Unseen Differences: How Gender Impacts Medical Diagnosis, Treatment, and Outcomes

By Kate Shields

Setting the Scene

When Haley Fenech was only nine years old, things started to go dark—both emotionally and literally.

Once a week, without fail, she would lose her sight, in addition to debilitating migraines, extreme nausea and vomiting, and a myriad of other life-altering symptoms. She had no other option but to put her well-being in the hands of medical professionals.

Her mental health would also soon begin to suffer, as it would be another 5 years before Fenech received any clarity, relief, or even empathy in a healthcare setting.

"I started seeing all kinds of specialists. I counted them, and there were 12 different ones between the ages of nine and 13," Fenech said. "I got so many tests done. I had procedures done. I got my blood drawn all kinds of times. I got put on so many different kinds of medications that didn't work or had horrible side effects."

Her first doctor, a male neurologist, even chalked her blindness up to "getting her period". She had never had one nor hit puberty yet.

Sadly, Fenech is not alone in this. While her specific circumstances may differ from that of other women, the general experience— one filled with gaslighting, misunderstanding, and extreme frustration— is a shared one.

According to an in-depth analysis of published scholarly literature, when compared to men, women have more negative experiences when communicating with their medical doctor, are less likely to receive proper pain management medication, and are more likely to be misdiagnosed.

Examining the Numbers

According to a 2023 study by David Newman-Toker published by <u>BMJ Journals</u>, women are 20-30 percent more likely to be misdiagnosed than white men. But the disparities don't stop there. According to a 2022 survey report by the Kaiser Family Foundation, 29 percent of women

said that in the past two years, their concerns have been dismissed by their medical doctor, as compared to 21 percent of men.

What's more, according to a Springer Journal article published in 1990, during a 72-hour postoperative period, only 27 percent of women were administered pain medication on a frequent basis, as compared to 53 percent of men. Rather, 17 percent of women received sedatives instead, while no men did.

These conclusions are bolstered by a similar <u>PNAS journal study published in 2024</u>, which found that pain management choices by physicians and nurses in the Emergency Department disfavor female patients.

It wasn't until Fenech was recommended to a geneticist that she finally got the diagnosis she had so desperately been waiting for. Not even four minutes into discussing her symptoms did the doctor opt to test Fenech for Ehlers-Danlos syndrome, a genetic connective tissue disorder.

After answering an extensive questionnaire, Fenech was told that she not only had a very high score, but she struggles with both hypermobile and vascular EDS, leaving her life threatened more than she ever thought possible. Now 21, Fenech fights her chronic condition daily.

"Ever since then, I've been working towards getting better, but essentially, if I had been diagnosed when I saw that male neurologist, I would be a hell of a lot better off," Fenech said.

The BMJ Quality and Safety study led by Dr. Newman-Toker of Johns Hopkins University aimed to provide rigorous estimates of harm from diagnostic errors through a cross-sectional study of national data.

The results were alarming: an estimated 795,000 Americans die or are permanently disabled each year due to misdiagnosis of serious conditions like vascular events, infections and cancers.

According to KFF Health News, Newman-Toker points out that women and racial and ethnic minorities are 20 to 30 percent more likely than white men to be misdiagnosed, calling the disparity "significant and inexcusable."

KFF's survey of 5,145 women ages 18-64 regarding medical provider communication and interactions, which was conducted in May-June 2022, found that one in 10 women experienced frequent health discrimination based on age, gender, race, sexual orientation or religion in the past two years, among other notable statistics.

The Springer Journals study published in *Sex Roles* examined gender differences in pain and sedative medication administered to patients recovering from coronary artery bypass graft surgery in the Emergency Department. The study confirmed the researchers' hypothesis that men receive more pain medication, while women are given sedatives more often, through analysis of medication records of 30 male and 30 female patients, ages 44 to 71, with identical surgery characteristics.

The *PNAS* study, conducted 30 years later, reaffirmed the findings that pain management differs by sex. Researchers analyzed patient data complete with discharge notes from two countries, revealing a consistent disparity in how pain medication is administered.

Researchers further concluded that female patients were 10 percent less likely to have their pain scores recorded and waited 30 minutes longer for care, despite reporting similar pain levels. Both male and female physicians contributed to the lack of pain relief, with women's pain often assumed to be less intense.

Contributing Factors

Fenech's years-long fight to be seen by the right specialist is common among many women, especially when it comes to specialized symptoms and concerns that a primary care physician may not have the resources or expertise to provide the necessary information on.

To Dr. Tasleem Padamsee, an Ohio State sociologist and scholar of health disparities, this reality is one women need to be aware of when navigating the healthcare system. While her research focus is on breast cancer prevention in high risk individuals, other specialized issues are certainly difficult for PCPs to diagnose as well, she said.

"There are, in fact, lists and requirement guidelines that show you what it is that a PCP is supposed to be doing, and they never have time to do all things on that list, ever," Dr. Padamsee said... "The other problem is that they don't have the education. This [breast cancer risk and prevention] is a very specialized area, and they don't have any education on how to deal with it."

In a utopia where all women are empowered, supported and in the "driver's seat" of their own healthcare decisions, Dr. Padamsee said access to a trusted PCP with whom a patient has a long term relationship characterized by respect and a listening ear is crucial.

"They should know who that person is. They should have access to that person. They should be able to afford to see that person whenever they need to," Dr. Padamsee said. "And then that doctor also then needs to be empowered to answer the question. They need to have enough

education to understand the healthcare issues that she's raising, and the ability to refer her on to somebody else."

The reality is much different. In 2022, 15 percent of women stated that their provider did not believe they were telling the truth, and 13 percent said they were personally blamed for their health problem, according to the Kaiser Family Foundation.

This proves a 3 percent difference between men and women, with 12 percent of men stating that they were not believed by their provider.

However, nearly twice as many women expressed that they felt discriminated against due to their gender.

Personal Blame

For Leah Hall, the effects of being blamed for her own symptoms still affect how she approaches healthcare settings to this day, despite her negative experience taking place nearly a decade ago.

Hoping to get a clearer understanding of her lifelong struggle to lose weight despite eating healthy and exercising regularly, Hall booked an appointment with the top rated endocrinologist at New York University Langone at age 18 when she went off to college.

"They did my blood work. It came back, according to her, fine," Hall said. "We had a consultation, and I went back, and she was like, 'Yeah, you know, there's nothing really wrong that I can see. So I think you just need to lose weight and then come back when you've lost 30 pounds.' If it was that easy, I wouldn't be here to start with."

Now 27, Hall is still searching for answers, but medical settings have been forever changed for the worse.

"After that, I haven't been back to a doctor with that issue, because I feel like I'll be gaslit or not taken seriously, or made to feel ashamed about my body," Hall said. "I'd rather just figure it out myself."

Hall is not alone in this feeling. When asked if a past negative experience influenced their overall comfort around medical doctors, five out of five women said yes.

These women — Tori Slabe, a fourth-year in microbiology, Cincinnati native Harper Esterle, Ohio State alum Casey Kuhlman, along with Fenech and Hall, shared nearly identical sentiments

regarding the ways in which they now avoid healthcare settings at all costs due to prior mistreatment.

Self-Advocacy In Action

Slabe was diagnosed with Hashimoto's disease, an autoimmune condition that gradually destroys the thyroid gland, at 18-years-old.

However, like Fenech, starting at the young age of 14, she fought for doctors to take her concerns seriously in the wake of debilitating symptoms including extreme fatigue, rapid weight gain and anxiety.

Similarly to Hall, Slabe's doctors told her to focus on losing weight, leading to a hellish High School experience spent doing "extreme diets", and "basically killing herself" to stop the weight gain, which created a vicious cycle, she said.

"It definitely impacts me today. I really wouldn't even say that I do have a primary care doctor anymore....I've been sick for like a whole month, and I still just don't like going to doctors because it scares me," Slabe said.

Like many women, Slabe finally hit a breaking point and took her medical education into her own hands when she became an adult.

"When I got to college, I was pre-med, so I started getting into more anatomy, and I took medical terminology, things like that, and started to educate myself to really get to the bottom of this... that's when I really started to demand to be referred to endocrinology," Slabe said.

Thanks to this self-advocacy, a term <u>health scholars define</u> as "representing one's own interests within the health-care decision making process", Slabe finally learned the truth of her condition through a single blood test: Hashimoto's disease has been affecting her nearly her entire life.

Research supports a positive correlation between patient self-advocacy and patient satisfaction, according to a <u>2009 Health Communications study</u> focused on measuring patient involvement in health-care decision making interactions.

Furthermore, a 2021 Advances in Nursing Science study looking at self-advocacy in women with cancer indicates that a patient's ability to influence care could increase their confidence in addressing other personal health concerns, thus reducing the disparities and inequities they may face.

Dr. Padamsee's first hand experience working with women as they navigate their healthcare decisions and work to make empowered choices regarding their own cancer prevention methods supports these findings, though she said self-advocacy can be hindered by other people surrounding the patient.

A major example of this can be seen in women who opt to have their ovaries removed due to a [ovarian cancer] mutation that makes that choice the most sensible and safest available, though many patients don't follow through due to outside forces.

"The women themselves were like, 'I'm ready to have my ovaries taken out. I've had all the kids I want', but their husbands were like, 'well, I'm not sure I'm done having kids, and so you can't have your ovaries taken out," Dr. Padamsee said.

Kuhlman, who was told she would have to get a cervical biopsy due to a positive HPV test result, said she did an immense amount of research on the procedure after being told very little by her doctor, and while she did not end up having to get the biopsy done due to the type of HPV, the countless experiences of women she came across online were inconsistent with her doctor's reassurance that the procedure would be generally painless.

"It's important to advocate for yourself in a health setting because you're paying for the procedure. Even though it's healthcare, you still are the client," Kuhlman said. "For any other industry you wouldn't settle for something that you aren't happy with."

Patient Support

Dr. Kimberly Bonar, an Obstetrician Gynecologist based in Cincinnati, Ohio, said giving women the space to express their concerns with a suggested procedure or medication is essential to ensuring they are empowered in their own healthcare decisions, especially if they have trauma from a past experience.

"I like to ask them what are their fears, and where did those come from, so I can understand, and there's lots of women out there that have been abused and been in some pretty bad situations...," Dr. Bonar said. "And so I just do what they're comfortable with. I show them the speculum, how we do the exam, and then ask them what they would like to do today. And so if they don't want to do an exam, we just talk about it. That's cool, no problem."

Dr. Bonar's gentle approach, which is supported by several pieces of scholarly literature including a <u>study</u> that states women want information prior to a pelvic exam, prefer a warmed

speculum, and want their doctor to consider their feelings, is unfortunately not prioritized by all OBGYNs.

For Esterle, "gentle" is certainly not the word she would use to describe her experience.

When she was in High School, Esterle went in for a routine Intrauterine Device insertion due to extreme periods that often led to fainting, hoping the IUD would stop, or at least limit them.

Before the process even began, her doctor expressed judgment and frustration in respect to Esterle's discomfort with pelvic exams, which she said was exacerbated by her being a virgin and not being allowed to have her mom in the room for support due to the COVID-19 regulations in place at the time.

"Instead of this doctor being sympathetic to that, she was extremely, extremely mean about it, frankly," Esterle said.

A study published in <u>Midwifery</u>, <u>An International Journal</u>, states that 54.8 percent of women felt anxious or worried about their health situation during a pelvic examination, and 41.8 percent were embarrassed about having to undress.

Like those women surveyed, Esterle was already uncomfortable with the procedure, so when she began to feel faint during it, she wished her doctor's response would have been a more supportive one.

"When she went to insert the IUD, I wasn't saying anything, I was being completely silent," Esterle said. "I was laying down, but I could feel myself start to get really warm like I was going to pass out. I didn't say anything, but she [the doctor] goes over to the phone on the wall, and I just remember she was so aggressive, tears the phone off the wall, and is like 'I'm going to need back up in here. This girl's about to pass out."

Thankfully, the nurse that was called in offered the support the doctor refused to provide, reinforcing scholarly research that concludes 30 to 50 percent of women would appreciate the presence of a nurse during the insertion procedure for emotional support.

Pain Management

The pain that followed was extreme, as Esterle was unable to take the recommended NSAIDs prior to the procedure due to a blood clotting disorder. This was further exacerbated by her struggle to properly insert the Misoprostol— a vaginal medication commonly used for medical

abortion, but also utilized by some doctors to soften the cervix before IUD insertion— she was prescribed, which made the process a bit more difficult.

This too was a point of verbalized frustration for Esterle's doctor, despite her failure to provide Esterle with any basic information on or instructions for utilizing the medication.

"She was like, this is to dilate your cervix, and I was like 'ok, cool'," but then when I went and picked it up from the pharmacy, I read the directions, and it said 'insert vaginally," Esterle said. "I thought it was going to be an oral medication. She didn't warn me... and so I did it, but I didn't do it well."

Dr. Bonar emphasized the importance of properly informing patients ahead of insertion.

"For IUDs, I try to give them something to read ahead of time, so they know what to expect," Dr. Bonar said. "A lot of people, they don't always hear everything you tell them, I like to read things myself, so I send them information and if we're counseling ahead of time, we talk about insertion."

Aside from some OBGYNS, including Dr. Bonar, that offer numbing for patients experiencing notable pain, the only medication suggested is an NSAID like tylenol or motrin.

However, according to an <u>article published in Medscape News</u>, a systematic review of roughly 79 percent of 14 studies included found that NSAIDS did not actually decrease discomfort for patients.

Even so, 80 percent of medical providers reported that they "always" recommend a patient take an over-the-counter pain reliever for post-procedure pain, according to a <u>study published in</u> *VCOM Clinical, Biomedical, and Educational Research*.

"It's a quick process, but it's really painful afterwards, at least for me," Esterle said. "I remember walking out of the office and I felt like I wanted to double over in pain, like it hurt just to walk out of there, and she [the doctor] was telling me 'you really shouldn't be in pain like that."

This is not the case. According to several studies, including one published in <u>Fertility and</u> <u>Sterility</u> evaluating different pain lowering medications, 70 percent of women who have not given birth reported moderate discomfort.

The study also concluded that lidocaine-prilocaine is the most effective at reducing this pain.

"You're going to get a big variation on discomfort, because everybody's got a different shaped uterus," Dr. Bonar said. "Sometimes they go in super easy, and then sometimes there's a tough angle to maneuver, and it can be a very difficult procedure, it just varies. If I think it's going to be difficult, or someone seems uncomfortable, I will inject some numbing medicine into the cervix to try to help."

Moving Forward

Though research and experiences of real life women may paint a seemingly hopeless picture of the reality of women's health, significant strides have been made in recent years.

While it wasn't until 1993 that women were required to be included in clinical trials as deemed by the National Institute of Health through the *NIH Revitalization Act*, the group is continuing to make major advances in women's health through the Office of Research on Women's Health. Since the act was passed, roughly half of the participants in NIH-funded clinical trials have been women.

According to a <u>Duke Health article</u>, ORWH director Dr. Janine Clayton said that because women have been studied less, we ultimately know less about them, leading to less-than-optimal care.

Dr. Padamsee acknowledged just how crucial proper and inclusive research is.

"I do think that there are considerable gaps in the [breast cancer prevention] research," Dr. Padamsee said. "That's kind of why I'm doing the research... it's not so much that the research is lacking on how to do the prevention in the first place. It's more that it's lacking on the application side or the translation side, which is 'what do we need to do in order to make women aware that these things are out there, and in order to make it possible for them to use these things when they want."

In 2017, the NIH launched the U3 Administrative Supplement Program, which is focused on health disparity research of underrepresented, understudied, and underreported women in biomedical research, and in 2019 they released their first research project grant to study the intersection of sex and gender in health disease.

The signing of an Executive Order on Advancing Women's Health Research and Innovation by former President Joe Biden in March 2024 marked another positive step in the right direction, though the page has since been removed since President Trump took office in January.

While Fenech wishes she would have received a proper diagnosis years before she did, she hopes other women know that they deserve to fight to be seen and heard.

"Doctors are still just people. If one doctor says something, go see another doctor—you have the freedom to see one hundred doctors. And gut intuition is always right, in my opinion. If you feel that something is wrong, then something is wrong."

Hall echoes this sentiment.

"I know that so many women are facing the same thing," Hall said. "So maybe if we talked about it more and forced the medical community at large to address these issues, maybe it would change."