$8,785	\$9,116	\$9,862	\$9,629	\$9,931	\$10,086
2	Genetics	\$4,840	\$4,878	\$4,878	\$7,000	\$6,872	\$7,066	\$7,173
3	Cancer	\$5,639	\$5,575	\$5,643	\$5,549	\$5,570	\$5,748	\$6,016
4	Biotechnology	\$10,889	\$9,974	\$9,814	\$5,344	\$5,179	\$5,390	\$5,468
5	Neurosciences	\$4,902	\$4,830	\$4,809	\$5,102	\$5,224	\$5,372	\$5,444
6	Prevention	\$7,100	\$6,815	\$6,729	\$4,596	\$4,623	\$4,752	\$4,822
7	Brain Disorders	\$4,784	\$4,732	\$4,670	\$3,592	\$3,729	\$3,835	\$3,888
8	Women’s Health	\$3,551	\$3,498	\$3,470	\$3,470	\$3,514	\$3,627	\$3,683
9	Infectious Diseases	\$3,188	\$3,132	\$3,059	\$3,433	\$3,575	\$3,678	\$3,725
10	Clinical Trials	\$2,863	\$2,767	\$2,949	\$3,422	\$3,562	\$3,663	\$3,719
11	Behavioral & Social Science	\$3,044	\$3,001	\$3,060	\$3,157	\$3,215	\$3,136	\$3,362
12	HIV/AIDS	\$2,921	\$2,902	\$2,906	\$2,906	\$2,928	\$3,010	\$3,055
13	Health Disparities	\$2,699	\$2,766	\$2,744	\$2,744	\$2,614	\$2,691	\$2,725
14	Pediatric	\$3,210	\$3,161	\$3,173	\$2,622	\$2,771	\$2,864	\$2,906
15	Bioengineering	\$1,318	\$1,546	\$1,469	\$2,610	\$2,853	\$2,932	\$2,973
16	Minority Health	\$2,404	\$2,423	\$2,407	\$2,407	\$2,396	\$2,474	\$2,508
17	Mental Health	\$1,848	\$1,824	\$1,853	\$2,061	\$2,086	\$2,142	\$2,173
18	Cardiovascular	\$2,333	\$2,349	\$2,370	\$1,942	\$2,027	\$2,081	\$2,103
19	Aging	\$2,415	\$2,431	\$2,462	\$1,879	\$1,965	\$2,019	\$2,045
20	Biodefense	\$1,696	\$1,766	\$1,735	\$1,735	\$1,735	\$1,777	\$1,793
21	Emerging Infectious Diseases	\$1,872	\$1,857	\$1,816	\$1,733	\$2,098	\$2,156	\$2,179
22	Immunization	\$1,438	\$1,438	\$1,342	\$1,713	\$1,734	\$1,779	\$1,804
23	Vaccine Related	\$1,450	\$1,449	\$1,358	\$1,659	\$1,632	\$1,675	\$1,698
24	Substance Abuse	\$1,508	\$1,490	\$1,523	\$1,636	\$1,763	\$1,811	\$1,836
25	Neurodegenerative	\$1,215	\$1,217	\$1,166	\$1,579	\$1,621	\$1,668	\$1,690
74	Pain Conditions - Chronic	\$229	\$220	\$224	\$277	\$279	\$287	\$291

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

An examination of the NIH research support per affected person allocated to these six pain conditions compared to other chronic conditions also brings

to light the dramatic underfunding of research on women’s pain conditions. Table 3 provides several examples.

Table 3: Comparison of NIH Grant Funding to Prevalence for Selected Chronic Conditions

DISPARITIES IN CHRONIC PAIN RESEARCH SPENDING BY NIH - 2009

(SELECTED CONDITIONS)

Chronic Condition	US Patient Population	NIH Research \$ 2009 ⁶⁰	NIH Research \$ Per Patient
Multiple Sclerosis	350,000 ⁶¹	\$162 million	\$463.00
Parkinson’s Disease	1 million ⁶²	\$186 million	\$186.00
Diabetes	23.6 million ⁶³	\$1.25 billion	\$53.00
Depression	20 million ⁶⁴	\$450 million	\$22.50
Interstitial Cystitis	1 million	\$12 million	\$12.00
Endometriosis	6.3 million	\$17 million	\$2.70
Fibromyalgia	6 million	\$13 million	\$2.16
Chronic Fatigue Syndrome	4 million	\$5 million	\$1.25
Temporomandibular Disorders	35 million	\$16 million	\$0.46
Vulvodynia	6 million	\$2 million	\$0.33

In testimony heard by the Department of Health and Human Services Chronic Fatigue Syndrome Advisory Committee in May 2009, patient advocate and CFS sufferer Jennie M. Spotila defined the research disparity another way:

“Consider that lost productivity due to diabetes cost \$58 billion in 2007. Last year [2008], NIH spent just over \$1 billion on diabetes research. In other words, NIH invested 1.7 cents for every productivity dollar lost. If NIH allocated research funds to CFS as it has to diabetes, then a 1.7 cent investment per dollar lost would translate into \$1.3 billion dollars in annual research. Apparently, NIH believes that CFS does

not merit such investment. Last year the NIH spent only \$4 million in CFS research—an investment of less than one one-hundredth of a penny for every productivity dollar lost.”⁶⁴

An expanded research effort for these six chronic pain disorders is essential - not only to help sufferers obtain relief, but to alleviate the economic, social and personal burdens that result from chronic pain conditions. The government’s current research investment is woefully inadequate for this task.

EFFECTIVE EVIDENCE-BASED TREATMENTS ARE LACKING

Due to a lack of basic research on the underlying mechanisms of chronic pain, as well as pain syndromes and their treatment, the causes of these conditions remain a mystery, and evidence-based treatment options are severely limited. Sufferers are forced to experiment with a myriad of therapies, most with unknown benefits and risks, until they find a treatment or combination of treatments to relieve some of their painful symptoms.

“The overall quality of treatment for pain in the United States remains unacceptable for millions of patients with persistent pain.”⁶⁶

Consider:

- **Chronic Fatigue Syndrome:** “Since no cause or cure for CFS has been identified, treatment programs are directed at relieving symptoms.

“Is it too much to ask that we, the patients, no longer be bound to a system where no one professional takes responsibility for the patient - a system of unbelievable referrals with unscientific, unproven treatments (and hope) sold to the patient by each referring physician?”

In many cases, patients end up worse and more and more destitute, yet they grasp for hope with each referral. Is it too much to ask that we get the protection we deserve under the Hippocratic oath to do no harm and the laws of the United States?”

*Terrie Cowley, President,
The TMJ Association*

There is no single treatment that fixes the illness at its core, but management aimed at reducing symptoms can improve function and allow people with CFS to engage in some of the activities of daily living.”⁶⁷

- **Endometriosis:** “No permanent cure for endometriosis has been found. Symptom relief is the primary goal of existing treatment options, which may be pharmacological or surgical.”⁶⁸
- **Fibromyalgia:** “There is considerable uncertainty surrounding the precise etiology, diagnosis criteria, and clinical management of [fibromyalgia] FM. Moreover, the extensive comorbidity associated with FM may increase potential for misdiagnosis by attributing painful symptoms to other causes. Given the ambiguity surrounding etiology and relatively recent development of treatment guidelines, management of FM likely has involved multiple visits to many different medical specialists... as well as multiple trials of different prescription drugs.”⁶⁹
- **Temporomandibular (TMJ) Disorders:** According to the NIH, “There is no widely accepted, standard test now available to correctly diagnose TMJ disorders.”⁷⁰ “Because more studies are needed on the safety and

effectiveness of most treatments for TMD, experts strongly recommend using the most conservative, reversible treatments possible.”⁷¹ Furthermore, “generally accepted, scientifically based guidelines for diagnosis and management of TMD are still unavailable. For the majority of TMD patients, the absence of universally accepted guidelines for evaluation and diagnosis compromises the goals of consistent and conservative therapy. The lack of standard treatment protocols accepted across

professional specialties means that many patients and practitioners may attempt therapy with inadequately tested approaches.”⁷²

- **Vulvodynia:** “The treatment of vulvodynia is confounded by the fact that the cause is unknown in a majority of cases... It is important to recognize that rapid resolution of vulvodynia is unusual even with appropriate therapy. Whereas a 100 percent improvement rate is desired in all patients, most women with vulvodynia do not reach that level.”⁷³

MEDICAL PROFESSIONALS RECEIVE LITTLE EDUCATION AND TRAINING IN WOMEN’S PAIN CONDITIONS

Physicians’ lack of understanding of chronic pain starts right from the beginning—in medical school. “Despite the clear need for competency in pain assessment and management skills, there is ample evidence that this competency is lacking at all levels of medical training.”⁷⁴ Few graduating physicians in the US have been exposed to comprehensive multidisciplinary pain education. In a recent letter to the editor of the journal *Academic Medicine*, professors and students from the Yale University School of Medicine wrote that an “Association of American Medical Colleges (AAMC) survey in 2000–2001...found that only three percent of medical schools had a separate course in pain management in their curricula; the situation is not much better today [2009].”⁷⁵ This is despite

multiple studies highlighting “the lack of training in chronic pain management for resident physicians and the need to develop programs that address the challenges of providing care to chronic pain patients.”⁷⁶

The lack of education for temporomandibular disorders is a prime example. “In dental school, most universities give 10 to 15 lectures on TMD and orofacial pain conditions with no clinical supervision or training at all, and physicians probably get one lecture at the most.”⁷⁷ It is thus no surprise that evaluating, diagnosing and managing TMJ disorders is not well understood by professionals in the dental and medical communities.

Notably, what medical students do learn about pain assessment and

management is focused primarily on the mechanics of pain and not the patient's experience of it. Medical students are taught to determine the presence, location, character and intensity of acute and chronic pain. Upon entering clinical training, students confront suffering patients. This lack of any discussion about patient suffering in their curriculum makes a potent, yet

hidden, statement about its apparent insignificance.^{78,79}

A comprehensive, patient-centered approach to medical and continuing education would not only help students and physicians better diagnose and manage chronic pain conditions, but also provide them with the tools necessary to address the associated suffering.

THE HEALTH CARE SYSTEM AND ITS PROFESSIONALS ARE ILL-EQUIPPED TO SERVE WOMEN IN PAIN

When Pain Becomes Too Burdensome For the Disease-Treating Specialist

"I am a 26-year-old female with fibromyalgia and a mixed connective tissue disorder (MCTD) closely related to systemic lupus erythematosus, and I experience widespread muscle and neuropathic pain that oftentimes becomes so debilitating that it impairs basic functioning such as standing and walking.

After several attempts at managing my pain through different narcotic pain relievers that had failed, my rheumatologist referred me to the medical center's pain clinic to have a pain medicine specialist take over the pain management aspect of my case. Among his reasons for referring me to a pain medicine specialist, the rheumatologist claimed, was that he was already overwhelmed with managing my disease to keep the MCTD from chronically flaring up and keeping track of the prescription medications relating to those goals. He explained that adding and monitoring narcotics further complicated his workload and required additional time to monitor interactions as well as his vulnerable Drug Enforcement Administration number."

Insufficient research efforts, coupled with the lack of education and training on chronic pain mechanisms and syndromes, leaves health care professionals ill-equipped to appropriately serve pain sufferers. Further, our health care system is "compartmentalized" by specialties, which is not conducive to comprehensive chronic pain assessment. For example, a woman might consult a clinician with expertise in the area of the body where she experiences pain, but that specialist likely lacks an appropriate understanding of chronic idiopathic pain.

Women with symptoms indicative of interstitial cystitis (painful bladder syndrome) will typically consult a urologist; others with TMJ pain will be sent to a dentist; and those with vulvodynia will seek help at the gynecologist's office. This is an important "first stop" for women, because known causes for their pain, such as infections or viruses, need to be ruled out. Once all of the potential instigators are eliminated as causes,

and it is determined that a woman has “idiopathic” pain, are these “organ-specific” providers the most appropriate professionals to manage chronic pain, which is likely a dysfunction of the central nervous system, and not a dysfunction of the “end-organ” where the pain manifests? If women shouldn’t be managed by these specialties, where do they belong? Today, no appropriate “medical home” for women with these conditions exists, and this is particularly true if they suffer from more than one of these conditions. The problem is easy to illustrate: Can you imagine a woman talking to her dentist about her jaw and her vulvovaginal pain, or to her gynecologist about her TMJ problems?

As a result of this lack of comprehensive chronic pain management, women with chronic pain experience delayed diagnoses, misdiagnoses and delayed initiation of appropriate treatment, which can cause the woman’s symptoms to worsen and may predispose her to developing chronic pain in other areas of her body. **It typically takes several months, even years, and multiple consultations for a woman with one or more of these chronic pain conditions to obtain an accurate diagnosis.**

GENDER BIAS AFFECTS WOMEN’S MEDICAL CARE

Even though women experience pain that is more frequent, are more sensitive to pain and are more likely to report pain than men are, they are often met with “disbelief or other obstacles at their initial encounters with health-care providers.”⁸⁶ Considering this disbelief, it is not surprising that women with

For example:

- Forty percent of women with chronic vulvar pain remain undiagnosed after three medical consultations.⁸⁰
- Fewer than 20 percent of CFS patients in the United States have been properly diagnosed.^{81,82} As there is no diagnostic test or biomarker to clearly identify CFS, diagnosing the disorder is particularly difficult.
- For those with TMJ disorders, it takes an average of four years from symptom onset to diagnosis.⁸³
- Fifty percent of women with endometriosis see at least five health care professionals before receiving a diagnosis and/or referral.^{84,85}

A new and sustained effort to educate both current and future health care professionals on the diagnosis and treatment of chronic pain conditions that exclusively or disproportionately impact women would be an important first step towards addressing this crucial shortcoming of our current health care system.

chronic pain conditions frequently experience difficulty in seeking an explanation for their suffering. It can take several years for a woman in chronic pain to obtain an accurate diagnosis and suitable disease management or standard of care.

Studies indicate that physicians demonstrate the least confidence in diagnosing women's medical conditions, and that women suffering with chronic pain are frequently told they have psychiatric conditions.⁸⁷ If a physician is unsure of a diagnosis, he or she is likely to try one of three strategies with a patient: (i) normalize the symptoms; (ii) tell patients there is no disease; or (iii) use metaphors to explain the symptoms.⁸⁸ However, "normalization of symptoms and telling patients that they don't have a disease is not effective and may even result in more health-care seeking."⁸⁹ It certainly creates stigma, and this problem is worse for women because most patients "with unexplained clinical conditions" are women.⁹⁰

A study of women with CFS and fibromyalgia showed that a lack of visible symptoms or changes in symptoms was also a cause for physician "disbelief." "Absence of visible external signs of the illness contributed to [the patients' reports] being called into question, and many believed that evident external symptoms would have enhanced their credibility."⁹¹

"My doctors just threw up their hands, not knowing what to do with me. I went to four doctors and each one said something different. I can't believe I have to go through this, and the expense is unbelievable. I am in so much pain and want my life back."

*Madalyn (19)
Suffers from TMJD, CFS & FM*

Gender bias in medical treatment has been studied extensively, and a clear pattern of treatment differences appears across medical diagnoses. Among the best-established examples of gender bias is coronary heart disease. Although the American College of Cardiology and the American Heart Association concur that treatment approaches should be the same for men and women, more than a decade's worth of studies demonstrate that women receive less frequent cardiac catheterization and have fewer revascularization procedures.⁹²⁻⁹⁵ Even though cardiovascular disease is the most common cause of death among women, a 2010 worldwide study analyzing "data on more than 2.5 million patients concluded that female patients were significantly less likely to undergo revascularization or receive lipid-lowering therapy at discharge. Indeed, over the study period, the gap between male and female patients actually widened, despite evidence-based guidelines that both sexes should receive the same treatments."⁹⁶

Specific to the treatment of pain, it is well-documented that women "report more severe levels of pain, more frequent incidences of pain, and pain of longer duration than men, but are nonetheless treated for pain less aggressively."⁹⁷ In 2007, Canadian researchers reported: "Among 50,000 patients presenting to an emergency department with a main ambulatory care diagnosis of acute myocardial infarction, unstable angina, stable angina or chest pain, we found that women were more likely

than men to be discharged home and less likely than men to undergo cardiac catheterization or revascularization.”⁹⁸

A recent study of emergency patients with similar presenting symptoms found paramedics gave morphine to men reporting pain, but did not provide morphine to treat pain in women.⁹⁹

Similarly, a review of electronic medical records of patients who had sustained a severe arm or leg injury proved that women routinely received less analgesic for pain relief before arriving at the hospital for emergency care. This analysis of more than 1,000 patient events was the first study to find “sex to be a significant risk factor for

oligoanalgesia—the inadequate provision of analgesia for patients in pain—in the prehospital setting.”¹⁰⁰

If women suffering from conditions with well-established diagnostic and treatment guidelines such as cardiovascular disease experience such neglect and discrimination, consider what women who suffer from chronic pain syndromes, for which diagnostic and treatment guidelines have not been widely established, experience in their quest for an appropriate diagnosis and treatment. Their reality is shockingly dismal.

THE COMMUNICATION GAP CONTRIBUTES TO POOR CARE

The gap between how men and women communicate their pain also contributes to the neglect and dismissal women with chronic pain too often encounter when they seek help from health professionals. The evidence demonstrating the differences in the ways women and men experience and explain pain is extensive.¹⁰¹ Women tend to describe pain more subjectively and discuss other symptoms concurrently, sometimes making it more difficult to diagnose the cause of their pain. “Women were found to use more words, more graphic language than men, and typically focused on the sensory aspects of their pain event. Men used fewer words, less descriptive language, and focused on events and emotions.”¹⁰² Men’s pain is often seen as related to something “tangible,” such as

an acute injury or illness. Alternatively, women’s pain is often perceived as less specific and as more likely to originate from mental illness, stress or fatigue resulting in stigmatization, more specifically described in the next section.

As demonstrated in the studies of coronary heart disease treatment, gender bias in medical treatment most certainly exists. This could partly be attributed to communication differences. In a classic study at an academic medical center, internists were shown videotapes of women explaining symptoms of chest pain. The physicians who found the female patient’s presentation to be “businesslike” were more likely to suspect cardiac problems than when the communication style was “histrionic.”¹⁰³

With this in mind, researchers are urging the pain medicine discipline to bridge the gap between gender studies and pain by assimilating “gender studies

concepts into pain research as a means of developing our understanding of the psychosocial influences on pain in men and women.”¹⁰⁴

WOMEN IN PAIN CONFRONT STIGMA

Women suffering from these pain conditions experience profound stigma as a result of the government’s inadequate research efforts, medical professionals’ lack of knowledge, society’s lack of awareness and gender communication differences. As one social scientist noted, “these illnesses are shrouded in great uncertainty, which can enhance their stigmatization potential.”¹⁰⁵

The following study results demonstrate the suffering and stigma experienced by women with these conditions, as well as the grave impact on their quality of life.

Consider:

- **CFS and Fibromyalgia:** A study of women with both CFS and fibromyalgia established that they experienced stigma from both health care professionals and those in their social network. “Fibromyalgia in particular can be classified by other people as a women’s complaint, which may be deprecatory. CFS is perceived as more dubious by the women themselves, their social surroundings, and their caregivers,” adding to the feelings of stigmatization.¹⁰⁶
- **Interstitial Cystitis/Painful Bladder Syndrome:** “Patients with IC/PBS reported significant sleep

dysfunction, depression, anxiety and stress compared to asymptomatic controls.” Further, these patients perceived lower levels of social support compared to patients without IC.¹⁰⁷

- **Temporomandibular (TMJ) Disorders:** In the case of TMJ, “failed treatments and recurrent pain episodes contribute to life stresses with a pattern of frustration, hopelessness, and even depression,” according to a technology assessment conducted by NIH.¹⁰⁸ The terminology itself can be stigmatizing. The general public and patients usually recognize these conditions under the abbreviation “TMJ.” Patients prefer such an abbreviation due to their fear that by the use of the term “disorder,” health care providers, insurance companies, as well as family members and friends, may be more inclined to believe that these conditions are psychological in nature—a perception rejected by the overwhelming majority of TMD patients.¹⁰⁹

As with sufferers of other overlapping pain conditions, women also experience stigma from their loved ones, professionals

and society. What differentiates TMJ sufferers from those with other illnesses is their invalidated status as “real” patients. Despite the large number of individuals who suffer from facial pain in the US—35 million—there is still a large institutional rejection of their pain as legitimate. Because TMJ patients are “turfed” to the dental community, medical professionals dismiss them as insignificant and outside their treatment jurisdiction. Such stigma, which comes from many sectors—medical, dental, insurance, and workplace—creates severe psychological, physical, financial and social burdens for the sufferers.¹¹⁰

- **Vulvodynia:** The presence of pain in patients with vulvodynia is correlated with psychosocial impairment and decreased quality of life.^{111,112} “Women with vulvodynia reported a substantial negative impact on quality of life, with 42 percent feeling out of control of their lives and 60 percent feeling out of control of their bodies.”¹¹³ Sufferers experience additional isolation and stigma because genital conditions are still not openly discussed in our society. Fewer than 25 percent of women reported feeling comfortable disclosing vulvodynia to their closest female friends.¹¹⁴

PATIENTS AND PAYERS INCUR UNNECESSARILY HIGH COSTS

As stated previously, these chronic pain conditions cost our society up to \$80 billion a year.* Much of this could be saved through improved diagnosis and treatment. Those afflicted are routinely shuffled from doctor to doctor before a diagnosis is made, each time incurring substantial costs. Often women are inappropriately treated and left to experiment with a multitude of therapies, most with unknown benefits. It typically takes several months or even years, and several consultations for a woman suffering from one or more of these conditions to obtain an accurate diagnosis.

For example:

- Forty percent of women with chronic vulvar pain remain undiagnosed after three medical consultations.¹¹⁵ Rapid resolution of vulvodynia is unusual even with appropriate therapy. Whereas a 100 percent improvement rate is desired in all patients, most women with vulvodynia do not reach that level.¹¹⁶
- Fewer than 20 percent of chronic fatigue syndrome (CFS) patients in the United States have been properly diagnosed.^{117,118} As there is no diagnostic test or biomarker to clearly identify CFS, diagnosing the disorder is particularly difficult. There is no single treatment that cures the illness, but management aimed at reducing symptoms can improve function and allow people with CFS to engage in some of the activities of daily living.¹¹⁹
- The fact that those with fibromyalgia (FM) frequently suffer from one or more other conditions may increase potential for misdiagnosis by attributing the condition's painful symptoms to other causes. Given the ambiguity around FM's etiology and relatively recent development of treatment guidelines, the management of FM can mean multiple visits to medical practitioners and several trials of different prescription drugs.¹²⁰
- For those with temporomandibular disorders, it takes an average of four years from symptom onset to diagnosis.¹²¹ For the many sufferers, the absence of universally accepted guidelines for evaluation and diagnosis means that many patients and practitioners may attempt therapy with inadequately tested approaches.¹²²
- Fifty percent of women with endometriosis see at least five health care professionals before receiving a diagnosis and/or referral.^{123,124} No permanent cure for endometriosis has been found. Symptom relief is the primary goal of existing treatment options, which may be pharmacological or surgical.¹²⁵

This delay in diagnosis and initiation of appropriate treatment can cause a woman's symptoms to worsen and may predispose her to developing chronic pain in other areas of her body, adding billions in unnecessary health care costs.

* This upper-level estimate is not an unduplicated total because the incidence of their overlap is still to be determined.

An example from The TMJ Association puts these unnecessary costs into black and white. Both from the point of view of the patient, and from society:

“We recently conducted a survey of patients in our database in which we asked them to rate the effectiveness of 45 treatment modalities in addition to drugs and surgical procedures. Among this vast array of heavily prescribed treatments, it was remarkable that the patients rated hot packs as the most effective. What was also remarkable were the array of

medications prescribed to patients and the numbers of surgical procedures they had undergone. The most jaw surgeries performed on one person in our database were 62 and the patient died at the age of 41. A most cited 1992 study estimated the annual cost of TMJ treatments to be \$32 billion.”¹²⁶

The lack of knowledge about the effectiveness of various treatments is not only expensive and inefficient; it imposes a huge burden to patients, payers and society as a whole.

WHAT DO WOMEN IN PAIN HAVE TO SAY ABOUT THIS?

In 2003, the CFIDS Association of America interviewed participants with and without CFS to comment on how they felt the health care system was set up to treat chronic illness. The discussion was revealing, yet depressingly accurate.

- “Trying to access treatment for chronic illness is like ‘throwing darts on a map’.”
- “You can’t go to the doctor every week.”
- Another blamed the insurance system for the lack of adequate care for chronic illnesses, noting that insurance does not cover patient visits on a frequent basis.

A woman with vulvodynia explained her frustration with the system as it took her seven months and eight doctor’s visits just to be diagnosed. She did eventually manage to find a responsive physician:

“The hardest thing was to approach my condition rationally, because I needed doctors to take me seriously. What I really wanted to do was SCREAM or CRY out of frustration and utter desperation.”

A woman with endometriosis describes how she became progressively weaker

while visiting various doctors for more than a year with no diagnosis:

“My periods were getting worse, but I was used to having debilitating pain so I did not think that it was necessarily unusual. Eventually, out of sheer desperation, I went to a local clinic ...and [the doctor there] found a pelvic mass of approximately 6-7 cm.... that needed surgical removal. I was in a state of shock. How did it get that way? I had seen doctors on a regular basis for the last year.” She continues, “While I awaited surgery, I had another period where I started hemorrhaging and drifted in and out of consciousness on the floor of a washroom at work. Finally the surgery took place and the doctor told me I had endometriosis.”

A patient with TMJ managed to skirt the insurance system another way so she could get the care she and her physician determined was best for her:

“I did get my insurance to pay for most of this by not calling it TMJ. (They don’t like those letters). My doctor called it Jaw Joint Surgery and a Bone Spur. The surgery cost over \$30,000 and I paid a \$100 co-pay.”

While these women eventually found a way to obtain access to and reimbursement for care, many do not. “Chronic pain can also limit patients’ access to diagnostic procedures as well as referrals to other health care professionals and medical specialists,

“It’s a relief to finally have names for my conditions after suffering most of my life with a myriad of symptoms.”

Susan, 53

Suffers from vulvodynia, IC, and fibromyalgia

particularly when third party insurers are involved.”¹²⁷

Additionally, because we have a paltry understanding of the underlying causes of these pain conditions, symptom management is usually the best level of care chronic pain sufferers receive. Unfortunately, it is commonplace for patients who need pain medications to be turned away or referred to another physician. A patient with TMJ pain faced a different experience when she went to the emergency room in extreme pain:

“The reason they gave me when they refused to treat me at the emergency room was, ‘We can’t treat you for pain because we would be treating a symptom rather than the cause of a problem.’ My response to them was, ‘After 12 years of surgeries and treatment and over \$200,000 in medical expenses, no one has fixed the problem, and in fact, it has gotten worse.’ The hospital then refused any treatment, even though my blood pressure/temperature was high, and then labeled me a ‘drug-seeker’ on my hospital records. Now, I am petrified every time I have to ask for pain medications.”

END RESULT: WOMEN'S HEALTH AND QUALITY OF LIFE SUFFER

It is not uncommon for women to feel misunderstood and anxious when seeking medical attention. These feelings are multiplied in women with chronic pain. Just as with any patient seeking medical care, women suffering from chronic pain are, first and foremost, looking for an explanation. “Many women’s main hope from the[ir] consultation was to have an explanation for their pain, even more than a cure.”¹²⁸

Health care professionals find treating patients with medically unexplained symptoms and co-existing pain conditions particularly difficult, exacerbating patient suffering. The interaction between provider and patient in these situations has been described as a “duel” rather than a “duet” patient–doctor relationship, with negative feelings such as frustration and powerlessness in the practitioner and the perception by both parties that effective management strategies are lacking.”¹²⁹

Complicating factors, such as physicians’ lack of knowledge, gender communication differences and bias make these interactions different, and more difficult, for women. Thus, women with chronic pain “must strike a balance between conveying their pain experiences accurately without inadvertently undermining their authenticity by being perceived according to negative gender stereotypes.”¹³⁰ Women acknowledge the “negative impacts on their self-esteem and sense of dignity when they perceived that physicians did not believe them.”¹³¹

Bioethicists have gone so far as to say that this spiral of delayed treatment and unnecessary suffering is unethical. “The failure to treat pain compounds physical suffering with feelings of rejection and despair. It therefore violates ethical principles and professional duties.”¹³²

RECOMMENDATIONS

ENDING WOMEN'S PAIN DISCRIMINATION: IDEAS FOR CHANGE

As documented in this report, chronic pain conditions that solely or disproportionately impact women exact a significant human and financial toll; however, they are poorly understood and neglected. An aggressive, comprehensive set of reforms is called for to address this major health care problem.

Implementation of these reforms will result in substantial short- and long-term improvements in patient care and quality of life, as well as substantial health care cost savings and major improvements in the productivity of our workforce.

The following policy recommendations would greatly improve the quality of health care and the lives of those affected, while also playing a crucial role in “bending the curve” of future health care costs:

Opportunity Area 1: Making Cost Effective Investments in Research

As documented in this report, by failing to invest adequately, effectively and efficiently in research on women's chronic pain conditions, our nation is missing a tremendous opportunity to make a difference in the lives of millions of American women and help to reduce our national health care bill. Increased research funding for, and a coordinated approach to, these conditions is urgently needed. Collaborative and

multidisciplinary basic and clinical scientific efforts are key.

National Institutes of Health (NIH)

- NIH-funded research on pain conditions that solely or disproportionately affect women, such as chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, temporomandibular disorders and vulvodynia, should be substantially increased in fiscal years 2010 and 2011 to be more commensurate with the collective toll these conditions take on individuals and the nation. Increased funding should be translational, expanding basic and clinical research on the causes, diagnoses, treatment and prevention of these chronic pain conditions. NIH-funded investments should be made more efficient and effective by placing greater priority on interdisciplinary research across these conditions.

Specifically, the NIH should heed the United States Senate's call to the NIH Director to:

1. Coordinate, with all relevant Institutes and Centers, a trans-Institute research initiative in FY2010 that will support studies aimed at identifying common etiological pathways, with the goal of identifying potential therapeutic targets;
2. Commit to and organize a conference in FY2010 that will bring together a wide range of

basic and clinical researchers from multiple specialties, as well as professional and patient advocacy organizations, to present and discuss the latest scientific discoveries and develop future research recommendations in this area; and

3. Report to Congress annually on the progress made in this area.

- NIH should support the creation of four or more regional Women's Chronic Pain Conditions Centers of Excellence, to be established at leading academic health centers across the nation. These centers should conduct multidisciplinary basic, clinical and translational research. Additionally, they should provide women with access to teams of health professionals with training in state-of-the art diagnostics, therapies and, where appropriate, prevention protocols focusing on chronic pain.
- NIH must also move aggressively to expand, in a multidisciplinary fashion, the scientific field dedicated to studying chronic pain conditions. Accordingly, the NIH Director should support initiatives to foster the careers of graduate students and postdoctoral fellows in all

areas of biomedical research related to chronic pain conditions. This effort should include loan repayment programs for those agreeing to work three or more years in this research field.

Centers for Disease Control and Prevention (CDC)

- Very little is known about the epidemiology of these conditions. The CDC should launch a program to study the prevalence and incidence of, and risk factors shared by, these chronic pain conditions.

Agency for Healthcare Research and Quality (AHRQ)

- The failure to appropriately diagnose and treat these conditions adds billions in unnecessary costs to the nation's annual health care bill. In order to better understand these costs and develop effective means of reducing them, AHRQ should provide a detailed analysis of the health care expenditures associated with the conditions identified in this report. The agency should analyze costs associated with the failure to promptly and adequately diagnose and treat these conditions, as well as those incurred by employers due to lost

productivity, increased number of sick days and increased disability claims.

- Government, health care payers and medical professionals should develop and utilize coordinated health information technology systems to better track pain conditions to determine their changing prevalence and treatment outcomes.

A component of the Patient Protection and Affordable Care Act, the major health care reform legislation signed into law by the President in March, is directly linked to these recommendations. Section 4305 of that new law calls for the Institute of Medicine to convene a “Conference on Pain.” The purposes of this conference are to: (1) increase the recognition of pain as a significant public health problem in the United States; (2) evaluate the adequacy of assessment, diagnosis, treatment and management of acute and chronic pain in the general population, in identified racial, ethnic, gender, age and other demographic groups that may be disproportionately affected by inadequacies in the assessment, diagnosis, treatment and management of pain; (3) identify barriers to pain care; and (4) establish an agenda for action in both public and private sectors that will reduce such barriers and significantly improve the state of pain care research, education and clinical care in the United States. Funding for this important initiative should be conditioned upon the conference including an appropriate emphasis on

chronic pain conditions that exclusively or disproportionately impact women. Equity demands no less.

Opportunity Area 2: Education of Health Care Professionals

Increased awareness of, and knowledge about, these pain conditions and their coexistence among health care professionals would greatly improve the quality of care given to sufferers. It would also result in substantial cost savings to the government, private sector health insurance plans and the afflicted by reducing duplicative visits, ineffective and/or harmful treatments and avoidable complications.

Using the latest scientific information on the diagnosis, treatment and prevention of these disorders, the federal government should launch an aggressive multi-year campaign to educate physicians, particularly those working in primary care settings, and other health care professionals. This campaign should include the development of continuing medical education courses for professionals in practice and curricula for medical schools and other health care training programs. Courses/curricula should emphasize learning objectives that will reduce gender-based, social, cultural, linguistic, literacy, geographic, communication and other barriers to effective care. Overcoming bias should be a core part of medical, nursing and allied health curricula, as well as a component of health professionals’ continuing medical education.

Section 4307 of the Patient Protection and Affordable Care Act, the major health care reform legislation signed into law by the President in March, authorizes the Secretary of the Department of Health and Human Services to fund an effort to educate and train health professionals in pain care. Funding for this initiative should be conditioned on the inclusion of education and training for women's chronic pain conditions as outlined above. Equity demands no less.

Opportunity Area 3: Expanding Public Awareness

Changing attitudes about, and behavior toward, women who endure chronic pain starts by expanding awareness. Due to the lack of understanding associated with their conditions, up to 50 million American women with these six chronic pain conditions often suffer in silence because they are told that they are imagining or overstating their pain. There is a tremendous need to educate the public about these chronic pain conditions and their negative impact on women, their families, our society, and the economy, as well as the need for increased federal funding of research on these conditions. As such, the federal government should support a multi-year campaign that will:

- Educate the public about the seriousness and societal costs of these conditions;
- Make available and promote sources of reliable information on the symptoms, diagnosis,

treatment and overlapping nature of the conditions; and

- Provide information to women with chronic pain about how to communicate effectively with their health professionals about these conditions.

Section 4308 of the Patient Protection and Affordable Care Act, the major health care reform legislation signed into law by the President in March, requires the Secretary of the Department of Health and Human Services to “establish and implement a national pain care education outreach and awareness campaign.” Funding for this initiative should be conditioned on the inclusion of women's chronic pain conditions as outlined above. Equity demands no less.

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ABOUT THE OVERLAPPING CONDITIONS ALLIANCE

The mission of the Overlapping Conditions Alliance, a group comprised of independent, non-profit organizations, is to advance the scientific, medical and policy needs of individuals affected by medical conditions that frequently co-exist, or “overlap,” including: chronic fatigue syndrome, endometriosis, fibromyalgia, interstitial cystitis, irritable bowel syndrome, temporomandibular joint and muscle disorders and vulvodynia.

Overlapping Conditions - How Are They Connected?

Research on the overlap of pain conditions that solely or predominantly affect women is in its infancy, so we don't know how or why they are connected. Though there are many unanswered scientific questions, research indicates that having one condition increases the likelihood of experiencing another.

Overlapping Conditions - What Is Their Impact?

Health care providers receive limited training in these types of disorders, and many patients are routinely misdiagnosed and thus receive inappropriate treatment, making life very difficult for millions of sufferers and their families. In addition, they cost the United States tens of billions of dollars each year in medical expenses and lost productivity.

Overlapping Conditions - What Is Needed?

An expanded federal research effort is urgently needed to investigate common underlying mechanisms and risk factors for these disorders so that preventive strategies, diagnostics and effective treatments can be developed.

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