

HYSTERIA, MEDICAL SEXISM, AND THE CONTEMPORARY IMPACT ON  
GENDER-BASED INEQUITY IN WESTERN HEALTHCARE

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## **Positionality**

I chose this topic as someone who experienced the effects of misogyny in healthcare settings firsthand. Nevertheless, as a white disabled woman from a middle-class background, I still have the best shot at navigating such a system compared to my marginalized peers. I would like readers to be aware that I have been intentional with my efforts to write this MRP in a way that was inclusive of everyone affected by misogynistic bias, not just others who look like myself. There are many disabled people who face the compounded effects with sexism in addition to other forms of marginalization (on the basis of race, ethnicity, sexuality, gender identity, socioeconomic status, refugee status, etc.) when seeking healthcare in a Western society's healthcare system; it would be disingenuous to present this issue as if every disabled woman or person assigned female at birth would experience it the same way that I have.

However, an MRP is not long enough to fully discuss the effects of both racism and sexism in healthcare. I will be focused on the aspect of misogyny and gender bias in healthcare overall, but will not be ignoring the reality that gender does not exist in a vacuum, independent of a person's other characteristics; Kimberle Crenshaw refers to this as a "single-axis framework", which contributes to the marginalization of those who fall in multiple categories of disadvantage (Crenshaw, 140).

## **Terminology**

I will be using the terms for different groups of people that are currently generally agreed upon by the academic institution as well as the advice of peers who belong to these groups. They are not perfect, and may be awkward at times- however, it is the best language available to me at the time of writing.

As is my personal preference and the preference of much of the disability community, I will be using identity-first language (“disabled person”) rather than person-first language (“person with disabilities”) as I do not believe “disabled” is an unflattering word that needs to be euphemized. The theory behind person-first language is that by placing “person” at the forefront, it emphasizes that the person before the disability, and therefore their humanity and value before their disability. It is well intentioned, yet it signals that the person’s identity is something that can be separated from their disability, as well as that their disability somehow detracts from their worth as a person (although ableism perpetuates this idea, the word “disabled” itself should not). This minimization contributes to stigma, making many people uncomfortable to acknowledge disability or even believing it improper to do so. “Those who advocate for an identity-first approach argue that the person-first approach subtly implies that there is something inherently negative about disability and that use of constructions such as ‘with a disability’ or ‘with diabetes’ unnecessarily dissociates the disability from the person” (Dunn et al). Identifying with disability allows one to gain a sense of community, belonging, and collective beliefs and heritage (Dunn et al). That collective is an important tool in

fighting societal prejudice and discrimination. This is why I have chosen to proceed with identity-first language.

It is important to me that nonbinary people, gender-nonconforming people, people assigned female at birth, or femme-presenting are not left out of this conversation. Not all the identities of the people above listed are the same. However, for the purposes of this paper, I will be using the term “women and people assigned female at birth”, as I believe it to be the most inclusive of my current options, despite not being perfectly encompassing. For referring to anatomy, I will be using “male body” and “female body”, which refers only to reproductive sex and does not refer to gender.

The same is true for the language I will use in this paper when discussing women and people assigned female at birth who are marginalized on the basis of race or ethnicity. There are criticisms of the term “people of color”, which groups many people into one “non-white” category. There is also the US-centric term “BIPOC” (Black, Indigenous, and people of color), which often is used inappropriately when discussing issues specifically affecting Black people more significantly than others.

I will also be using the term “Black” capitalized, in addition to the term “Black American” rather than “African American”. Black Americans share a unique culture, history and linguistic dialects which warrant their own identity distinction. The Associated Press made this official change in the official AP Style guide in 2020, in addition to the capitalization of the word “Indigenous”.

For the purposes of this paper, I will be using the phrase “marginalized on the basis of race or ethnicity” or a variation of it. In this context, I am only distinguishing

people by race or ethnicity because of the additional discrimination they experience in this context; or because of the historical events that have led to that persistent discrimination. If I am referring to a specific group of people or a statistic, I will use the name of that group.

## Summary

From the beginning of the Western development of medicine and understanding of health, women and people assigned female at birth and their bodyminds have received a level of medical care that reflected the misogyny and misunderstanding of the female body in their respective societies. The resulting fallout is centuries of medical neglect, misguided attempts at treatment, and persistent disparities in care between genders in modern Western societies.

Greek scholars tried to explain the symptoms and behavior of women and people assigned female at birth by theorizing about a uterus detaching from its natural position and “wandering” around the body, wreaking havoc (Aretaeus). A moving uterus was not a novel concept- the Egyptians had similar theories. However, as other scholars and physicians around Europe and the Middle East built on Greek knowledge, the idea of a wandering uterus faded, though remains quite active in the cultural imagination. Speculation about the behavior and symptoms of women and people assigned female at birth remained. The interpretation of symptoms shifted more from a physical condition to a psychological one, which the reproductive system may or may not be involved in.

Many physical and mental illnesses were grouped under this “diagnosis” or a similar “women’s ailment” label before biomedical science was able to advance. Often this was blamed on an inherent female inferiority, whether a spiritual, emotional, mental, or physical. These practices were undoubtedly additionally devastating to chronically ill, mad, and disabled women and people assigned female at birth whose conditions were unknown, misunderstood, and mistreated. On the other side of the coin, behavior



considered deviant or outside of societal norms was also pathologized- women and people assigned female at birth who did not want to marry, have children, or did restricted actions were often considered psychologically afflicted, and incapable of making independent decisions.

In this MRP, I chose several large-scale Western historical events or periods of significant development to demonstrate the effects that still exist within healthcare for women and people assigned female at birth today. This includes the “Golden Age” of Greece, which saw large advancements in medicine, architecture, art, and literature; the Medieval European witch trials, which saw their peak from 1550-1782; and the Victorian era, in which thousands of women were declared insane and imprisoned in institutions and asylums. This will provide groundwork to understand Western culture’s treatment of women and people assigned female at birth within their societies and by extension, within healthcare. Historical context will also serve as foundational to ask questions about how this history contributes to the ongoing trauma and harm that disabled and chronically ill women and people assigned female at birth still experience when interacting with such systems today. In this MRP, I use an intersectional framework and autoethnographic methodology to examine key examples in the past timeline of Western healthcare and ask what direct consequences can be observed in the modern system today for chronically ill, mad, disabled women and people assigned female at birth.

## **The Origin of ‘Hysteria’**

The English word “hysteria” comes from the word “ὑστερικός” (husterikós) which roughly translates to “originating from the uterus”. In its modern descriptive form, the word “hysterical” is defined as “deriving from or affected by uncontrollable extreme emotion” with synonyms like “emotional”, “wild”, and “deranged”. In the modern day, such language is often weaponized against women and people assigned female at birth in any circumstance where their emotions are on display- but very frequently in healthcare settings (Mieres). “There is still this pervasive belief in the medical community that anytime a woman complains about her health, it is either related to her hormones or all in her head. Female hysteria was once a common medical diagnosis for women, applied whenever women displayed ‘inappropriate’ emotions such as anxiety, anger and even sexual desire” (McNally). This persistent attitude regarding the health of women and people assigned female at birth is not simply the result of contemporary versions of misogyny, but originates from historical interpretations of bodies and behavior. Additionally, due to the wide range of definitions and interpretations of ‘hysteria’, its symptoms, or even who it affects, the ideas and associations that stem from it are entangled with many areas of medical practice in modern Western societies. This work does not reflect an exhaustive history of every instance of the condition being studied, but highlights the best examples that can be used to answer the research questions at hand.

The oldest known Egyptian medical text, the Kahun Gynaecological Papyrus, dated to approximately 1825 BC, did not use the word “hysteria” but identifies the cause of the symptoms they observed as “spontaneous uterus movement within the female

body” (Shetty). There are also indications of the therapeutic measures to be taken depending on the “displacement” of the uterus. Believing the uterus to be “lured” by smell, the Egyptians employed the use of pleasant and unpleasant smelling odors near areas of the body they wanted to attract or repel the organ from. If the uterus had ‘moved upwards’, they believed it could be fixed by placing unpleasant-smelling substances near the person’s face, while scented ones were placed near the person’s vagina; on the contrary, if the uterus had lowered, the document recommends placing the unpleasant-smelling substances near the person’s vagina and the perfumed ones near the person’s face (Tesca, Sigerist, Cosmacini).

In Greek mythology, one of the Argonauts, Melampus- a physician with healing powers- was called to the city of Argos to contend with a group of young virgin women who had refused to worship the phallus (which was believed to be a powerful symbol of fertility). They began acting strangely and ran away to the mountains. In the story, Melampus describes the madness as “as derived from their uterus being poisoned by venomous humors, due to a lack of orgasms and ‘uterine melancholy’” (Sigerist, 50). He offers the women an herb called hellebore, and encourages them to have sex with the young men of Greece- after which they are ‘cured’ of their supposed madness.

While fictional, the story carried implications. Mythology and religion often use stories or parables to teach lessons or convey cautionary messages about how people should behave in society. Generally, the Greeks in the Golden Age had a positive view of sex and did not associate it with shame or a measure of modesty, which is reflected in their mythology’s values. In this story, the behavior of these women was abnormal and

against what their community was expecting of them. Their rebellious choice of behavior was instantly labeled as madness, even within a myth.

In this story, the supposed madness in the minds of women and people assigned female at birth are tied to their inherent biology as well as their outward behavior deemed socially unacceptable. Cultural beliefs influence perspective, and in turn, the products of such an environment carry imprints of those cultural beliefs. Medicine is no exception, especially in a time when much of it was speculative.

Hippocrates, a Greek physician who lived during the Greek Classical period (approximately 510 to 323 BC), is regarded as the ‘father of medicine’. He wrote over 60 volumes of medical literature, the *Corpus Hippocraticum*, many of which became foundational works for modern Western medicine. Observing symptoms like anxiety, a sense of suffocation, tremors, sometimes even convulsions and paralysis in his patients, Hippocrates attributed the symptoms to a physically wandering uterus within the body. He wrote that the cause was “poisonous stagnant humors which, due to an inadequate sexual life, have never been expelled” (Tasca, et al). Hippocrates suggests that the unmarried and widowed should get married and live a satisfactory sexual life within the bounds of marriage as a means of treating their symptoms. Hippocrates also wrote that the uterus was prone to get sick if deprived of the “benefits” of sex and procreation. He is allegedly the first to use the term “hysteria” to group this set of behaviors and symptoms; there is evidence to suggest that the accreditation may be due to a mistranslation (King, 6-7), however his beliefs about the symptoms’ origins and how to treat them remain. “The idea that it is in the Hippocratic corpus that hysteria is not only described but also

given its name can be traced back... to Emile Littré... and the additional French material provided” (King, 7). Emile Littré was a French lexicographer, politician, and physician, who published his own book “Medicine and doctors” in 1822. In his works, for many Hippocratic texts, Littré added section headings for each chapter. These were original to him and had no corresponding Greek text. This occurs in three volumes of *Gynaikeia* (in English, “Diseases of Women”) where he added the headings, “Hystérie”. (King, 7). Subsequent translations of Littré’s work from French into English would attribute the entirety of the text as Hippocrates’, which would be cited by future researchers. King claims that Littré also took liberties with his interpretations of what Hippocrates wrote—such as, whether Littré thought Hippocrates was writing about an *imagined* movement of the uterus or a *physical* one. Despite this additional context, information still exists about the symptoms Hippocrates was observing and attempting to treat. He also was not the only one trying to learn and theorize about the uterus and its effects on the health of women and people assigned female at birth. “A concept may exist even if it is not named.” (King, 8).

Plato (428-348 BC) surmised that the uterus would become “sad and unfortunate” if it did not join with the male and create a new birth- Hippocrates and Aristotle (384 to 322 BC) agreed (Tasca, et al). Aretaeus of Cappadocia (130-200 AD) even described the uterus as “closely resembling an animal, for it is moved of itself hither and thither in the flanks, also upwards in a direct line to below the cartilage of the thorax, and also obliquely to the right or to the left, either to the liver or spleen; and it likewise is subject to prolapsus downwards, and, in a word, it is altogether erratic. It delights, also, in

fragrant smells, and advances towards them; and it has an aversion to fetid smells, and flees from them; and, on the whole, the womb is like an animal within an animal” (Aretaeus). Reflected in these physician’s writings is the pressure for a woman or person assigned female at birth to engage in behavior that their society had a positive view of (sex and procreation), as a means of cure.

Another Greek physician, Soranus of Ephesus (98-138 AD), made significant contributions to what would become the field of gynecology and obstetrics (Karamanou, et al). He also practiced in Alexandria and Rome. Roman scholars also recognized that there were some symptoms being experienced more exclusively by women and people assigned female at birth and attributed them to the uterus or female reproductive system.

Claudius Galen (129-216 AD), a Roman-Greek physician, surgeon, and philosopher, made major contributions to Western medicine’s progress during his life. Galen was heavily influenced by the Greeks’ medical advances, and his own contributions to medical science would “[dominate] thinking for some 1,300 years and became accepted as dogma by both the State and Church” (West). “His prodigious output (22 massive volumes) was said to represent over half the bulk of extant medical literature of that time, and so thorough was his discussion that every facet of bodily function, illness, or remedy was extensively and dogmatically detailed. It is difficult for modern readers accustomed to a rapidly expanding body of medical literature to comprehend that Galenic views were taught, virtually unchanged, from his lifetime well into the 16th century” (Bagwell). Galen was demonstrably successful, and based on his studies and experience, he remained skeptical that the uterus could move (Shetty). Soranus was also

skeptical of the uterus' comparison to an 'animal'. Soranus and Galen are just a few examples of the lack of consensus during this time period about the female reproductive system, despite the ailment and ideas about treatment spreading. There were even those like Vesalius, the founder of modern human anatomical study, that perceived Galen's work as lacking (UC Berkeley). This was most likely because Galen was subject to the laws of Rome, which prohibited the actual dissection of human bodies. In order to do his work, Galen gained insight into the anatomy of muscles, nerves, arteries and veins by vivisectioning Barbary apes (Cosans). This in itself is concerning because he was so heavily drawn on for centuries for future work, despite his work being incomplete or inaccurate even in basic anatomy.

When the Roman empire fell, many fled and resettled in other areas, which naturally spread their knowledge and theories to other places. Byzantium (which includes parts of modern-day Turkey, Greece, and Bulgaria) became the new epicenter for Greek-Roman medical culture (Tesca, et al). The entirety of the Middle Ages brought political turmoil and conflict all over Europe and the Middle East- which eventually facilitated more cultural exchanges, especially because of Avicenna (980-1037) and Maimonides (1135-1204). Due to their efforts, "the legacy of Hippocrates and Galen is not only maintained, but spreads throughout Europe... Avicenna's *Canon of Medicine* and Galen's *Corpus* are diffused along with the Latin translations ascribed to Gerard of Cremona (1114-1187), while Maimonides' texts are disseminated in the Jewish world, along with other basic medical texts, thanks to translations by the Ibn Tibbon family between Arabic and Hebrew (13-14th centuries). In particular, the medical schools of

Salerno and Montpellier were vehicles for the dissemination of these works” (Tesca, et al). All of these events facilitated the type of cultural exchange that would allow for medical practice to continue to develop across many areas. This allows the continuous cultural impacts entwined with medicine.

### **Post-Reformation**

We will quickly skip forward to summarize some of the key events in Middle Ages Europe, in order to set the scene for the post-Reformation era and up to modern times.

The Crusades were a series of religious wars from 1095 to 1291 initiated by European Christians and the papacy. The Crusades created major political and religious turmoil in the Middle East and Europe. However, this conflict and conquest made the Church immensely wealthy and powerful. They sold “indulgences” that promised forgiveness or shorter sentences in purgatory in exchange for money or army service. “The Church's teachings on purgatory – an afterlife realm between heaven and hell where souls remained until they had paid for their sins – generated enormous wealth for various clergy who sold writs known as indulgences, promising a shorter stay in purgatory for a price. Holy relics were another source of income....which would allegedly bring luck or ward off misfortune” (Mark). The pope “could intervene in affairs of state, collect taxes, appoint high-ranking officials, instigate crusades, and summon councils” (Walton). “The hierarchy of the Church – pope, cardinals, bishops/archbishops, priests, and those in monastic orders – began to exercise their authority more for their own personal gain and comfort than the spiritual well-being of the people” (Mark). This corruption, among other



factors, would lead to an incredibly significant split in the Church, developing the two groups that would be known as the Protestants and the Catholics. This was known as Reformation, or the Protestant Reformation, occurring approximately at the start of the 16th century.

This was significant because after this split, the two denominations now had to compete for constituents. Before 1400, despite popular belief in witches, Christian authorities would not state that they were real. Pope Alexander IV even issued a canon to prevent people from being tried for the crime of witchcraft (Leeson and Russ, 1). However, after the Protestant and Catholic split, there was more turmoil regarding the orthodox Christian doctrine itself, leading to an increase in the prosecution and punishment of heresy and witchcraft. Both denominations then claimed they could protect people from this evil better than the other. By 1550, witch trial activity was common for communities in both denominations. “Europe’s witch trials reflected non-price competition between the Catholic and Protestant churches for religious market share in confessionally contested parts of Christendom. By leveraging popular belief in witchcraft, witch-prosecutors advertised their confessional brands’ commitment and power to protect citizens from worldly manifestations of Satan’s evil. Similar to how contemporary Republican and Democrat candidates focus campaign activity in political battlegrounds during elections to attract the loyalty of undecided voters, historical Catholic and Protestant officials focused witch-trial activity in confessional battlegrounds during the Reformation and Counter-Reformation to attract the loyalty of undecided Christians” (Leeson and Russ, 2). For the next 150 years, a minimum of 80,000 people

were tried for witchcraft in Europe, with half of those being executed (Leeson and Russ, 1).

Women and people assigned female at birth made up the overwhelming majority of the accused population- about 75 to 80 percent (Thurston, 65). In 1911, Wallace Notestein estimated the ratio was about 20:1. “The mainstream view of the time is one in which the woman is a physically and theologically inferior being, an idea that has its roots in the Aristotelian concept of male superiority...The inferiority of women is considered a consequence of sin, and the solutions offered by St. Thomas’ reflection leaves no doubt about what will overturn the relationship between women and Christianity: the concept of ‘defective creature’ is just the beginning” (Tasca, et al). This commonplace belief system, which viewed women and people assigned female at birth as inherently inferior by way of intentional divine construction, left them more vulnerable to accusations and blame. Women and people assigned female at birth that experienced “melancholy” or “hysteria” were supposedly more susceptible to the Devil’s influence.

If a sick woman or person assigned female at birth sought medical care, and a physician could not identify a physical source for their symptoms, it would be considered evidence that the ailment comes from the Devil. Considering the limitations of scientific knowledge during this time, the possibilities for who was swept up in witchcraft accusations are endless. Women or people assigned female at birth who were widowed or single often were the victims of tragedy or violence in the past, making them prone to “melancholy”, landing them in the pathway of suspicion. Women and people assigned

female at birth likely felt pressure to conform to social and cultural norms, and resist challenging authority, lest they be accused as well.

Women or people assigned female at birth who were experiencing symptoms of illness relating to the reproductive system that we might recognize today as premenstrual syndrome (PMS), premenstrual dysphoric disorder (PMDD), ruptured ovarian cysts, endometriosis- the list of unknown medical problems during this time is practically all-encompassing. Any outward signs of mental illness were certainly grouped into the accused as well- “melancholy” already points to being a euphemism for clinical depression or Major Depressive Disorder. While men and people assigned male at birth were a minority in the accused population, 20-25%, those that were outwardly mentally ill were most likely to have been caught up in the panic. In certain cases, even young children were arraigned and murdered (Arnold).

During this time, “...many manifestations of mental illness are seen as obscene bonds between women and the Devil. ‘Hysterical’ women are subjected to exorcism: the cause of their problem is found in a demonic presence. If in early Christianity, exorcism was considered a cure but not a punishment, in the late Middle Ages it becomes a punishment and hysteria is confused with sorcery” (Tasca, et al). Such symptoms were said to come from associations with the Devil or a demonic presence- so in a way, the afflicted were often blamed for their own suffering. “By the fourteenth and fifteenth centuries this explanation had expanded to embrace witchcraft. Not only were the mad possessed by the devil – they were in league with him. Elizabeth Sawyer’s life was dramatized as *The Witch of Edmonton*. In her confession to the clergyman Henry

Goodcole, she admitted that the devil first came to her when she was ‘cursing, swearing, and blaspheming. This sacrilege assured the Devil that she was of his party’” (Arnold).

“The early church viewed sickness as punishment for sin; healing could only occur through the grace of God as a miraculous event” (Bagwell). The blending of the connotation between sin and poor health is one that still exists today.

While not an official Church document, the book *Malleus Maleficarum* or “Hammer of Witches” was published in 1484 and was a popular and comprehensive work on the subject of demonology. It detailed specific instructions on how to violently persecute ‘witchcraft’ (which could range wildly in definition) and who to suspect of participating. This book was highly influential during the witch trials of its time particularly because it was accessible and popular amongst commonfolk, rather than simply those of elite or ruling class. Despite being published in 1484, the book was very influential in the next two hundred years- “the most infamous of all medieval texts” (Brodel, 3). The word “maleficarum” is also a gendered word referring to female witches only, whereas the male version of the word, “maleficorum”, would have been gender neutral or all-encompassing (Tasca, et al). It was authored by German Catholic clergymen Heinrich “Institor” Kramer and Jacob Sprenger.<sup>1</sup> It advocated for particularly brutal punishments, like torture as a means to acquire confessions, and for burning the accused at the stake. The Latin word *foemina* is used in this work, from the words *fe* and *minus*, translating to “who has less faith” and used it to draw conclusions about the nature

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<sup>1</sup> Jacob Sprenger was listed as co-author, but not until 24 years after his death. He had a better reputation than Kramer, which may have been why his name was added. Reports conflict about his involvement in the actual writing- some even state that he and Kramer were bitter rivals. It is likely that Kramer is the main (if not sole) author of the *Malleus Maleficarum*.

of women. Kramer often presented his own opinions as the Church's official stance, and the book was even condemned by theologians that were members of the Inquisition at the University of Cologne. The book also presented the papal bull, a public decree from the Pope usually issued to authenticate and endorse a written work (Deyrmenjian). However, the book was misrepresenting the papal bull (which gave them permission to prosecute heresy) two years before the *Malleus Maleficarum* was even published. This is how the book gained widespread legitimacy in many places, despite it not technically being endorsed by the Church.

“The most suspect women were widows and spinsters, those who lived alone: according to the [authors of the *Malleus Maleficarum*], their crimes included killing and eating children and orgiastic sex with the devil, who came equipped with a twenty-three-inch member for the purpose. Once caught, these unfortunate women were stripped and shaved and underwent a cavity search for ‘the mark of the witch’, a catchall phrase which covered moles, birthmarks or scars. So-called witches were then tortured, a procedure that included beating, thumbscrews and gang rape, until a ‘confession’ was wrung out of them, a practice which led one commentator to observe that ‘they are racked and tortured, so they can hardly stand or hold themselves from confession. In which case I doubt but that the Pope would blaspheme Christ, and curse his mother for a peacock’” (Arnold).

The events that immediately preceded Kramer's authoring of the *Malleus* is demonstrative of how religious and political power could be used to perpetuate misogyny from the systemic to the individual level. It is also a near-perfect anecdote about how women and people assigned female at birth were treated when they did not conform to

social norms- whether that was lifestyle, behavior, or religion. Even when witchcraft accusations were not being leveled at the mentally or physically unwell, they were used to target women and people assigned female at birth who were considered rebellious or deviant.

Kramer began writing the *Malleus* after his failed attempt to prosecute Helena Scheuberin and several other women in Innsbruck, Germany. Kramer was at this time, “easily the most experienced inquisitor in Germany, and was held in high esteem in Rome” (Brodell, 12). He was also widely disliked, belligerent, self-righteous, and refused to compromise on any issue (Brodell, 12). Kramer arrived in Innsbruck in the fall of 1485 to look for witches, and when he could not incite enough people to come forward with accusations, “began a vigorous schedule of preaching, in an effort to educate his audience about the dangers of witchcraft, its signs and telltale characteristics, and to recommend permissible countermeasures.”

Scheuberin was an Innsbruck native known to be an “aggressive, independent woman who was not afraid to speak her mind” (Brodell, 1). She reportedly called Kramer a heretic- when questioned, she answered, “Because you do not preach, except against witches” (Brodell, 8). Scheuberin declared she would no longer attend his sermons and encouraged others not to as well. She spat at Kramer once in the street in front of others, yelling, “Fie on you, you bad monk, may the falling evil take you.” Scheuberin’s name was on the short list of Innsbruck residents suspected of witchcraft that Kramer produced not long after.

Scheuberin was by all accounts, the perfect target. She had already very publicly denounced and shamed a religious, male authority figure. She was rumored to be sexually promiscuous and have “questionable morals” and was known to voice her opinion. She was even rumored to have used magic to cause the illnesses of two people who eventually died. In this instance, while we cannot know if she was mad or disabled, we can conclude that it was her refusal to adhere to the social expectations that got her into trouble with Kramer and the Inquisition. Reportedly, Kramer became “obsessed” with Scheuberin. During her trial, he inquired so deeply about Scheuberin’s virginity and sexual history that the other members of the commission “exceedingly uncomfortable” and eventually “his manner was so offensive to the episcopal commissioners that they protested and called a halt to the morning’s proceedings” (Brodell, 2-3). The next day, the rest of the commission dismissed the trial.

After the trial was dismissed, he “refused to let matters rest, and he spent the next several months hanging around Innsbruck collecting evidence, harassing witnesses, even briefly seizing a suspected witch or two on his own initiative, all in all making of himself an insufferable nuisance” (Brodell, 17). Kramer’s obsession with Scheuberin, as well as his consistent disruption of the town of Innsbruck, actually led the town’s leadership, Bishop Golser, to order him to leave in February of 1486. By this time, Kramer had already begun working on what would become the *Malleus*.

Kramer’s obsession with Scheuberin can likely be attributed to her refusal to respect him- the descriptions of his character certainly match such an assumption. We can also draw from the *Malleus* itself, which details how witches are responsible for men

experiencing powerful lust towards them, that even causes them to cheat on their wives (Brodell, 26). If Kramer felt anger towards Scheuberin as well as desire, it would have explained his intense fixation on her, as well as his improper questioning during her trial. In fact, if Kramer truly ascribed to the beliefs he later wrote about in the *Malleus*, he may have even interpreted his desire for Scheuberin as evidence of witchcraft. Writing the book was Kramer's own act of self-justification and revenge (McCullough).

Notably, the *Malleus* specifically names epilepsy and leprosy as illnesses that could be caused by witchcraft. Despite acknowledging that "these diseases arise from some long-standing physical predisposition or defect", the document argues that these conditions could *also* be caused by witchcraft. The text also insinuates that even if the one experiencing the illness is not the 'responsible' party, that they are less of a righteous person than others, since "the witch" chose to afflict them. "God does not allow so great power of evil against the just and those who live in grace, as against sinners; and as the devils have more power against sinners...so they are permitted by God to afflict them more than the just" (Summers, translated). As mentioned previously, the afflicted were often blamed for their own suffering, especially when a physical cause could not be determined. Epilepsy was also called, "the falling sickness", reflecting the belief that during a seizure, the sufferer would fall to the ground towards Hell and the Devil, possibly pulled at by demons (Nakken and Tuft). Speculative supernatural causes of illness served only to harm the person with the illness- many people with epilepsy were undoubtedly among the disabled people who were sentenced for involvement in witchcraft during this time period. "Hysteria and epilepsy were the two illnesses that



were most frequently confused with witchcraft or demonic possession, especially if they were accompanied by tremors, convulsions or of loss of consciousness” (Quintanilla).

It is also interesting that there were people that suspected madness rather than witchcraft at the time, yet the social and cultural power of the Church likely overpowered them. Reginald Scot, a Justice of the Peace in Kent, often had people accused or allegedly suffering from witchcraft brought before him. Scot “was among the first to suggest that an element of insanity informed the diagnosis of the ‘witch’ and the ‘bewitched’ . He surmised that many ‘bewitched’ people were suffering from a disordered brain, rather than enchantment. Careful observation convinced him that the accused and the accusers were not bewitched at all, but mad, arguing that a belief in witchcraft was ‘contrarie to reason, scripture and nature’ . Witches, argued Scot, were not possessed by the devil at all, merely delusional, and suffered from ‘not witchcraft but melancholie’” (Arnold). Scot was reportedly able to rescue many mad people from persecution- and for his efforts, was persecuted by the heir to the throne, James the I. Any number of recognized medical conditions could have come under the umbrella of ‘hysteria’ or associated symptoms that were then attributed to witchcraft. Jane Ussher also points out that there may have been a concerted effort from the Church to eradicate healers who used herbal medicine (especially with regard to pregnancy and abortion) that were a competitor and threat to the religious establishment (Ussher, 48, 49, 89). “We also know that many witches were midwives or “wise women”, traditionally the depository of women’s reproductive knowledge and control...The *Malleus* dedicated an entire chapter to them, arguing that they were worse than any other woman, since they helped the mother destroy the fruit of

her womb- a conspiracy made easier, they charged, by the exclusion of men from the rooms where women gave birth” (Federici, 347). From the end of the 16th century, in several European countries, few women and people assigned female at birth were allowed to practice obstetrics. This was also fueled by the emphasis in Europe that a large population was the key to more wealth and power. “What is certain is that the witch-hunt was promoted by a political class that was preoccupied with population decline and motivated by the conviction that a large population is the wealth of the nation” (Federici, 344). In a way, the assessment was correct. Large populations meant a larger labor force with which to generate wealth for the state. By making it unacceptable for women and people assigned female at birth to have the choice to abort a pregnancy and eliminating those with the knowledge to help them do so, more pregnancies were forced to be carried to term. In the mid-19th century in America, “there were concerns that these other groups were demographically outpacing white, Anglo-Saxon, Protestant women. And so they thought to limit the bodily autonomy of white women and limit access to contraception in order to force them to have children. That they felt would keep up with the demographic birth rate” (Samuels and Potts). That rhetoric persists today in the modern American anti-abortion movement that eventually led to the overturning of *Roe v. Wade* in June of 2022. Heavily fueled by conservative and reactionary Christians, the “pro-life” movement has sought to restrict women and people assigned female at birth from making reproductive choices, often for the above stated reasons. This demonstrates the longevity of such ideas and attitudes for them to still be so powerful and influential in some modern Western countries like the United States.

“Witchcraft had for centuries remained on the periphery of Church doctrine and, although always a grave sin and a serious concern, it had never before been considered a cause for real alarm. In the *Malleus*, though, witchcraft was elevated to a pivotal position in the struggle between man and the devil, and was given new responsibility for the world’s ever-increasing ills” (Brodel, 19). Due to the invention of the printing press, the *Malleus* had twenty printed editions by 1520 and another sixteen editions between 1574 and 1669 (Russell) that were available to the public and played a large role in shaping a public consensus on the mythology. During the height of the European witch hunts (about 1450–1750, with the greatest intensity from 1550–1650), an approximate 40,000–60,000 people were executed for witchcraft (Levack, 1987). From the estimated 75-80% gender imbalance in the accused, that means roughly 30,000–48,000 of those executed were women and people assigned female at birth. The Church and Christian doctrine were a central part of this story. Within the context of Western history, Christianity has remained a dominant driving cultural force- therefore some beliefs or attitudes that persist today are reminiscent of the same justifications during the Middle Ages and post-Reformation era. This is a much larger topic than this paper can cover in and of itself- however I use a quick comparison simply to demonstrate how the past and present are connected and entangled with one another.

In simplistic terms, to believe in a “just world”, in which good was rewarded and evil punished, then it is harder to accept or justify when bad things happened at random or without a just cause. This is generally referred to as a “moralizing model”. These stigmas towards mental illness within some wider Christian communities in the West are

still common today. “Moralizing accounts of depression include the idea that depression is a sin or the result of sin, and/or that depression is the result of demonic possession that has occurred because of moral or spiritual failure” (Scrutton, 285-311). In the 1960s and 70s, there was a popular anti-psychiatry movement which “perpetuated the idea that the causes of mental illness are solely spiritual in nature (e.g. personal sin, lack of faith) and thus should be dealt with in a pastoral counseling context separate from all secular psychiatric or psychological involvement” (Stanford, 445-449). This is potentially harmful to all those in Christian communities that are affected by mental illness, but it exposes more gender disparity. According to one study’s data, “women were significantly more likely than men to have their mental illness dismissed by the church and/or be told not to take psychiatric medication” (Stanford, 445-449). This is simply one example of the evolution of ideas over time within Western history; I encourage readers interested in more in-depth research on the relationship of mental illness and Christianity to consult authors listed in the reference section<sup>2</sup>.

### **Insane Asylums and Mental Institutions**

There were very few public institutions specifically for psychiatric patients before the 19th century. When mental health treatment was needed prior to institutions, it was seen as a domestic issue for families to deal with themselves. If they were unable to care for their mentally ill or disabled family member, they might send them for a short-term treatment at a hospital or fund their stay in a private “madhouse”. If the mentally ill person had no family to take care of them, they often roamed the streets and had to fend

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<sup>2</sup> See references (Scrutton) and (Stanford).

for themselves<sup>3</sup> (Suzuki). The Bethlem Royal Hospital in London, best known by its nickname 'Bedlam', is one of the most infamous. The word, "bedlam" is used as a synonym for "uproarious", "chaos", or "pandemonium" even today. Public-facing and charitable institutions became more common after the Age of Enlightenment (approximately 1685 to 1815). With advancements in science, mathematics and philosophy, much European thinking began to change from previously used supernatural and divine forces to explain the world around them (Zafirovski). "Scientific and medical doctrine was becoming more sophisticated and less credence was given to the supernatural as a cause of mental illness. The mentally ill were regarded less as being possessed, evil or practicing as witches, but suffering from some mysterious disease process" (Carron and Saad, 5). There was more institutional legitimacy afforded to places that were more disconnected from the common European perception of a "madhouse" (Arnold). Unfortunately, as it was still unknown how to treat this 'mysterious disease process', mentally ill and disabled patients in these institutions were subjected to experimental and unscientific attempts at "treatment" that was nothing short of torture. "In addition to being whipped and chained and beaten to rid them of demonic possession, the new arrivals at Bethlem would have endured the vagaries of mediaeval medicine, an inexact science at the best of times" (Arnold).

Bedlam in particular, having been a hospital long before its transition to primarily mad patients, had its own infamous reputation that worked its way into popular culture and literature in post-Reformation era London. "Madness, in all its grotesque

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<sup>3</sup> For more information regarding institutions in the early modern period, see the works of Andrew Scull, Roy Porter.

manifestations, appealed to the sensibilities of the tragedians” (Arnold). Famous dramatists and writers like Thomas Dekker, Thomas Adams, and even Shakespeare specifically mentioned Bedlam in their works. It was common practice for people to visit asylums simply to gawk at the patients. It is also interesting to note that in late 18th century London, as many as one-in-five citizens had syphilis, a sexually transmitted disease (Szreter and Siena). If left untreated, syphilis causes dementia, lesions, ulcers and destruction of cartilage in the nose (saddle nose), blindness and deafness, and more- and there was no real treatment for the illness until after the invention and widespread use of penicillin in the mid- to late 1940s (American Academy of Pediatrics). It is likely that syphilis was not the only disease that is treatable today that commonly reached late-stage neurological complications back then. That means that those with purely psychological symptoms were likely not the only ones who would be imprisoned in asylums.

Like everything else that spread during European colonization, so did these institutions.<sup>4</sup> In what would become the United States, the Pennsylvania Hospital in Philadelphia provided a few basement rooms specifically set aside for the mentally ill- “complete with shackles attached to the walls” in 1752 (NIH). Australia’s first psychiatric institution, Tarban Creek Asylum, (later Gladesville Hospital), opened in Sydney in 1838. Canada’s first asylum opened in St John New Brunswick in 1835 (Wong). The United States also opened facilities separately for Black people who were mentally ill post-Civil War. The first was the Central Lunatic Asylum for Colored Insane,

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<sup>4</sup> Mental institutions were also established in other countries and European colonies, but for the purposes of this paper and focusing on Western culture, I will mostly focus on the countries that are today considered part of the “West”; the United States, Canada, and Australia/New Zealand.

which opened in Petersburg, Virginia, in 1870 (Davis). Other hospitals, like Eastern State Hospital, admitted one freed Black patient a year before the end of the Civil War, and others would have segregated wards until the Civil Rights Movement in the 1960s (Davis). Before the abolition of slavery, even enslaved people attempting to escape their captors were pathologized. The term ‘drapetomania’, a supposed mental illness, was defined as "vagabondage, dromomania; an uncontrollable or insane impulsion to wander." After abolition, the effort to secure freedom and equality by Black Americans was pathologized to rationalize the need for an inordinate rate of long-term institutionalization, involuntary admissions, sterilization, imprisonment, segregation, police surveillance, and control (Davis). Sadly, it is unlikely that much if any thought was given to how to assess and treat post-traumatic stress from being enslaved. There were even predictions by social scientists that claimed mental illness in Black Americans would dramatically increase after gaining their freedom; this was an attempt to use pathologization as a justification for incarceration. From 1870 to 1968, the Central Lunatic Asylum also had a rate of hospitalization twice that of the Black proportion of the population in the state (Davis). This is similar to the situation within the prison-industrial complex today, in which Black people make up 13% of the overall US population but represent 33% of incarcerated individuals (Pew Research Center). Additionally, today, “66% percent of incarcerated people self-reported a disability, with Black, Hispanic, and multiracial disabled men especially overrepresented in prisons” (Bixby, et al).

“By 1890, every [US] state had built one or more publicly supported mental

hospitals, which all expanded in size as the country's population increased" (NIH). Despite the increase in hospitals to meet the growing need, these facilities intended to provide care were home to rampant human rights abuses. Torturous "treatments" and unhygienic conditions were still as common as in the early modern period in Europe. "Overcrowding was common, relationships between patients and staff were paternalistic, and patients reported experiencing verbal, emotional, physical, and sexual abuse by other patients and staff. Asylums often became custodial institutions, providing limited food and shelter with inadequate treatment. There was an over-reliance on seclusion and chemical and physical restraints" (Ontario Human Rights Commission).

The Victorian era (approximately 1837-1901) is generally when most of these institutions appeared in the newer Western countries. It is also when some gender disparities began to emerge in the patient population. While it is still disputed whether women and people assigned female at birth were incarcerated at higher numbers than men and people assigned male at birth, the former was certainly admitted on false pretenses or pathologized behavior more than the latter. In the Victorian era, "the ideal woman was willing to be dependent on men and submissive to them, and she would have a preference for a life restricted to the confines of the home. She would be innocent, pure, gentle, and self sacrificing. Possessing no ambitious strivings, she would be free of any trace of anger or hostility. More emotional than man, she was also capable of self renunciation" (Gorham, 5). Therefore, evidence of "insanity" in women and people assigned female at birth was often simply behavior that was at odds with this description. Women and people assigned female at birth that did not desire to be submissive and



dependent could be 'insane' instead. Focusing too much on education or spending too much time writing could be evidence of insanity. Deviant behavior like premarital or extramarital sexual behaviors could be evidence of insanity. Of course, this pathologization extended to women and people assigned female at birth who were too angry, too emotional, too *hysterical*. "In the nineteenth century it was anticipated that large numbers of women were likely to fall prey to mental disorders resulting from the challenges of childbirth and maternity...practitioners and psychiatrists took great interest in mental disorders linked to pregnancy and childbirth. By mid-century these conditions accounted for 10 percent of female admissions in many asylums" (Marland). "Merely to be in possession of a cervix predisposed one to insanity" (Arnold). It is evident that the female population in asylums were there for a mix of many reasons- mental or physical illness, deviant behavior, trauma, burnout, their husbands, and more. The smallest, most innocuous behavior was able to be pathologized and especially assigned to the female sex. "Auguste Fabre, who declared 'all women are hysterical and . . . every woman carries with her the seeds of hysteria. Hysteria . . . is a temperament, and what constitutes the temperament of a woman is rudimentary hysteria.' Nineteenth century physicians were highly critical of this 'feminine temperament', describing hysterical women as difficult, narcissistic, impressionable, suggestible, egocentric and labile" (Ussher).

Common 'treatments' at these types of institutions "... included insulin shock or insulin coma therapy, which involved injecting patients with insulin to induce temporary comas, and electroconvulsive therapy without anaesthesia, which involved passing an electric current through the brain to induce seizures, and lobotomies, which involved

surgically removing part of the brain” (Braslow). Insulin shock therapy was hypothesized to relieve symptoms like anxiety, paranoia, hallucinations, obsessive-compulsive thinking, and more. From the 1930s to 1960s, it was considered the mainstream medical treatment for schizophrenia (Wright-Mendoza). The problem with this was that there was never any evidence that the treatment worked. “Developed by psychiatrist Manfred Sakel in the 1920s, insulin coma therapy was based on the premise that patients could be “jolted” out of an episode of mental illness. The therapy itself took place over a number of weeks or months, with patients daily receiving insulin injections that induced a coma-like state persisting for an hour or so before it was reversed by supervising hospital staff with an injection of glucose. The insulin dosage was increased every day, inducing increasingly deeper states of unconsciousness until doctors decided the patient was at “maximum benefit,” at which point they would be tapered off the insulin. This process was repeated again and again until the patient had experienced anywhere from 30-50 of these comas” (Wright-Mendoza). This is a direct example of healthcare providers being complicit in the abuse of the patients under their care. Despite no solid evidence of the technique working, healthcare providers continued to perform and assist in the infliction of this therapy on psychiatric patients. Paternalistic attitudes and power dynamics in the healthcare provider-patient relationship contributed (and still contributes today) to harm caused to disabled and mad patients. Of course, this effect was heightened for disabled and mad women and people assigned female at birth. The increased social status and power of a white male with doctorate credentials and the decreased social status and power of the institutionalized woman or person assigned female at birth who was

disabled or mad, intensified the imbalance of power. The removal and minimization of the patient's autonomy, consent, and voice allowed for dehumanization and abuse rather than actual care fueled by compassion. This paternalism and power dynamic still exists within provider-patient relationships in the Western healthcare system today. The doctors and medical staff who performed these procedures and worked at these facilities "...played a central role in this, assigning diagnoses and acting as custodians of the mental institutions where the women were kept" (Launer). This reminds us that scientific ignorance was not the sole cause of insufficient and abusive treatment of patients by healthcare providers, in the past or the present.

Women and people assigned female at birth also were not exempt from gender roles even if they were ill and institutionalized. The "women remanded to state asylums were involved in sex-typed forced labor. They worked as unpaid domestics, laundresses, ward aides, cooks, and commissary saleswomen. If they refused these jobs they were considered "crazy" and "uncooperative" and punished with more drugs, shock treatments, beatings, mockery, and longer hospital stays" (Chesler). The surviving firsthand testimony from the women and people assigned female at birth who lived through the experience of being incarcerated in an asylum is limited. Written correspondence was prohibited or extremely restricted, and in the case of many poor or formerly enslaved women and people assigned female at birth, they may not have been able to read and write. Therefore, much of the surviving testimony comes from white women and people assigned female at birth who were fortunate or affluent enough to be able to escape or be released. The testimony of others, who spent their whole lives incarcerated, are lost. The

most vulnerable- the disabled women and people assigned female at birth that were also marginalized on the basis of race, ethnicity, sexual identity, socioeconomic status, and more were common victims of this system.

Mrs. H. H. Hanley of Minneapolis wrote, “I was sent because of family troubles, but was not insane, and was as strong and well as a woman could be. I was given no opportunity to get my friends to testify in my behalf... Dr. Baker told me that he saw that I was not insane, but was placed there for other reasons... He said he could send me to some of my relatives until the time came that I might be legally discharged, but none of them were convenient. At one time I ran away, but was persuaded to go back, thinking I would soon be allowed to go free. Some of the doctors did not wish me discharged as my cooking suited them. The patients were not permitted to have anything left from the tables of the officials, although much food was thrown away... The superintendent, Dr. Tomlinson, sometimes insulted or laughed at women who begged of him to be allowed to go home to their children. I heard him tell a German lady who begged to go home: ‘Your husband don’t want you; he told me so; you’re no good at home.’ People are sometimes driven insane by treatment and despair in the hospital... Dead people are carried like animals to the dissecting room or their bodies sold. Patients are locked in their rooms at night, sometimes ten or twelve in one room.”<sup>5</sup>

Kate Lee was held in the Elgin Insane Asylum in northern Illinois from 1899 to 1900. She wrote a book<sup>6</sup> about the experience. “Some became insane after sickness,

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<sup>5</sup> Mrs. Hanley’s account was recorded by Alice Bingham Russell, and published in *Women of the Asylum: Voices from Behind the Walls, 1840-1945*.

<sup>6</sup> See *A Year at Elgin Insane Asylum*.

especially typhoid fever. Some came from overwork or overstudy. Some came from grief at the loss of friends. One because an “unprincipled girl” stole her lover away, just before they were to have been married. Another because ‘My boy learned so many things that I did not want him to.’ One became insane from witnessing a tragedy, in which her betrothed shot and killed his brother. One came because the husband whom she married late in life ran away with her savings. Some are ‘insane on religion.’ Then there were those who were sent for family troubles of various kinds.... An old lady, who did not appear to be insane, claimed that she was sent to Elgin by a son-in-law who wanted her out of her house, so that he and his family could live in it.”

Lydia A. Smith, who was committed to the Kalamazoo Asylum in Michigan from 1867 to 1871, wrote, “It is a very fashionable and easy thing now to make a person out to be insane. If a man tires of his wife, and is befooled by some other woman, it is not a difficult manner to get her into an institution of this kind. Belladonna and chloroform will give her the appearance of being crazed enough.” (Ussher).

One of the most well-known figures and activists who escaped this predicament was Elizabeth Packard, who was committed to the Illinois Hospital for the Insane in 1860 by her own husband. She was invited to present some of her unorthodox religious ideas “for discussion” at a Bible class at her reverend husband’s church, seemingly so that the church officials could publicly disparage them. Instead, Elizabeth’s involvement quadrupled the attendance of the class. Suddenly, the church and her husband no longer wished for her to participate, and wanted her to publicly renounce her ideas, which she refused. Her husband presented this as evidence that she was mad. With the assistance of

two doctors (who were attendees of the class) and the local sheriff, Reverend Packard attempted to force her to go to an asylum. She locked herself in her room. With their five children and a crowd watching, Reverend Packard broke into the room with an ax and carried her from the house and placed on a train to the Illinois Hospital for the Insane. Elizabeth claimed that her husband had even admitted to her that he had done this because her religious beliefs were “heretical” and that he needed to give others the impression that she was insane, so that they did not listen or believe what she espoused. Elizabeth was diagnosed with “moral insanity”, and the more she protested and lashed out, the more ‘evidence’ the hospital had. Elizabeth fought back against violent treatments of patients like near-drownings and other forms of abuse- at one point even organizing a revolt. She realized that many of her fellow patients had been committed for similar familial disputes. Elizabeth began keeping covert records and journals of her experiences in the asylum, which would later become her first published book.

Elizabeth fought back against the hospital staff and caused trouble so persistently that after three years, she was able to secure her release. Once released, Elizabeth’s husband confined her to his house, nailing her bedroom window shut, while he rushed to find another way to have her hospitalized, perhaps in Massachusetts. Her friends intervened legally, accusing Reverend Packard of mistreatment of his wife- this sparked a week-long trial in 1864. At the end of the week, an all-male jury unanimously declared her sane in just seven minutes of deliberation. Elizabeth would go on to start the Anti-Insane Asylum Society, and she personally secured the passage of 34 bills in 24 different states regarding mental institutions and married women’s rights. For instance, in Iowa,

“Packard’s Law” made it illegal for asylum officials to intercept patients' mail and interfere with communication on the outside.<sup>7</sup>

A stunning work from this era, “The Yellow Wallpaper” by Charlotte Perkins Gilman, detailed the incredible harm perpetuated by a popular treatment of the time, “rest cure”. Gilman was an artist and a writer, and modeled the short story based on her experience with what we recognize today as postpartum depression. She was seen by neurologist Dr. Silas Weir Wilson, who notoriously invented “rest cure” in line with his views about the “danger” to women’s minds if they are “too active”. Dr. Wilson observed Gilman’s symptoms of “exhaustion and apathy associated with mothering, housekeeping and relations with her husband” that were “exacerbated” by her desire for engagement in learning and intellectual writing. To treat this, he instructed his patients to lie in bed for 24 hours a day, for weeks or months at a time, isolated from friends and family, without any creative or intellectual stimulation; patients were also instructed never to touch a pen, brush or pencil for the rest of their lives. The ‘treatment’ is likened to solitary confinement, which we know now can “lead to the onset of conditions like depression, anxiety, paranoia, delusions and psychosis and either worsen or create insomnia, anorexia and palpitations.”<sup>8</sup> Gilman adhered to the treatment for three months, in which she says she “ came so near the borderline of utter mental ruin that I could see over”. Gilman discarded the neurologist’s instructions and began to work and participate in activities again and was able to recover. She also recognized that she not only was being confined

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<sup>7</sup> This section on Elizabeth Packard is reworked from an earlier research essay of mine written during this MA program, “*Madness, mental institutions and their weaponization against women in the 19<sup>th</sup> century and beyond*”.

<sup>8</sup> “Solitary Confinement”, *John Howard Society of Ontario*. 2017.

by her room, but by her marriage. “The Yellow Wallpaper” is written as the diary of a woman being forced into rest cure by her doctor and husband. She’s been locked in her room by her husband, a doctor, who continuously tells her how kind he is to her. As the harrowing story goes on, the reader notices how the woman is clearly losing her grip on reality from the confinement. “Where the two women [Packard and Gilman]’s narratives most obviously intersect is in their message that husbands and doctors could not automatically be trusted to protect women and could drive them insane while believing they were doing good. Nor, it appears, were the men they defied capable of change” (Launer).

The imprisonment of women and people assigned female at birth in asylums continued in the twentieth century, often with the utilization of substances and pseudoscientific medical knowledge. Frances Farmer, a fairly well-known Hollywood actress at the time, was incarcerated from 1943-1950 at Western State Mental Hospital in Steilacoom, Washington. “For eight years I was an inmate in a state asylum for the insane. During those years I passed through such unbearable terror that I deteriorated into a wild, frightened creature intent only on survival. And I survived. I was raped by orderlies, gnawed on by rats, and poisoned by tainted food. And I survived. I was chained in padded cells, strapped into straitjackets, and half drowned in ice baths. And I survived. The asylum itself was a steel trap, and I was not released from its jaws alive and victorious. I crawled out mutilated, whimpering, and terribly alone. But I did survive. The three thousand and forty days I spent as an inmate inflicted wounds to my spirit that could never heal. They remain, raw edged and festering, for I learned there is no victory



in survival- only grief.” (Ussher).

“In general, twentieth-century female patients (and sometimes male patients, too) were imprisoned against their will—sometimes for up to 30–40 years; medicated against their will; lobotomized against their will; given electro-convulsive and insulin coma shock treatments against their will; denied medical treatment for other ailments; and were, afterwards, stigmatized as “mentally ill” when they sought employment and housing or pursued legal actions. Adolescent lesbians and homosexuals were subjected, usually by fundamentalist families, to especially horrific institutionalizations. They were put in isolation, physically beaten, subjected to propaganda and verbal abuse, were bullied, and were kept incommunicado... pregnant, unmarried teenagers were also psychiatrically pathologized, and separated forcibly from their newborn infants. In the early 1970s, in the UK, it was discovered that a number of women had been psychiatrically incarcerated for fifty years because they had borne “illegitimate” babies. It also became clear that for years, sexually active teenagers in Ireland had simply been put in nunneries, often for the rest of their lives, and were supervised by highly abusive nuns who put them to hard labor for their sexual sins” (Chesler). Some of the women incarcerated were put away for exhibiting “opposite sex traits”, like anger, cursing, love of women, aggressiveness, or increased libido. Velma Demerson was one of the victims incarcerated in 1939 under Canadian law for being engaged and living with her fiancé, a Chinese man (Demerson). She was arrested under the authority of the Female Refuges Act of 1897, a law that allowed authorities to jail women for "incurable" behaviour such as promiscuity, pregnancy out of wedlock and public drunkenness. Demerson was

given no trial and no legal counsel. She suffered horrible medical malpractice, undergoing surgical procedures with no consent nor anesthetic. She would give birth to her son while incarcerated, and her son would suffer side effects of medications she was forcibly given. Her son was removed from her and placed with a foster family. The suffering she experienced shaped the entire rest of her life. Advances in medicine and medical technology did not necessarily mean that such advances were being used correctly and ethically.

At many of these types of facilities “all of the women received massive drug dosages (such as thiorazine, chlorpromazine, mellaril, and librium), and many received shock therapy and/or insulin coma therapy routinely, and often before they were psychiatrically ‘interviewed’” (Chesler). This cocktail was even known as a “chemical straitjacket” and the FDA acknowledged that it was over-prescribed for mild symptoms.

“Most of the women [I interviewed] were humiliated, confused, fatalistic, or naive about their hospitalization and about the reasons for it. Most dealt with the brutality by (verbally) minimizing it and by blaming themselves. They were “sick”—weren’t they?” (Chesler).

### **Autoethnography**

With this historical contextual foundation, we can now analyze the modern consequences of such a system by examining my personal medical history and experience.

In 2013, at the age of 14, I contracted mononucleosis, an infection caused by the Epstein-Barr Virus (EBV). This was unalarming to my family. I often contracted strep

throat and other upper respiratory infections as a teenager, due to the size of the student population at school. Mononucleosis causes fever, swollen lymph nodes, sore throat, and intense fatigue that can last up to two months. When the patient recovers, EBV becomes dormant, and most people remain infected throughout their lives without any symptoms (NIH). The infection is also able to reactivate later, especially if you have a weakened immune system (Cleveland Clinic). The fatigue I experienced never went away after contracting mononucleosis and I never would recover my health to what it was before this infection. Additionally, during this school year, I dealt with severe depression and bullying, which would leave me with symptoms of post-traumatic stress. Post-traumatic stress is known to be associated with the subsequent development of autoimmune diseases (Song, et al).

Symmetrical joint pain started not long after. I frequently complained about pain in my hip sockets, knees, shoulders, hands, ribs, feet, even collarbones. Unexplained skin rashes and cysts became normal to me. My heart felt like it was “beating too hard”, and I would get lightheaded from bending over. Sometimes the hearing in my right ear “went out”, and everything would sound muffled. While I had trouble articulating some symptoms like those, the most straightforward and constant one was always joint pain. I complained that my bones were what hurt, insisting that the joint was the definite location of the pain. Taking high amounts of ibuprofen daily to cope with the pain would bring me dangerously close to developing a stomach ulcer.

Fatigue was the second most intense symptom. It was overwhelming. I slept any chance I could- during study hall, during lunch, on the bus, even between the sections of

my SAT exams. When I started driving, I drove myself to and from school. In the afternoon, while I drove home, my eyes would physically close on their own from the exhaustion. I had many near misses that could have been accidents. I was not only a danger to myself, but others.

My parents would take me to different doctors over and over- but the only specialist we were referred to was a psychiatrist. Like many other women and people assigned female at birth in the past and present, I was told that I had somatic symptoms from my depression and anxiety, without any physical cause. “Somatic symptoms” is defined by the American Psychiatric Association as “...when a person has a significant focus on physical symptoms, such as pain, weakness, or shortness of breath, to a level that results in major distress and/or problems functioning. The individual has excessive thoughts, feelings and behaviors relating to the physical symptoms...The emphasis is on the extent to which the thoughts, feelings and behaviors related to the illness are excessive or out of proportion” (APA). I was disappointed that my symptoms were “all in my head” because that meant that there was no medication or treatment that would take this physical pain away. My parents believed the doctors- why would they not? They pushed me and threatened me to go to school even when I felt unwell because according to the experts, I was not ‘really’ sick. The notes of a psychiatrist I visited in 2015 read, “Somatization is indicated by the report that Madison almost always complains of headaches, complains of shortness of breath, says she thinks she is sick, complains about her health, complains about pain when nothing is wrong.” The symptoms were documented back then. Yet, no further care was recommended for me.

I spent years thinking that I was an unbearably lazy person. I was only a teenager- I had not developed a sense of self yet. I questioned my reality- why was everyone else handling their “growing pains” so well, and I could not? Was I so deeply flawed as a person, as a being, that I could not cope with regular existence? I was born to a two-parent, middle-class family; I never had to wonder where my next meal would come from; I went to a good school. Was I so weak that I could not keep up or function normally, even with these advantages? If all this physical pain was caused by my own mind, then *it was my fault*. At any time, theoretically, I could make my own suffering stop. My family are devout Evangelical Christians in the Southern United States- we attended church services multiple times a week and were heavily engaged. Was my suffering really being given to me as some test of my faith? Was I just not praying hard enough?<sup>9</sup> Try as I might, the pain, fatigue, and other physical problems persisted. My mental health problems were exacerbated by the endless physical symptoms. How was I going to keep a job, if I had problems standing or walking for even short periods of time? Would I ever be able to go to college or move out of my parents’ home? What about my dreams of traveling? The questions always far outnumbered the answers. Every year, my physical health got worse, not better. I began to feel those dreams siphon out of me. My dream was simply to get through one more day. Then, the day after that one. I had no plans or dreams for “after” I survived this. I just hoped there was an ‘after’.

One day, I developed abdominal pain around one side of my hip and abdomen. It gradually built until the pain was searing and white-hot. I would writhe while laying

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<sup>9</sup> Take note of the ‘moralizing model’ described on page 27-28 influencing my thinking during this time, despite not knowing the term for what I was experiencing.

down, unable to even lay still. My parents took me to urgent care, while I cried and vomited from the sheer amount of pain. The doctor took an x-ray of my abdomen, and said I had indigestion. “See, you didn’t need to be dramatic, it’s just some tummy trouble,” the female urgent care doctor joked. We were sent home with some liquid laxatives and no pain medicine. In the next five months, we would return to the emergency room for the same issue four more times, with the same diagnosis and treatment. I remember one of the emergency room doctors- a young, white man in his thirties who lacked any urgency in his demeanor. His notes from the visit say, “Patient is hunched over and resists eye contact, speaks quietly and only asks for pain medicine”. It made me seethe to read the words, even years later. I remember the single time I asked for pain medicine during that particular visit. I was in my sweaty pajamas, with a bare face and messy hair, feverish and probably covered in a few vomit stains. As a self-conscious teenage girl, I was mortified, but in so much pain that I remember mustering up the courage to say, “Could I please have pain medication now, please?” He said, “In a minute,” waving his hand at me as if it wasn’t a priority. I remember him patronizingly asking if I had been having “boy troubles at school”. He told my mother, “You know, teenagers eat so much junk food, that’s probably why her stomach hurts.” The person in charge of caring for me was suspicious of me simply for being in pain and seeking care- seemingly because of my age and gender.

On the fifth visit, the emergency room doctor asked if we wanted to do an ultrasound to check for an ovarian cyst, “even though those are very rare”. This is not true. The Cleveland Clinic’s website states that “ovarian cysts are extremely common”.

Ovarian cysts are sacs of fluid and blood that can form on the outside of the ovary. The most common type occurs typically after ovulation. These cysts can rupture and leak that fluid and blood into the lower belly and pelvic floor, and at that stage, it is incredibly painful and can require surgery (Healthline). We opted to do the ultrasound- an invasive, transvaginal ultrasound- and a 4-centimeter-wide ruptured ovarian cyst was finally discovered. This kind of invasive procedure was even frowned upon by other providers at the time because of my age and sexual inactivity. Despite that, more appointments would be necessary in the following months that were just as invasive- sometimes even making walking painful after exams. I was forced to become used to allowing doctors access to any part of me that they needed to examine.

At 17, I was diagnosed with Celiac Disease, an autoimmune disease that causes a reaction to gluten. A 1999 study found that for people with celiac disease, the later the age of diagnosis, the greater the chance of developing another autoimmune disorder (Ventura, et al). I spent the car ride home crying, thinking about how much more difficult traveling someday would be with a major food allergy. By this point in time, half of the time my mother and I spent together was going to my doctor's appointments. At the time, we did not recognize it as part of a larger, more systemic problem.

I applied to one university, a 30-minute drive north from my parents' house. I chose it solely because it was close enough that I could continue seeing the doctors I had already become established with. The university campus was sprawling, and I immediately began missing classes due to the long walks to class in combination with the Texas heat, which made me feel flu-like symptoms. I began using a cane to walk. I still

did not have a diagnosis that explained *why* I needed it. I felt uncomfortable with the long stares and uncomfortable questions I received from strangers. Often, I would opt not to use the mobility aid I needed just to avoid unwanted attention. The fatigue was still as debilitating as in high school- I would frequently sleep over 20 hours at a time. My final grades for the first semester of school were a C, a D, an F, and a medical incomplete. I considered dropping out.

In 2018, still during the first year of university, I was referred to a rheumatologist for the first time. I recall sitting in his waiting room, circling every joint on a chart of the human body that read, “Where do you experience pain?” The doctor waved my blood test results as he came into the room, declaring that everything looked normal. He was an elderly white male, typical for my doctors in North Texas. He poked and prodded at me and my joints while I grit my teeth from the pain. The doctor shook his head and said that I might have fibromyalgia, but that I needed to get better at managing my stress levels about school. “You don’t have to get hysterical when you notice something different with your body, that’s normal, you’re still growing,” he said. There was that word again... “hysterical”. At that moment, this doctor utilized centuries of medical misogyny to his advantage, explaining away what he did not actually have an answer for. Despite ‘hysteria’ being rejected from the DSM before I was even born, such a label was used to reassert the superiority of the white male medical provider over my own lived experience. He did not offer any fibromyalgia treatment. He also refused to sign a paper that would allow me a handicapped tag on my car, which would allow me to drive to my classes and reduce the distance I needed to walk. No diagnosis meant no accommodations. No



diagnosis meant I stayed miserable. I cried into my mother's arms in the doctor's parking lot. The same power structures that allowed white male doctors to act as gatekeepers to effective care for women like Charlotte Perkins Gilman were still securely affixed in the present day for me.

It would take approximately four more years after that for me to see a second rheumatologist. During this four-year gap, I had developed numerous new symptoms and had been self-managing my care as best as I could, with the support of my family. We had also been to several expensive naturopath doctors who prescribed treatments like special supplements and diets, none of which worked except a drug called hydroxychloroquine, or Plaquenil. Through my own investigation, I learned that the drug is used to treat rheumatoid arthritis and lupus by calming an overactive immune system (Cleveland Clinic). This was what pushed me to seek a rheumatologist's care once again and landed me in Dr. Lomibao's office in 2021.

Dr. Lomibao agreed that I met the clinical standards for a rheumatic illness, perhaps seronegative rheumatoid arthritis or "overlap syndrome" in which a patient has many distinct symptoms but spread across many rheumatic diseases. "Seronegative" means that a patient meets the clinical standards for diagnosis but does not have the blood markers typically looked for to diagnose the disease, RF (rheumatoid factor) and the presence of ACPA (anti-citrullinated protein autoantibodies). In her opinion, I should have been evaluated by a pediatric rheumatologist at that time since my symptoms had emerged at the age of 13. "An estimated 20-25% of cases of RA are seronegative, meaning that patients do not express RF or ACPA in the serum despite meeting clinical

classification criteria for RA.” (Coffey, et al). Despite a long family history of arthritis, as well as my own personal suspicions, it still took 9 years from symptom onset to first rheumatic treatment. “Patients with seronegative RA experienced a delay in diagnosis, according to both 1987 and 2010 classification criteria, and delay in initiation of DMARD<sup>10</sup> therapy. Patients with seronegative RA also were less likely to attain remission, suggesting that the window of opportunity for intervention may be more frequently missed in this group” (Coffey, et al). Dr. Lomibao was also a young woman, which I felt made a world of difference in my quality of care. She listened to me for two hours- making furious notes on her laptop, asking questions, and making photocopies of all my records and lists of symptoms I had brought for her to read. I made a comment about how I had not been taken seriously in the past, and she made a joke about how she was an Asian-American woman within the medical profession, so she understood what that felt like. I left her office feeling optimistic and cared for- something I suddenly realized I had never experienced before. As a result of this appointment, I gained access to my first disease-modifying anti-rheumatic drug (DMARD), which improved my symptoms. I recommended her to everyone in my vicinity, including my mother. As a result, at the age of 53 and more than 20 years of symptoms, my mother received a diagnosis of psoriatic arthritis, and with it, access to DMARDs that lowered her daily pain levels significantly and greatly improved her quality of life.

Dr. Lomibao also ordered a large comprehensive autoimmune disease panel blood test, which had not been done before this point. I tested borderline positive for Sjögren's

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<sup>10</sup> DMARD stands for ‘disease-modifying anti-rheumatic drug’. This was not clarified within the quote itself.

syndrome, another autoimmune disorder that happens when the immune system attacks the glands that make moisture in the eyes, mouth, and other parts of the body (NIH). I also exhibited symptoms consistent with Raynaud's syndrome, where the hands and feet turn white when experiencing extreme emotional distress or intense cold temperatures. Both Sjögren's and Raynaud's can occur secondary to rheumatic conditions like rheumatoid arthritis, scleroderma, or systemic lupus erythematosus (Pope). Dr. Lomibao also sent me for a full body set of x-rays, which revealed some minor additional issues like the beginnings of Degenerative Disc Disease (DDD), mild dextroscoliosis, and mild spinal birth defects.

Cardiac testing during this same time period revealed that I had complained that my heart felt like it was "beating too hard", it turns out that what I meant was that I was experiencing supraventricular tachycardia (SVT)- an irregularly fast heartbeat that occurs when faulty electrical connections in the heart set off a series of early beats in the atria, the upper chambers of the heart (Mayo Clinic). It also confirmed venous insufficiency in my legs, all of which was clear evidence of postural orthostatic tachycardia syndrome (POTS). When I had described the hearing in my right ear "went out", I had been straining myself to continue physical activity so much that I had built intracranial pressure, which built pressure in my ears (Victory).

It is also important to recognize that because of my personal demographics and circumstances- despite all the suffering I have experienced in the 9 years from symptom presentation to when I first received treatment- I am still one of the privileged. I am a white woman, which unfortunately raises my chances of receiving better care than other

women and people assigned female at birth. My father's employer and the insurance they provided allowed me access to the revolving door of healthcare providers in the seemingly endless search for answers. In America, which has mostly unregulated for-profit healthcare, such open access to medical care is a luxury. My mother did not have to work to assist in our family's income, so she was able to take me to those appointments before I could drive on my own. I was able to remain on my family's health insurance even after I turned 18, and my family continued paying for any out-of-pocket costs I incurred. I was born to a family that had planned to be able to send me to university without student loans. Therefore, while many of my friends were working part-time jobs in university, I had the time and resources to go to my doctor's appointments. Dr Lomibao's office was a three-hour round-trip drive from my house. So was my cardiologist, who I had to see a total of 15 times to complete the full set of testing. I was able to make those trips. These demographic and socioeconomic factors- also called the 'social determinants of health'- played a role in my own health journey, just as they play a role in others'.

## **Analysis**

This is a diagnosis list of conditions I am being treated for at the time of this publishing (Figure 1). Note that the overwhelming majority of these conditions have a documented correlation with the Epstein-Barr Virus, which causes mononucleosis. "Previous studies suggested that EBV infection may play a role in the development of systemic lupus erythematosus and other autoimmune illnesses" (NIH). In recent years, researchers have also identified a viral protein that binds itself to sections of genetic code

Diagnoses	Associated with the Epstein-Barr Virus?
Seronegative Rheumatoid Arthritis	<input checked="" type="checkbox"/>
Postural Orthostatic Tachycardia Syndrome (POTS)	<input checked="" type="checkbox"/>
Celiac Disease	<input checked="" type="checkbox"/>
Sjögren's Syndrome	<input checked="" type="checkbox"/>
Raynaud's Syndrome	<input checked="" type="checkbox"/>
Degenerative Disc Disease (DDD)	<input checked="" type="checkbox"/>
Moderate Dextroscoliosis	<input type="checkbox"/>
Obsessive-Compulsive Disorder (OCD)	<input checked="" type="checkbox"/>
Mild Endometriosis	<input checked="" type="checkbox"/>

*(Barcelos, F., et al); (Alpantaki K., et al); (Harley, JB., et al); (Kvantaliani, T. and Akhvediani, M); (Pope, J.E.); (Martensen, Pia, et al); (Jonathan N. Johnson, et al), (Massa, L.)*

Figure 1

that is “associated with the risk for multiple sclerosis, rheumatoid arthritis, inflammatory bowel disease, type 1 diabetes, juvenile idiopathic arthritis, and celiac disease” (Harley, et al). While researchers know that a relationship exists for many of the conditions listed in Figure 1, it is still unknown definitively how the virus causes or contributes to the development of these diseases or conditions.

The reach of the virus’ impact is not limited to autoimmune or rheumatic conditions, as demonstrated in Figure 1. My struggle with contamination-type obsessive-compulsive disorder (OCD) began at about 16 years old, two years after my initial mononucleosis infection. Not only is there a correlation for OCD with Epstein-Barr Virus, but the findings of a recent study “strongly support the impact of hypovitaminosis and Epstein-Barr infections on the overall severity and specific symptom patterns of OCD” (Massa). Complications from post-viral infection are not a new phenomenon. One

of the most well-known examples is poliovirus, which can cause post-polio syndrome (PPS). Post-polio syndrome affects between 25 and 40 out of every 100 polio survivors and starts anywhere from 15 to 40 years after the initial infection. People affected by PPS experience muscle weakness, joint pain, fatigue, and progressive muscle atrophy (CDC). The 32nd President of the United States Franklin D. Roosevelt famously used a wheelchair due to post-polio syndrome. My own great-grandmother contracted rheumatic fever as a child, which left her with permanent cardiac damage. She was not expected to live past the age of 21. Rheumatic heart disease weakens the valves between the chambers of the heart. She developed benign tumors as well as arthritis- whether these were triggered by or associated with her viral infection will remain a mystery. She had three children and lived to the age of 83, with the help of two heart valve surgeries.

There is a line from Kate Lee's *A Year at Elgin Asylum* that bothered me continuously after I read it. "Some became insane after sickness, especially typhoid fever." Lee was imprisoned at Elgin from 1899 to 1900, over a hundred years ago. "An underlying host factor or environmental exposure that may predispose persons to develop neurologic illness in the setting of severe systemic infection due to typhoid is possible" (Sejvar, et al). Typhoid is just one of many viral infections that cause long-term health problems. Before the invention of modern vaccines, people died in much higher numbers from unmitigated spread of viruses and flu. Even today, *after* the invention of disease-specific vaccines, post-viral illness is still a problem. The 2019 novel coronavirus is the most recent example. A study published in December 2022 estimates that 65 million people worldwide are living with "long Covid", which has over 200 identified symptoms

in multiple organ systems (Davis, et al). This 65 million estimate is likely on the conservative side of the estimated number of people dealing with long-term, disabling effects of the virus, which is only a four-year-old virus as of 2023.

As we know, unexplained physical symptoms were also regarded as ‘madness’ and therefore a reason to persecute and imprison people. It would be unacceptable to institutionalize anyone in these conditions for any cause, but plenty of people who were not even the intended target of such ‘healthcare’ were caught in the crosshairs. If someone like me who assuredly has genetic predispositions for autoimmune disease and mental illness, suffered a viral infection during this time, the physiological responses of their body and mind would have been enough to lock them away. Reflecting on my behavior during disease onset, I am certain I would have been one of them. With the medical knowledge available back then, anyone who fell into this unknown disease category would be at risk for this type of abuse. Autoimmune disease patients are 80% women and people assigned female at birth, and 20% men or people assigned male at birth, overwhelmingly skewed towards one sex over the other. “Autoimmune diseases present with a clear gender bias with a greater prevalence amongst women, occurring at a rate of 2 to 1. Many autoimmune disorders tend to affect women during periods of extensive stress, such as pregnancy, or during a great hormonal change” (Angum, et al). With the evidence we have today, it is reasonable to assume that an unknown portion of those women and people assigned female at birth who were victims of institutionalization were suffering from autoimmune diseases and post-viral complications. I argue that this is not only a probable hypothesis, but a likely one. The Western healthcare system and

the doctors of the day did not have the expertise and technology to diagnose and name the conditions these women and people assigned female at birth may have been suffering from. Whether it was a mental illness, post viral illness, autoimmune disease, menstrual dysfunction, or another condition unknown at the time, it did not mean that their suffering was not real.

A theme prevails from the relative beginning- when Western healthcare and Western knowledge had no answers, the patient's sex often became the culprit for their suffering. The proof that this concept has persisted until the modern era can be demonstrated in something as simple as the fact that in the United States, the National Institute of Health did not require women or racial or ethnic minorities to be a part of clinical health research until 1993 (NIH). Research that was not conducted with women or racial or ethnic minorities involved in any stage was still being used as the foundational knowledge for the development of drugs, medical protocols and procedures, and more that were all being used to treat those same excluded populations. This likely led to inconsistencies between research and real-life application that were dismissed on the patient-facing side. Even in research pre-human clinical trials, historically, "researchers have favored male mice over female mice in experiments, in part due to concern that the hormone cycle in females causes behavioral variation that could throw off results" (Caruso) - a prime example of how misogyny permeates all aspects of a system. The Aristotelian assumption of the male body as the 'default' and the female body as 'other', casts anything and everything women and people assigned female at birth do into the category of medical abnormality. When Greek physicians could not



explain their female patients' symptoms, they immediately concluded that the female reproductive system must be responsible. In medieval Europe, when women and people assigned female at birth questioned authority figures or social norms or even practiced herbal medicine (threatening Church authority as the source for healing) they were accused of witchcraft and persecuted. When women and people assigned female at birth became sick or 'inconvenient' to their families and communities in Western countries during the Victorian era, they were locked away for the rest of their lives. The same language and pathologizing behavior that was utilized against those women and people assigned female at birth, was utilized against me in the 2010s. "Hysterical", "dramatic," "complains of pain when nothing is wrong"- this language and the structure where it originates was used against me in healthcare settings the same way it had been used against other women and people assigned female at birth for hundreds of years. In that healthcare setting, that language is used in tandem with neglectful or dismissive medical care that has severe consequences for patients. "Back in 1965, British psychiatrist Eliot Slater warned that too often a label of hysteria allowed doctors to believe they'd solved the mystery when, in fact, usually they hadn't. After following up with 85 patients who'd been diagnosed with 'hysteria' at the National Hospital in London throughout the 1950s – including by Slater himself – he discovered that, nine years later, more than 60% had been found to have an organic neurological disease, including brain tumours and epilepsy. A dozen of them had died" (Dusenbery, Slater). While 'hysteria' is no longer an official diagnosis with its removal from the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1980, that did not remove the disparities in care. Similarly

stigmatized conditions like mental illnesses and female reproductive system disorders simply absorbed the ‘symptom’. In a 1986 study, researchers examined a group of patients with serious organic neurological disorders who had initially been diagnosed with hysteria. Two of the characteristics that the researchers identified that made a patient vulnerable to such a misdiagnosis was a prior diagnosis of a psychiatric disorder or just being a woman (Miller, et al). Psychiatric diagnoses still hold a significant amount of social stigma in Western countries, but they also carry this particular stigma within healthcare as well. Modern psychiatric diagnoses are documented with the same phenomenon of becoming the ‘easy answer’ to the patient’s symptoms that “hysteria” used to have. A comprehensive Eurordis study on 12,000 rare disease patients found that while being misdiagnosed with the wrong physical disease doubled the time it took to get to the right diagnosis, getting a psychological misdiagnosis extended it even more – by 2.5 up to 14 times, depending on the disease (Dusenbery, Eurordis).

This particular study also demonstrated the Western healthcare system’s mishandling of complex chronic illness patients who are women or assigned female at birth. They found that for men and people assigned male at birth with Crohn’s disease, they were diagnosed in an average of 12 months, while it took 20 months for women and people assigned female at birth to be diagnosed. Men and people assigned male at birth with Ehlers-Danlos syndrome (EDS), a connective tissue disorder, were diagnosed in an average of four years. Women and people assigned female at birth with EDS were diagnosed in an average of 16 years. This makes delays in accurate diagnosis and effective treatment not only common, but a hallmark of the Western healthcare

experience for women and people assigned female at birth.

For chronically ill and disabled women and people assigned female at birth, these delays and barriers to care have much more severe consequences than the average person seeking acute care. I will use myself as an example, with my working diagnosis of seronegative rheumatoid arthritis or overlap syndrome. It is a known fact that patients with seronegative rheumatoid arthritis experience delays in diagnosis and treatment (Coffey). These patients are also less likely to achieve disease remission than seropositive patients; remission is possible with enough early intervention and preventative measures. Those delays in medical care cost the patient a chance at a higher quality of life. I am lucky- at 24, I have minimal visible damage to my spinal vertebrae, not any of my joints yet. However, once that damage occurs, it is irreversible. Whether I have seronegative rheumatoid arthritis or overlap syndrome- as far as the consequences of medical neglect, this is still one of the best-case scenarios. It depends on the chronic illness or disability, but that delay in care in an urgent scenario could (and has) cost someone their life.

Whenever a woman or person assigned female at birth attempts to interact with this system to receive health care today, they are likely to face misogynistic bias, whether implicit or explicit. However, the overall system is built off of centuries of misogynist practice and ideas (not limited to the ones I have discussed) which in turn has harmful effects on the way quality and effective healthcare can be provided. Unfortunately, misogyny is not the only form of bigotry that is built into this Western institution. Women and people assigned female at birth who are marginalized on the basis of race or ethnicity face at least two fronts of discrimination in Western healthcare settings.

Unfortunately, this lowers their overall chance at receiving effective healthcare and positive health outcomes. Additionally, living in societies that are systemically racist is a documented cause of chronic stress, which contributes to conditions like heart disease, type 2 diabetes, and even cancer (Salleh). “Structural violence operates in such a way that it renders the marginalized voiceless. Structural violence has the effect of enforcing division as to entitlement to health care but also who is entitled to dignity through patterns embedded in everyday practices of society, including health care” (Farmer).

In Western countries, these are just some of the various disparities that have been documented within research studies that compare racial groups and ethnic groups. In the United States, “racial and ethnic minority groups experience higher rates of illness and death across a wide range of health conditions, including diabetes, hypertension, obesity, asthma, and heart disease, when compared to their White counterparts. Additionally, the life expectancy of non-Hispanic/Black Americans is four years lower than that of White Americans” (CDC). A 2015 study even found that white children with appendicitis were almost three times as likely as Black children to receive opioids in the emergency room (Hoffman, et al), likely due to false beliefs that Black people do not feel as much pain or are more likely to abuse prescription painkillers.

A 2015 study in the UK revealed a longer lag time from the onset of symptoms to diagnosis in female patients in six out of 11 types of cancer compared to male patients (Din, et al). This also was measured without factoring in how long it took for patients to first visit their general practitioner. This reflects a lack of urgency within the healthcare system for the systems of a woman or person assigned female at birth with the same

symptoms as a man or person assigned male at birth.

In Canada, the rate of diabetes among Black women is double that of white women. Additionally in Canada, “Indigenous peoples experience lower health outcomes than non-Indigenous peoples, which is exacerbated by the lack of access to quality health care and lower socio-economic situation” (Gunn). In New Zealand and Australia there are similar reports for Indigenous peoples. “For example, Indigenous peoples are unlikely to get timely access to coronary angiography or revascularization following acute myocardial infarction in spite of high rates of cardiovascular disease. Māori patients reported health care issues similar to those of Indigenous people in Canada, including gaps in understanding of the patient experience and beliefs that the patients are responsible for their own poor health status” (Boyer). Indigenous women and people assigned female at birth in many Western countries faced coercion to undergo sterilization or had it performed on them without their consent (Stote). Not only does this constitute a human rights violation, but it is also an act of genocide.

“Existing evidence shows that factors such as social and economic standing, ethnicity, age, sex, disability and migration status impacts on an individual’s level of health and ability to access healthcare” within the European Union (FRA). “Implicit racial bias in patient-provider interactions is pervasive, thus exacerbating health disparities in minorities” (Lim, et al). All of these statistics simply demonstrate the effects of sex, race or ethnicity, and disability within Western healthcare. The consequences of this lapse in care creates more serious problems for chronically ill and disabled women and people assigned female at birth who are marginalized based on race

or ethnicity.

Of course, not every individual healthcare provider is being purposefully discriminatory towards their patients. While there may be individual good or bad actors, the institution itself was only built to serve a certain demographic. Ever since then, we have been attempting to mold it to serve everyone instead. There is demonstrable evidence that as diversity has increased in healthcare, the quality of patient care has gone up. According to the Canadian Medical Association, women physicians usually spend about 10% longer with patients and communicate more effectively, resulting in 6% fewer visits per patient. “Women also tend to emphasize preventive medicine more than their male colleagues, allowing for earlier detection and intervention” (CMA). This was reflected in my own experience. Misogyny can certainly still be perpetuated by doctors who are women or people assigned female at birth, but the likelihood decreases. “It is important to have a healthcare workforce which represents the tapestry of our communities as it relates to race/ethnicity, gender, sexual orientation, immigration status, physical disability status, and socioeconomic level to render the best possible care to our diverse patient populations” (Stanford). While this will not solve misogyny in healthcare, it is an essential component of the solution. One thing I subconsciously learned in my experience as a chronic illness patient was that I was likely to get better care if I had a doctor that was a woman or person assigned female at birth. The psychiatrist who tried over a dozen medications until we found the one that stabilized my mental health was a woman. The cardiologist who diagnosed me with postural orthostatic tachycardia syndrome (POTS), the gynecologist who treated my ovarian cysts, and Dr. Lomibao were

all women and part of groups marginalized based on race or ethnicity. While it is still anecdotal evidence, it is my experience that doctors who were similar to me and therefore had similar experiences, were able to understand and treat me more effectively as a patient. For instance, Dr. Lomibao took the time to ask about my personal plans for the future regarding childbearing, if I was dating or married, and more. Many medications for rheumatic disease can affect fertility or cause birth defects and miscarriage. When she learned I was already voluntarily sterilized, not only was she able to approve stronger medical treatments for me, but she was also able to *save* time in the appointment overall. She essentially could skip ahead. Taking that brief moment to learn about her patient personally made her a *more* efficient provider, not less.

## **Conclusion**

At the height of the Covid-19 pandemic from 2020-2022, I leaned on the pandemic as an excuse not to return to the doctor unless I needed a prescription refill. I was done with the shrugs and the suggestions of ‘mindfulness’ or yoga. If my health was not going to improve, then I was done spending time, energy and money to go see more doctors to see if there was something someone could do. Some research circles refer to this as a ‘disengaged patient’. I focused on maintaining my current prescriptions and trying to mitigate symptoms on my own. Sometimes I was tempted to skip taking medications because I was tired. What was the point of making such effort to keep up with taking care of myself, if it never seemed to make any difference? This, in its own way, is contributing to sex-based health disparities for chronically ill and disabled people. Amongst disabled friends and the community, we joke that the pain levels we live with

every day could send a 'normal person' to urgent care, and how it is difficult to discern what is a 'normal' concern for our bodies versus something truly emergent. All of us would wait until we were on death's doorstep to go to urgent care. The likelihood that an emergency room would even have a provider who knows of my illnesses and how to treat them is low in and of itself. The likelihood that I will be treated like a liar, faker, or drug-seeker feels higher than the likelihood of receiving any relief. Therefore, if something truly emergent happened to me, doctors may miss crucial opportunities to help me because I chose to decline interacting with the system until I absolutely had to. Additionally, in the United States, emergency care is so expensive that it is sometimes necessary to forgo or to self-mitigate any health concerns on one's own. Considering the poorer health outcomes of the United States versus those of comparable nations, there may be many people doing the same thing for one of these reasons.

Education has to be at the forefront of the efforts to fix these disparities. "A 2016 study suggested that healthcare providers may underestimate black patients' pain in part due to a belief that they simply don't feel as much pain. When 200 white medical students and residents were quizzed on a series of claims about biological differences between the races, like "black peoples' skin is thicker than white peoples'," a full half thought one or more of the false statements were true. And, when they later read case studies of two patients reporting pain, those who had endorsed more false beliefs thought the black patient felt less pain, and undertreated them accordingly" (Dusenbery). This specific instance is a prime example of how bias in Western healthcare continues even in modern times. Incorrect knowledge, often stemming from biased beliefs of the past, make



direct impacts on the people being treated by the Western healthcare system here and now. Considering the centuries of history examined in this MRP, there is more than sufficient reason for women and people assigned female at birth to be wary of depending on the Western healthcare institution. The patient's wariness likely increases with the addition of any other marginalized identities to the equation. Diagnostic errors may account for 40,000 to 80,000 preventable deaths annually in U.S. hospitals. An estimated 12 million Americans are affected by diagnostic errors each year, and about one-third are harmed as a result. Something commonly missed is minor, early strokes- currently "missed 30 to 50 percent of the time, often when patients have common symptoms — dizziness, vertigo, headaches — that are diagnosed as a less serious problem" (Johns Hopkins). Investments into advancing diagnostic technology in the future could potentially mitigate part of this problem.

A large amount of Western healthcare is still based on clinical observations, opinion and perception. Opinion and perception can both be affected dramatically by the implicit biases of healthcare providers even unconsciously. Healthcare providers are not immune to their own implicit biases, which makes it even more necessary for education and inclusion in all areas of healthcare from top to bottom. It is the best we can do for the victims of the past to ensure that we create a better, more caring and inclusive health care system that serves everyone, not the privileged few.

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