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“Not a Reliable Witness to my Own Body”: Women, Trans and Non-Binary People with Ehlers-Danlos Syndromes and their Encounters with Power and Gender Bias in the Access of Medicine

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Declaration

I, Anja Stelzer, declare that this thesis is a result of my research investigations and findings. Sources of information other than my own have been acknowledged and a reference list has been appended. This work has not been previously submitted to any other university for award of any type of academic degree.

Signature.......... Date: March 15th, 2023

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Abstract

“Western” Medicine is not, as commonly assumed, impartial but has been embedded with prejudice about the female body. Simultaneously, it has reinforced these myths by establishing theories about female biological inferiority to justify women’s oppression in society. Western medicine conceived the male body as the human ‘norm’ and ‘othered’ the female body, which still causes tangible impacts. This thesis explores the lived experiences of women, trans, and non-binary people diagnosed with Ehlers-Danlos Syndromes (EDS) – a group of connective tissue disorders – to analyse how they encounter power, gender bias, and intersectionality when accessing care. The thematic analysis is based on eleven semi-structured interviews. Six themes were identified: (1) Disease Burden, (2) Power in Accessing Medicine, (3) Assigned Female ‘Hysteria’, (4) Impact of Experiencing Bias, (5) Intersecting Identities and (6) Significance of Access. Power was a dominant thread in the lived experiences of the interviewees, particularly through the power/knowledge nexus. Patients’ increased access to collective knowledge through the internet and online patient spaces have shifted power/knowledge between patient and provider. The interviewees experienced gender bias in their medical encounters, where the hysteria discourse was especially relevant to their experiences. Female pain was disbelieved, trivialized, normalized, or attributed to mental health. This has led to negative psychological fallout and the experience of institutional betrayal. Furthermore, it led to diagnostic delays which worsened physical health. Intersecting identities impacted the experiences of the interviewees. Relevant categories were gender, ethnicity, class, sexuality, mental health status, disability, neurodiversity, body size, age and education. The effects of various systems of power and oppression were interrelated. Intersectionality also influenced the interviewees’ access to health insurance, care and diagnosis. To improve female health in Western medicine, pervasive beliefs about ‘hysterical women’ whose sole purpose lies in bearing children must be deconstructed. Lastly, there needs to be a better understanding of the normalizing power that Western medicine has on our society.

Keywords: Feminism, Gender Bias, Western Medicine, Ehlers-Danlos Syndromes, Power/Knowledge, Patriarchy, Intersectionality

Abbreviations

Abbreviation	Definition
ADHD	Attention Deficit Hyperactivity Disorder
AFAB	Assigned female at birth
EDS	Ehlers-Danlos Syndrome(s)
ER	Emergency Room
GP	General Practitioner
hEDS	Hypermobile Ehlers-Danlos Syndrome
HRT	Hormone Replacement Therapy
IB	Institutional Betrayal
IR	International Relations
MCAS	Mast Cell Activation Syndrome
NSD	Norwegian Centre for Research Data
POTS	Postural Orthostatic Tachycardia Syndrome
PTSD	Post-Traumatic Stress Disorder
UK	United Kingdom
US	United States of America
WHO	World Health Organization

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1. Introduction

Modern “Western” medicine has undeniably come a long way in recent history. Achievements that were made especially in the last 50 years are broadly acknowledged (Schattner, 2022). Advances and medical breakthroughs have enabled medications and treatments that were thought impossible beforehand. In the fast-paced environment of modern medicine change occurs continuously. Nonetheless, while the medical field is charging ahead with revolutionary progress and technology – such as the use of artificial intelligence in medical diagnosis (Greenfield, 2019), 3D bioprinting (Sundaramurthi et al., 2016) or robotic surgery (Diana & Marescaux, 2015) –decades, even centuries, of gender bias in medicine and clinical research still need to be addressed (Cleghorn, 2021; Dusenbery, 2018).

While “Western” medicine¹ tends to be seen as impartial and evidence-based science, one should not disregard its social history and fabric (Cleghorn, 2021). Western medicine is an institution of the man-made world (Moss, 1996) – with its origins in Ancient Greece – that still “carries the burden of its own troubling history” with it (Cleghorn, 2021, p. 1). Though biomedicine is commonly positioned as “above ideology” (Krebs & Schoenbauer, 2020), superstitions about female bodies and prejudice ideology about women as the inferior gender have predisposed medical knowledge (Cleghorn, 2021; Dusenbery, 2018). Simultaneously, medicine not only integrated these myths but reinforced them by constituting medical theories about female biological inferiority presented as fact, which then were used to justify women’s oppression in society (Tuana, 1993). Hence, Western medicine impacted gender structures in society by reinforcing socially constructed gender divisions (Ellialtı-Köse, 2022). Although much of this past knowledge has been medically refuted, their shadow lingers. Contemporary medicine is still built on decades of biomedical knowledge produced by men, for men (Dusenbery, 2018), and based on the male body as the human ‘norm’. This led to systemic neglect of bodies that do not comply with the “misguided standard in medical research” (Turbes et al., 2002, p. 214).

According to contemporary studies (Chilet-Rosell, 2014; Daly et al., 2006; Green et al., 2007), gender bias is rampant within the medical institution. Such biases, be they implicit or explicit, lead to health inequities (Fowler et al., 2007; Hamberg et al., 2002; Liaudat et al.,

¹ Referring to the tradition as “Western” medicine is politically loaded, as there are key contributors to the medical tradition outside of the West (Wiseman, 2004), with continuous flows of ideas, practices, and people which shaped the tradition (Harrison, 2015). Nonetheless, medical traditions are normally labelled by their origin, making “Western” medicine a commonly used term in the world context (Wiseman, 2004).

2018), which are negatively affecting female health. Scholars have begun to examine Western medicine's role "in reflecting, reinforcing, and perpetuating deeply held gender stereotypes that systematically work to the disadvantage of women, particularly poor, racialized minorities" (Elliälti-Köse, 2022, p. 195).

To emphasize, women are not a monolithic category or 'sisters in struggle' (Mohanty, 1984). In an attempt to broaden the framework and consider gender through intersections of structural identities, such as race, class, or sexuality (Crenshaw, 1989), Western Feminist analysis of women as a singular group based on shared oppression (Mohanty, 1984) has been criticized. While this research aims to examine contemporary lived experiences of women and people assigned female at birth (AFAB) within the medical institution, I intend to look beyond gender to explore possible variances that come from inhabiting intersecting identities across systems of power.

1.1. Objectives & Research Questions

The research objective is to explore the lived experiences of women and people AFAB (who are or were read as women in medical settings) when seeking health care, to analyse how they encounter power, gender bias, and the role of their intersecting social categories. With the objective in mind, the thesis focuses on one condition, Ehlers-Danlos Syndromes (EDS), an "inherited heterogeneous group of connective tissue disorders" (Parapia & Jackson, 2008, p. 141). Interviewing patients diagnosed with the same disease – or with a disease in the same group, as EDS is an umbrella term for a cluster of disorders – allows controlling for the likelihood of patients experiencing comparable symptoms. This is important, as patients with the same disorder and similar symptoms may still have diverse experiences when seeking health care. Furthermore, patients diagnosed with EDS, which is incurable (EDS Society, s.a.), are expected to have more extensive experience with the health care institution and its providers compared to individuals that do not have a chronic disease. The research inquiry is as follows:

MRQ: How do women and people assigned female at birth (AFAB) diagnosed with Ehlers-Danlos Syndromes (EDS) experience seeking care within Western medicine?

RQ1: What significance does power have in accessing medicine in the experiences of women and people AFAB diagnosed with EDS when seeking medical care?

RQ2: What do women and people AFAB diagnosed with EDS report about experiences of gender bias in medicine when seeking medical care?

RQ3: What significance do intersecting identities have on the experiences of women and people AFAB diagnosed with EDS when seeking medical care?

1.2. A Note on Terminology & Inclusion

In this work, I examine how medical science was built on the bodies which fall into the category of ‘man’, and how it simultaneously excluded bodies which fall into the category of ‘woman’ (Bigg, 2023). Gender and sex are two distinct concepts, though in public and medical discourse are often conflated or used interchangeably (Johnson et al., 2009). Both concepts will be elaborated in the upcoming section.

In the Western world, gender has traditionally been considered as binary – women or men – and following directly from the biological sex of a person – female or male – which is referred to as gender/sex binary. Research over the last decades found neither gender nor sex is binary, and gender does not always follow sex (Morgenroth & Ryan, 2021). In reality, there is a lot more diversity in gender and sex than the two categories that are imposed on them (Dusenbery, 2018).

Western medicine, since its origins, embraced discriminatory, patriarchal myths of binary gender/sex differences into the formation of its knowledge and has insisted on pathologizing ‘femaleness’ (Cleghorn, 2021). This has adverse consequences for everyone that is by Western medicine’s standards considered to fall in the ‘woman’ category. It is evident Western medicine puts “comparatively less effort into understanding the bodies of one half of the population, and the ailments that happen to especially affect them” which has left gaps in scientific knowledge (Dusenbery, 2018, p. 12). Today, not only women are greatly affected by this historical mythologizing of their bodies, but everyone AFAB, regardless of gender identity. In effect, all bodies that did not fit the ‘human norm’ – which according to Western medicine has traditionally been a white, 180cm, 70kg male – were ‘othered’ in medicine (Bigg, 2023), which most impacted female bodies. Therefore, women, trans, and non-binary people were effectively marginalized genders within the Western medical framework.

The gender of a person is not defined by their biological sex, and the narrow gender/sex binary commonly followed in Western thought and medicine is incorrect (Morgenroth & Ryan, 2021). Hence, I am aware that not all people born into a female body are women, and I do not want to erase their experiences from my research. Throughout this research, I nonetheless use the category ‘woman’ when more correctly, it should be people AFAB. Partly this occurs when I refer to studies and other literature, as I use the terms the researchers themselves applied.

Also, my work focuses on prejudiced myths about binary gender differences embedded in Western medicine and how they are relevant and alive today, therefore at times I refer to ‘woman’. Ultimately, our current language is restrictive and does not reflect the realities in our society. Nonetheless, I aimed to use correct and inclusive terminology to reflect my research population, since the terminology we use in research is significant and constitutive of our reality and therefore matters.

1.2.1. (Biological) Sex, (Social) Gender & Gender/Sex

False assumptions about sex and gender are deeply embedded in Western society and the medical system, namely that they are binary, static and concordant (Albert & Delano, 2022). In medical research, there is a tendency to conflate both concepts or use them synonymously (Johnson et al., 2009). Sex commonly refers to biological characteristics (chromosomes, hormones, genitals) and is usually assigned at birth (Hamberg, 2008). Though often regarded as a binary (female vs male), research has demonstrated many variations of sex, which are categorized under the umbrella term intersex (Johnson et al., 2009).

Gender is a “constantly ongoing social construction of what is considered ‘feminine’ and ‘masculine’ and is based on power and sociocultural norms about women and men” (Hamberg, 2008, p. 237). Also long deemed as binary, gender does not consist of two categories of women and men, but there are non-binary, genderfluid, or trans people among others (Albert & Delano, 2022). According to Kirby (2019, p. 174) gender “has the force of a fact because we behave as if it is a fact”; hence gender includes behaviours and practices that convey and enforce social codes. West & Zimmerman (1987, p. 125) see gender “as routine accomplishment embedded in everyday interaction”, and as a “powerful ideological device” producing, reproducing, and legitimating choices and limits predicated on the sexes (West & Zimmerman, 1987, p. 125). Butler (1988) argues gender is not a stable identity, rather it is tenuously constituted in time. Gender is performative, meaning “it is real only to the extent that it is performed” (Butler, 1988, p. 527).

Gender can be regarded at the individual level through gender identity – how an individual sees themselves on the spectrum –, on the interpersonal level through gender relations – how individuals interact with another based on their ascribed gender –, and lastly at the macro level as institutional gender. “Institutionalized gender reflects the distribution of power between the genders” in political, educational, medical, and cultural institutions in society (Johnson et al., 2009, p. 4).

Shai and colleagues (2021) state recent scientific evidence has proven it is impossible to have a clear separation of sex and gender in health. While gender and sex are separate concepts, they are inextricably linked, and mutually reinforce each other (Johnson et al., 2009). There are complex associations between sex, gender and health and while both have to be considered in research, they cannot be regarded as separate (Shai et al., 2021). To illustrate this, I also apply the term gender/sex at times, to emphasize the usefulness of distinguishing between gender and sex and their ultimate interrelatedness (Morgenroth et al., 2021).

2. Background

2.1. Western Medicine & the Female Body

To address the MRQ assessing the experiences of women and individuals AFAB diagnosed with EDS in Western medicine, it is first necessary to understand the nature of Western medicine.

Modern Western medicine, also referred to as modern biomedicine, dominates health care around the globe. It is the medical tradition taught in modern medical education, and even though there are older medical traditions, it was often simply referred to as ‘*medicine*’. From the Latin term *medicina*, medicine “essentially means the art of healing” (Wiseman, 2004, p. 327). This medical tradition has achieved domination far beyond its Western origin, with Wiseman (2004, p. 327) describing Western medicine as “the arbiter of health matters for the government of virtually every nation of the world”. However, while it is still considered as ‘Western’ medicine today, it has major contributors outside the West (Wiseman, 2004), with “flows and counterflows of ideas, people and practices” since the 19th century, which shaped the tradition along the way (Harrison, 2015, p. 666).

Western medicine came to dominate the world due to several factors. European imperialism was a fundamentally disruptive force and the main driver for the expansion of Western medicine worldwide (Harrison, 2015). Global integration also shaped “the rise and expansion of Western medicine and concepts of health” (Harrison, 2015, p. 645), and while other medical traditions also benefitted from globalization, Western medicine is its leading beneficiary. Furthermore, Western medicine was different from other traditions because of its universal truth claims, and its close connection to ideas of progress and development, serving as a tool of modernization (Harrison, 2015). This dominance of Western biomedicine as the predominant form of medical intervention around the globe is also referred to as Western

“medical hegemony” (Weber, 2016), meaning Western medicine is a tool of Western dominance.

The consensus is that modern Western medicine emerged in Europe towards the end of the 18th century (Harrison, 2015), which is when it began to be defined by its scientific stringency (Wiseman, 2004), effectively moving from the classical period to modern scientific medicine (Rawlinson, 1987). Nonetheless, Western medicine’s roots reach as far back as antiquity (Harrison, 2015). These origins have strongly influenced modern scientific medicine that emerged in 18th-century Europe (Mercer, 2018) and substantially impacted how the female body and nature were perceived in medicine, and as an extension, in society.

2.1.1. Rooted in Ancient Greece

To further address the MRQ, how Western medicine has historically interacted with female bodies and people it categorizes as women also needs to be examined.

Mercer (2018) argues that the ideas of prominent ancient philosophers, such as Aristotle, and medical theorists like Hippocrates, about the male and female body played a significant role in Western thought, directly affecting medicine. The arguments justified the belief “that female bodies are imperfect or ‘mutilated’ compared to male bodies from which it is supposed to follow that women are morally inferior to men” (Mercer, 2018, p. 183). These theories left men superior to women and substantiated “the need for women to subjugate themselves to their procreative powers and to the wisdom of their superiors” (Mercer, 2018, p. 183). Residues of these ancient ideas are still embraced today. Male dominance and consequently the superiority of the male over the female body, “was cemented into medicine’s very foundations, laid down in ancient Greece” (Cleghorn, 2021, p. 1). The *Hippocratic Corpus* – a collection of medical texts written during the fifth and fourth century BCE – is written by multiple authors and attributed to the teachings of Hippocrates. One-quarter of the writings are concerned with women’s health and diseases (King, 1998; Mercer, 2018). These medical writings contained “the first clear differentiation of female and male bodies and were foundational in the western medical tradition” (Mercer, 2018, p. 188). Written in the context of the patriarchal social order of Ancient Greece, where women were the property of their fathers and husbands, they were viewed as weaker and smaller versions of men, defective and deficient (Cleghorn, 2021). All disorders befalling women – whose sole purpose was to bear children – were related to their most valuable yet mysterious organ, their uterus (Cleghorn, 2021; King, 1998). The idea of a wandering womb evolved, caused by menstrual suppression, sexual

abstinence, or lightness of the womb (King, 1993), wreaking havoc along the way in search of male ‘seed’ (Cleghorn, 2021). This condition could be cured, like other diseases befalling women at that time, through marriage, regular sex with one’s husband and pregnancies to weigh the womb down, cures which Cleghorn (2021) identifies as being just as social as medical. These writings are conflated by later interpretations and used as groundwork for a ‘disorder’ that would play a significant historical role for women: ‘Hysteria’.

Such myths from Ancient Greece around female biology, specifically that “woman was her biology; that she was ruled by it, governed by it, at the mercy of it” (Cleghorn, 2021, p. 2) later influenced modern scientific medicine and its subsequent knowledge creation about the female sex (King, 1998). Aristotle’s biological and medical-related writings directly influenced medicine and biology (Modell, 2010). He referred to a female as a “mutilated male”, a definition later transferred into biological and obstetrical areas of medicine (Horowitz, 1976, p. 184). Aristotle’s theories of the female body offered substance to “standard Western arguments for the inferiority of womankind and for the political subordination of women to men in home and in society” (Horowitz, 1976, p. 183).

Though over 2.000 years passed between the Ancient Greeks and the advent of modern Western medicine, Victorian doctors reinterpreted and constructed Hippocratic medical teachings to support their theories and provide authority to them (King, 1998). This is especially pronounced in the speciality of gynaecology, which is characterized by a particularly strong inequality in the patient-provider relationship until the present day (King, 1993). In the Western biomedical tradition, gynaecology has until well into the 20th century oriented itself on the Hippocratic Corpus (King, 1998). Ultimately, residues of these ancient myths were long embraced and incorporated into medical practice (Cleghorn, 2021).

2.1.2. An Instrument of Social Control: Enforcing Gender Roles & Divisions

RQ1 is concerned with the significance of power in women’s experiences when accessing medicine. This section gives background on Western medicine as an institution of social control and how the medical community routinely asserts power over female bodies, women’s ‘place’ in society, and gender roles.

Western medicine absorbed and enforced socially constructed gender divisions over its history (Cleghorn, 2021). Furthermore, medicine is criticized as an institution of social control (Moss, 1996) which exercises a deeper level of control over women’s lives, bodies and minds (Raymond, 1982). Historically, Western medicine used theories on sex differences to naturalize

the gender order – where men were advantaged and women disadvantaged – and patriarchal social structures (Connell & Pearse, 2015). The medical system is a “powerful instrument of social control, replacing organized religion as a prime source of sexist ideology and an enforcer of sex roles” (Ehrenreich & English, 2011, sec. Concluding Thoughts). Though Western medicine did not invent female social roles, it interpreted them as biological fact (Ehrenreich & English, 2011).

In the 19th-century women began demanding more education, political equality, and challenged stereotypes about a woman’s place. Medical practitioners, who were almost exclusively men, entered the struggle with arguments that even considering the context of the time, were value-laden and not based on scientific findings (Bullough & Voght, 1973). A popular belief facilitated through medical discourse was women’s bodies were too weak to withstand the strain of formal education, especially medical education, as they would lose their ability to menstruate and endanger their reproductive destinies (Cleghorn, 2021; Ehrenreich & English, 2011). Clarke (1873) argued rigorous studying would make women sick, masculine, sterile, could cause their uterus to atrophy, their ovaries to be undeveloped, and ultimately lead to death. Some theories were firmly based on the ancient Greeks, and menstruation was pathologized as ‘menstrual disability’ (Bullough & Voght, 1973).

Medical theories were used to rationalize barring women from voting, because they were seen as too ‘hysterical’ to be granted suffrage, enter politics and hold positions of power (Ehrenreich & English, 2011). They justified keeping women confined to the private sphere of their homes, rather than venturing into the public arena (Cleghorn, 2021). Ehrenreich and English (2011) emphasize medicine removed malice from sexual oppression, as it was framed that preventing women from undertaking stimulating activities was for their own good.

Bullough and Voght (1973) argue this was triggered by physicians' belief structures being threatened, even outside of the field of medicine, and thus they used medical expertise to justify their prejudices. As doctors are seen to speak with authority, their arguments have influence beyond those of ordinary people (Bullough & Voght, 1973). Hence, their claims had political power in the past, and arguably still have today.

Though over a century has passed since then, these myths are alive and well today in a society that still believes menstruation and menopause are adequate reasons why women should not have positions of political power (Cleghorn, 2021; Neville-Shepard & Nolan, 2019), as hormones lead them to become too irrational, emotional and ultimately dangerous (Frasca et al., 2022; Gannon, 1998; Grandey et al., 2020).

2.1.3. *Hysteria: A pervasive Entity across Time*

Providing further background to MRQ and RQ2 – which seeks to explore gender bias in the access to medicine – this section contextualizes a significant ‘disorder’ befalling women across time, laying the groundwork for an environment that tends to disqualify women’s narrations of their bodies in which gender bias can become rampant.

When discussing bias in the history of medicine and the female body, few examples are as instructive as “the history of hysteria” (Bueter, 2017, p. 522). Hysteria is derived from *hysteria*, which is the Greek word for uterus. According to Micale (2019), hysteria was first recorded on an Egyptian medical papyrus around 1900 BCE, describing the movement of the uterus and how it caused bizarre physical and mental symptoms. Ancient Egyptian, Greek and Roman sources became the historical origin of the medical concept of hysteria in Western civilization (Micale, 1994) which would become a significant entity for the centuries to come.

Eventually, the idea of a wandering uterus, and other gynaecological assumptions were replaced by demonological theories. During the middle ages, hysteria received supernatural formulations, and hysteria symptoms were seen as signs of possession by the devil (Micale, 2019) and witchery (Bueter, 2017) and accordingly persecuted (Micale, 2019).

In the 17th century, hysteria was deemed a neurological disease caused by sudden and violent emotions, like anger, fear or love, which almost exclusively afflicted women because of their “fragile nervous apparatus” (Micale, 2019, p. 22).

By the end of the 19th century, “hysteria came to mean the appearance of disease where no medical or physical pathology existed” (Jones, 2015, p. 1095). It developed into a ‘garbage can’ diagnosis used to pathologize nonstandard expressions of femininity. Hysteria pathologized “not only certain physical symptoms, but also social and cultural deviations from female gender norms” (Jones, 2015, p. 1084). A disease of the feminine condition, women were labelled as hysterics if they took feminine roles to the extreme or failed to abide by social expectations (Jones, 2015).

The last paradigm shift occurred at the beginning of the 20th century towards a psychological theory of hysteria, which Sigmund Freud, the father of psychoanalysis, furthered. Freud claimed hysteria was a psychological disease that had quasi-physical symptoms and was caused by repressed traumatic experiences, which could be cured if brought into the conscious mind of the patients (Micale, 2019).

During the 20th century, a dramatic decline in the incidence of hysteria occurred (Micale, 2019). It was deleted in 1980 from the Diagnostic and Statistical Manual of Mental

Disorders III (Tasca et al., 2012). Hysteria was broken down into constituent symptom logical parts to be distributed to other medical categories, such as epilepsy, syphilis, or Freud's anxiety neuroses (Micale, 1993)

Hysteria in Western medicine has a long history, moving through paradigms, from gynaecological, demonological, and neurological models to psychological theory. In over 4.000 years of history, cures and therapies were various, including marriage, sex or sexual abstinence, punishment and purification by fire (Tasca et al., 2012), clitoridectomies (Sheehan, 1981)², or psychoanalysis (Micale, 2019).

Medical discourse used the hysteria diagnosis to 'other' women's bodies based on their reproductive capabilities (Jones, 2015). The hysteria discourse and understanding of 'hysterics' today is centred around women's illnesses being merely a product of their psyche (Young et al., 2019). Ultimately, calling a female patient hysterical presently means 'it's all in your head' (Jones, 2015). Theories, symptoms, causes, and therapies changed over time (Micale, 2019), yet hysteria "survived the centuries as a concept of female suffering that was always interacting with cultural assumption about women and their inferiority" (Bueter, 2017, p. 322). To this day, women are portrayed as hysterical in much of medical literature (Hoffmann & Tarzian, 2001), and it was found physicians endorse the hysteria discourse around patients who are considered 'difficult women' (Young et al., 2019).

2.2. Female Health today: A Snapshot

This subchapter contextualizes gender bias in medicine to provide further background to RQ2. Gender bias in medicine is receiving growing interest in the academic sphere. Studies bear witness to the ways the medical institution and providers are biased towards women and the female body. "[T]he term bias means 'prejudice' or 'distortion' and is a threatening phenomenon in all kinds of research and human activity", hitherto, it is not exclusive to medicine (Hamberg, 2008, p. 237). According to Hamberg (2008) the central causes of gender bias in medicine are gender blindness, stereotyped preconceptions about women and men, or exaggerations of sex and gender difference. She also emphasizes that a patient's health issues can rarely be ascribed to only sex or gender.

Furthermore, a "great deal of contemporary knowledge about diseases is constructed without considering the relevance of either sex or gender", (Hamberg, 2008, p. 238). Verdonk

² The excision of the clitoris was performed as proposed cure to "all of the feminine weaknesses", such as hysteria (Sheehan, 1981).

and colleagues (2009, p. 135) further state that “the largest body of knowledge on health and illness is about men and their health”. It is difficult to quantify how much of the medical knowledge applied today was built on layers of partial, androcentric data that systemically excluded half of the world’s population.

2.2.1. The Male ‘Norm’ as the Human ‘Norm’

As recently as two decades ago, the medical community realized “women are not small men” (Roeters van Lennep, 2018, p. 3). Before that, differences between the sexes were mostly disregarded in medical bioscience, with the white 180cm tall and 70kg heavy male being deemed as the ‘standard human body in medicine. The only differences considered significant between the sexes were the reproductive organs (Roeters van Lennep, 2018). Until the late 20th century, males were studied as representatives of the species, and it was assumed sex differences outside of the reproductive functions were explained by body size, organ size, or body fat. (Marts & Keitt, 2004). Krieger and Fee (1994, p. 270) emphasize that “[o]utside the specialized realm of reproduction, all other health research concerned men’s bodies and men’s diseases” and that “[r]eproduction was so central to women’s biological existence that women’s nonreproductive health was rendered virtually invisible”. This practice has been called ‘bikini medicine’ (Gulati, 2017), reinforcing the patriarchal dogma that a woman’s sole purpose is reproduction (Cleghorn, 2021). With it, Western medicine effectively ‘othered’ the female body.

Until the mid-1990s in the United States (US) and other nations, new treatments and conditions were mostly, or exclusively, studied on men, and the results were extrapolated to women (Liu & Dipietro Mager, 2016). This custom was criticised for being unscientific and “producing biased knowledge” (Hamberg, 2008, p. 238). Female bodies were not always excluded from biomedical research, but the Thalidomide tragedy in the 1960s – when a medication given to women for morning sickness caused deformities in their babies – led to policy changes, such as the exclusion of “women of childbearing potential” from drug trials in the US (Marts & Keitt, 2004, p. vi). However well intended, these changes did more harm than good, with women being prescribed drugs not tested for either safety or efficacy (Marts & Keitt, 2004). Females and males metabolize drugs differently, and those sex-differences are not limited to body weight or size, but include, e.g. slower gastrointestinal transit times of females. While there were changes in the policies from the mid-1990s (Liu & Dipietro Mager, 2016), there is still no equal participation of women in clinical trials (Feldman et al., 2019; Whitelaw

et al., 2021; Yakerson, 2019). Even if females were included in medical trials, it did not mean sex-stratified analysis of the results was guaranteed (Hamberg, 2008; Mazure & Jones, 2015).

Chilet-Rosell (2014) identified that if separated by phase, only 30% of participants in 58 clinical trials were female and around 85% of studies did not stratify the results by sex. Other authors had similar results, indicating that while guidelines to improve female participation are in place, policies are not adequately implemented (Feldman et al., 2019; Whitelaw et al., 2021; Yakerson, 2019).

Arguments for excluding the female sex from clinical trials were e.g. risks to a potential foetus, the menstrual cycle, or complementary use of exogenous hormones (hormonal contraceptives like the pill) (Chilet-Rosell, 2014). Notwithstanding, these are some reasons why female participation in these trials is crucial. One primary argument for not analysing by sex is that conducting trials with enough statistical power to detect sex differences is more costly and takes longer. However, in the US market withdrawing a drug from the market is more expensive than sufficiently testing differences before the product is put on the market (Simon, 2005). Lastly, the argument loses its impact when some pharmaceutical companies spend more on marketing than on research and development (Chilet-Rosell, 2014). While progress was made in the past thirty years (Sosinsky et al., 2022) as the number of female trial participants rose, studies have shown those only go so far (Geller et al., 2011; Whitelaw et al., 2021).

There is a fear that if biomedical research will conduct more research on sex differences, findings could be misrepresented (Maney, 2016), to excuse the gender order in our society (Connell & Pearse, 2015). This concern is not irrational, as historically, sex differences in Western medicine were used to justify patriarchal social structures (Connell & Pearse, 2015). Maney (2016) found when sex differences are discovered, they are often distorted by news headlines or framed in fallacious ways. Hence, there has to be caution when reporting on sex differences.

2.2.2. Impact of Omitting half the World's Population from Research

There is a number of studies documenting the adverse effects of the above (2.2.1). Generally perceived as a men's disease (Mosca et al., 2011), Ischaemic heart disease is the leading cause of female deaths globally (WHO, 2019). However, most knowledge on heart diseases was learned by studying men. Doctors are trained to recognise signs of heart attacks in men, like the classic tell sign of chest pain. When women present with what is referred to as 'atypical'

symptoms, they are frequently misdiagnosed or sent home with anxiety (Jackson, 2019). A study found that females under 55 are 6.7 times more likely to be discharged while experiencing a heart attack than males (Pope et al., 2000).

The underrepresentation of women in separate trials of a heart failure therapy did not allow the results to be aggregated by sex. When later the trials were combined and analysed by sex, significant differences were discovered, showing female patients benefitted from a 75% reduction in heart failure and death if they met specific criteria. The problem though was that the criteria to receive the therapy was based on data which overrepresented males, not considering the sex differences. Therefore, females who strongly benefited from the treatment would not receive it under those guidelines (Zusterzeel et al., 2014). This is an example of how medical treatments that would work better on female bodies could fall through the cracks if data is not analysed by sex.

This is not to say the focus should exclusively be on sex differences, at the cost of neglecting gender aspects that matter in health outcomes. As previously illustrated, gender/sex are interrelated. This must be integrated into medical research, ensuring both are considered and linked. Studies have suggested that gender-related social factors can impact biological measures considered sex differences (Shai et al., 2021), such as testosterone levels. Testosterone levels are higher in men, which is attributed to innate sex differences. Van Anders and colleagues (2015) found that gender socialisation may have a role as the different socialising of girls and boys can affect testosterone levels, thus indicating that it is not purely a sex difference. This illustrates how gender/sex are intrinsically linked.

2.2.3. Under-researched & Underfunded

Diseases which occur exclusively or predominantly in females are not just under-researched but also underfunded. The US National Institute of Health (NIH) is the “largest public funder of biomedical research in the world” (NIH, n.d.). A recent study showed in $\frac{3}{4}$ of cases where a disease afflicts primarily one sex, the NIH funding patterns favour males. This occurs when diseases that affect more women are underfunded or diseases that affect more men are overfunded. Thus, the NIH disproportionately applies its resources to diseases primarily affecting men, at the expense of conditions primarily affecting women (Mirin, 2021). Another example is endometriosis³. It afflicts at least 11% of women and people AFAB worldwide, and

³ Endometriosis is an inflammatory chronic pain condition which is caused by tissue that should grow in the uterus to migrate and grow outside of the uterus (Ellis et al., 2022).

though it was identified around 160 years ago, significant knowledge gaps remain. Researchers compared funding for endometriosis (around 11% of US women) and diabetes, which around 12% of women in the US have. The funding for endometriosis came to 2\$ per patient per year, and the funding allocated to women with diabetes was 31.30\$ (1,500% more) - if endometriosis were funded at the same level, the yearly budget would increase almost 16 times (Ellis et al., 2022). Furthermore, the coronary artery disease budget from NIH in the US in 2019 equated \$4 per man, compared to 17 cent per woman (Baird et al., 2021). A substantial disparity in research funding can be detected, which shows that female bodies are discriminated against in health research.

2.2.4. Gendered Treatment in Clinical Medicine

Risberg, Johansson and Hamberg (2009, p. 1) state “[d]uring the last decades research has reported unmotivated differences in the treatment of women and men in various areas of clinical” medicine. Men receive more extensive treatment in various medical conditions than women, even if women experience the same conditions with equally severe symptoms (Hamberg, 2008). Some examples are coronary artery disease (Chang et al., 2007), tuberculosis (Yang et al., 2014) and Parkinson’s disease (Picillo et al., 2017). Broad gender health inequities were also identified in intensive care use, where women above 50 were less likely than men of the same age to be admitted into intensive care units after adjustment for diagnosis and comorbidities. They were less likely to receive life-saving interventions and thus more likely to die of critical conditions (Fowler et al., 2007).

Gender differences in the diagnosis and treatment have also been found in research where ‘paper-patients’ and ‘video-vignettes’ were used, thus controlling for the effects of behaviour (Arber et al., 2006; Hamberg et al., 2002), such as communication differences. These are often seen as ‘culprits’ for differences in medical treatment during patient-provider interactions. It is hard to explain these results in terms other than bias (Hamberg, 2008).

Studies found physicians tend to interpret men’s symptoms as ‘organic’ compared to women’s symptoms as ‘psychosocial’ (Bernstein & Kane, 1981; Samulowitz et al., 2018), showing physicians do not equally evaluate women’s and men’s complaints. Women’s reports of pain are more likely discounted as “emotional” or “psychogenic” and seen as ‘not real’ or not taken seriously compared to men (Hoffmann & Tarzian, 2001). The subject of pain

illustrates complexities of gender/sex differences and their relevance in medical care. There are sex differences between women and men regarding pain, which are influenced by hormones, menstrual cycle, or nervous system function. However, beyond the biological, social aspects of pain come into play. Through masculine gender norms, young boys are socialized to be tough and act impervious to pain, while through feminine gender norms, girls are raised to be more delicate and sensitive to pain (Samulowitz et al., 2018). Hence, when women report pain, they are not taken as seriously as men (Hoffmann & Tarzian, 2001).

Gender bias in health care does not exclusively apply to ‘othered’ bodies which are subordinate to the male standard, such as women, transgender, non-binary or intersex persons, but can also apply to men. Bias cuts both ways, and men also experience gender bias, for example with migraines. Generally seen as a ‘woman’s disease’ with about three-quarters of patients being female, male patients are overlooked and less often receive a correct diagnosis when they consult their doctor (Tepper et al., 2004). However, considering power dynamics of the patriarchal society, including its socially constructed gender divisions (Cleghorn, 2021), are reflected and reinforced through Western medicine, we can delineate women and other marginalized genders are more affected.

Women and people AFAB are ‘othered’ bodies in Western medicine and have not only experienced systemic omission and discrimination in the past, as shown in the previous subchapter, but still are in the present. This affects their access to medicine and quality of care.

2.3. Ehlers-Danlos Syndromes

As the research examines the lived experiences of individuals diagnosed with EDS and their access to medicine, this section explores the disease, how it manifests, its classification(s) and ultimately relevant gender/sex aspects of EDS. It thus informs all RQs, asking about experiences of patients with EDS when accessing medicine.

EDS are defined as “a clinically and genetically heterogenous group of heritable connective tissue disorders” (Malfait et al., 2017, p. 8). They are “characterized by abnormal collagen synthesis, affecting skin, ligaments, joints, blood vessels and other organs” (Parapia & Jackson, 2008, p. 141). The underlying concern of all EDS types is an abnormal structure or function of collagen (EDS Society, 2022). The manifestation of EDS varies between undiagnosed cases with mild symptoms, to cases with severe symptoms (Berglund et al., 2000). Physical symptoms differ, but most commonly they are hypermobile joints, skin hyperextensibility and tissue fragility (Malfait et al., 2017). Joint hypermobility occurs when

joints have an uncharacteristically large range of motion (NHS Inform, 2022). Skin hyperextensibility is evident if an individual's skin can be stretched further than normal (EDS Society, 2022). Tissue fragility is characterized by thin, fragile skin prone to bruising, abnormal scarring, and poor wound healing (De Paepe & Malfait, 2012). Further common symptoms are joint instability – partial separation of the joint surfaces – or joint dislocations, whereby a full separation of the surfaces of a joint occurs (EDS Society, 2022). Pain is common and considered severe in EDS patients, contributing to functional impairment and affecting people's quality of life (Voermans et al., 2010a). Voermans and colleagues (2010b), showed 77% of EDS patients suffer from severe fatigue, which leads to stronger impairment and higher levels of psychological distress. Considering collagen is deemed “the most abundant protein in the human body”, being “essential for the structure and function of tissues and organs, including the joints, skin and heart” (Gensemer, 2022) it is not surprising a disorder in which collagen is affected would lead to an array of diverse symptoms that can strongly affect quality of life. There is no cure for EDS (Malfait et al., 2017).

While Ehlers-Danlos syndrome (singular) is the formal eponym, patient organizations and public bodies began using the plural form of Ehlers-Danlos Syndromes to emphasize the heterogeneity and diversity of the subtypes (EDS Society, 2022; Ghali et al., 2019; NHS, 2022), thus I apply the plural form.

2.3.1. EDS Classification(s)

EDS's clinical and genetic heterogeneity has long been recognized (Barabas, 1967; Malfait et al., 2017). There have been two previous classifications, namely the ‘Berlin Nosology’ in 1988, recognizing 11 subtypes and the ‘Villefranche Nosology’ in 1998, classifying six types (Beighton et al., 1998). After improved genetic testing and critique of confusing diagnostic criteria, the need for new guidelines for symptom management of the subtypes became clear, and an International Consortium was formed. As clinical symptoms of EDS extend beyond realms of skin and joints (cardiovascular, gastrointestinal, orthopaedic, psychological aspects etc.) specialists from all areas of medicine were represented (Malfait et al., 2017).

The international classification was published in 2017 and recognized thirteen subtypes (Malfait et al., 2017)⁴. There are clinical overlaps between the different types and thus, a definitive diagnosis needs molecular confirmation with genetic testing, to inform treatment.

⁴⁴ A comprehensive overview of the different types, criteria, genetic basis and management paths of the subtypes can be found in Malfait et al. (2017).

All subtypes, except hypermobile EDS (hEDS), include a genetic classification and major and minor clinical criteria. Reports about the estimated prevalence of EDS overall are cited at 1 in 5000 births (Ghali et al., 2019). Steinmann and colleagues (2002, p. 445) argue EDS is probably highly underdiagnosed. There are various possible causes for this, such as vague symptoms that are not easily connected or understood holistically. Another reason medical diagnosis is difficult to establish is that it is largely externally invisible, contributing to limited knowledge among health care providers (Berglund et al., 2010). Hypermobile EDS is the most common form of EDS, with an estimated 80-90% of EDS cases falling under hEDS (Tinkle et al., 2017). This is especially problematic since hEDS is the only type with no genetic testing available that will lead to a definite diagnosis (Malfait et al., 2017).

2.3.2. Gender/Sex Aspects of EDS

In most literature, EDS patients and study participants are predominantly female, ranging from 80-90% (Kole & Faurisson, 2009; Voermans et al., 2010a; Schubart et al., 2019; Song et al., 2021). As the hypermobile subtype is by far the most common form of EDS, much of the research is focused on studying hEDS specifically, like a recent study in Wales, United Kingdom (UK), which found that out of 957 individuals that were diagnosed with hEDS⁵, 73% were female (Demmler et al., 2019). While the prevalence of EDS in the female sex is frequently alluded to in research and is known in clinical practice, literature is not conclusive as to why so many people diagnosed with EDS are female. Some state there should be no sex predisposition as it should affect males and females equally (Schwartz & Ceccolini, 2021), also argued specifically in hEDS (Castori et al., 2010). One hypothesis is that women suffer from more severe manifestations and symptoms, therefore, they are more often diagnosed than men. Reasons for this are currently believed to be connected to sex hormones. Hugon-Rodin and colleagues (2016) believe sex hormones and reproductive life play a role. A subset of women with hEDS reported to be sensitive to hormonal fluctuations during puberty, before menstruation, postpartum and when using oral contraception. Half of the participants say puberty had a deleterious influence, either worsening symptoms or leading to onset of symptoms. Whether this is related to an increase in estrogen or rapid growth during puberty is unclear (Hugon-Rodin et al., 2016). Castori et al. (2010) suggest that differences in muscle pain perception, which are also related to the effects of sex hormones, could be relevant.

⁵ As a reminder, 80-90% of EDS patients are diagnosed with hEDS (Tinkle et al., 2017).

Other relevant aspects of EDS regarding sex/gender are found surrounding diagnosis. A recent study identified a significant difference of 9.6 years in the mean age of diagnosis between women and men. As early diagnosis is crucial to patients for preventative therapies and management of the disorder (Demmler et al., 2019), such a pronounced difference is significant. A further study has found considerable diagnostic delays in EDS diagnosis. While the delay for males is, on average, four years from the onset of the first clinical manifestations, the diagnostic delay for females is, on average, 16 years. The report explains women experience diagnostic delays that are four times longer than men because their pain is “not considered a physical symptom but rather as psychological symptoms or common complaints” (Kole & Faurisson, 2009, p. 138). Physicians more often interpret women’s descriptions of symptoms as psychosocial problems, which means they assign psychological explanations to the symptoms rather than physiological ones (Werner & Malterud, 2003). When women report pain, the reports are more likely discounted as either psychogenic’ or ‘emotional’, and thus seen as ‘not real’ (Hoffmann & Tarzian, 2001). These are potential explanations for the significant diagnostic delays reported. So, while the road to an EDS diagnosis is long for most individuals, it is especially protracted for women and people AFAB.

3. Theoretical Framework

3.1. Power, Power/Knowledge & Governmentality

Power has a wide variety of definitions, this is not different in the discipline of International Relations (IR) for which the study of power is central (Owens et al., 2019). One conceptualisation of power used in parts of IR (Dillon & Reid, 2001; Hutchings, 1997; Neal, 2004; Pasha, 2010) was developed by 20th-century French philosopher Michel Foucault. Foucault’s work is particularly useful for this project, as health and medicine were significant themes in Foucault’s work. He used them to demonstrate his broader theory, especially the relationship between power and knowledge (Petersen & Bunton, 2002). Foucault analysed the role the institution of medicine plays in governing individuals by regulating their bodies (Turner, 2002, p. xvi). While Foucault is critiqued for “his inattention to gender in his own analyses”, his concepts have nonetheless been influential in feminism, as his inquiries offer a refined perspective on power relations of medicine (Petersen & Bunton, 2002, p. 6). Thus, his conceptualisation of power is especially useful in examining the medical profession in Western society through the experiences of women and people AFAB.

Instead of focusing, as it is common in theories of power, on the power of the state or sovereign, Foucault (1980) opens the field of inquiry to extend to other forms of power beyond the limits of the state. He considers power as omnipresent, as “[p]ower is everywhere”, being “produced from one moment to the next, at every point, or rather in every relation from one point to another” (Foucault, 1976, sec. 93). Individuals are continually in the position to concurrently undergo power and exercise it (Foucault, 1980). It is evident Foucault does not apply a narrow definition of power but regards “power as a relationship which was localised, dispersed, diffused and typically disguised through the social system” (Turner, 2002, pp. xi–xii). Furthermore, power relations are unstable, as power circulates and “is never localised here or there, never in anybody’s hands” (Foucault, 1980, p. 98). Power is not limited to a specific arena but scattered throughout our society (Sharma, 2018). Instead of considering power in old, monarchical forms – as something an individual possesses, being wielded over others – Foucault contemplates how power operates through culture, customs, norms and institutions (Feder, 2011). Then again, power is not merely negative, coercive and repressive but also productive, *inter alia*, by forming knowledge and producing discourse. Lastly, Foucault (1976) emphasizes that where there is power, there is always resistance.

Foucault (1980, p. 96) proposes that in all societies, various power relations affect the social body and that power relations could not be established or employed without discourse, as power cannot be exercised without “discourses of truth”. Discourse produces and reinforces power, but it can also undermine power, expose it and make it fragile (Foucault, 1976). Discourse, in Foucault’s work, constructs a topic, it defines and produces knowledge and its objects. Discourse governs how an issue can be discussed and reasoned about, it influences ideas and regulates conduct. It both ‘rules in’ – how to discuss an issue – and ‘rules out’, limiting and restricting the way an issue is discussed (Hall, 2005). These discursive procedures determine what is possible to say about something, who is authorized to speak, what is becoming an object of scientific inquiry, how knowledge is tested, accumulated and dispersed (Rawlinson, 1987).

Foucault firmly places power in relation to knowledge and vice versa through the concept of power/knowledge. He argues power produces knowledge and both are mutually dependent, supportive and implying one another (Foucault, 1975). Power cannot be exercised without knowledge, and it is impossible for knowledge not to generate power (Foucault, 1980). Hence, power and knowledge are inevitably interconnected and cannot be fully separated since one cannot exist without the other. They are mutually dependent and reinforce one another.

An example of the workings of power/knowledge through discourse is the case of homosexuality, which demonstrates how medical discourses had a ‘normalizing power’ on sexuality in the 19th century, categorizing homosexuality as an abnormality. Foucault demonstrated how these same mechanisms allowed the formation of ‘reverse’ discourse later on, when homosexuality spoke up on its behalf and demanded its legitimacy to be acknowledged, at times with the same medical terminology used before (Foucault, 1976). Therefore, the normalizing power that made the ‘homosexual person’ an object of medical inquiry also produced the concept of ‘gay pride’, and the de-pathologizing of homosexuality in the US in the 20th century. In essence, Foucault proposes our conceptualization of what is ‘normal’ or ‘abnormal’ sexuality, our standards and norms of “health” and “madness” all result from complex operations of power/knowledge (Feder, 2011).

Medical discourses have played a significant role in understanding the human body and behaviour through constructing “the norm” (Feder, 2011). In the name of medicine, people were classified as mad, sick, sexually deviant, or criminal (Foucault, 1980). It might be assumed medicine always inhibited the role of shaping the norm, however, Foucault’s work suggests otherwise. In the classical period of medicine, there was a focus on the balanced functioning of the individual rather than a conception of health in terms of a singular standard that people should be measured against (Feder, 2011). Medicine provided “techniques for curing ills” (Foucault, 1973, p. 34), a focus which persisted into the 18th century. According to Foucault (1973, p. 34), at that time, medicine created a conceptualisation of “the *healthy man*, that is, a study of the *non-sick man*, and a definition of the *model man*”, assuming a normative posture that began dictating standards of relations of people and society. This change in Western medicine from a focus on health of the individual to normality, a standard imposed on people in society by the profession itself, and the public at large was significant (Feder, 2011). Such conceptualisations of normalcy and abnormality through procedures of normalisation divided and regulated populations (Rawlinson, 1987). The nature of these categories are not organic but were socially constructed through power/knowledge (Turner, 2002) which emerged out of scientific medical discourses that produced truth. Normalisation, which can be considered also as institutionalization of “the norm” (Feder, 2011), thus created and distinguished ‘normal’ from ‘abnormal’ behaviour, and ‘normal’ bodies from ‘abnormal’ ones.

Foucault’s concept of governmentality describes how modern bureaucratic states govern or control the body of its populace (Muller, 2011). Foucault (1980, p. 170) identifies the 18th century as a significant point where health and physical well-being of the ‘population’

became vital objectives of political power, intending to “raise the level of health of the social body as a whole”. Since then, health is a core function of the modern state. Foucault (1980, p. 171) connects this transformation broadly with “the preservation, upkeep and conservation of the ‘labour force’”. The state’s population became the “end of government”, both “subject of needs” but also “object in the hands of the government” (Foucault, 1991, p. 100). For Foucault, it makes more sense to identify people not as individual citizens (the liberal view), but as members of a population, considered in their forces and capacities, as resources to be fostered, used and optimized (Dean, 2010). Hence, governmentality aims to better the welfare of the population, improving its condition, increasing its wealth, longevity and health (Foucault, 1991). Governmentality cannot operate without the state; it is its main source and promoter of its techniques (Joseph, 2010). Through governmentality, states, and societies more broadly, produce subtle methods of power, exercised through institutions, practices, procedures, and techniques to regulate social conduct (Joseph, 2010). To extract, governmentality aims to govern aspects of human life of its population so that their bodies fit the needs of the modern capitalist state.

Western medicine plays a powerful role in modernity and is a central institution of governmentality (Tierney, 1998), especially through its power of normalization. Foucault (1996, p. 197) emphasizes “[m]edical power is at the heart of the society of normalization”, its effects being everywhere, in schools, law, sexuality, education, work and crime. Hence, medicine became an instrument of social control (Foucault, 1996). Both governmentality and medicine converged on this new understanding of population, expanding their presence throughout society (Tierney, 1998). Medicine is not separate of the state, regardless if it is ‘private’ or ‘socialised’ – public – medicine (Foucault, 1980). The modern state influences the medical profession in various ways, and with it influences its governmentality on the body populace. This occurs e.g. through policies, regulatory bodies dictating how the profession is regulated (Bhugra, 2014), or public funding decisions (Mirin, 2021).

3.2. Patriarchy

The concept of patriarchy developed within feminist theory is neither a single nor a simple concept, it rather has a variety of meanings. In the women’s movement, it is applied to analyse the principles underlie women’s oppression (Beechey, 1979). Theorizing patriarchy was the beginning of a reconceptualization of women’s subordination. Feminists argued social theory before the Second Wave was inadequate to explain the phenomenon, since they accredited the

domination of women to nature or social necessity, instead of structural processes or unequal power. These theories had also been developed by men from their perspectives (Acker, 1989). Patriarchy is also “associated with an ideology that explains and justifies male dominance and attributes it to inherent differences between men and women” (Mohan, 2022, p. 98). The concept of patriarchy acknowledged a political goal, specifically “the whole structure of male domination would have to be dismantled if women’s liberation were to be achieved” (Acker, 1989, p. 235). To assess, patriarchy is an essential instrument to analyse gender relations (Walby, 1989). Initially, the term patriarchy had a more restrictive use and referred to rule by fathers, meaning the power the male head of the household had within the family (Witz, 1992). Now, the concept is used more broadly by feminist scholars, referring to a “societal-wide system of gender relations of male dominance and female subordination”, (Witz, 1992, p. 10) going far beyond the family. Therefore, the concept expanded from focusing on men’s domination over women in the private sphere to broadening it to include their subordination in the public sphere.

Patriarchy is criticized as too static of an idea to sufficiently explore the diversity of gender relations (Kirby, 2019). It does not adequately deal with “historical and cross-cultural variations in gender inequality”, nor the differences between women, especially concerning race and class (Walby, 1989, p. 213). Patriarchy does not incorporate intersectionality (Kirby, 2019), a critique also directed towards Western Feminism overall. Nonetheless, as Witz (1992, p. 10) illustrated, “[t]o speak of the patriarchal structuring of gender relations is to describe the ways in which male power is institutionalised within different sites of social relations in society”. Considering patriarchy’s role in society, it is therefore appropriate to apply it to the institution of Western medicine. Medicine – with law, religion, and politics – is one of the “major social institutions of control” (Lorber & Farrell, 1991, p. 2)⁶. For this thesis, I apply the wider, gender-based concept of patriarchy, described as a social system of gendered “power relations between men and women, in which men are dominant and women are subordinate” (Witz, 1992, p. 12).

However, I want to expand this beyond its binary gender definition, to refer not only to women but also to people perceived as such by society, referring to individuals AFAB. People born in a female body perceived as such by others will feel the effects patriarchy has on women,

⁶ Gender is woven into the social order in vital ways, one of them being into the social institutions of control as referenced above, which treat women differently from men, commonly disempowering women. However, this also extends to men from disadvantaged ethnicities and from the working class (Lorber & Farrell, 1991). I expand this to include all people who do not identify as cisgender, meaning people whose gender identity does not neatly align with their assigned sex at birth.

even if they do not identify as such. By referencing the social system in the definition, it is distinctly implied that biological determinism is rejected as a cause for domination, and further that this does not mean that each man finds himself in a dominant position whereas each woman finds herself in a subordinate one (Walby, 1989). Patriarchal power structures were identified in various areas of the medical field not limited to gender bias and inequities in patient treatment. In medical institutions, gendered issues such as sexual harassment, bullying of female doctors, wage gaps, leadership inequities, and gender segregation into different specialities are some of the barriers women face to this day (Sharma, 2019).

3.3. Intersectionality

In 1989, Kimberlé Crenshaw coined intersectionality, and in the three decades since it has evolved to “the key analytic framework through which feminist scholars in various fields talk about the structural identities of race, class, gender and sexuality” (Cooper, 2015, p. 1). Western or mainstream feminists have long been criticized for universalism by putting the white, middle-class female experience at the centre of gender oppression in the patriarchal social order (Mohanty, 1984). Intersectionality illuminates the problematic consequences that follow when race and gender are treated as mutually exclusive categories of experience and analysis. Crenshaw (1989) put Black women at the centre of her analysis to show their multidimensional experiences. She argues “the intersectional experience is greater than the sum of racism and sexism” hence all analysis which does not take intersectionality into account is not able to adequately examine Black women’s experiences of subordination (1989, p. 140). Black feminists have a long history of “theorizing about interlocking systems of power and oppression” (Cooper, 2015, p. 1). Their “intersectional identity as both women *and* of color” in discourses is shaped to react to either one *or* the other, however, black women are marginalized in both identities (Crenshaw, 1991, p. 1244). Nonetheless, it is important to remember intersectionality is not an account of personal identity but about power (Cooper, 2015). The focus is to understand and subsequently respond to the consequences of converging systems of power. Thus, power and power relations are the focus of intersectionality, and it aims to promote equity and social justice (Shannon et al., 2022). Bowleg (2012, p. 1267) asserts social identities intersect at the micro level – in people's lived experiences – but “reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level”.

Initially, intersectionality was focused on racism, sexism and its intersection for Black women, however, since then the concept was extended and applied to the interconnectedness

of various systems of power. These include but are not limited to classism, ableism, ageism, heterosexism, cissexism, and colonialism (Totenhagen et al., 2019). These multiple axes of power are used to analyse the flow and interconnectedness of power within these systems, and how they shape oppression on the one, and privilege and systemic advantage on the other side (Shannon et al., 2022).

Recent research began to use intersectionality in health to analyse inequities among marginalized populations. Health inequities become more pronounced when women and people AFAB are on multiple axes of systems of power (Kelly-Browet al., 2022; Lopez & Gadsden, 2016). Structural racism, classism, ableism, heterosexism or nationality/citizenship are some systems that can intersect, enhance health inequities and worsen health outcomes (Lopez & Gadsden, 2016).

The concept of intersectionality has also been applied in Feminist IR (Kirby, 2019) to expand the gender analysis in IR beyond a singular axis of difference between women and men, and to open up to multiple axes of difference (Ackerly & True, 2010). For instance, Ackerly & True (2008) employed the concept to examine the intersection of gender, nation and discipline in IR.

3.4. Other Concepts of Interest

Androcentrism is the tendency of society to be centred around men, their needs, priorities and values, while women are consigned to the periphery (Bailey et al., 2019). Androcentrism is used across feminism in multiple fields, and has also been considered by IR feminists, particularly regarding androcentric biases in traditional knowledge creation (Tickner, 2005). The concept was first articulated by Gilman (1911, p. 27), when she described society as an “androcentric culture” in which “all human activities” is monopolized by men, while women are subordinate and only seen in relation to men. Bem (1993, p. 41) asserts “androcentrism is the privileging of male experience and the ‘otherizing’ of female experience”, meaning males are considered neutral for our culture and species, whereas females are seen as a sex-specific deviation. Thus, androcentrism sets men as gender-neutral and women as gender-specific (Bailey et al., 2019). The consequence is not simply “that man is treated as superior and women as inferior but that man is treated as human and woman as ‘other’” (Bem, 1993, p. 2). Through this positioning, androcentrism sustains and reinforces men’s greater power in society (Bem, 1993). With the ‘othering’ of women, “humanity is male and man defines woman not in herself but as relative to him; she is not regarded as an autonomous being” (De Beauvoir, 1949, p. 4).

The tendency to centre men and male experience does not stop at men's needs, priorities and thoughts, but also includes the centring of male bodies (Bem, 1993), which is especially visible in Western medicine. This can have serious consequences in medicine and beyond (Perez, 2019), however female health is often considered a prime example of the adverse effects of androcentrism (Bailey et al., 2019).

There is an increasing attention towards the role of trauma in IR and political discourse (Fierke, 2006), and thus trauma research has found its way into the discipline, through the consequences of traumatic events such as terrorist attacks on the political community (Hutchison, 2010). I explore trauma through institutional betrayal (IB), a novice concept developed within trauma research. Experiencing trauma can lead to both mental and physical health consequences, which can last long-term (Tamaian et al., 2017). When a person depends on an institution for their survival, and said institution violates this trust, it can exacerbate negative effects resulting from trauma (Freyd et al., 2008). This phenomenon, termed IB, occurs when an institution betrays its members' trust or, more specifically, fails to prevent or respond effectively to negative experiences (Smith & Freyd, 2013). IB was first researched within the context of sexual assault at universities. Examples of institutions that can cause IB are schools, the military (Smith & Freyd, 2013), religious organizations and the police (Smith & Freyd, 2014). The exacerbated effects of IB on the psychological well-being of people are consistent with betrayal trauma, such as higher rates of Post-Traumatic Stress Disorder (PTSD), dissociation, anxiety, and depression (Smith & Freyd, 2014).

Naturally, an institution people depend on for survival is the medical institution. Researchers have started to analyse IB within the medical context (Gómez, 2015; Tamaian et al., 2017; Tamaian & Klest, 2018). Individuals suffering from chronic health conditions rely more on the health care system and interact with providers more frequently. Thus, they may be more at risk of having their trust violated, leading to IB (Tamaian et al., 2017). Tamaian and colleagues' (2017) study has identified IB occurring on two levels, namely the doctor level (i.e. inadequate medical care, lack of psychological support) and the system level (i.e. medical culture, system barriers to care).

4. Methodology

4.1. Feminist Methodology & Perspectives

This study was guided by feminist methodological considerations discussed below. While there is diversity among feminist scholars regarding methodological preferences, one unique aspect of feminist research is its aims to challenge androcentric biases, that were often unseen, in the way knowledge has conventionally been constructed in the past across disciplines (Tickner, 2005). Within feminist research the objective is therefore to transform knowledge frameworks – created by studying men’s lives and extrapolating it as “universal” knowledge claims – by creating knowledge based on women and other disempowered people’s lives (Tickner, 2005, p. 4). To convey it more clearly, feminists aim to make the invisible visible through bringing the margin into the centre (Reinharz, 1992). Feminists have examined gender hierarchies, and hierarchies of power existing in varying degrees in all societies, and what effects these have on the subordination of women and other disempowered people (Tickner, 2005). My research design is informed by these feminist objectives, with my participants’ – women, trans, and non-binary people – lived experiences engaging with Western medicine, an institution of social control and power, in the centre.

In feminist research, reflexivity is a core part of inquiry. Research conducted by feminists should not be separated from the identities of the researcher (Tickner, 2005). As Harding (1987) asserts, acknowledging one own subjective element in social science research does not decrease but increases objectivity in research. This starkly contrasts conventional, androcentric social science methods which strongly value neutrality (Tickner, 2005) and do not examine the social scientists' beliefs (Harding, 1987). Within this tradition, I as the researcher strive to recognize my own beliefs and motivations to understand how they shape my interpretations. My understandings are directly connected to personal, cultural and historical experiences I made throughout my life (Creswell & Creswell, 2017). Awareness of my position in the research project also aims to correct what is referred to as “pseudo-objectivity”, since social research cannot be fully value-free and objective and studies thus benefits from the scholar situating themselves (Tickner, 2005).

I am a white cisgender woman from Europe, who has not needed to rely on the medical system beyond the needs of a young and healthy person. Nonetheless, while my experiences with medical encounters are limited to the occasional infection, cold, or preventive health checks, I did have negative experiences. There were occasions where I felt my concerns about my health status were not considered at face value, and doctors did not take me and my

experiences about my body seriously. Such dismissive encounters have occurred and were relevant to my inquiry. For most of my life, I have lived in a high-income country with a strong social healthcare system⁷ to which I had direct access. That I nevertheless had negative experiences only illustrates how relevant my research framework is. In line with feminist research, I see my personal experiences and motivation as an asset rather than a hindrance in the research process (Tickner, 2005), as long as I exercise reflexivity. Throughout the interviews and analysis, I am reminded that the interviewees experience issues regarding access to and affordability of health care services.

4.2. Ontology & Epistemology

My approach in this thesis is informed by a constructionist ontology “that asserts that social phenomena and their meanings are continually” created by social actors (Clark et al., 2021, Chapter 2). Not only does this mean social phenomena are produced through social interactions, but their meanings are constantly in a state of revision. Furthermore, I am incorporating the idea that my accounts as a researcher of the social world are also constructions, meaning I present a specific version of social reality since social knowledge is not fixed or definitive (Clark et al., 2021). This also aligns with the feminist research perspective I have discussed above. Additionally, I follow an interpretivist epistemological position, which recognizes people and institutions – the subjects of social sciences – and the objects of natural sciences are fundamentally different. Hence, to study the social world different research methods are needed, as the human world is distinctive from the natural world (Bryman, 2016; Clark et al., 2021).

4.3. Study Setting & Population

As one of the aims was to apply an intersectional feminist approach to my analysis, I decided not to restrict my sample pool to one specific country. I aimed at interviewing participants from various countries with other intersecting identities. My research focuses on how, historically, women, the female sex and body were conceived by Western medicine and how this legacy still affects lives today. As the phenomenon of gender bias is not limited to the experiences of ciswomen and is relevant to people AFAB who do not identify as women, such as nonbinary

⁷ A recent health system review from Austria, conducted by the World Health Organization (WHO), has shown that across the European Union, Austrian residents are reporting the lowest levels of unmet needs regarding medical care and that nearly the entire population is covered by social health insurance (Bachner et al., 2018).

people, and trans men. Their experiences are valid in my research inquiry. Overall, I was interested in the experiences of people who are or were perceived as women in medical settings by healthcare providers. In addition, this added another opportunity for me to apply an intersectional lens.

Because of the reported sex differences in EDS, I decided initially not to include trans women in my participant call. However, as I had discovered in various online spaces (Reddit, Facebook) within the EDS community, Hormone Replacement Therapy (HRT) in transgender people noticeably affects their EDS symptoms (r/ehlersdanlos, 2022), which I found noteworthy. Therefore, I extended the participation call to include trans women and their perspectives. However, from the around 50 respondents that reached out to me, none of them identified themselves as a trans woman. This could be a possible subject for further study.

My final sample of interview participants consisted of women and people AFAB, who identified as non-binary and/or trans but were at some point perceived as women in medical encounters. Another criterion for participation was an official EDS diagnosis, no matter which subtypes were diagnosed, or if the diagnosis was done clinically or genetically. Lastly, participants had to be at least 18 years old.

4.4. Research Methods

To explore the experiences of women and people AFAB diagnosed with EDS during their medical encounters I chose a mixed methods approach. Firstly, I sent out a short questionnaire in which I collected both quantitative and qualitative data. Secondly, I conducted qualitative research through semi-structured online interviews, which were the main source of my primary data. Qualitative research emphasizes words, instead of quantifying data through numbers (Bryman, 2016). The qualitative approach aims to understand the social world “through an examination of the interpretation of that world by its participants” (Bryman, 2016, p. 380), which is why I selected it for my main research strategy.

I chose semi-structured interviews to keep flexibility, compared to structured interviews which are more rigid. The questions in my interview guides were framed openly and allowed me to adapt or change their order, but also to include follow-up questions that emerged from the participants’ responses (Clark et al., 2021). I created two interview guides to avoid guiding participants in a pre-determined direction. While the introductory and demographical questions were identical in Guide A and B, the guides diverged on the questions specific to participants' experiences with medical providers. Guide A was for interviewees who

had experienced gender bias in their medical encounters, and Guide B for interviewees who did not experience bias because of their gender. The two guides offered a suitable case-by-case approach.

4.4.1. Sampling

The sample selection approach was purposive and conducted with the research questions in mind. Purposive sampling is a form of non-probability sampling, meaning I strategically did the sampling to ensure relevance to the research (Bryman, 2016). The online survey was predominantly used as a sampling tool to identify and recruit respondents with diverse identities (ethnicity, class, sexuality and so forth). In addition, snowball sampling was applied through one of my initial contacts in the EDS community.

4.4.2. Recruitment Challenges

Locating a sample when researching a rare disease comes with challenges, mainly because cases with the diagnosis are difficult to find and contact (Berglund et al., 2010), and because patient information is confidential and highly sensitive. As expected, I came across challenges in my recruitment process. My first strategy to find participants was to reach out via online health communities such as Inspire, RareConnect or Smart Patient which all have designated spaces for people with EDS. I read the communities' terms & conditions and contacted the admins of the online spaces, however posting a participation call was either prohibited, or my post was retroactively deleted. The website Inspire offers to partner up and, if approved, share one's participant request with the community, however, this was geared towards large public health initiatives and clinical trials. Ultimately, I could not use any of the above-listed websites for recruitment.

Next, I focused on interest groups and organizations that might be able to help me with my sampling. The Ehlers-Danlos Society is a non-profit organization dedicated to EDS research and education, is globally active, and is the largest interest group in EDS circles. When I contacted them about the submission of research for them to share, I did not receive any answer. The Ehlers-Danlos Support UK and other smaller organizations were only active in one country, and therefore I did not reach out.

As third approach I turned to Social Media platforms, joining private EDS groups on Facebook and subreddits on Reddit. I contacted the admins of these spaces but did not receive permission to share my research due to alleged users' protection and privacy concerns

I was informed by multiple Facebook groups –managed by what appeared to be private individuals – they would only share my research if I had prior approval from the Ehlers-Danlos Society. It appeared as if the organization, though not directly leading the groups on Facebook, acted as a gatekeeper on what research studies could be distributed. This was a noteworthy discovery, that the Ehlers-Danlos Society – as my research showed, the most influential EDS organization within the community – has this level of influence over online spaces. After various failed attempts I found one large, moderated, international Facebook group with around 36.000 members, where I could share my participation call. However, it received minimal traction.

Contacting health community forums, interest groups and social media spaces had not had the desired outcomes. In my last attempt, I reached out to my contact in the EDS community, someone established in the community, via Twitter. My contact kindly shared my participation call on their personal Twitter feed and reached out to some people personally. This was the breakthrough in my purposive sampling approach, and I received a total of 52 survey submissions, out of which 44 indicated their interest to participate further through an online interview. Two people also reached out to me directly via email. This sample pool allowed me to use the survey answers to identify participants on different identity intersections and recruit them.

4.4.3. Data Collection

The interviews were held online because I interviewed participants from different countries, and it was not feasible to conduct these as part of fieldwork because of financial and time constraints. In addition, the recent pandemic has forced people around the globe to conduct their work, or studies, online via services like Zoom. Thus, I felt confident potential interviewees would feel comfortable enough with this form of communication. Ultimately, I conducted a total of eleven online interviews with ten interviewees. During the process I used a research checklist, to remind me of all the vital aspects I wanted to communicate to the interviewees before and after the interview. The interviews were conducted and recorded via Zoom between October and December 2022.

4.5. Interview Participants

There were a total of ten participants interviewed and their ages ranged between 18 and 43 years. Six of the participants identified as women, two as non-binary, one as a non-binary trans

person and the last participant as a trans man. Most have an American nationality (7), and one person each is Australian, German, and Canadian. Seven interviewees were Caucasian/white, one was Middle Eastern, another one was African American/black, and the last interviewee was Caucasian/white and Native American. The majority of participants identified themselves as lower income (4), two as middle income, one person has indicated to be between upper-low to lower-middle income, one interviewee is upper-middle and lastly, one individual comes from a higher income background. Four individuals have completed high school, four have a Bachelor's degree, one person has completed primary school and one has a Master's degree. The diagnostic delay of the participants' EDS ranged from four to ten years, though I could not delineate a year estimate from four interviews.

4.6. Ethical Considerations

My aim was to honour the ethical principles in social research and I was familiar with all potential risks, including harming participants, a lack of informed consent, an invasion of their privacy or deception (Diener & Crandall 1978, as cited in Clark et al., 2021). I obtained ethical approval from the Norwegian Centre for Research Data (NSD) by submitting a form that detailed personal data content, processing, and security.

The data obtained from participants concerns their medical patient information, which is sensitive. Besides the health data, I also collected other sensitive personal data such as ethnic origin. In addition, according to the NSD, transgender people are considered as being part of vulnerable groups. This enhanced the level of precaution I had to take to avoid behaviour that could lead to further stigmatization (NESH, 2022).

Some of the topics discussed in the interviews could potentially trigger emotional distress in the interviewees, causing them harm. I created a document with free mental health resources before the interviews. Had an interview gone in a particularly sensitive direction, or had I felt talking about certain experiences might have triggered a trauma reaction in the participant, I inquired if I should forward the document to the interviewee. I felt it was a more cautious approach in asking, instead of sending it unexpectedly, as I did not want to create a situation where an interview partner felt I had interpreted their mental state as being in turmoil. Nevertheless, none of the interviewees felt they needed the resources I offered.

Preceding the interviews, I sent an invitation letter to the interviewees, notifying them about the study purpose, participant criteria, and the research process. In addition, they were informed about their rights, privacy, how their personal data will be handled and contacts to

relevant persons. Attached to the invitation letter was a consent form they had to sign and send me before the interview, as I needed their voluntary, informed and unambiguous consent (NESH, 2022). If the interviewee could not or forgot to send me the signed consent form back beforehand, I asked for consent verbally, which was recorded via Zoom. Nonetheless, before the start of the interview, I made sure to repeat the most important aspect, namely their consent. Lastly, before starting the interview, I asked them if they had any questions about their rights, consent, or the research project. In this way, I aimed to ensure their consent is informed.

The right to privacy and informed consent are closely linked, and with informed consent, the participant in a way surrenders this right for a restricted domain. Nonetheless, it does not revoke it completely (Bryman, 2016). I ensured participants were aware, through the invitation letter and the information I repeated to them verbally before the start of the interview, they had a right not to answer any question if they felt it was too private, or they were uncomfortable. In addition, privacy is connected to anonymity, which has to be respected (Bryman, 2016). After conducting the interviews, I anonymized the participants, which I initially did by providing them with numbers. I ensured their personal information was kept confidential and omitted personal identifiers from the thesis to the best of my ability.

However, I noticed during data analysis that using numbers for participants did not align with my feminist research perspectives, as it distances the research participants from me through further increasing power differentials between the researcher and research subjects (Tickner, 2005). Lastly, for me, it felt dehumanizing towards the interviewees. Therefore, I decided to use pseudonyms instead and contacted the participants to allow them to choose their pseudonyms. Recent research has shown that renaming has psychological meaning to the participants, making it important in the sociocultural world, but it is also meaningful as an act of research which is affected by matters of power and voice (Allen & Wiles, 2016)

The issue of deception in research is assumed to be widespread since researchers want to limit the participants' knowledge and understanding of the research, so they respond more naturally, especially in experimental research (Bryman, 2016). The invitation letter included the study purpose and a short description, informing potential participants of the research's focus and direction.

4.7. Analysis

For the analysis, I conducted a thematic analysis drawing on Braun & Clarke's (2006) framework. The researchers define thematic analysis as a method to identify, analyse and report

patterns (themes) within qualitative data (Braun & Clarke, 2006). It is important to emphasize, as with most other qualitative research methods, I as the researcher inhabit an active role in the process of analysis, since I searched the data set “to find repeated patterns of meaning (Braun & Clarke, 2006, p. 86). I followed the researchers' six phases of thematic analysis: (1) familiarizing yourself with your data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report (Braun & Clarke, 2006).

During the transcription process in phase 1, I applied a naturalized transcription style, where I conformed the spoken text to written discourse conventions (Bucholtz, 2000). Also referred to as ‘intelligent verbatim’ (McMullin, 2021), I chose this approach to make participants' quote's more readable by omitting excessive repetitions, verbal fillers such as ‘like’ or ‘um’ and correcting grammatical mistakes.

During the analysis, I used a combination of an inductive approach, where the codes and themes came from the data and a theoretical approach, where they were informed by my prior theoretical understanding (Ryan & Bernard, 2003). Initially, I found it challenging to understand what was considered a theme. However, how central a theme is, or what makes a theme a theme in the first place, is not dependent on quantifiable measures, like how often it is captured in the data, rather it needs to capture something significant in the data and/or about the research questions (Braun & Clarke, 2006). A theme: (1) is a category of interest, (2) relates to the research focus, (3) is built on codes, and (4) provides the basis for a theoretical understanding of the data (Clark et al., 2021, Chapter 23). I used these descriptions as a guide for actively searching the data set for themes and patterns of meaning.

4.8. Reflexivity

The term reflexivity refers to the act of reflecting on oneself and one's own experiences. In the context of research, this requires examining my own subjectivities, meaning I reflect on my values, biases, and decisions, while also considering the cultural, social and political context I am in, for the knowledge creation I conduct (Clark et al., 2021).

According to constructionism, social reality does not exist objectively and independently from the outside but is constructed and revised by social actors (Bryman, 2016). In addition, my “ability to understand, describe and interpret experiences and perceptions is key to uncovering meaning in particular circumstances and contexts” (Maguire & Delahunt, 2017, p. 3351). I have an active role each step of the way and have also situated myself within

the wider frame of the research in this methodology chapter. As previously described, I had experiences with the medical institution where I had felt dismissed and not taken seriously, which occurred as recently as the summer of 2022, when I had already started working on this project, and hence was more sensitive to the subject. Nevertheless, to ensure there would be no steering or influencing of participants or their interpretations in a predetermined direction on my end, I took several precautionary steps.

Firstly, I developed two different interview guides. One guide was for participants who had identified gender bias in their medical treatment, and the other was for participants who had not experienced it. I did not have the prior assumption that every female-born person with EDS has experienced gender bias and wanted to prepare for this with the two versions. Secondly, I invited women and persons AFAB that reported in the survey to have not experienced gender bias to an interview, to add their stories to the research. The vast majority had indicated (perceived) gender as a relevant factor. Only two respondents reported that no aspect of their identity had influenced their treatment, including gender. However, I did not receive an answer from them, hence the Interview Guide B (see appendix) was not used.

Next, I inquired about feedback from several peers regarding the interview guides, to ensure that the questions were not guiding participants in a certain direction. Initially, some of my questions were leading, included technical terms, or had two questions in one, which is not recommended (Clark et al., 2021). After several rounds of feedback from peers, I revised the questions to a point where I was satisfied. Lastly, I conducted a mock interview on which I received more feedback on the interview guide, how I asked them, react to prompts, and more generally, my interview style.

This was the first time I conducted qualitative interviews, and I was initially unsure how to react to sensitive and difficult topics relayed to me by the interviewees. My first reaction was not to show any emotion, however, when I engaged more with feminist literature which contrasts the “scientific ethic of detachment and role differentiation between researcher and subject” (Reinharz, 1992, p. 27), I decided to be emotionally engaged in these instances. Informed by “an ethic of care” (Blakely, 2007, p. 65), I tried to show how these stories affect me too, intending to make the interviewees feel safe and listened to, and decrease the power differentials between us.

This methodology chapter illustrated my understanding of the social world, biases about the research topic, beliefs, and research perspectives. Engaging with these aspects is considered by conventional social scientific methods and researcher as less scientific (Tickner,

2005), however from a feminist methodological point, it increases standards of objectivity.

4.9. Challenges & Limitations

Coming from International Relations, I was unfamiliar with working on projects in the medical field. A notable amount of the literature I read for this thesis is within the medical research field and thus use medical language and terminology. At times it was challenging to understand the results and conclusions drawn by the scholars, and I had to spend additional time to comprehend the content better. Furthermore, I also aimed on taking medical expressions and terms that were too complex to understand with little medical knowledge, and described them in more simple language, without losing the original content.

The target population in my study can be considered hard to reach. Locating a sample of people with EDS, a rare diagnosis, is challenging (Berglund et al., 2010) as my own experience confirmed. My intention to find interviewees from different countries further limited the number of organizations I could contact. The challenges of recruitment led to time delays in the research process.

This research aimed to find a diverse sample of interviewees who, for example, had different ethnical backgrounds, were from varied countries or had been treated under a different medical tradition than Western medicine. Nonetheless, I could not find that level of diversity among the survey respondents. I was not able to recruit participants who lived or were treated in non-Western countries. This likely is connected to my final recruitment strategy, in which an informant in the EDS community shared my participation call on Twitter. This strongly limits and skewed the individuals I could reach in the first place. Nonetheless, as this is a qualitative investigation, the results were not aimed to be generalizable to the whole population (Bryman, 2016).

The recruitment of participants on Social Media, especially through a private individual in the EDS community, has likely influenced participants' absence, or silence, outside the anglosphere. Those who speak English well, which is now not merely considered an international language anymore, but a global language (Nguyen, 2008), might have felt empowered to reach out. Especially if they were active in forums beforehand, which allowed them to speak out in the past, and partake in collective knowledge sharing, gaining confidence in using the power/knowledge nexus to express themselves.

Both language barriers and the power/knowledge nexus of who is empowered to speak could be relevant. Or it might be that my attempts to find participants did not reach beyond the

anglosphere in the first place. Either way, the result was that I encountered silences in my data, which restricted the extent to which I could apply an intersectional focus.

Another possible aspect to consider could be that the women and people AFAB that did reach out to me, might have done so specifically because they made negative experiences with their medical providers, or the medical institution at large, leaving them frustrated. Those who have instead made positive ones, might not feel as compelled to reach out in the first place to share their stories.

5. Findings & Analysis

First, I discuss the findings of the questionnaire, which was predominantly used as a tool for recruiting participants but offers important insights into the study population I was able to reach. After, I describe what themes I identified in the thematic analysis of the interviews: Disease Burden, Power in Accessing Medicine, Assigned Female ‘Hysteria’, Impact of Experiencing Bias, Intersecting Identities, and Significance of Access.

5.1. Questionnaire Analysis

The questionnaire, published through Nettskjema, received 52 delivered replies. When asked for their gender identity, 65,4% identified as women, 30,8% as non-binary, 5,8% as transgender men, 3,8% as men, and 5,8% didn’t find their identities listed⁸. The respondents were predominantly of American nationality (28 participants). There were eight British nationals, four Australian, three German, two Canadian, two Dutch, one Romanian and one Irish national. Three respondents held double citizenship: American-British, American-Canadian and American-Irish. The respondents received medical care in the above-mentioned nations, Cyprus, and Israel. 96,2% of respondents describe themselves as Caucasian/white, 5,8 % as First Nations/indigenous, and 1,9% each as Middle Eastern and South Asian⁹. The vast majority has indicated having hEDS (47 respondents). Two respondents have a classical EDS diagnosis, two have received an EDS diagnosis but not a specific type, and one participant reported having a clinical diagnosis of classical EDS but an hEDS diagnosis genetically. This shows 90,38% are diagnosed with hEDS, which aligns with the literature (Tinkle et al., 2017).

⁸ The question allowed the participants to choose multiple identities.

⁹ Respondents were again able to select multiple answers, which three of them did (Caucasian/white and First Nations/indigenous).

To get an understanding of what intersecting identities could be relevant, the participants were asked what part of their identity, if any, they felt had influenced their experiences during medical encounters. The responses were varied, but the answer referred to most frequently was being a woman, or a person AFAB being read as a woman by providers. Besides gender (woman, individual AFAB, transgender), weight, age, mental health (anxiety, depression, PTSD), neurodiversity (autism) and queerness were repeatedly reported. Three respondents described that in their experience, their identity did not influence the care they received.

Out of 52 participants, I approached eight with a request for a follow up interview, selecting them by their varying experiences described in the open questions, and intersecting identities (gender identity, nationality, ethnicity). Two of the participants I interviewed I was put in touch with through personal contacts, and thus they did not complete the survey.

5.2. Disease Burden

What does it mean to have EDS? This question has woven itself through all interviews, and the subjective experiences of women, trans, and non-binary people I talked to show the impacts are far-reaching for the majority of them. The theme Disease Burden contextualizes their experiences and reliance on providers, and Western medicine more broadly.

Nearly all of the interviewees have other health conditions in addition to EDS. Conditions that were mentioned repeatedly sorted by frequency are Postural Orthostatic Tachycardia Syndrome (POTS), anxiety, Attention Deficit Hyperactivity Disorder (ADHD), chronic migraines, Mast Cell Activation Syndrome (MCAS), autism, depression, endometriosis, and gastroparesis.

More health conditions raise not only the complexity of treatment approaches but also increase EDS patients' dependence on the medical institution at large, and their doctors as an extension. What we can extract is EDS seldom comes in isolation and is rarely experienced separate from other conditions.

5.2.1. Physical Impacts of EDS

The physical manifestations of the disorder vary among the interviewees. Nevertheless, pain is central to their experiences. “Tee” (25, non-binary, black, American) describes how they first realized their pain experience could not be a “normal” part of growing up. “Claire” (26, woman, American) narrates hitting a wall with her symptoms when she could not get out of bed. “It’s a

lot to wake up with all of your joints dislocated and be like f*** I have to go to work”, she voices. When she lost mobility in her legs, leading to a weight loss of around 45 kg, she felt she was “rotting” away. The physical limitations are the hardest part for her, as she is “still a person inside this body that still wants to do (...)”. At that point, Claire starts tearing up. “Kiera” (24, woman, American) confides chronic pain and fatigue are the most challenging aspects of having EDS. She says:

I've always felt like what my mind wants to do and what my body wants to do are kind of at war with each other. I think that my body is the biggest antagonist in my life. It's always been a constant struggle (...).

When “Carter” (37, trans man, Canadian) hit his lowest point physically he:

got to the point that I could do one thing every day. I had to choose very carefully what it was and then I was couched for the rest of the day. I was unable to function, and it was scary for me that this was my reality, and I couldn't make anybody understand this.

Around half of interviewees identified an aggravation of symptoms either during puberty, pregnancy, (induced) menopause, or the menstrual cycle. In addition, three individuals informed me their male relatives also had EDS but were only diagnosed because their female family members were first.

Two interviewees were born into a female body and later transitioned with HRT. Carter and “Orion” (22, non-binary trans person, American) both experienced an alleviation of their symptoms. Orion realized the changes by mere accident when they forgot to take a dose of testosterone, which led to a “big flare-up of symptoms”, where they felt worse than in a long time. Carter was concerned about going on testosterone in the first place since his EDS symptoms always fluctuated during his cycle. Hormonal changes led to every symptom becoming worse. Once he began taking testosterone he noticed enormous differences, as every EDS symptom improved. His “baseline levels of chronic pain have come way, way down”, dislocations stopped occurring, subluxations went from multiple a day to a couple per week, and migraines reduced drastically from three to four weeks a month to three of four days. These experiences indicate sex hormones play a significant role in the severity of EDS manifestations.

5.2.2. Administrative Burden

Disease burden does not stop at the physical impacts of EDS. Another aspect identified was the

significance of the administrative burden of having a disabling condition. EDS affects individuals differently, with some people living ordinary lives not noticing they have a disease, while others experience disabling manifestations. In the case of my interviewees, all women, trans and non-binary people I talked to are disabled. One challenge they face is the administrative burden of being disabled. Be it paperwork for disability schemes, organizing medical records, interacting with doctor offices, getting insurance to cover specific treatments or mobility aids, the amount of work can be substantial. Orion concludes, “there is so much labour on my end for what feels like minimal results”. Carter speculates, “[h]ow much money would we make if this was the part-time job that we have to treat it as”? He used to spend around 10 hours a week on tasks that non-disabled people do not.

Carter has a noteworthy insight into his administrative burden pre- and post-transition. His interactions with medical support staff have dramatically changed. Before transition, he had to “fight so freaking hard” to access appointments, documents, and administrative matters. However, since he is perceived as a man, he does not have to ask for the same things because people volunteer to make them happen for him. He considers this one of the biggest changes in the medical context, which has changed the administrative burden around his care. He estimates the weekly time spent on it has halved since his transition.

The central finding that developed from the theme of Disease Burden was the multi-faceted ways in which having EDS impacts the experiences of women and people AFAB. This provides a contextualization of the realities of EDS patients and the far-reaching implications having EDS can have. It illustrates patients' dependence on the medical system to manage their symptoms and improving quality of life. Their existence and survival depend on the Western medical institution they are forced to rely on.

5.3. Power in Accessing Medicine

This theme corresponds to RQ1, as it explores the significance of power and power/knowledge in the experiences of women and people AFAB diagnosed with EDS when seeking care. The analysis has shown how central power is in the interviewee's access to medicine. It structures and affects their interactions with doctors, primarily through the power/knowledge nexus. Other relevant aspects of power are explored through reproductive power and normalizing power. Power is omnipresent which affects the experiences of women and people AFAB diagnosed with EDS.

5.3.1. Power/Knowledge during the Patient-Provider Interaction

As Carter explains, the power differential between doctors and patients can impact their lives, and how they can "exist in the world" by denying interventions or treatments that help patients exist in different ways. There is a strong dependence on what a group of people in medicine believe about your condition, which is often far removed from your lived experiences.

I extracted different forms of knowledge relevant in the sphere of power/knowledge between patient and provider: medical, bodily, and collective knowledge. Medical knowledge is scientific knowledge from journals and scientific studies. Bodily knowledge is derived from the lived experiences of patients diagnosed with the disease and is centred around how they experience living in their bodies. Collective knowledge is shared knowledge, which is built from two parts: (1) medical knowledge that through tools like Google Scholar is no longer limited to medical providers but accessible to others; and (2) shared knowledge from online patient communities (e.g., Facebook, Inspire). Hence, collective knowledge combines medical knowledge through self-research online, and community-shared knowledge – including bodily and medical knowledge – from patient spaces.

Shifts in Power/Knowledge Nexus

Traditionally, medical knowledge was almost exclusively available to doctors, and the patient had virtually no access to medical knowledge besides what the doctor shared (Bristowe & Harris, 2014). Through changes linked to the internet – easier access to medical knowledge online and patient communities who readily share knowledge – the power/knowledge dynamics between patient and provider are shifting. The interviewees report that doctors' reactions to this power/knowledge shift are mixed.

"Sarah" (41, non-binary, Middle Eastern, Australian) talks about instances in which sharing collective knowledge was either helpful or made doctors uncomfortable. Orion discussed doctor-patient dynamics and how the roles are reversed since they were first diagnosed, as Orion has a better understanding of EDS than the providers. The reactions from the doctors are varied, they can be condescending, dismissive, even aggressive, or grateful and appreciative. When Kiera went to the doctor for a sinus infection, and he made an incorrect comment about EDS, Kierra corrected his statement, upon which she was met with defensiveness. He proclaimed, "I don't know why I even came here if you're the medical expert", expressing discomfort about the power/knowledge shift. "Helen" (24, woman, Native American and white) recounts instances where being well versed helped her gain respect as a

patient. Yet, she also had doctors where she learned to “just keep it shut and be quiet”, as to some, an informed patient is seen as a threat to their authority and access to power/knowledge. Carter calls it a line you have to walk in which you cannot use medical language and knowledge too much, but you also have to use it just enough to show you have understanding, an impossible standard to meet. To extract, applying medicalized language taken from medical discourses can influence power/knowledge dynamics between patient and provider. There is a continuous negotiation of power through language and knowledge.

“[S]top doing your own Research”: on the Path to Self-Diagnosis

Four of the interviewees found their own EDS diagnosis and other health conditions before their doctors did because of collective knowledge. “Rachel” (43, woman, American) found out what was going on with her body online, which drove her “doctors completely crazy”. Doctors had dismissed her for so long, telling her to “stop pursuing these diagnoses, let us tell you what’s wrong”.

“Eva” (18, woman, German) and Helen were repeatedly brushed off by doctors, and their physical symptoms were attributed to anxiety. They found their answers online beforehand. After 7,5 years of diagnostic delay, Carter’s doctor offered to look at information he brought, so he went on google and found EDS. Carter proceeded to self-evaluate his symptoms, recorded it in a document with his medical history and scientific articles and brought his doctor a 120-page long ‘thesis’ diagnosing himself with EDS. His doctor was convinced yet had no interest in further working with him, which Carter believes was because of his self-involvement in his care. These instances of successful self-diagnosis illustrate the importance collective knowledge can have for patients.

Among the interviewees, doctors’ reactions to their patients bringing collective knowledge and through it shift power/knowledge was mixed, and depended on the individual doctor. However, the patterns of adverse reactions to patients becoming more active participants in their care are more pronounced than the positive ones, and patients' access to information for some doctors becomes a disruption of authority.

The (Lack of) Significance of Bodily Knowledge & Collaboration

The interviewees' knowledge of their bodies was often not deemed relevant by doctors. Tee discusses their experiences with having their bodily knowledge disregarded.

I'm still the person who's in this body. I'm still the person who experiences day in, day

out. You only know me off of a chart in the 10 minutes we share a room together. You do not see my every day. You don't.

Though the patient-provider hierarchy is visible throughout, there are instances where the patient-provider relationship is centred around collaboration. This occurs when doctors are receptive to the interviewees being “active participants in [their] own care”, as Orion tells. Information – from bodily and collective knowledge – is shared between the patient and the provider. The provider is receptive to the patient increasing their power/knowledge over their condition, collectively and independently. Combining medical knowledge and professional expertise that the doctor has with the bodily and collective knowledge from the patient can lead to a more holistic understanding. Thus, this power/knowledge process is productive. Sarah, Helen, Orion, and Carter positively accentuate this collaborative model.

5.3.2. Reproductive Power as a Female Patient

Tee had experienced excruciating periods since they were 14, “writhing with pain days on end”. They decided to have a hysterectomy when diagnosed with adenomyosis¹⁰ and endometriosis. Tee never wanted children as a disabled black person AFAB in the US because of their conditions and the risks pregnancy could pose to their life. They had to “fight tooth and nail to get it”. On the day of the surgery, the hospital's ethics board denied it because Tee was 25 and would not be able to have children. This denial was “soul-crushing”, especially since going to another city for the surgery was not financially accessible. Luckily, they received help and found a doctor elsewhere willing to do the surgery, giving Tee considerable pain relief. Helen, who besides endometriosis has a considerable number of other health conditions, approached her gynaecologist about a hysterectomy. He told her to come back after she had two kids. She explained her decision not to have any children whom she would pass her genes, but the doctor ignored her wishes. Helen had to find another doctor willing to do a hysterectomy, and after a two-year wait time enacted by the insurance company, received surgery. However, she reported she needed her husband to “sign off on it”, meaning her husband needed to give his signature for her to be able to get the hysterectomy.

I argue these instances show a lack of power of Tee and Helen over their bodies, who could not choose a life-improving surgery without fighting the paternalistic and patriarchal

¹⁰ Adenomyosis is a condition where endometrial tissue – which is the inner lining of the uterus – grows into the muscular wall of the uterus instead (Cronin, 2017).

institution of medicine, which puts the womb above the person. Though both had expressed not wanting children, their reproductive ability was initially put above their health and wishes. Effectively, they were not considered able to decide about their own reproductive life in our patriarchal society.

Helen needing her husband's signature to access the surgery opens the question of the persistence of patriarchal power structures. Her needing approval from her husband to perform the surgery reinforces the marital authority of the husband over the wife. Further, one of Helen's doctors never talked to or looked at her when her husband was in the room. Even though she was his patient, he would not acknowledge her, directing all attention to her husband. When she asked him to talk to her instead, he was angered. Here, the doctor subordinated Helen to her husband during her patient-provider encounter.

5.3.3. Power of Normalization

Western medicine had and has a constituting role in defining the 'norm' of the human body (Feder, 2011). What is considered as 'normal' or 'abnormal', 'abled' or 'disabled' are significant categories that impact society. These categories are upheld by some physicians the interviewees encountered, who adhere to the 'norm' or take it as an aim to reach. This is especially pronounced in the realm of disability through access to mobility aids for Sarah, Tee, Orion and Carter.

Sarah exclaims wearing splints, braces or using a wheelchair can lead to pushback by physicians and being confronted with "why would you need that? (...) You're strong". Tee, who entered the doctor's office in a power chair as they had lost the ability to stand or walk for a long time, was met with scrutiny by their doctor. She confronted Tee with, "you're going to lose muscle in your body if you don't move", but they were unable to move, leaving them with no other choice. Orion approached their general practitioner (GP) to access a disabled parking placard. The doctor denied the request, arguing 'they' were trying to get Orion to a point where EDS would not affect them. However, this was the GPs objective, not Orion's, who wanted an increased quality of life, knowing that forcefully exceeding their abilities is unsafe. Carter experienced doctors wanting him to "adhere to their standards of non-disability". What they thought was necessary and what his body should be able to do – walking more – was at odds with what he knew his body needed: to manage pain and fatigue to increase functionality. He wants an improved quality of life; they want him not to be disabled anymore.

In these cases, the doctors focus on adhering to medical 'standards'; hence, their aversion

to mobility aids leads them to react negatively or gatekeep patients' access. Most patients need a doctor's approval of the aid to have insurance cover the expenses, which can be immense. Medicine functions on the basic idea that 'healthy' equals 'normal' and 'unhealthy' equals 'abnormal' (Neilson, 2020). Western medicine was constitutive of ableist medical 'standards', and through medical training, these are ingrained in doctors, who then reinforce them on their patients. In the cases, the doctors placed the 'norm' above the patient's well-being. Through power/knowledge of the medical field, doctors can determine how a patient can and 'should', live.

Here the medical institution can be considered in terms of governmentality, and the conforming of bodies to fit the needs of the modern state. States want their body populace to be healthy. Disabled bodies could be considered less 'valuable', as they might not be able to fully participate in the labour force for example, or they might rely on disability benefits and be thus seen in terms of expenses the state has to incur. In these instances, doctors are normalizing tools of governmentality that decide what a body should conform to, how health should be approached, and what medical access patients should possess.

5.4. Assigned Female “Hysteria”

This section partially seeks to answer RQ2, to examine the interviewees experiences of gender bias when accessing medical care. Being a woman, or being born female and perceived as woman, is central to the interviewees' experiences. Each interviewee had their concerns about their body being disregarded, dismissed, or distrusted. I identified the role the 'hysteria' discourse can have in the medical encounter, and patterns surrounding female pain perception.

5.4.1. An Age-Old Tale: Hysteria

The label 'hysterical woman' has significance among four interviewees but can be more broadly discovered in most interviews. Tee referred to it in the broader discussion of their experiences, specifically the tendency to treat women as hysterical when they voice their concerns. Kiera relays how doctors commented to her mother that her daughters – Kiera's sister also has EDS – are being “hysterical”. Kelly found hysteria and conversion disorder¹¹ noted in her chart after an ER visit where she was not believed. This had consequences, as once her

¹¹ Conversion Disorder is one of the modern forms of 'hysteria', which is partly connected to somatization – physical symptoms that occur because of the psyche of a patient -, hypochondriasis, or malingers who intentionally feign their symptoms (Owens & Dein, 2006).

neurologist saw, he no longer found her credible and refused treatment. Carter remembers an appointment where besides the doctor, there was also a psychologist present. Mid-appointment Carter realized he was evaluated for hysteria and conversion disorder, as the doctor referred to it. He believes his negative and traumatic experiences with the medical institution before diagnosis and transition occurred because he “was treated as a hysterical woman”. There is weight behind using a word with strong connotations like ‘hysterical’ or ‘hysteria’. The terms produce power by influencing the trajectory of the patient-provider interaction and treatment. The discourse around ‘hysterical women’ is a relevant framework for the gendered experiences the women and people AFAB reported about their medical encounters.

5.4.2. Female Pain

I identified four patterns among the interviewees when they shared concerns about pain with their doctors, specifically pre-diagnosis. Their physical pain is either not believed, trivialized, normalized as part of the female reproductive life, or attributed to their mental health.

Disbelieved

Kelly told me about a visit to the ER room, where later they found she had herniated disks. As an EDS patient with an array of other conditions, she experiences pain daily and has a higher pain tolerance. Since she was not presenting as a patient with high pain levels, she was accused of making it up to seek drugs. Claire, Kiera and Helen were also accused of faking their pain to get drugs. When Helen reported experiencing dislocations at home, her doctors disbelieved her accounts until she started taking pictures of them. She had to provide them with proof before they were willing to consider her experience accurate. When Tee depicts their first ER visit, they describe, “everybody in there looked at me like I was imagining my pain”.

Trivialized

When Kiera first started developing chronic pain, doctors said, “it is what it is and there’s nothing we can do to help you”. She started receiving treatment that eased her pain five years after. Helen tells me that when her husband went to the ER because of a shoulder dislocation, he received several drugs and was sedated to relocate the shoulder. She parallels her experiences when reporting high pain levels, like when she got an Advil (Ibuprofen, an over-the-counter medication) for a shattered leg. When she had high levels of pain because of endometriosis, she was told she was fine, “the pain is not bad, just go home, take some Tylenol,

you're fine". In this instance, androcentrism in the health care system can be identified, as in comparison, male needs and bodies were prioritized over female ones. Carter adds a relevant perspective as he experienced how medical practitioners reacted to his pain before and after his transition. When Carter was read as a woman, doctors presumed pain sensitivity as the cause of chronic pain and tried to diagnose Fibromyalgia¹². Carter was sure the symptoms did not fit his experiences, yet doctors insisted. Since transitioning, fibromyalgia has never been mentioned again. Transitioning entailed that nobody attempts to tell Carter how he experiences pain anymore, while beforehand, it was believed he was too sensitive to pain. Curiously, since starting HRT, he is much more sensitive to acute pain than he was before hormones, reacting more to injections for instance. Even though he expresses more sensitivity now, he has more credibility as a man. Before his transition, he was not treated "as a reliable witness to my own body"; this has definitively changed since he is perceived as man. Stories like Helen's and Carter's reveal existing patriarchal power relations in which 'women' are subordinate to 'men', and androcentrism in our society which is built around men's needs and thus believes their experiences more.

Normalized as a natural part of the female reproductive life

When Rachel approached her neurologist, explaining she had "excruciating headaches every day of [her] life", she was asked if she considered her periods were the cause. Eva experiences severe menstrual pain and believes she has endometriosis¹³, but her doctors do not consider her theory, stating, "that's just normal menstrual pain". Discourses around menstrual pain are not confined to the medical sphere. The blanket statement that period pain is 'normal' can lead to difficulties. How do you define 'normal'? Tee experienced agonizing menstrual pain and thought intense pain was just a 'normal' part of life. They noticed something was not 'normal' when they experienced severe pain outside of periods and were diagnosed with endometriosis and adenomyosis. This illustrates Western medicine's power as an authority that defines the 'norm' through discourses that do not stay confined within medical circles.

It's all in your head: pain attributed to mental health

Half of the interviewees had their physical pain attributed to mental health. When Sarah's health declined, both of their thumbs stopped working. When looking for the cause, their GP

¹² Fibromyalgia is a controversial diagnosis where individuals experience high levels of pain that are not medically detectable. Women with fibromyalgia report that their pain is often dismissed (Quintner, 2020).

¹³ Females with EDS have a higher rate of endometriosis than in the normal population (24,1%) (Nee et al., 2019).

referred to anxiety and stress. Eva's severe joint pains were also misdiagnosed as anxiety. Some doctors treated it like “it was all in [her] head”. She knew the issue was her joints, not anxiety. “I couldn’t do much about it because I needed doctors to help me get a diagnosis, but they wouldn’t help”, she reports. Helen started having dislocations around the age of 12, and doctors told her she was anxious, needed to exercise more, or try out yoga. When Carter’s health deteriorated, doctors listed various possible reasons: exercise, diet, sleep, hormones, stress, and depression. When he began diagnosing himself, he revealed: “This whole-time, doctors almost never touched me, and almost never looked at anything. It was always across the desk like ‘tell me how you’re feeling’”. For most doctors Carter encountered, it was the get-go to assume the issues were not physical, hence they did not conduct physical exams.

From the experiences conveyed it appears the bodily knowledge of the interviewees is not considered valid or relevant compared to the outcome of tests like X-Rays, or in instances when no physical diagnostic work is performed, the professional knowledge and biased assumptions of doctors. Medical knowledge from doctors is ranked above lived knowledge of the patients. This compounds with the displays of disbelief, distrust and disregard linked to gendered norms and stereotypes about ‘hysterical’ women, leading to discriminatory treatment because of (perceived) gender. Ultimately, they are not considered reliable witnesses to their bodies. Most interviewees— dependent on medical providers – found themselves in a state of powerlessness, a position which made them vulnerable to IB. In the next theme, I discuss the impact that experiencing gender bias had on the interviewees.

5.5. Impact of Experiencing Bias

This theme further corresponds to RQ2 – which seeks to explore the reports of women and people AFAB diagnosed with EDS about gender bias – by investigating the consequences of experiencing bias. ‘Othered’ bodies that do not fit the narrow human ‘norm’ can be considered as marginalized genders in medicine. As people’s lives depend on Western medicine, specifically doctors, bias in medicine can have far-reaching impacts. The analysis has shown these impacts include psychological fallout and worsened physical health.

5.5.1. Psychological Fallout

Most interviewees recount experiencing emotions that can be classified under psychological distress. They report feelings of hurt, anger, worthlessness, dehumanization, inferiority, despair.

Tee recounts coming home after doctors' appointments, breaking down and crying. For them, it was apparent when doctors did not listen, and the whole experience was dehumanizing. However, as a black person AFAB in America, they did not voice their anger out of fear of being stereotyped. Tee shares:

It's hard to keep doing it because I would leave appointments and I would want to give up. But if I give up, I will just be sick and waste away because I've felt near death before. There have been multiple occasions where I knew that if I didn't get care, I was going to die.

Intense self-doubt made Tee consider if they imagined their pain. Claire reports self-doubt, questioning her reality and feelings of worthlessness, as "it gets into your head that you're not worth being taken care of". Helen, reports being frustrated, mad, judged and feeling inferior after meeting doctors who did not believe her.

In some instances, the interviewees' interactions with providers not only left them with strong negative feelings but led to tangible psychological consequences. Rachel developed severe anxiety around doctors, causing panic attacks in the waiting rooms. Sarah's psychologist confirmed they had developed PTSD from medical situations. "[T]he whole lack of agency and autonomy that can occur; and the dismissing and the belittling and the reducing and the constant arguing, and the need for asserting oneself" caused demonstrable harm. When providers continually dismissed Kiera as a teenager, it compounded with other problems, and she felt no hope of getting better, leading to a deep depression. "I was genuinely suicidal because I felt nobody would ever take me seriously", Kiera confides. When Carter talks about the years before diagnosis, he describes feeling trapped, like after a car accident where firefighters are beside him with the jaws of life but refuse to help. Though he has a good care team now, he deals with residual trauma, and interactions can take him back to that state. "I feel like I don't have any value or voice or power. There's something so fundamentally traumatizing about asking for help and receiving scorn, ridicule, and disbelief. That is always going to stick with me," he discloses.

5.5.2. Physical Health

It is challenging for the interviewees to give detailed examples of how their physical health was affected. However, care delays are reported in the form of diagnostic delays, denial of accommodation, treatments, or minimizing health concerns. All of the above exacerbate the

health condition of the interviewees. Helen had to look for another gynaecologist who would agree to a hysterectomy, which prolonged her time until the surgery. In between, her endometriosis developed to stage four and attached to her appendix, bladder and colon. Carter's health deteriorated during the diagnostic delay, which impacted his health outcomes. He states, "[doctors] close the door after you leave their office, but you continue to live with the consequences of that appointment, for the rest of your day, for the rest of your week, for the rest of your life".

The interviewees are strongly dependent on their providers. Therefore, when doctors are dismissive, prolonging diagnostic delays and the commencement of treatment, which leads to tangible psychological and physiological consequences, the institution is betraying the trust of its members. Hence, considering Rachel, Sarah, Kiera and Carter's narrations about anxiety, PTSD, depression, and trauma, I argue they experienced strong levels of institutional betrayal, affecting them until now. Correspondingly, most of the other interviewees also endured IB, but the effects were less palpable.

5.6. Intersecting Identities

The theme seeks to partly answer RQ3, which inquiries about the significance of intersecting identities on the experiences of women and people AFAB diagnosed with EDS when accessing medicine. All interviewees found themselves on the intersection of gender and disability. Not all interviewees identify as women; however, they all share that they were read as women at some point. Besides those common denominators, the identity design of the interviewees varies to some extent. According to the interviewees' lived experiences, different aspects of their identity affected their medical access: gender, ethnicity, class, sexuality, mental health status, disability, neurodiversity, body size, age, and education.

5.6.1. Not in Isolation

"I don't think it's ever one factor", Sarah says when discussing negative interactions with medical providers. They report their perceived gender, Middle Eastern background, and weight play a role. These biases pile onto each other, making them visible but "hard to extract one from the other". Hence, they decided not to share their non-binary identity with providers, as they "can't afford to light the fuse" by adding another intersection. Similarly, as a black person AFAB from a lower-class income background in the US, Tee decided not to share they are non-binary or queer. Unless it is relevant to the medical situation, they refrain from providing

information that “could be used against [them]”. This aligns with the concept of intersectionality, which aims to illustrate that one cannot separate the social categories that impact one’s oppression (or privilege) within society. The categories are greater than their sum (Crenshaw, 1989), and it is impossible to distinguish or separate what aspect affects an encounter.

Nonetheless, there are occasions where interviewees can identify a protruding identity category that appears more significant in a specific situation through witnessing instances which highlight imbalances first-hand. Kelly recalls an incident where she waited in the emergency room (ER) for seven hours, barely able to move because of her back pain without any pain management, just to be given over-the-counter painkillers and sent home. While she was waiting, a man entered the ER who also experienced pain and was directly given morphine. Kelly believes were she a man complaining about the same pain that she had, she would have less wait time and be given proper pain treatment. Rachel’s neurologist told her to stop looking for medical issues and if she did not undergo a recommended procedure, she should not return to the practice. Though he never told her he disregarded her concerns because she was a woman, he talked to her husband differently than to her. Thus, she believes being seen as “just some woman with headaches that wouldn’t stop coming to the neurologist where people with serious problems should be” negatively affected her care.

5.6.2. Mental Health & Neurodiversity

Once a mental health condition is noted in the medical records, it can influence the perceived reliability of a patient. Claire’s PTSD diagnosis affects her trustworthiness to the providers she approaches for help with her EDS. Orion believes their anxiety disorder diagnosis “has been detrimental” in their experiences, causing their GP to be dismissive, with arguments such as “stop checking your blood pressure, it’s bad because you keep checking because you’re anxious about it”. Helen describes her Bipolar II Disorder diagnosis influenced how health care workers view her credibility.

Similarly, falling in the neurodivergent category – which half of the interviewees do by being autistic, having ADHD, or both – adds another dimension. Tee, who has ADHD in their medical chart, refers to their neurodivergence as a reason doctors shifted their conversational tone. Furthermore, they chose not to seek an official autism diagnosis to avoid it weighing against them. Tee is aware their identity design is dangerous in the medical sphere considering the health inequities between black and white Americans (Bailey et al., 2017), thus, they do not

want to add more.

5.6.3. Interlocking Systems of Privilege & Oppression

While belonging to specific social categories leads to oppression for some groups, it leads to privilege for others (Crenshaw, 1989). Among some interviewees, I identified awareness regarding the privilege their ethnicity and/or class background provides. They highlighted that being white afforded them privilege. Claire doubts she would have received a diagnosis if she were not white. “I know that I’m a very persistent, tenacious white woman and the reason why (...) I finally got my f***** diagnosis is because I was determined to get it”, Claire adds. Rachel considers if her ethnic identity and class were different, she “may not be in as good shape as [she] is today”. Carter wrote a ‘thesis’ where he diagnosed himself, and as a PhD candidate, he needed to apply all his research skills towards this project. He is white, from an upper-middle-class background and has considerable educational privilege, yet he still faced barriers and long delays. If that was Carter’s reality, his access to diagnosis being predicated on “so much privilege”, “[what] hope does anyone else have?”.

This shows how structural systems can affect interviewees on the micro level, their lived experiences. Intersectionality, while using identity categories, is not an account of personal identity, but is about oppression and privilege, which is essentially about power (Cooper, 2015). In these accounts, we can identify how power flows and is omnipresent on all levels of society (Foucault, 1980). Claire, Rachel and Carter simultaneously undergo power – by being born female interacting with an androcentric institution riddled with structural gender/sex discrimination, but also implicit and explicit bias by providers – and exercise power, afforded to them because of their white privilege and/or class background. Parts of their identity leave them in a disadvantaged position, whereas other at an advantaged one. This also demonstrates why Western Feminists are critiqued for putting everyone born female into a monolithic category of “woman”, treating them as a singular group exposed to shared oppression (Mohanty, 1984). Other issues the interviewees encountered are diverse. Kiera’s young age affected how seriously doctors took her pain. Claire reports that when emergency hospitalizations occur, her fiancée, a woman, is never contacted even though she is her emergency contact. Instead, they only reach out to Claire’s secondary emergency contact. Sarah, Claire and Helen all experienced their symptoms being dismissed because they were overweight. Their weight becomes a barrier and the go-to reason for health issues. Lastly, Claire was homeless in the past and could not seek care because she had no health insurance.

The absence of care in her chart is used to minimize her disability, by questioning why she would not seek continuous care if she were disabled. A complex web of intersecting discriminations and privileges occur, compound and are mutually constitutive.

Nearly all the interviewees identified being born female as a critical aspect of their experiences. However, gender bias was not the only form of discrimination they encountered. Their ethnicity, class, sexuality, disability, mental health status, neurodiversity, body size, education and age have all affected their treatment. Depending on the unique identity design of the interviewees, the obstacles to accessing treatment compound. With multiple interlocking systems of power reflected in their stories, the complexity of their experiences was identified.

5.7. Significance of Access

This last theme also corresponds to RQ3, since the data showed that the significance of access to medicine relates to people's intersecting identities. Patients' interactions with their doctors facilitate access to diagnosis, treatment and interventions. Access to insurance is a prerequisite of going to the doctor – or being able to afford to particularly for Americans – as a chronically ill person.

5.7.1. Medical Insurance

I interviewed people from the US, Canada, Australia, and Germany, which all have different healthcare policies. However, access to health insurance was a subject of importance in eight interviews. The US – as the only one of the four countries – does not have universal health insurance coverage (Schneider et al., 2021), hence there is no guarantee Americans will have access to insurance. Tee did not have insurance when their knee pain worsened, and they had to go to the ER. An X-ray, a 2-minute conversation with the doctor, and a prescription for Ibuprofen 800mg later, they were billed \$3,000. This discouraged them from further seeking help, considering they were told nothing was wrong and left with a bill they could not pay. Getting insurance took them a while, during which their symptoms worsened. Claire, who experienced homelessness as a queer youth, had no health insurance during that time, making it impossible for her to seek help.

Nonetheless, having insurance did not guarantee the interviewees would get the treatments they needed covered, or that they did not have problems with high co-pays. Unsurprisingly, these were especially troubling for the people I interviewed that came from a low-income background. Kiera has foregone tests, which she was advised to do because they

were not covered. Claire, now insured through Medicaid, struggles finding a doctor in her area with EDS knowledge that accepts her insurance. Tee expresses how finding doctors who accept their marketplace insurance is difficult.

Insurance was also an area of concern for middle- and upper-middle-class interviewees. In Rachel's case, having access to "good" insurance does not mean she is not having financial issues because of medical expenses. She explains, "most treatments for Ehlers-Danlos issues are considered experimental and not covered by insurance". In Carter's experience, public health insurance in British Columbia covers ten physical therapy sessions, a regulation suitable for acute injuries. Still, as a person with EDS, Carter needs physical therapy indefinitely. Hence, he has to pay out of pocket and receives a partial reimbursement from his supplemental insurance.

5.7.2. The Meaning of Official Diagnosis

The diagnostic delay interviewees experienced ranged from four to ten years. However, it was not always possible to delineate a timeline.

Eva has become more trustworthy to her doctors through diagnosis and has to explain herself less when seeking care. Tee expresses intense relief when they finally found out what was going on. Carter "thought everybody had pain all the time and that was just what I lived with" before his diagnosis. Knowing about EDS taught him how his body worked and what he could do to alleviate symptoms. Claire, who had been told by medical providers she had EDS long before she found a doctor willing to diagnose her, experienced how powerful an official diagnosis is. While she had the inner relief of knowing what was causing her issues for years, she could not convince a doctor to believe her, prolonging her access to treatment.

The data shows diagnosis means different things, such as access to knowledge, care, treatments, community, and other resources. Especially after a diagnostic delay, getting clarity is meaningful to the interviewees. Here, we can also recognize traditional power relations in medicine, where the doctor has the power/knowledge to diagnose, and the patient depends on the doctor, regardless of any power/knowledge shift.

Here we can see the interplay between the state and medicine and their crucial responsibility in people's access to health care. Access to medicine is essential for the body populace and social body as a whole to improve the population's health. State governmentality regulates access to medicine via public policies and private insurance regulations. Power/knowledge

between patient and provider further affects the access to quality care and diagnosis, meaning that access to medicine through insurance is insufficient to guarantee access to proper care. Who can access health care and to what extent and quality is thus dependent on both.

5.7.3. Intersectionality in Access

Intersecting identities are relevant regarding their access to insurance, diagnosis and medicine broadly. Tee is disabled, black and born female in the US, and is well aware of the realities black Americans face in the health care system that are deeply ingrained within (Nuriddin et al., 2020). In half of their experiences with doctors, they felt like they were dealing with medical racism, which prolonged their path to diagnosis. They worked through doctor after doctor in the system that accepts their insurance, but what happens when they run out of providers that can help? Though Tee is only one person, they have learned through conversations with other people of colour that their experiences align.

Helen is native American and can access tribal resources, such as health stipends and hospitals. Without access to these resources, she would find herself in horrible debt or as she says “I feel like I would just shrivel up and die”. Here we can see how positive discrimination is assisting Helen, who as a native American is part of a marginalized group, and expanding her access to counteract oppression she might face otherwise.

5.7.4. International Comparison

Health Care accessibility and affordability were particularly relevant for the American nationals. As there is no universal health insurance coverage, as in Canada, Australia, and Germany (Schneider et al., 2021), interviewees were not guaranteed a basic level of care. Interviewees that used either Medicaid or marketplace insurance found it challenging to locate providers that would accept their insurance in the first place, and doctors that have experience with EDS patients. Yet, even having “good” insurance does not guarantee that health care bills are no concern, as some EDS treatments can, depending on insurance provider, be considered experimental and thus not be covered. Access to insurance, especially affordable one, in the US context is complex and predicated on different aspects, such as what state a person resides in, their income, what subsidies are available etc.

The interviewee from Australia, which has universal public health care coverage, emphasized they also need to use private insurance since the public system has long delays and is not always well suited for complex conditions like EDS. The German interviewee also had

private insurance instead of public insurance.

Lastly, the Canadian system is divided into public insurance (medical visits, acute care, treatments), and supplemental insurance (treatments, medications, mobility aids), and the regulations and coverage differ between provinces. It was described as a complex environment, with the interviewee navigating between public and supplemental coverage.

There can't be a comparison between the interviewees' diagnostic delays regarding nationality. There are seven Americans, the other countries are represented by one individual. However, the experience of the nationals from four different countries are similar in terms of the meaning of diagnosis, and how their EDS diagnosis has led to access of further relevant resources. All participants from all countries were ultimately dependent on power/knowledge of their doctor to access diagnosis, regardless of the shift, or that some of the interviewees diagnosed themselves prior.

Intersectionality plays a significant role in insurance and diagnostic access for Americans. For instance, the predominance of white individuals diagnosed with EDS puts into question who can receive a diagnosis in the first place. Intersecting identities, like class or ethnicity, which are all interconnected, can affect access to insurance. In the other three countries, at least public health coverage is guaranteed, so a basic level of care is provided, though that does not mean quality or timely care is accessible. Further, in these countries, there is also a separate, private insurance, which will be more accessible to some, such as middle, or high-income families, compared to others who struggle with paying for private or supplementary options.

6. Discussion

The disease burden contextualizes how the women and people AFAB with EDS rely on their medical providers and Western medicine for how they can exist in society. Further, the burden is complex and includes other health conditions, physical manifestations and how they affect day-to-day life. This aligns with a previous study, which found pain was central to the study cohort with hypermobile EDS, to the point that it affected their ability to participate in their everyday lives, and further found that individuals experience a wide array of other co-morbid conditions (Murray et al., 2013). The significance of reproductive life and cycle on EDS manifestations, identified previously (Hugon-Rodin et al., 2016), has been observed among the interviewees. HRT decreasing the severity of EDS symptoms among the two trans-people I

interviewed was a key finding, on which I could not find scientific literature that examined this particular aspect.

While these insights I recognize as distinctive to EDS, administrative burden can be considered in a wider frame of disability. Administrative burden was identified as an area of concern e.g. disability schemes (Carey et al., 2021; Yates et al., 2022), or higher education (Lister et al., 2021) for people with disabilities. The interviewees referred to administrative burden in more of a holistic way, instead of focusing on the navigation of one particular institution, though it was concerning their medical care. Carter reports he experienced drastic changes regarding medical administrative burden before and after his transition. He spends half the time now than he did when he was still read as a woman.

6.1. Power, Medicine & Access

Power/Knowledge

Traditionally, doctors adopted a position of power in consultations as they alone possessed medical knowledge, the authority and ability to diagnose a patient (Bristowe & Harris, 2014), hence medical knowledge was a power instrument. This knowledge was hardly accessible to people outside of medicine. However, the analysis showed a shift in this traditional power/knowledge nexus between patient and physician. This form of knowledge has become more attainable in recent years. I describe this form of knowledge as collective knowledge, which consists of: (1) medical knowledge available online through tools like Google Scholar, and (2) knowledge derived from patient online spaces, like Social Media groups, which is a combination of bodily knowledge from lived experiences and shared medical knowledge. Thus, knowledge is more accessible and more understandable with the help of other patients.

The finding about the shift in power/knowledge is also corroborated by Bristowe & Harris (2014), which refer to the change coinciding with increased empowerment of patients. This occurs through “the rise in alternative sources of truth and knowledge (such as Internet-based patient information)” and how it moves “the authority to diagnose, and access to power/knowledge, out from the physicians' exclusive grasp” (Bristowe & Harris, 2014, p. 552). This change in status quo is prominent in the data. Nimmon & Stenfors-Hayes (2016) found a subset of doctors in their study perceived the power of physicians as waning in the physician-patient encounter because of the rise of the “informed patient”. Hence, the encounter becomes a site of struggle for knowledge/power.

While the power/knowledge shift changes patient-provider interactions and gives

people access to tools that enable self-diagnosis, it does not break the power hierarchy. Nearly half of the interviewees successfully self-diagnosed their condition(s) before a doctor, which was valuable to them for learning about their bodies, and knowing what is causing their symptoms. Yet, they still needed to find a doctor to help them obtain an official diagnosis and access treatments and accommodation.

The sharing of collective knowledge in patient spaces such as Facebook Groups or Reddit subreddits can be interpreted as an act of resistance to power/knowledge. Hereby, the ‘gatekeeping’ of medical knowledge is disrupted, which influences patients' reliance on their physicians as the sole source of medical information (Bristowe & Harris, 2014). Sharing and creating collective knowledge is also productive, as it creates discourse and knowledge about aspects of the disease that are not yet studied by medical research.

The Significance of Bodily Knowledge

During the past few decades, changes in healthcare systems around the globe emphasize the importance of lived experiences of patients. In tandem, this dynamic has also brought attention towards the patient’s voice (Gaille, 2019). Bodily knowledge becomes especially significant in a disease like EDS, which is hard to diagnose because of subjective symptoms of chronic pain where a physical cause cannot easily be detected (Halverson et al., 2021). This compounds with the high prevalence of female patients diagnosed with EDS – about 80-90% (Kole & Faurisson, 2009) – and the issue that female patients’ pain is more often dismissed (Schäfer et al., 2016). What I call bodily experiences, meaning the lived experiences of being inside a body with certain health conditions, should have higher regard and be considered relevant and important knowledge for doctors to make accurate and timely diagnoses and treatment plans, at least according to the mentioned paradigm shift. Even more so, this becomes more relevant for women and people AFAB who are more likely to be dismissed and disbelieved in their complaints. Nonetheless, the analysis has shown all interviewees experienced their bodily knowledge and input being disregarded, or not believed.

Reproductive Power

Tee and Helen’s stories about their hysterectomies illustrated how doctors and the medical institution at large restricted their autonomy over their own bodies. Though both had expressed not wanting children for different reasons, they encountered resistance to this decision. Tee was denied surgery last minute because of the hospital ethics board, and Helen had to switch

gynaecologists because he did not agree to do a hysterectomy on a childless woman her age. For both, it was an odyssey to get the surgery that would lessen their pain significantly. Parallels can be drawn back to ancient Greece where a women's sole purpose was bearing and raising children (Cleghorn, 2021) and where procreation was "the most significant contribution she could make to communal and worldly good" (Mercer, 2018, p. 186). Even today over 2.000 years later, Tee and Helen's uterus and procreative 'destiny' was initially put over their health interests and wishes. This demonstrates how pervasive some of these old beliefs still are to this day. In addition, the need for Helen to get her husband's signature for the hysterectomy is disquieting, as it impeded her rights over her bodily autonomy. Though no state mandates require spousal consent for sterilization in the US, as they would be unconstitutional, private hospitals or clinics can choose to require signed consent from the husband, on grounds of religious refusal policies or similar (National Women's Health Network, 2019).

Normalizing Power, the Human 'Norm' & Disability

Medical disciplines "discursively shape the identity of disabled people through the authority of scientific knowledge" (Anders, 2013, p. 13), which allowed power/knowledge in medicine to produce disability as an abject identity. Considering that through normalization practices in medical discourse (Feder, 2011), the categorization of "normal" and "abnormal" bodies was created. Furthermore, medicine is not only the primary paradigm for the treatment of disabled bodies, but it also shapes the way decision-makers, legislators, and society think about disability (Campbell, 2009). Therefore, medicine has a significant role in affecting disabled people's lives. In addition, medical professionals are not immune to the influence of societal understandings and attitudes towards "othered" groups (Janz, 2019, p. E478), like people with disabilities. Together this could explain why some of the interviewees encountered doctors who were opposed to mobility aids or other accommodations, and generally had different aims for their patients, like them not being disabled anymore, or having EDS not affect them, even though this was far removed from the realities of the interviewees, whose aim was to increase quality of life. As disability studies scholars have emphasized, it is significant for medical curricula to include perspectives of people with disabilities (Janz, 2019) to ensure the biomedical conceptualization of disablement as "personal medical tragedy" will be discounted (Campbell, 2009, p. 221).

6.2. Experiencing Bias & its Impacts

A pervasive Tale: Hysteria

The hysteria discourse is pervasive and deeply entrenched with meaning, as it is a value-laden concept (Jones, 2015). It is not confined to medicine but has expanded into wider society and entrenched our culture. The narratives of “hysterical women”, show them overly sensitive and emotional, effectively at the mercy of their bodies (particularly their reproductive organs and menstrual cycle) and minds (Young et al., 2019), or as malingering even. To this day it is invoked to discredit women or to ‘prove’ that they are physically and especially mentally not fit to hold positions of power (Frasca et al., 2022; Neville-Shepard & Nolan, 2019; Vales, 2017), in politics and beyond.

Hence, it is not surprising that it would still be relevant in the medical context where it first originated, specifically in the patient-provider encounter. The lingering discourse was detected among the narrations of the interviewees, and while four of them directly refer to hysteria or hysterical in different ways, the significance of the discourse can also be identified as a red thread throughout other interviews.

Women are portrayed as hysterical in much of medical literature (Hoffmann & Tarzian, 2001). Young and colleagues (2019, p. 337) have examined clinicians’ discursive construction of women with endometriosis and found they “were constructed as reproductive bodies with hysterical tendencies”. A literature review about gendered norms towards patients with chronic pain also demonstrated women are still perceived as hysterical, emotional, and accused of either fabricating their story, or their pain is attributed to psychological causes (Samulowitz et al., 2018). However, I have not been able to link the hysterical discourse with other studies that examine women and people’s lived experiences with EDS.

An Odyssey of Female Pain

Pain is a central subject on which grounds the women, trans- and non-binary people in the study are distrusted, dismissed, and disregarded. This is where I could most clearly identify the biased behaviour the interviewees encountered. I found four patterns about female pain: disbelief, trivialization, normalization as a natural part of the female reproductive life, or attribution to mental health.

I want to draw parallels between my findings and Krebs & Schoenbauer’s (2020) study on women’s experiences of endometriosis diagnoses. The authors found two dominant paradoxical discourses in the women’s narrations, namely a discourse of psycho-abnormality

and a discourse of biological-normality. In the psycho-abnormality discourse, their symptoms are “all in their heads”, which disqualifies women from being rational patients who can narrate their bodily experiences to medical professionals, instead they are considered insane. In the biological normality discourse, symptoms are “just part of being a woman”, and are effectively naturalized, instead of denied (Krebs & Schoenbauer, 2020). The four patterns I identified in the data can be assigned to the discourses. The interviewees' pain being either disbelieved or attributed to their mental health can be viewed through the discourse of psycho-abnormality. On the other hand, their pain being trivialized or normalized as part of the female productive life can be considered through the biological normality discursive lens. EDS is not a gynaecological disorder like endometriosis, yet interviewees are still confronted with normalization of pain, like when Rachel mentioned her “excruciating headaches every day of my life” and the neurologist asked if she had considered it might be her period.

Medical discourse has played a relevant role in normalising female pain, however, it is also rooted in literary works, most significantly the creation story in the book of Genesis. When Eve eats the forbidden fruit and convinces Adam to do the same, god punishes her and all women that follow with reproductive pain during childbirth, and though the passage does not reference menstrual pain, it extended to include menstrual maladies over time (Krebs & Schoenbauer, 2020). Tuana (1993) demonstrated Western medical thought was influenced by religion and superstition, such as the curse on Eve.

The analysis found the interviewees had trouble accessing and receiving proper pain medication for their symptoms. This corresponds to the results of a systemic review that found that women, compared to men, are prescribed less and less effective pain relief medication (Samulowitz et al., 2018). Furthermore, while women are more likely to seek treatment for chronic pain, they are less likely to be treated adequately by providers (Hoffmann & Tarzian, 2001).

Four interviewees from the US were accused of drug seeking when reporting their symptoms. This can be considered contextually through the US opioid epidemic, an escalating nationwide public health crisis (Lyden & Binswanger, 2019). Nonetheless, the overall levels of distrust against the interviewees were not limited to the US.

Trans Dimension

Carter and Orion had noteworthy experiences to add, as they both transitioned. According to Orion’s account, they did not see noticeable changes after transition, compared to before,

however, this could be related to Orion not having a great deal of EDS-related care before transition, as well as a comparatively shorter diagnostic delay for Orion, who was diagnosed relatively young compared to Carter.

Carter could identify significant differences between when he was still perceived as a woman and when he was read as a man after his transition. Especially his trustworthiness as a patient and “reliable narrator” of his own body has changed. Where before, he was treated as a “hysterical woman” who was seen as depressed, stressed and too sensitive to pain, he is now a “reliable witness” to his own body.

Consequences on Mind & Body

A previous study on EDS patients has shown 43% of respondents with ongoing needs have experienced institutional and provider betrayal in the past (Langhinrichsen-Rohling et al., 2021). This corresponds with my results, as I identified four interviewees who I conclude have experienced significant levels of IB, resulting in anxiety, PTSD, depression and trauma around the medical institution. According to the analysis of what they have confided in me, other interviewees also withstood IB, but to a lesser degree.

The literature shows inconclusive findings, as Langhinrichsen-Rohling and colleagues (2021) have not found significant differences in PTSD, anxiety, and depression among the respondents with IB compared to those without. On the other hand, a study into IB in the Canadian medical system has found associations between Canadian adults with chronic medical conditions who experienced IB and depression, dissociation, and anxiety (Tamaian & Klest, 2017). In addition, this can then affect physical well-being, according to Bulbena (2021) who found psychological processes such as fear, emotional distress or negative emotions significantly impact EDS outcomes.

The physical impact of gender bias, specifically from diagnostic delay, is hard to quantify. Approximately half of the interviewees believe experiencing dismissal and diagnostic delay has affected their physical health in the long run. Compared to other chronic illnesses such as diabetes or cancer, a delayed diagnosis for EDS patients does not lower life expectancy, but it was found that among hEDS patients, diagnostic delay was a predictor for severe pain, hence diagnostic delay led to increased pain (Kalisch et al., 2020) Furthermore, when people with EDS are misdiagnosed, they may be exposed to risky treatment like surgery, hence “[w]ithout the right treatments, patients’ quality of life is seriously altered” (Hamonet et al., 2016 as cited in Kalisch et al., 2020, p. 2).

6.3. Intersecting Identities & Access

All of the interviewees in this study found themselves at the intersection of gender and disability, trying to navigate a system of power that is misogynistic (Mercer, 2018) and ableist (Janz, 2019), bearing in mind “medicine functions according to the basic idea that ‘healthy’ is ‘normal’ and ‘unhealthy’ is ‘abnormal’” (Neilson, 2020, p. E411), and it had, through normalizing processes, been productive of the very labels of “disabled” and “abled”.

Limited Diversity of Population Sample

It was a challenge to find women and people AFAB to interview that were at different intersections of systems of power. The majority of respondents to the survey were white Americans. There was very little ethnic diversity among the survey respondents; the vast majority were white. This corresponds with other studies on EDS patients, where, if ethnicity/race is listed which often it is not, there is a proportion of between 90,9 – 95,3 % of white participants (Murray et al., 2013; Nee et al., 2019; Schubart et al., 2019). Nonetheless, considering there should be no racial or ethnic prevalence (Germain, 2007; Tulika & Kiran, 2015), this opens the question of who can access diagnosis in the first place and who feels willing to reach out to a participation call.

As the respondents were from various countries, it is difficult to make claims about the over- or under-representation of ethnicities in the survey population. The majority of respondents were Americans, and the US has a more diverse racial make-up, with Hispanic or Latino (18,9%) as second, and black or African American (13,6%) as third largest group (U.S. Census Bureau, 2022). Nonetheless, as I have approached possible respondents via Social Media, this could also to a degree explain the relatively similar respondent sample.

Of the participants I was able to interview, all had lived and been treated in high-income countries that are considered Western nations. I could not recruit any individual receiving care in non-western countries, or under a different medical tradition than Western biomedicine, even though EDS is found all over the globe (Beighton, 1970). Lastly, 90,38 of survey respondents have indicated having hEDS, which aligns with the literature stating 80-90% of EDS cases have hEDS (Tinkle et al., 2017).

Relevant Social Categories in Medical Encounters

The interviewees indicated that among the categories that I initially considered relevant –

(perceived) gender, ethnicity, class, sexuality – they also found their mental health status, disability, neurodiversity, body size, age and education as relevant in their medical encounters. In the analysis, I found it is hard to extract which social category is affecting the interviewees' treatment, especially if they have multiple marginalized identities, which aligns with the concept of intersectionality that shows that the categories cannot and should not be considered in isolation (Crenshaw, 1989). I also identified an awareness of privilege, which is the flip side of oppression, among some of the interviewees, who considered them being white, and partly their class as relevant in their access to care.

The more “boxes” an interviewee checks, the more complex their situation can become. Tee as a black American AFAB is strongly aware of the medical racism that black people have endured in the US in the past, and ongoing racial health inequities. The exploitation of enslaved black people who were experimented to further US medical education and medical specialities in the 19th century and the eugenic laws of the 20th century that overwhelmingly targeted women of colour, and forced involuntary, coercive and compulsory sterilizations are only two examples of a long list of practices marked by racial injustice (Nuriddin et al., 2020). The legacy of centuries of slavery, segregation and ongoing white oppression restricts black Americans' access to socioeconomic resources, adequate health care and health outcomes (Feagin & Bennefield, 2014). Racial health inequities in the US are pervasive to this day (Nuriddin et al., 2020). For instance, medical students still hold beliefs about biological differences between black and white people, like black people having less sensitive nerve endings (Hoffman et al., 2016). Tee knew of the high mortality rates for black women in the US, who are three to four times more likely to die from a pregnancy-related death than white women (Howell, 2018). To contextualize, the US has the highest maternal mortality rate among developed nations (Commonwealth Fund, 2020). On top of their identity as black person, Tee is disabled, queer and non-binary, has multiple health conditions, and limited financial resources. With all of these social categories intersecting, Tee's risks of maternal death would have increased even more. This is an example of how these types of identity categories can affect people's health outcomes.

The two trans people I interviewed, Orion and Carter, both reported they did not have outward transphobic experiences within the medical system. This is a positive finding, which is not corroborated by other research (Grant et al., 2011; Safer et al., 2016; Tami et al., 2022)

Access to Insurance & Diagnosis

Lastly, it was demonstrated that intersecting identities did not only play relevant roles in the patient-provider interactions but also the access to resources, mainly access to insurance and a proper diagnosis. Insurance played a significant role for most of the interviewees. Tee and Claire both experienced a time when they had no health insurance coverage, so they could not seek help in the first place, worsening their health. This is a reality for many people in the US, where it was estimated that 31.6 million (9,7%) people of all ages were uninsured in 2020 (Cha & Cohen, 2020). Individuals with incomes under a certain level below the poverty line are eligible either for Medicaid or marketplace insurance, which the US government regulates on the state and federal level. Medicaid in most states provides health care coverage without premiums and deductibles, while marketplace coverage requires premium contribution but also offers federal subsidies at lower incomes (Bhanja et al., 2021). However, people insured through Medicaid or marketplace insurance have greater difficulty accessing providers because of narrower networks (Hsiang et al., 2019; Polsky et al., 2016). In addition to these barriers of finding care, it is even more challenging to find a provider that has experience with EDS patients.

Even if interviewees were (privately) insured, they still faced financial struggles because of health care bills, as certain treatments are considered experimental and thus not covered, or what Carter calls EDS “maintenance”, such as continuous physical therapy or Botox injections against migraines. Two interviewees did not refer to insurance as a subject of concern, with one being from a high-income background in the US and the other living in Germany.

Lastly, the significance of receiving the correct diagnosis is pronounced among the interviewees, as it allowed further access to doctors, specialists, treatments, symptom management and other relevant resources. One study found diagnostic delay for hEDS patients led to increased pain levels, showing that patients' health status and quality of life can be impaired by prolonged diagnostic delay (Kalisch et al., 2020) or misdiagnosis that has to be corrected.

7. Conclusion

Western medicine, with its persuasive origins in Ancient Greece, is not as impartial and value-free as commonly assumed, but is “every bit as social and cultural as it is scientific” (Cleghorn, 2021, p. 1). The female body was ‘othered’ by medicine for most of its history (Bigg, 2023),

making women and people AFAB marginalized genders. In recent years, there is growing attention towards persistent health inequities between women and men in health care, referring to gender bias in medicine as a relevant phenomenon (Hamberg, 2008).

To answer the MRQ of how women and people AFAB diagnosed with EDS experience seeking care within Western medicine, I examined the lived experiences of the interviewees on how they encounter power, gender bias and intersectionality when accessing medicine. EDS, a connective tissue disorder, affects collagen and with it the structure and function of tissues and organs (Gensemer, 2022), making it a complex multi-systemic condition with an array of diverse symptoms.

The questionnaire produced insights of the reached study population, such as the diversity in gender identity, and the predominance of hEDS. Moreover, the majority of participants were from anglophone countries, and all were from Western nations. When asked what part of their identity influenced their care, the most frequent answer of respondents was being a woman or AFAB, demonstrating the significance their (perceived) gender had.

The disease burden of the interviewees included physical impacts through pain and other EDS symptoms that affect quality of life. One of the key findings was how HRT eased the symptoms of people who transitioned holistically. As I could not find research on trans people with EDS regarding how transitioning influenced their symptoms, this could be a relevant study direction for future research. The administrative burden of being disabled and having a chronic disease was an important subject. A notable insight was that the medical administrative burden of one of the interviewees halved after he transitioned to a man. Here, the (perceived) gender affected how medical staff interacted with the patient. Ultimately, the theme contextualized the extent to which the interviewees depend on their providers, and in the wider perspective, Western medicine, for their existence.

Access, Medicine & Power

In reference to RQ1, which sought to answer what significance power has in the experiences of women and people AFAB diagnosed with EDS when accessing medicine, the findings showed that power was a dominant red thread in the narrations of the interviewees. It was exercised in different forms, most strongly through the power/knowledge nexus. I classified three forms of knowledge from the data: (1) medical knowledge, (2) bodily knowledge and (3) collective knowledge. Patients now can access collective knowledge, which includes scientific literature online, and shared knowledge in online patient spaces. This shifts the previously rigid

power/knowledge nexus, as now patients are not exclusively relying on knowledge their physician chooses to share with them (Bristowe & Harris, 2014), making the medical consultation a continuous negotiation of power/knowledge.

Two interviewees experienced the effects of Western medicines' patriarchal and paternalistic power-laden characteristics (Shai et al., 2021) when they encountered resistance to their hysterectomies, affecting their power over their bodies. I identify here also the legacy of ancient Western medical beliefs that a women's sole purpose was childbirth (Cleghorn, 2021), and thus the uterus is placed above all else.

Lastly, Western medicine's normalizing power, which is a productive form of power, defined what is 'normal' and 'abnormal', and created ableist standards some doctors impose on their patients, putting what they strive for above the patients' health. This can also be considered in relation to governmentality, how the body populace is regulated via institutions of governmentality such as medicine to optimize the population.

Experiences of Gender Bias in Medicine

Further, this study pursued answering RQ2, by exploring the reports of women and people AFAB diagnosed with EDS regarding their experiences of gender bias when seeking medical care. The findings show that the interviewees experienced bias, and the 'hysteria' discourse, which is alive and well in the narrations of their experiences during the medical encounter, had a vital role in it. Though four interviewees were directly confronted with 'hysteria', it was concealed but present throughout most of the interviews. It is one example of how pervasive these old narratives can be, as they are still counted as proof of women's inferiority to men, and even used to justify keeping them from positions of influence in society.

Pain is a central subject in the interviewee's experiences of gender bias, with four patterns being identified: female pain being disbelieved, trivialized, normalized, or attributed to mental health. Drawing on Krebs & Schoenbauer (2020), I classified them under the biological-normality and psycho-abnormality discourse. All interviewees have experienced this, leaving them in a state of powerlessness, dependent on an institution that did not provide the care it should.

This impact can be subdivided into psychological fallout – feeling hurt, angry, dehumanized, inferior or worthless – and four interviewees encountered stronger consequences, namely anxiety, PTSD and depression, related to their healthcare experiences. I argue they experienced significant levels of institutional betrayal. Another key finding was how

one interviewee was treated as reliable witness to his bodily experiences only after transitioning from a woman to a man.

The interviewees' physical health also suffered, especially through diagnostic delays which prolonged the time until they could begin treatment or access accommodations. A recent study also found diagnostic delay was associated with increased pain experience (Kalisch et al., 2020).

The Role of Intersectionality

Lastly, the studies inquiry to answer RQ3, which sought to explore the significance of intersecting identities on the interviewees' experiences, found that the various systems of power that they inhabit influenced and impeded their access to medicine and quality care. All interviewees found themselves on the gender and disability intersection. Other categories indicated as relevant were ethnicity, class, sexuality, mental health status, neurodiversity, body size, age, and education. Social categories were hard to extract from one another, but as the intersectional framework argues, interlocking systems of oppression and power cannot be separated (Crenshaw, 1989). The interviewees simultaneously exercise privilege and undergo oppression. In addition, the more an interviewee finds themselves in social categories that are commonly marginalized, the more the discrimination stacks onto each other and compounds into a complex, multifaceted situation.

Intersecting identities also influenced the interviewees' access to health insurance and official diagnosis. Two interviewees had no access to health insurance for a certain timeframe, which negatively influenced their health. Even interviewees in North America who did have health insurance, struggled with paying medical bills, partly because some EDS treatments are considered experimental, and thus not covered, and partly because patients with EDS need continuous care, which is not always covered by insurance. Finally, access to official diagnosis is central, as it allows further access to specialists, treatments, accommodations, disability, and other relevant resources for the interviewees.

Closing Remarks – Outlook for Future Research

Western medicine, as a system of power and a vital institution of governmentality, has played a constitutive and reinforcing role in the structuring of society, normalizing who was deemed as the 'normal' human – thereby rationalizing unequal access to power - and who was 'othered', thereby excusing their oppression. It produced women's inferiority as a

biological ‘fact’, justifying patriarchal power relations where women had less access to economic wealth, political power, and other resources. These power hierarchies still structure our society beyond the category of gender, but also class, ethnicity, and other social locations.

Specifically on the subject of EDS, which as the odyssey of pain from my interviewees showed, is still hard to be diagnosed. The role of HRT and sex hormones in the manifestation of EDS symptoms is a relevant field of potential future inquiry. One wonders if the group of disorders were better understood, more studied and easier identified in the medical community if EDS would not predominantly be diagnosed in women and people AFAB since female prevalent diseases are underfunded (Mirin, 2021). Here we can also consider the influence of governmentality of the state on the trajectory of medical science through funding decisions. When funding bodies prioritize male predominant diseases and underfund diseases more prevalent in females, it upholds a status quo where medical research is androcentric, and ‘othered’ bodies are neglected. Thus, it is not merely the research interest of medical researchers and the medical institution at large that are relevant in determining research trajectories, but also governmentality techniques.

My research was operating within global power structures, that are dominated by the West. I found much of the literature on EDS was conducted in the anglosphere, showing where the discourse is mostly centred, and the research population in these studies reflected this. Overall, I noticed a central aspect in my research inquiry was silence, and how who I was able to reach and who felt empowered to speak to me defined to what extent I could integrate intersectionality and what voices I was able to amplify.

I want to emphasize that, although my study is focused on the interpersonal level where patients meet their physicians, I do not see gender bias in medicine as positioned solely there. Ideally, an approach to strengthen Western medicine in female health beyond bikini medicine has to be considered on all levels. On the individual level of power – where patients meet their physicians who could harbour implicit or explicit bias –, on the institutional level – where biomedical research has ‘othered’ female bodies –, and on the structural level, meaning the wider and intersecting systems of power in our society, such as racism, or classism.

Ultimately, Western medicine must deconstruct pervasive beliefs about women and the female body that are still present in medicine, through the hysteria discourse or the exclusive focus on reproduction and bikini medicine in female health. Further, there needs to be more understanding of the normalizing role Western medicine played in how the female body and mind were ingrained in Western society, with some of these beliefs still visible today.

This issue goes beyond the female body and applies to all bodies that do not conform to the medically constructed understanding of the 'norm' which medical inquiry is still centred around. I argue this does not align with what we can expect from advanced state-supported and -regulated medicine of the 21st century. Society has the right to influence this trajectory, as medicine does ultimately not belong to medical professionals, but to the individuals it is supposed to care for.

8. Reference List

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Appendix

Questionnaire

For my master's degree in International Relations at NMBU in Norway I am conducting a study to explore the experiences of *women & people assigned female at birth* who are diagnosed with **Ehlers-Danlos Syndromes (EDS)**. I aim to examine their experiences with the medical institution and medical providers. This includes their journey from the onset of symptoms to the diagnosis and the treatment they have received after.

If you are interested in participating in this study, I would appreciate it if you could answer this brief survey about yourself. It will take less than **5 minutes** to complete.

- Your data will be safely stored and will only be accessible to me and my supervisors. You can contact me at any point to ask for the deletion of your personal data.
- In my research, your data will be anonymized & can't be traced back to you in any way. No one will know you have participated in the study.
- None of the answers will be used for discriminatory purposes.
- Your participation in my research is voluntary. You may withdraw your participation at any time during the process, without any consequences.
- The data & results of this study will be used exclusively for scholarly purposes.

If you have any questions upfront, please email me under anja.stelzer@nmbu.no

If you click on "Agree" below, you indicate the following:

- You have read the information above
- You voluntarily agree to participate in this study
- You are at least 18 years of age

- Agree
- Disagree

What is your assigned sex at birth?

- Female
- Male
- Intersex
- Prefer not to disclose

Which gender identity do you most identify with?

- Woman
 - Man
 - Non-binary
 - Transgender woman
 - Transgender man
 - Prefer not to disclose
 - Not listed (answer in next question*)
- (*What gender identity do you most identify with?)

What is your nationality?

How would you best describe yourself? Choose as many as apply

- Caucasian/white
- Latinx/Hispanic
- Middle Eastern
- African
- North African
- Caribbean
- South Asian
- East Asian
- First Nations/Indigenous
- Prefer not to disclose
- Not listed (answer in next question*)

(*How would you best describe yourself?)

In what country/countries have you received medical care because of EDS?

What type of EDS were you diagnosed with?

Do you believe that certain aspects of your identity had an influence on the experiences you had and the quality of care you received during medical encounters? If so, please name them (you can choose multiple)

Would you be willing to conduct an online interview to further participate in this study?

- The interview will take around 45 minutes, and you do not need to prepare for it in any form. It will be conducted online via Zoom or Microsoft Teams.
- The questions I will ask are about your EDS journey from the onset of symptoms, to a diagnosis and the treatment after. Then we will talk about your experiences with medical providers in more detail. Lastly, we will end the interview with some demographic questions, like your age or occupation.
- With your consent, I will record our interview, and later transcribe it.
- All information about you will be anonymized in my research. This means that nobody will be able to trace the research back to you.

Yes

No

Interview Guide A

(Gender Bias Identified by Interviewee)

Introductory Questions

1. Can you tell me about your journey with EDS? (→onset of symptoms, diagnosis)
2. How long from onset of symptoms to diagnosis?
3. Has something changed for you since you have received the diagnosis, specifically in medical encounters?
4. What has diagnosis meant for you?
5. What are the most challenging aspects about having EDS? Symptoms

Experiences with medical providers

6. What has been your general experience with your medical providers with regards to EDS?
7. Do you believe you have experienced biased or discriminatory behaviour on the basis of your sex and/or gender in medical encounters?

Sex/Gender Bias identified by participant

8. Could you elaborate on this? Would you tell me about some of the experiences that you have had with medical providers that left you feeling exposed to bias or discrimination based on your sex and gender?

If not discussed before:

9. How did these situations affect you?/ What were the consequences of these challenges?
10. When you found yourself in such a situation how did you navigate it?
11. Did you find a way to reduce these challenges in future interactions from your end? How?
12. Do you believe that other aspects of your identity beyond your sex/gender might have had influence on your experiences with the medical system? What aspects?
 - a. [Do your providers accept your gender identity?]
13. Do you consider yourself disabled?
14. In your medical interactions, was there any differences you can identify in the treatment you received by doctors considering their gender?
15. To what extent do you think that your sex/gender impacted not only patient-provider-interactions but your medical treatment and health outcomes?
16. Do you have trust in your current medical providers? Why?
17. Do you have health insurance? Did you ever have trouble paying medical bills?
18. What do you believe could be done to improve the experiences of women or marginalized groups in the future? From the end of the medical institution, policies, politicians
19. What else would you like to share with me? Was there anything missing that you would have liked to discuss?

Demographic questions

20. How old are you?
21. What is the highest degree or level of education you completed?
22. Would you consider yourself in a high, middle- or low-income situation?
23. What do you do for a living?

Do you have any questions for me before we end this interview?

Interview Guide B

(Gender Bias not Identified by Interviewee)

Introductory Questions

1. Can you tell me about your journey with EDS? (→onset of symptoms, diagnosis)
2. How long from onset of symptoms to diagnosis?
3. Has something changed for you since you have received the diagnosis, specifically in medical encounters?
4. What has diagnosis meant for you?
5. How would you describe EDS to someone that has never heard about it?
6. What are the most challenging aspects about having EDS?

Experiences with medical providers

7. What has been your general experience with your medical providers with regards to EDS?
8. Do you believe that you have experienced biased or discriminatory behaviour on the basis of your sex or gender by your health care providers?

Sex/Gender Bias not identified by participant

9. Could you elaborate? Do you think there are specific reason for this?
10. Do you believe that your sex or gender played a role in your medical encounters?
11. Generally, do you believe women and men [people categorized by providers as women and men] are treated the same by medical providers? Why?
12. In your medical interactions, was there any differences you can identify in the treatment you received by doctors considering their gender?
13. Do you believe that other aspects of your identity (such as race, class, national origin) did have any influence on your experiences with medical providers?
Elaborate
 - a. [Do your providers accept your gender identity?]
14. Do you have trust in your current medical providers? Why?
15. Do you know other women (people assigned female a birth diagnosed with EDS who have informed you about any bias or prejudice they have experienced because of their sex or gender?
16. Do you have health insurance? Did you ever have trouble paying your medical bills?
17. What else would you like to share with me? Was there anything missing that you would have liked to discuss?

Demographic questions

18. How old are you?
19. What is the highest degree or level of education you completed? How many years of education did you complete?
20. Would you consider yourself in a high, middle- or low-income situation?
21. What do you do for a living?

Do you have any questions for me before we end this interview?



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