The Gender Gap in Healthcare

This speech was given after a screening of the documentary film "*Unrest*" at the Newtown Women's Library on the 20th September 2018. The topic: Medical Sexism and the Gender Gap in Healthcare, by Tessa Barratt

Introduction:

While it will be unsurprising to feminists that sexism exists in medicine, many women are completely unaware of how poorly their bodies have been researched and how often they are dismissed when they report their symptoms. It took until the 90s in the United States (where many of our medicines and treatments come from) to mandate women be included, in some capacity, in studies. People are surprised to learn that women are decades behind men when it comes to understanding everything from certain diseases, to the effect of certain drugs on women's biology. Yet when you shine a light on this issue, and ask women to come forward with their stories, there is a veritable tidal wave of frustration, humiliation and anger in their responses. [1]

Indeed, even with my own miserable experience of being mistreated by the medical profession, I was myself still horrified when I started researching this topic in depth. There is less of a gender gap in healthcare than there is a gender chasm, not to mention a woeful lack of research on so-called "minority" groups, such as the LGBT community or people colour. And as I continue this talk, I want to acknowledge that many of the issues that affect women also affect Transgender people, who are in many ways doubly ensnared by discriminatory practices and mindsets.

Why Is This The Case?

When you look at how women are seen and treated as a whole, this medical sexism is to be expected. We live in a world that is sceptical of women's bodily autonomy, even threatened by. This takes place in the debates around reproductive rights, to marital rape to laws on consent. We exist in societies that actively try to control the bodies of women and to dictate to us how we should feel about those bodies. It positions us as reproductive vessels or sex objects. Women are othered, seen as secondary to males. This view has permeated the way medical research has been done throughout the ages and continues to impact us to this day. If women aren't seen as fully human, then they won't be treated as such. They have been and still are left out of everything from clinical trials, to major longitudinal studies, to research grants to treatment programs.

How Deep Does it Go?

It starts right at the preclinical research stage, where animal models are almost exclusively male mice and rats. The excuse is that females have hormonal cycles which muddy the results, and males are just simpler to use. They dismiss the importance of looking at gender and sex differences, waving them away is if they don't really matter, and then complain that female hormones impact too much on their experiments to warrant their use, creating a double standard that is rarely challenged. There is also scant research on how different drugs affect pregnant people, the excuse being that researchers don't want to harm the fetus. But that has led to a situation where many people don’t know whether or not they can take a medicine while pregnant. Some choose to go untreated to err on the side of caution, which can in turn harm both the parent and developing baby. This is been a long-standing problem, but the medical community seems to have little will to address it. Then there is the fact that much of the research is being done on middle-class, often white men as that is the default model in medicine. This can have long reaching consequences.

In her excellent book, _**Doing Harm**_, feminist author Maya Dusenbery highlights some examples of where a lack of research into sex and gender differences has resulted in the injury or death of countless women [2]. She discusses pharmacokinetics, which is how the body processes a drug, and the story of Ambien. Because Ambien was only tested on men, the leaflet inside the box based its potency on a male physiology. Women reading the leaflet were led to believe that by eight hours after taking the medicine, they'd be alert and functional. That did not turn out to be the case. In fact, the drug stayed in women’s systems for longer than in men, leading them to have car accidents the next morning. There's also the fact that heart attacks present differently in women who frequently exhibit so-called “atypical symptoms”, such as dizziness and fatigue, and often don't experience chest pain. This has resulted in many missed heart attacks both from the women themselves and from doctors in the ER who often tell them they're simply stressed and/or having a panic attack. Then there's the tragic case of Ovarian cancer, so long known as the silent killer, even though women were repeatedly reporting symptoms long before the cancer was detected in their bodies. It took decades of advocacy from survivors to get the medical community to pay some attention and change strategy. Sadly, it takes decades longer for this information to filter down to the everyday GP, and so even today many Ovarian cancers are missed because women's symptoms are disregarded.

Women’s Illnesses and Neglect:

Myalgic Encephalomyelitis is one of many women-majority illnesses that suffers from ignorance and disbelief. In turn, it is poorly understood and has received little research funding around the world. It has taken many years of awareness-raising from patient activists to get the syndrome any attention whatsoever. Unfortunately, there are hundreds of other conditions that primarily affect women that are enduring the same fate. Everything from endometriosis, to vulvodynia, to chronic pain disorders are being criminally neglected. Non-fatal illnesses that cannot be easily verified by conventional and current day methods are almost automatically dismissed as being all in the patient’s head. As the documentary illustrated, the notion that women are fragile and prone to a nervous disposition is one that hangs over us today and manifests itself in more subtle forms of discrimination. A term like hysteria has now become somatisation disorder or conversion disorder, and this is something we should resist and fight against, as it is little more than a deeply misogynistic excuse to dismiss women's pain and their knowledge of their own bodies.

This is why an illness like endometriosis take an average of seven years before a woman is diagnosed; she’s often only taken seriously when she is trying and failing to conceive. Her other symptoms, like dysmenorrhea and Irritable Bowel Syndrome might have been ignored for years. It would seem that only when the disease affects her ability to reproduce is it worthy of any attention, and even then, the path to treatment is slow, expensive and painful. [3[

Medical Sexism:

This subtle and pernicious sexism has ensured that many illnesses have been neglected or outright dismissed, simply *because* they are women's illnesses, and have therefore lost out on grants for studies. It's a vicious circle: these diseases are not taken seriously because there’s not enough research on them to satisfy doctors; but there’s not enough research on them because are not taken seriously in the first place. This is why conditions like Fibromyalgia remain a mystery, because few researchers are interested in pursuing a “contested disease”, and those that do often have trouble securing funding.

Medical prejudice exists everywhere. Studies have found that transgender people are often reluctant to see a doctor due to past experiences of discrimination, or because GPs and specialists have a tendency to blame all their symptoms on their Trans status. Women of colour are less likely to receive pain medication, even after surgery, due to the stereotype that black women are drug seekers and/or more tolerant to pain due to their race (an ancient idea that has, like hysteria, persisted to the 21st-century). Older women are also frequently discriminated against as any and all symptoms are blamed on menopause. And menopause itself is not well understood or adequately managed by a medical system that sees women’s suffering as both natural and a foregone conclusion. Women perceived to be overweight, even slightly, are often told that their weight is the cause of all their discomforts, meaning that many illnesses, some serious, are missed. Studies also showed that overweight men do not get treated in the same way. Gender bias, racial bias, ageism, ideals around women's bodies, trans phobia, homophobia, stereotyping of all kinds, has a seriously negative effect on a great many people.

Where Feminism (And You) Come In:

Feminism is, and always has been, integral to changing the status quo. It was feminist advocacy around the world that led to women being included in research at all. Patient activists insisted that sex and gender differences be looked at when reviewing medicines and treatments. It has been women who have been campaigning to get the news out about when to get a Pap smear or about the symptoms of ovarian cancer or about how women are suffering heart disease at a greater rate than men. We’re certainly not getting taught these facts in schools and that includes medical schools. The truth is many doctors just don't know this information because it takes anything from 15 to 25 years for new research to make it down to the general public.

It has been feminists trying to break down the myth of hysteria, openly agitating for us to be taken seriously when we discuss our bodies. They have also been pushing for the inclusion of more women in STEM (science, technology, engineering, math) fields, so that the gatekeepers of medical research and grant applications are not always men, that the people setting the curriculum aren't always men and that the people teaching this curriculum aren't always men, either. Feminists have long argued that the default shouldn't always be male, and that diversity matters in all forms of research. And while it's true that women doctors are not immune to internalizing prejudiced views, the more women there are in the field, the more likely female-centric illnesses are to be picked up and analysed.

But patients and what amounts to a handful of activists can't be the only ones pushing for change. We all need to demand better. We need to get behind initiatives that raise awareness about these issues, lobby for better policies, petition members of Parliament and hold power structures responsible. Medicine needs a “me too” movement of its own; systemic sexism and other forms of prejudice need to be outed and eradicated. The truth is that many doctors, and the medical profession in general, are not aware of, or owning up to, these failures, so we need to hold them accountable.

One way they can start is by re-examining all the conditions that have been lumped into the box of “unexplained / somatization disorders”. Until we look for the root cause of these illnesses they're going to continue to be dismissed. And we know the root cause of this dismissal now, so *we* can act on that. Today’s feminists have to put healthcare at the forefront of their agenda. We need to keep agitating for reproductive rights but we mustn't stop there; beyond reproduction, we are beings deserving of healthy lives, and we’re being denied this for no better reason than that it's convenient for the patriarchal system to do so. Going forward, 4th wave feminism has to be more inclusive of women with disabilities and chronic illnesses; we need to join forces with these women, amplify their voices and to prioritise their needs within the movement. Too long, disabled and chronically ill women have been kept out of a movement that hasn't tried hard enough to accommodate us. We need to change this and start making medicine one of our priorities.

The “Millions Missing March” is an important step in acknowledging that women are missing on every front of medicine. We are missing from society because we are stuck with sicknesses that no one has bothered to research or cure. We are missing in STEM fields. We are missing in trials and studies. We are missing in laboratories in cell data. We are missing in the discourse and we are missing out in general. It is, sadly, not just the millions of women with CFS that have been invisibilized by society; there are so many other debilitating illnesses keeping women out of the workforce, housebound and miserable. So much of that suffering is completely avoidable if we only bothered to pay the issue more attention, and take women seriously.

Here are just some examples of **how you can be part of the change** we need to see in medicine:

1. Come to an event like this and bring some friends - raising awareness is the first step towards change.
2. Donate to organisations that are advocating on behalf of lesser-known or stigmatised illnesses. It's so hard for these groups to get funding, so your donation can go a long way.
3. Support your local women's health care centre. These centres are often under the threat of closure and need community support to stay open.
4. Lobby the health Minister to action policy changes that will ensure that neglected diseases and medicines get studied or covered by Medicare/PBS
5. Protect our healthcare system from cuts and rollbacks. Protect national scientific organisations from being defunded. March, petition, phone your MP, be heard.
6. Become better informed: do some research into this issue so that you are well-equipped to make a case for change
7. Believe us. Support people in your life who have a chronic illness and believe them when they say they are sick. There are so many areas of life where people, especially women, are not validated, so kindness and support can be a tremendous help and relief.

For facts, stats and further information, please read our Medical Sexism Fact Sheet

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[3] **Endometriosis: Millions of women suffering due to chronic lack of research,** The Independent, Pub 2017 https://www.independent.co.uk/news/uk/home-news/endometriosis-women-suffer-chronic-underfunding-research-uterus-womb-lining-pain-endometriosis-a7623731.html

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