



Testimony: Women's Chronic Illness During a Pandemic

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Panelist at Roundtable Discussion. Co-Sponsored by Bipartisan Women's Congressional Caucus for Women's Issues, Solve M.E., The Headache and Migraine Policy Forum, and Miles for Migraine.

Moderator:

Jedediah Bila, TV Host and author

Panelists:

Joanna Kempner, Ph.D., Associate Professor, Department of Sociology, Rutgers University (Women's Health)

Nancy Klimas, M.D., Director, Institute for Neuro-Immune Medicine, Nova Southeastern University, Medical Expert (ME/CFS)

Jaime Sanders, Patient Advocate (Migraine)

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Oral Statement: "Gender Bias in Medicine"

I always begin my classes at Rutgers by explaining that disease is never just a biological phenomenon. It is always also social, economic, and deeply political. This year, the pandemic might teach my class for me.

The pandemic has revealed deep structural problems and profound inequities in American healthcare. But, in doing so, it has produced an opportunity for us to build a more just healthcare system.

Over the next ten minutes, I'd like to provide a framework for understanding how gender bias operates structurally, ensuring that women —especially Black women and women of color—are systematically underserved by our current healthcare system. Gender bias is endemic and pervasive in contemporary medicine and this gender bias is made all the more complex and dangerous when mixed with additional structural disadvantages, like racism, xenophobia, homophobia, and transphobia.

I will be highlighting the following points:

1. Women's diseases are stigmatized
2. We don't know enough about diseases that disproportionately affect women.

3. And we don't have sufficient policies in place to support women who are disabled by these diseases.

Women's Diseases are Stigmatized

Women and women's health have long been systematically ignored in Western medicine. Many of you will be familiar with this phenomenon. I learned this lesson early, when, at the age 5, a pediatrician diagnosed my recurring headaches as a symptom of a "Type-A personality." And these slights continued-- a psychologist once even suggested a boyfriend as a treatment for my migraine, evoking that all old canard that women with headaches are simply frigid.

Research suggests I am not alone in these experiences.

1. Women with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) report that they must "work hard" to be credible patients (Werner and Malterud 2003).
2. Women with fibromyalgia talk about how the constant delegitimation of their symptoms begins to make them question themselves (Asbring and Närvänen 2003; Barker 2008).
3. Black women with invisible illnesses must fight multiple stigmas simultaneously:
 - a. The pervasive stigma that Black women are all on welfare or are seeking drugs (Lara-Millán 2014).
 - b. The continued misperception that people of African descent don't feel pain (Hoffman et al. 2016).
 - c. And then, counterintuitively, the pervasive misconception that Black women are so accustomed to suffering that they can "deal" with pain when it occurs (Kempner 2018).

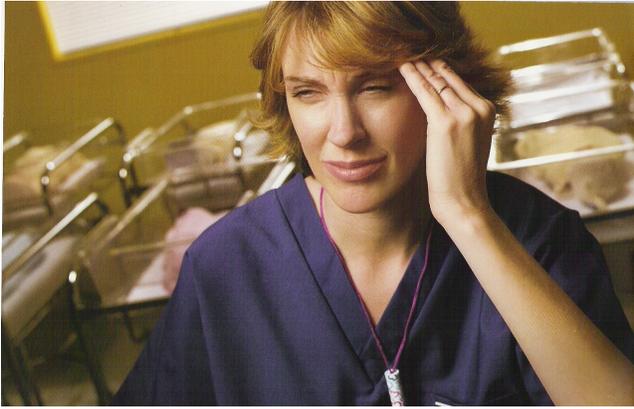
These gendered stigmas are deeply ingrained in our culture. We sometimes think of these overtly sexist images as part of our past:



Exhibit 1: An ad from the 1960s exemplifies what we normally consider an "old" sexist view – the domestic wife who is overwhelmed by her duties, which in this case are her daily chores—laundry, dishes, etc. She takes a pill, and now she can go about her normal duties, which in this case is a date with her handsome husband (Kempner 2014).

But these ideas remain firmly embedded in our present:

Exhibit 2: The below ad represents migraine as a woman stressed out, with her hand on her head – as though she can't find her keys. (Note here, the ominous lighting as the nurse turns her back on all of those babies). But after the medicine, she can resume nurturing babies.



These stigmas are deeply embedded in our institutions, from the National Institutes of Health (NIH) and medical hospitals where education happens, to places of employment, where women with chronic illness often find their ability to work curtailed by stigma and discrimination, and even, perhaps especially, at home. Addressing sexism in these arenas matter--not only because they limit what we think of as normal, but because they limit what we imagine as possible for women and for our daughters.

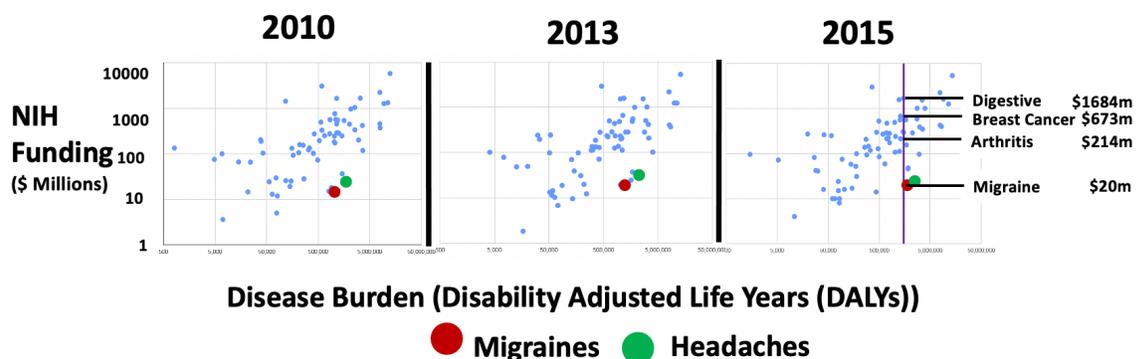
We Do Not Know Enough About Women's Diseases

Medicine has a long history of excluding women from its ranks. Prior to Congress's approval of Title IX legislation, fewer than 10% of medical students in the US were women. The Office of Research on Women's Health was only set up in 1990 ("Title IX at 25: Report Card on Gender Equity" 1997). It took an additional three years for the NIH Revitalization Act of 1993 to ensure the inclusion of women and minorities in clinical research. These efforts have improved women's health, but they do little to direct attention towards diseases that predominantly affect women.

As you can see in Table 1, many diseases that affect women—including ME/CFS and migraine—receive much less funding from NIH than one would predict (as indicated by the red regression lines) given their overall burden, as measured by “disease adjusted years life years” (DALYs) lost subsequent to a disease. ¹

¹ Breast cancer's relative success at NIH appears to be an outlier, when compared to the poor funding outcomes of most other feminized diseases.

Migraine: NIH Funding vs US Disease Burden



the "relative burden that various diseases place upon human health and wellbeing will serve as a crucial, but not the only, consideration in aligning NIH's research priorities with public health needs"

- NIH-Wide Strategic Plan (2016-2020)

https://report.nih.gov/info_disease_burden.aspx

Why doesn't the NIH fund these diseases? Sociological research suggests that diseases affecting stigmatized groups don't receive as much funding as other diseases (Best 2012). My research on migraine strongly suggests that NIH isn't interested in funding migraine—it's just not viewed as a serious disease (Kempner 2014). We might also consider who reviews these grants—are they men or women? Do they themselves conduct research in these underfunded areas? Do they represent other demographic groups that are rarely studied?

We Don't Have Sufficient Policies in Place to Support Women Who are Disabled by These Diseases

Women live longer than men, but we also know that women experience many more disabling diseases than men. In addition to more research, we must always remember that there is more to women's healthcare than biology.

Women are not simply different than men because they have ovaries – women live different lives.

Women already earn less than men, so it's worth wondering whether women's increased rates of disability exacerbate this wage gap.

Women tend to be the primary caregivers in their families – so it's worth asking what happens to families when women are disabled.

And during this pandemic, women and especially women of color, have been out on the frontlines, working as nurses, teachers, and other essential workers. What will we do if women are more susceptible to long-term disability post-covid?

We can support women by supporting their ability to live whole lives, whether or not they have an illness.

Women with chronic migraine and ME/CFS experience extraordinarily high rates of disability. When women cannot get to work, and when women cannot care for their families—entire households experience downward mobility.

We also know that our social safety net for women with chronic illnesses is broken. The Social Security Administration prohibits patients from supporting their applications for disability with symptom reports – but migraine has no reliable diagnostic physical signs or laboratory findings; it is an “invisible” disease. As a result, SSDI claimants for migraine have among the lowest participation rates relative to its disability burden.

I worry about these families, who cannot access basic supports. Their loss is devastating. But I also think about what our country loses when we don’t make support women with chronic illness: the ingenuity, creativity, productivity, and joy of tens of millions of women and their families.

We can do something about this.

The pandemic has by necessity required us to find creative solutions to gaps in social policy. Congress has an important role in formalizing policies that will help women and families in the long term. Today you're going to hear from panelists about some things that could be effective in helping bridge some of these gaps.

Thank you.

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