

**BARRIERS AND FACILITATORS TO UROGYNECOLOGIC CARE:  
AN INVESTIGATION INTO PATIENT, PROVIDER,  
AND STRUCTURAL FACTORS  
INFLUENCING ACCESS  
AND TREATMENT**

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by  
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## ABSTRACT

As a healthcare provider focused on women's health, injustice is something that I see in my patients' experiences daily. The reasons behind the injustice go far beyond the walls of the hospital. They are related to provider awareness and training, patient access and cultural ideals, as well as structural bias against women, specifically non-English speaking women and women of color. They exist in an entangled web, in which the compilation of multiple factors results in further bias and further distance between the actual care the patient is in need of and the care they receive. My planned future role is to be a provider in Urogynecology, and I will be starting my fellowship in July 2024. This field has a unique lens into the care of women, spanning all ages, races, ethnicities, and education levels. So many women experience incontinence and prolapse, yet so few get help and present to care. Often in the literature, there is documentation that Black and Brown women do not have these issues as frequently as White women. However, there is little acknowledgment of the role that race and culture plays in obtaining care, and how this view could be distorted given so few women feel comfortable speaking on the topic of incontinence and prolapse. This thesis investigates the possible reasons associated with either no presentation or late presentation to care for incontinence and prolapse, and questions whether the captured prevalence in the literature is the true prevalence in our population. I review the research that exists, both quantitative and qualitative, regarding care patterns, patient attitudes and cultural factors, provider knowledge and awareness, and structural factors that facilitate and hinder access to urogynecologic care. I then use an urban bioethical lens to further identify structural bias and racism within healthcare, and inform strategies that may be used to better patient knowledge and education, to

allow for more comprehensive and equitable care for women within the field of urogynecology.

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## CHAPTER 1

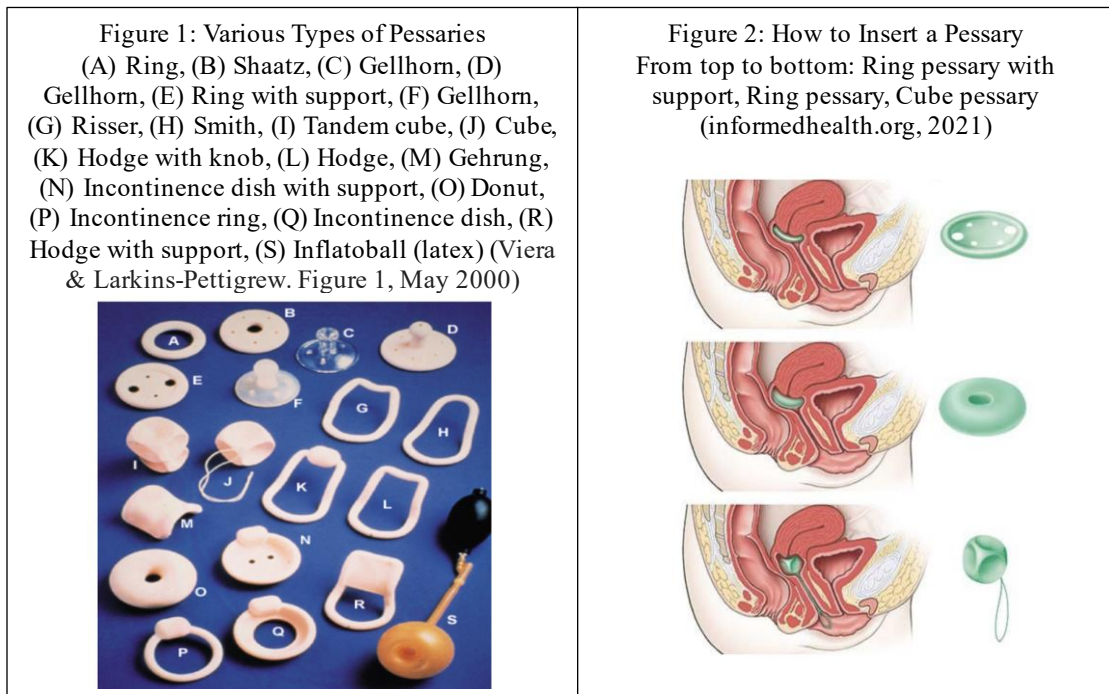
### INTRODUCTION AND OVERVIEW

#### **Section One: The History of Urogynecology**

Healthcare is not accessible to many people who need it. This was something I realized clearly in my transition from a fairly wealthy, affluent community that I helped to care for in medical school, to a community in North Philadelphia, where we have a 50% show rate in our residency run clinics. This is due a variety of factors, most commonly due to lack of access to childcare, transportation and lack of other social support. Those who are most affected by these factors are often women, and specifically women of color. My passion for women's health began in medical school, where I realized my determination, practice and care was most valuable when applied to women's health, and I decided to become an Obstetrician/Gynecologist (OBGYN).

Within the field of OBGYN there is one subspecialty, urogynecology, which I found to be incredibly rewarding, with almost immediate effect on quality of life for the majority of women. I will be using the term woman throughout this thesis, however not all patients who have the ability to have issues with incontinence and prolapse identify as women, and these problems are also prevalent in many other populations. This field was recognized as a distinct subspecialty in the 1980s and received accreditation as a fellowship by the graduate medical education programs in 2011 (Daneshgari et al., 2014). Use of pessaries, and mention of vaginal or uterine prolapse, however, has been documented in ancient Egypt. Treatments were implemented, such as succussion, recommended by Hippocrates, where the patient was flipped upside down and shaken, to

allow the prolapsing organs to return to their anatomic position with the aid of gravity (Reeba et al., 2011; Hedge et al., 2023). A half a pomegranate was used as an early “pessary” and placed in the vagina as described by Polybus, a Greek physician (Reeba et al., 2011). The first device purposefully made to be used as a pessary was created in the 16<sup>th</sup> century, as compared to naturally occurring objects, with the invention of various shapes and sizes of pessaries by William Fabry in 1592 (Daneshgari et al., 2014). There are numerous types of pessaries now used (see fig.1 and fig. 2 below).



With the invention of modern surgery and anesthesia, more options became available for the treatment of prolapse. Urogynecology has grown into a subspecialty of gynecology that focuses on treatment of urinary and fecal incontinence and pelvic floor disorders, including chronic pelvic pain and prolapse.

Urinary incontinence is a highly prevalent condition, affecting one to two thirds of women greater than or equal to 50 years of age in the U.S. (Grodstein et al., 2003; Jackson et al., 2006). The prevalence of symptomatic prolapse in the U.S is estimated at 2.9% (Wu & Vaughan et al., 2014); however, prolapse and incontinence are two of the most common indications for benign gynecologic procedures. Prolapse is the third highest indication for hysterectomy, and urethral slings for stress incontinence, with more than 338,000 surgeries annually in the U.S. (Hendrix et al., 2002; Wilcox et al., 1994; Wu & Matthews et al., 2014). Incontinence and prolapse become more prevalent as one ages and can greatly affect quality of life for many people. They are commonly associated with poor mental health and poor subjective wellbeing in women of all races (Townsend et al., 2014; Ghetti et al., 2015).

There are multiple treatments available for incontinence and prolapse. First line treatment options for incontinence include lifestyle modification plus pelvic floor physical therapy, with second line treatment of medication (depending on the type of incontinence). Surgical intervention is the third line option and definitive management for stress incontinence, specifically. For symptomatic prolapse, first line option includes pelvic floor physical therapy, second line option includes pessary (or if a poor surgical candidate), and third line treatment is surgery. Unfortunately, no treatment regimen has a guarantee of complete resolution of symptoms, but success for prolapse is anywhere from 75-90% with surgical intervention (Jelovsek et al., 2021). This success rate, however, decreases as time passes, and many patients will need re-operation. There is about a 60-80% success rate with surgical intervention for stress incontinence (Abdel-Fattah et al., 2022). These statistics highlight that the treatment options available in urogynecology

still need improvement, however some improvement is better than nothing, and therefore the available treatment options should be easily accessible to all women.

There is mixed data on the racial distribution of prolapse and incontinence, where many papers state that there is a higher prevalence of prolapse and incontinence among White women as compared to Black, Latina, Asian and Native American women (Townsend et al., 2014; Brito et al., 2021; Brown et al., 1997; Waetien et al., 2003). Some papers, however, report similar prevalence and severity of prolapse among Black and non-Black women (Bump, 1993; Sears et al., 2009). In all of these studies, notably, the percentage of Black women in the study population was <30%. Those studies that did show a decreased prevalence of prolapse among Black women are mostly population-based studies, which reinforces the assertion that the lower prevalence of prolapse in Black women is because of lack of representation in these studies (Brazell et al., 2013).

Prolapse and incontinence can significantly affect quality of life and has been associated significantly with mental health (Townsend et al., 2014). In looking at the difference in depression between Black women and White women, Townsend et al. found the prevalence of depression was found to be similar among White and Black women with urinary incontinence: however, they suggest that it was likely due to the small numbers of Black women in their study. The severity of depressive symptoms among Black women was higher, suggesting that with more Black women in the study a difference may have been found (Townsend et al., 2014).

Notably, although there is such a high rate of incontinence, one large population-based study showed that only 25% of women with incontinence seek care with only 23% receiving any type of care, and 12% receiving care by a subspecialist (Minassian et al.,

2012). For those who do receive care by a sub-specialist, often by the time that they present they have more advanced disease meaning a higher grade prolapse or more frequent episodes of incontinence (Minassian et al., 2012). This leads to worse symptoms and less responsiveness to treatments.

## **Section Two: Thesis Overview**

In my training as an OBGYN resident at Temple Hospital in North Philadelphia, the majority of patients I see in clinic and the operating are women of color, mostly Latina and Black women. This population is often poorly represented in academic literature and studies.

When noticing the difference of captured prevalence in the literature compared to my own experience of actual prevalence seen in our resident and hospital clinic, I decided I wanted to help elucidate why this occurs. My hope is that if we can better identify the true population at risk, can we find a way to get those women into care and hopefully impact a larger number who need the services that urogynecology can offer. This thesis will present a thorough investigation of the barriers and facilitators to getting into urogynecologic care. With a focus on improving access to care for underrepresented women, I will use an urban bioethics lens to support discussion of three particular areas of possible intervention. I will first discuss barriers and facilitators related to provider care, specifically investigating provider biases, basic knowledge regarding care within the field of urogynecology and differences in referral rates. I will then move on to discuss factors related to the patient including patient's baseline knowledge of the field, cultural differences, such as the ability to discuss gynecological issues, treatment adherence

related factors, societal norms that have been spread among communities as well as language barriers. I will end by investigating policy and structural related factors, such as time allotted for visits, reimbursement policy for hospitals, physicians, and patients, and most importantly racism, ableism and ageism within the healthcare system. It is clear from the literature that exists, that there is a significant difference in rates of diagnosis and treatment by race within urogynecology and to a larger extent gynecology. I aim to investigate the reasons why this occurs through an urban bioethics lens and attempt to find ways in which we can facilitate more comprehensive care for our patients.

## CHAPTER 2

### PROVIDER RELATED FACTORS

#### **Section One: Provider Knowledge**

When I decided to enter the field of urogynecology one of the first questions I received from friends within the medical community is, ‘what is that?’ It continues to be a question that I answer almost daily from both patients and other clinicians. In this chapter, I will focus on three main provider related barriers and facilitators to care within this field; provider awareness and knowledge of the field and referral rates, provider knowledge of urogynecologic problems and appropriateness in treatment, as well as provider biases. There are other factors that are related, such as geographic location or providers and medical training, provider ability to screen for incontinence and prolapse, as well as provider counseling abilities, which will all be mentioned within the discussion.

As mentioned previously, urinary incontinence affects one to two thirds of women in the U.S. (Hegde, 2023; Grodstein et al., 2003). One would expect that the majority of primary care providers will be in contact with patients with urinary incontinence. Primary care physicians (PCPs) play a major role in patient’s healthcare and access to other subspecialties, and are often the first contact of care for the patient. Therefore, PCPs must be familiar with a range of medical disorders as recognition is the first key step. Some providers may feel comfortable treating pelvic floor disorders on their own; however, it is important to recognize their limitations of knowledge and identify when a referral to a specialist would be the most appropriate (Minassian et al., 2012). An observational cross-

sectional study by Wong et al. (2019) explored this question and sent out surveys to over 800 family medicine and internal medicine physicians, assessing perceptions of pelvic floor disorders and familiarity of urogynecology as a sub-specialty. A total of 108 physicians responded and they found that PCPs were more familiar with incontinence and overactive bladder compared to pelvic organ prolapse and almost 1 out of 5 physicians were completely unaware of urogynecologists being present in their system. (Wong et al., 2019). In general, PCPs underestimate, under screen, and are not familiar with common treatments for pelvic floor disorders (Wong et al., 2019). This study also showed that only 27% of providers were very familiar with urogynecology and <50% would refer to urogynecology (Wong et al., 2019). There is likely selection bias within the study above, given the nature of survey-based studies, however assuming those who answered were likely those more interested in pelvic floor disorders, this then underestimates the number of providers comfortable and familiar with treatment of pelvic floor disorders. A prior study by Mazloomdoost et al. (2018), which distributed surveys nationally via the American Medical Association residency database for internal medicine physicians and family practitioners, received 391 responses and showed similarly, that almost 50% of providers were unaware of the field of urogynecology (Mazloomdoost et al., 2018).

Another interesting finding from the study by Wong et al. was that male providers were more likely to underestimate the prevalence of urinary incontinence and overactive bladder. In the study by Mazloomdoost et al., it was noted that male providers were less likely to have female patients report bothersome incontinence symptoms, which could possibly explain why male providers may underestimate the prevalence of these disorders (Wong et al., 2019; Mazloomdoost et al., 2018). Female providers were found to be more

proactive with diagnosis and management of continence issues (Dovey et al., 1996), and male providers were less likely to screen for prolapse symptoms or be approached by female patients regarding continence issues (Mazloomdoost et al., 2017).

## **Section Two: Provider Screening and Management of Pelvic Floor Disorders**

Notably, there is an association between management of urinary incontinence and years in practice for the provider. PCPs who had been in practice for >20 years were more likely to refer immediately (15%) as compared to PCPs who had practiced 11-20 years (5%) and 1-10 years (3%) (Wong et al., 2019). This finding could represent greater knowledge in the field of urogynecology for recent graduates or rather that those who have been in practice for longer recognize their own limitations and necessity for specialized management.

When investigating ways to increase rates of screening, diagnosis and treatment of incontinence, Eckhardt et al. conducted a prospective quality improvement multi-phase study. The study investigators looked at possible interventions including additional education for internal medicine residents regarding incontinence (physician-directed intervention) and placing posters throughout the clinic (patient-directed). The physician-directed intervention included a urogynecology fellow giving 1-hr lectures about incontinence, along with screening methods and treatments that could be started in the primary care setting (Eckhardt et al., 2022). This lecture was given to the internal medicine residents during their didactic sessions a total of three times to ensure all residents were exposed to the same level of knowledge. Additionally, a screening tool was added into the electronic medical record to help assist PCPs in remembering to

screen for incontinence at routine visits. Separately, a poster was placed in the clinic asking patients, “50% of women leak urine. Do you? Ask your doctor, we can help!” The results showed that the physician-directed intervention did not improve rates of screening. However, the patient-direct intervention resulted in a 2.5-fold increase in screening for incontinence (Eckhardt et al., 2022). This result raises more questions related to how to increase physician knowledge if the current tools used (didactic lectures) do not provide enough so that a PCP feels comfortable screening. How do we ensure that there is consistent and clear information about pelvic floor disorders provided to clinicians so they feel like they have ample credibility and agency in delivering this care to patients?

Although PCPs are important gateways for patients, often times gynecologists are the PCPs that women see for their general health needs. This means that general gynecologists should also have the knowledge and understanding of pelvic floor disorders and treatment. Given that general gynecologists are exposed to this field more closely in residency than general practitioners, one would think that more gynecologists feel comfortable treating or referring to urogynecology. Among general gynecologists, there is a wide range of comfort levels regarding treatment of pelvic floor disorders, mostly based on the complexity of the disease (Yune & Siddighi, 2013). In an observational study in 2013, it was found that the majority of general gynecologists who responded to the survey felt comfortable managing urinary incontinence and overactive bladder as well as prolapse (Yune & Siddighi, 2013). However, the majority of providers did not feel comfortable with management of fecal incontinence, intrinsic sphincter deficiency, recurrent incontinence after failed surgery, and complications involving mesh

after surgery, and more than half of those who responded to the survey had very limited access to subspecialty care with urogynecology (Yune & Siddighi, 2013). Interestingly, Yune and Siddighi did find that general gynecologists who had more experience (>10 years since residency) had more comfort performing a wide range of procedures that are commonly thought of as urogynecologic procedures as compared to younger surgeons (<10 years since residency) (Yune & Siddighi, 2013).

When dissecting the role race plays in urogynecologic care, there is an abundance of literature showing the significant differences noted in care that Brown and Black women receive as compared to White women, including differences in prevalence of treatment as well as complications following treatment. In a retrospective cohort study by Boyd et al., the investigators looked at women who underwent repair for apical prolapse (either vaginal colpopexy or abdominal colpopexy, both forms of prolapse surgery) and whether or not there was an association between race and/or ethnicity with route or surgery. They found that after colpopexy, Black women were more likely to need a blood transfusion OR 3.04 (95% CI 1.95-4.73) and have venous thromboembolism OR 2.46 (95% CI 1.1-5.48) as compared to White women. However, Black women were less likely to present with post-op UTI as compared to White women OR 0.68 (95% CI 0.49-0.96) (Boyd et al., 2021). Another study by Shah et al. (2007) looked at the racial characteristics of women undergoing surgery for prolapse. The investigators looked at the population-based data from the 2003 National Hospital Discharge Survey. The cohort was 67% White, 3.8% Black, 3.1% other and 25% race not stated. There were astounding differences in surgical injuries with 3.9% of White women having a surgical injury as compared to 20.2% of Black women and 7.1% other race (Shah et al., 2007). Infectious

complications and genitourinary complications were also more common in Black women as compared to White women. Total morbidity within the study was 19.4% for White women, 34.1% for Black women and 27.4% for other races (Shah et al., 2007). Similarly, in a study by Ringel et al. (2022) looking at disparities in complications by race after prolapse and incontinence sling procedures between 2010 and 2018, they found that Black women had higher odds of experiencing post-operative complication, particularly vascular complication, after prolapse surgery. The investigators did not find that this complication rate decreased over time, whereas the vascular complication rate for other races and ethnicities did decrease (Ringel et al., 2022). This difference persisted even after adjusting for possible confounders.

There is literature that exists that argues there are anatomic and intrinsic differences within the urinary and bladder system between White and Black women, that aims to explain the greater prevalence of incontinence in White women than in Black women (Howard et al., 2000). However, many of these studies have serious flaws. The study by Howard et al. shows no statistical significance, and concluded that there are functional and morphologic differences that exist in the urethral support system between races. This study was severely underpowered with a total of 35 participants, however, and fails to address behavioral and learned mechanisms that may affect pelvic contraction, such as accessibility of bathrooms and cultural differences.

When looking at these results, one wonders whether these differences in outcomes may be related to bias, or if there is some inherent difference between races that explain these drastic differences. Bias included provider biases regarding patient pain thresholds, along with baseline knowledge leading to inadequate counseling. There is likely a

component of systematic bias within the healthcare system, such as algorithms that are embedded into the literature and within the electronic health system which perpetuate health inequity, leaving Black and Brown women with limited access to proper care after surgery. As race is a social construct which often acts as a surrogate for other markers such as socioeconomic status, housing insecurity, access to adequate food supply and transportation (along with many other social determinants of health), it is likely that these differences are more so related to bias rather than true anatomical differences. We need to continually question the studies that incorporate race-based medicine, which then leads to further dichotomy in care for minoritized women compared to White women. When looking at the study by Howard et al. (2000), one also thinks about whether the studies that support anatomical differences between races has perpetuated the bias that providers have and therefore leads to lower rates of screening, inclusion, and exclusion of certain subgroups of people from obtaining the care they need.

## **CHAPTER 3**

### **PATIENT RELATED FACTORS**

The onus often falls on the patient to remember to ask specific questions at their healthcare visits such that all of their ailments are addressed. Too often, because of the necessity for patients to remember to voice specific concerns, providers are missing basic screening questions. This chapter will focus on patient-related factors that affect facilitators and barriers to urogynecologic care. I will first discuss data that shows that overall knowledge among patients regarding urinary incontinence and prolapse is poor. Often, when patients do have knowledge, it is based on advertisements by drug companies or surgical companies advertising their specific treatment, or information found on the internet (Fantasia et al., 2015). While the internet can act as a facilitator for patients, there is sometimes information that may mislead patients, as every patient is different and may be eligible for different treatments. I will then discuss other pertinent patient-related factors including cultural differences among different patient populations, specifically immigrant populations, along with patient understanding regarding counseling and ability to follow-up and time of presentation due to societal beliefs and cultural norms.

#### **Section One: Patient Knowledge**

Lack of knowledge about urinary incontinence and prolapse is very common among women presenting for primary care and is more common among women with low educational attainment, those who were unaware that incontinence and prolapse are

medical conditions, and those who have never experienced accessing care for incontinence or prolapse (Chen et al., 2019).

As discussed previously, many women suffer from urinary symptoms and pelvic organ prolapse. However only a fraction of these women presents for medical care due to these issues after the start of symptoms (Krissi et al., 2012; Hunter Koch, 2006). In a prospective cohort study by Krissi et al. (2012), the investigators found that the average length of delay (time from first symptoms start to presentation in clinic) was 43.8 months for both women experiencing urinary incontinence and prolapse symptoms. Patients had significant symptoms that affected their daily activities 41% of the time, yet they did not present for over three years to address the issue (Krissi et al., 2012). Within this cohort, 66% of women reported the delay was their own doing, often related to the embarrassment felt due to the stigma attached to their problem (Krissi et al., 2012). Women ultimately presented due to the worsening in severity of symptoms in 76% of cases and exposure to new information regarding pelvic floor disorders in 23% of cases. Interestingly, out of the total study population, 22.5% of women within this study reported that they believed the delay in care was due to their PCP, and 2.2% of the women blamed the medical system for the delay (Krissi et al., 2012).

In a paper by Shah et al. (2008), they looked at racial differences in knowledge about urogynecologic issues. Women who presented for their annual gyn exam were handed a questionnaire assessing knowledge about incontinence and prolapse. One hundred twenty-six women participated in this study. A total of 58 White women and 68 non-White women completed the questionnaire. The results of the study showed that White women may have improved urinary incontinence knowledge as compared to non-

White women ( $p= 0.019$ ); however, this result was not significant for knowledge of prolapse ( $p= 0.354$ ). In general, women had more knowledge about incontinence rather than prolapse. There were baseline differences among the women, with the majority of White women being nulliparous as compared to non-White women, and more White women had attended college as compared to non-White women. According to this study, the most common reason that patients did not seek medical help was because they did not know it was abnormal (Shah et al., 2008). Based on this data, it is clear that the healthcare system needs to find ways to educate more patients about normal and abnormal functions of the human body, specifically the genitourinary system. Given that there is a disparity in the amount of knowledge between races, additionally there need to be interventions that allow equitable access to this information for everyone.

## **Section Two: Cultural Beliefs and Attitudes towards Gynecology Care**

Less than 50% of women with incontinence will discuss these symptoms with their healthcare provider (Kinchen et al., 2003). Why is this? Is this due to cultural values that exist within our society that expect women to suffer quietly? Why is there shame associated with discussing a medical problem with people who are trained to diagnose and treat medical conditions? Urination is not a topic of discussion commonly expressed around dinner tables or gatherings, but perhaps this should be a topic that is more readily discussed freely to allow patients to feel comfortable at least discussing issues with their medical providers.

In a study by Roa et al. (2021), done in Canada, it was shown that there is a significant difference in knowledge about urinary incontinence and prolapse among

immigrant women as compared to Canadian women, even though urinary symptoms and prolapse symptoms were as prevalent if not more prevalent in the immigrant population. Within the United States, urinary incontinence is a topic that has become more widely discussed, although is still not freely spoken about among the general population. In Korean culture, urinary incontinence is considered to be completely taboo (Kang, 2015). Many prior studies have shown that Korean women who have symptoms of urinary incontinence are more reluctant to seek care from a professional (Kang, 2015; Minassian et al., 2003). This happens for many reasons as discussed above, but specifically within the realm of urinary incontinence, Korean culture views this as losing one's dignity because something that is supposed to be private suddenly becomes public when urinary leakage is seen (Kang, 2015).

In looking not only at urogynecologic care, but gynecologic care in general, there are many themes that arose when looking at barriers in healthcare for immigrant women. These themes include preference in having a female gynecology provider, timing of visits during times of pain or pregnancy only, lack of knowledge surrounding the basic care recommended within the field of gynecology in the U.S. (i.e., screening protocols), as well as language and transportation barriers (Kang, 2015; Mehta et al., 2018; Betancourt et al., 2013; Lee & Lee, 2017).

As mentioned above, one of the major themes identified was the cultural differences among immigrant women, where they believe there is little need to see a gynecologist outside of pregnancy or active pain. In a study by Mehta et al. (2018), that examined perspectives on gynecologic care of Congolese and Somali immigrant women living in Boston, it was expressed by women of both cultures that an exam without

having pain was not warranted (Mehta et al., 2018). Additionally, women would be looked at as having an affair or being sexually active if they presented to a gynecologist leading to false rumors about them within their communities. There is a stigma associated with the gynecologist, if a woman seeks routine preventative care that they are unfaithful to their husbands or “have done something bad.” Women reported as well that there is concern over modesty, that they should not be having a full examination of the pelvic region. There was a specific concern among Somali women about having a gynecologic provider that was familiar with female genital mutilation. There was also an interesting dichotomy noted in this particular study comparing the expectations of the provider for preventative health and patient expectation based on cultural expectations and values. There was a notable lack of personal agency among the women patients when talking about preventative gynecologic care (Mehta et al., 2018). While these studies look more so at general gynecology it is important to note that as previously elucidated, the majority of women who are able to obtain the necessary urogynecologic care obtain this knowledge through their gynecologist (Krissi et al., 2012). Therefore, if immigrant women are scared to present to the gynecologist, how do we capture and care for these women who have incontinence and prolapse if they do not present? We need to develop a set of systems that will encourage peer support in normalizing preventative gynecologic care for unmarried and/or sexually active women (Mehta et al., 2018).

There is a large amount of prejudice towards women’s clinics, specifically gynecology specialized clinics among the Korean population, as it is expected that women remain asexual until marriage and gynecology clinics are thought to be associated with women having sex (Lee & Lee, 2017). Timing of accessing care was a constant

theme throughout many immigrant populations. Similar to the African immigrant population in Boston, many Mexican women in New York City noted that the most opportune time to enter the U.S. healthcare system and integrate into routine gynecologic care was during pregnancy (Betancourt et al., 2013). There are biases that exist within Somali, Congolese and Korean culture, that accessing gynecologic care outside of pregnancy is either seen as unnecessary, unless experiencing pain, or as mentioned previously is associated with being sexually active and/or married (Mehta et al., 2018; Lee & Lee, 2017). Therefore, there is good evidence that we should be integrating pelvic floor screening and knowledge more frequently during prenatal care and in the postpartum period. Urinary incontinence is also highly prevalent among pregnant women, affecting 1 in 3 pregnant women (Liu et al., 2019). The current knowledge on pelvic floor disorders is overall poor among pregnant women, as found in a cross-sectional study by Liu et al., where overall knowledge regarding incontinence was measured at 46.2% and 35.3% for prolapse, with increasing knowledge associated with age and educational level (Liu et al., 2019).

Since there are more women captured in care due to pregnancy, there is advantage to begin education surrounding pelvic floor dysfunction during and immediately postpartum. By implementing early patient education during a time when many of pelvic floor disorders arise, we could significantly improve overall function, increase quality of life, and decrease future risk of incontinence and prolapse with decreased intervention both surgically and medically in one's lifetime.

### **Section Three: Language Barriers and Facilitators**

One of the most consistent findings is the inability for immigrants to access care due to language barriers (Mehta et al., 2018). In the context of language barriers, even when immigrants learn the native language of the country they have migrated to, the medical field has a unique “dictionary” of words that even native English speakers do not know, which makes it difficult for immigrants to clearly express their concerns. There is an additional frustration felt by immigrant women of Western medicine’s inability to recognize, validate and treat difficult and complex conditions such as pelvic pain (Mehta et al., 2018). Language is a key concept in allowing clear communication and if this taken away, it makes it that much more difficult to express one’s concerns.

In one study, a common theme found among Spanish-speaking women was that the bulge that they felt (prolapse) was cancer and that the interventions that were available (creams, pessary or surgery) would additionally cause cancer (Alas et al., 2016). The hesitancy and reluctance to accept the offered treatments played a significant role, as it was found that more Spanish-speaking women were hesitant to try a pessary and had worry about anesthesia effects of surgery. Additionally, Spanish-speaking women reports that they were offered Kegel exercises and pessaries more often as a first line treatment as compared to surgery than English speaking patients (Alas et al., 2016).

Addressing these challenges starts with the recognition that all women deserve care that educates them about their own bodies, and provides a medical response that makes them feel as comfortable as possible in a foreign situation. The challenge in helping women seek care, however, is that too often immigrant patients feel marginalized, misunderstood, or are concerned about the stigma of being judged poorly

by others in their culture (Mehta et al., 2018; Betancourt et al., 2013; Lee & Lee, 2017). To help encourage free discussion, it is pertinent for patients to have access to interpreters so that any concerns can comfortably be discussed without the patient feeling misunderstood and improper care being given. It is important to acknowledge, though, that even with an interpreter many Spanish speakers had a negative experience with medical staff or a physician, noting that their specific complaints were not being addressed and the interpreter was not translating correctly (Alas et al., 2016). In-person interpreters may help so that social cues can be read and real time adjustment can be made when interpreting.

## CHAPTER 4

### POLICY AND STRUCTURAL FACTORS

Much of the time spent navigating the healthcare system by patients and providers could be better spent by investigating structural and policy factors that can be remodeled or frankly abolished, such that providers and patients alike have more time to tend to the medical problems at hand. So much of medicine is dependent on a capitalist healthcare system that is reliant upon profit. When phrased like this, it can be better understood as to why providers and patients often have to look for alternative treatments because insurance requires a specific treatment first. This decision of what treatment is best, and who has access to such treatments should not be determined by insurance companies or hospital administrators, but rather by providers and patients. It should be as simple as if a patient has a medical problem, they can make an appointment, be seen within a couple weeks, and be offered all possible treatment options without limitation. Unfortunately, it is not this simple. Because healthcare is something that all people need, it can be used as a weapon or even held hostage to be made as desirable as possible and create as much profit as possible. The healthcare system that exists is one that was created within the scope of colonialism, with racism deeply embedded, and unethical medical experimentation on men and women of color (Khan et al., 2022). This is something that should be at the forefront of all medical research and understanding so that people are encouraged to have healthy skepticism when learning about different facets of the medical system. In chapter 4, I will focus on investigating insurance companies and coverage that exists for patients who desire treatment for incontinence or prolapse and

more broadly gynecologic care. I will also investigate how social determinants of health (access to stable housing, food, transportation, child care) can affect the treatment of women desiring urogynecologic care. I will dive a bit deeper into the history of racism, agism and ableism in healthcare and how this may affect women from accessing urogynecologic care. Lastly, I will discuss the normalization of incontinence in media and the effect of social influence on patients.

### **Section One: Coverage**

Twenty-nine million U.S. residents, many of whom identify as Hispanic or Black, have no prescription coverage or insurance (Conti et al., 2020). For those who do have insurance, many insurance companies and prescription plans require a prior authorization for certain medications, or require that one medication is first trialed before providing “the go ahead” to move to the next medication. This is seen with the coverage for the medications available for overactive bladder (OAB; previously urge incontinence). Oxybutynin (an anticholinergic medication) is considered first line treatment by many insurance companies, despite the fact that there is recent data to show that this medication is associated with an increased risk of cognitive decline or dementia (Raffeld et al., 2023). Despite this fact, many insurance companies first require a trial of oxybutynin prior to approving treatment with a B3-adrenoreceptor agonists, another medication that is as efficacious and safer for one’s cognition (Luchristt et al., 2023). Additionally, even when the insurance company does approve a B3-agonist, it is associated with a much higher deductible and co-payment leading to financial strain (Luchristt et al., 2023). It has been shown that a lack of insurance coverage was a major barrier in presenting to care

among those who receive their care at a public clinic as compared to patients who receive care at a private clinic (Smith et al., 2021).

Similar to those who identify as Brown or Hispanic in the U.S., a big factor in accessing healthcare for immigrants is limited by barriers to obtaining health insurance, which then requires money to pay out of pocket for services and medications they receive (Mehta et al., 2018; Barnes & Harrison, 2004). It was noted that some women did not even know they could obtain coverage for care, even when they resided in a state that provides more easily assessable care for immigrants or undocumented patients, such as Massachusetts (Mehta et al., 2018).

Another treatment option utilized in urogynecology is surgery. Many surgeries are often performed in the operating room; however, many can also be performed in the office. For patients who have insurance and choose a provider who is in-network to perform their procedure, there is still a risk they may end up with a large bill after surgery due to use of providers that are out of network on the day of surgery. In a retrospective analysis of commercially insured patients who underwent elective procedures at a facility that was in-network by an in-network provider, 20.5% of surgeries had a bill due to out of network care (Chhabra et al., 2020). The bill received was most commonly related to the surgical assistant or anesthesiologist being out of network with an average cost of \$3,633 and \$1,219 respectively (Chhabra et al., 2020). I was astonished with these values and was concerned about the number of patients who anticipate feeling relief after surgery, finally without incontinence or prolapse, only to have a large medical bill to pay afterwards. Many providers do not even know about these hidden fees, I did not until about three years into my training. We must be able to work within the system that exists,

however we can also envision a more inclusive system, in which the provider and the patient have agency in their choices.

## **Section Two: Racism, Ageism and Ableism in Healthcare**

Race is a social construct, which often acts a surrogate for other social determinants of health such as continued exposure to racial trauma, discrimination, systemic racism, and implicit bias that is pervasive in healthcare (Hailu et al., 2002). As mentioned previously, there are many treatment options available for incontinence and prolapse. A popular treatment used for OAB after lifestyle modification is medication, such as oxybutynin or B3-agonists. Oxybutynin has recently been shown to be associated with cognitive decline with long term use (Raffeld et al., 2023). In a study by Luchristt et al. (2023), they looked at whether patients race and SES were associated with receiving oxybutynin vs B3- agonists in a cross-sectional analysis of over 2 million patients. They found that patients who self-identified as non-Hispanic Black were significantly less likely to fill a prescription for a B3-agonist prescription than oxybutynin for OAB compared to non-Hispanic White patients (Luchristt et al., 2023). At baseline, non-Hispanic Black people are at higher risk for dementia than non-Hispanic White people. Therefore, the fact that a modifiable risk factor for dementia (i.e., medication) is prescribed more often for non-Hispanic Black people is evidence of inequity in pharmacologic treatment that results in harm, when B3-agonist offers comparable efficacy and outcomes for patients (Luchristt et al., 2023). The study posits the many reasons why this may occur, with the most relevant being the issue of insurance coverage, where many people who identify as Black and Hispanic do not have insurance or

prescription coverage as discussed previously, and opt for a treatment that will be less expensive (Luchristt et al., 2023).

In a surgical field such as urogynecology, there is much data out there looking at surgical outcomes following prolapse or incontinence surgery. Much of the literature shows an association with Black race and an increase risk of complication rates (Boyd et al., 2021; Shah et al., 2007; Ringel et al., 2022; Trowers-Cardenas et al., 2021; Kasey et al., 2020). However, some studies show no differences in complications, but show differences in the type of prolapse repair surgery performed (Winkelman et al., 2021; Rodriguez et al., 2023). In a retrospective study by Trowers et al., there were differences found in the type of urogynecology procedure performed, with obliterative procedures (i.e., closing the vagina) were more likely performed in Black, Hispanic and other minority women (Trowers-Cardenas et al., 2021; Winkelman et al., 2021). Obliterative procedures end up closing the vagina so that women are no longer able to participate in penetrative intercourse.

Racism within healthcare is further emphasized through ageism and ableism. Patients who are minoritized races, disabled and elderly often have the most difficulty navigating the healthcare system as the assumption is made that patients should easily be able to have the physical ability, mental and emotional intelligence to function at a certain level. When investigating disability, most often people think about physical disabilities, which can be limiting in obtaining healthcare access. This can include exam tables that do not move up and down, buildings without ramps on all entrances, limited access to wheelchairs, and many other equipment failures. The other aspect of disability that people do not discuss as freely is mental and emotional disability. This does not mean

that one has a mental health diagnosis, rather than many people have not been taught the skills to read and process information or emotion. A little over a third (36%) of U.S. residents have basic or below-basic health literacy (Magnani et al., 2018). The rate of health literacy declines as one ages and with non-English speakers (Berkman et al., 2011; Fleary & Ettienne, 2019). The implication of low health literacy is that when counseling patients on their diagnosis and treatment options, the shared decision-making model of healthcare, where the patient processes the information and chooses the treatment of choice, is limited (Perez-Stable & El-Toukhy, 2018). Additionally, when counseling patients, it is imperative to use language that is easily understandable so that there is higher adherence to treatment plans (i.e., physical therapy, medication) (Barvakova et al., 2023). There are many social factors that determine a patient's ability to obtain, understand and participate in their care. By acknowledging these factors, it encourages continual introspection within the healthcare system to provide more comprehensive and compassionate care.

### **Section Three: Social effects of incontinence as “normal”**

Urinary incontinence is not normal. Women present for prolapse sooner than women with incontinence as it tends to be more bothersome (Krissi et al., 2012). However, in addition to the lack of knowledge and stigma associated with incontinence, incontinence has been marketed as something that “happens with aging” which can be helped by wearing pads or diapers. While normalizing discussion of incontinence is pertinent, advertising incontinence as normal only furthers the amount of time it takes for women to present for treatment for incontinence. The media stigmatizes female

urinary incontinence and yet also encourages it to be normalized, fixed and avoided (Wanich, 2004). In the narrative interviews collected by Wanich, she documents just how much incontinence controls a person's life. They only drink a finite amount, they are aware of every bathroom around them at all times, they give up so much in their life to avoid embarrassment or humiliation in case of an episode of incontinence. While the media advertises pads and diapers as solutions to incontinence, advertisements about transvaginal mesh lawsuits from organizations are also prevalent (Koski et al., 2014). The media has slowly transitioned from advertisements on TV to social media avenues. With this transition, it was found that social media was 10 times more effective than search engine advertising on distributing information regarding treatment for incontinence (Bennett et al., 2022). Social media could be used beneficially, so that more information is spread throughout communities on problems such as incontinence and prolapse. If we can incorporate the narrative aspect of women's lived experiences with incontinence and prolapse with social media, it could make a larger impact on findings those who need care and providing that care.

## CHAPTER 5

### REFLECTIONS THROUGH AN URBAN BIOETHICS LENS

#### **Section One: The impact of Incontinence and Prolapse**

When beginning this thesis, my goal was to help identify barriers and facilitators to urogynecologic care. There is so much stigma surrounding urinary incontinence which creates fear for the patient on how to manage incontinence from a day-to-day basis and emotional distress (Mitteness, 1987; Dowd, 1991; Mason et al., 1999; Ghetti et al., 2015). So many people have evolved ways in which to live with incontinence and prolapse, such that they are actively planning for the next episode and integrating it in to their life as a part of their routine (Mitteness, 1987; Dowd, 1991; Mason et al., 1999). The role of the provider in my opinion is one that acknowledges the difficulties associated with incontinence and prolapse and to make the patient feel competent and capable of handling the difficulties that come with living with these diseases.

The patients that are seen in clinic are only a proportion of patients with incontinence and prolapse due to the factors related to patients themselves, providers, and the healthcare system (as described above). Imagining that there are many more patients out there who have the daily experience of having to cope with incontinence and prolapse and are unable or do not want to present to care due to the stigma or difficulty discussing this topic, is frankly unacceptable. There has been research investigating the treatments and perceptions of incontinence since the 1980s and although there has been improvement in the tools we have and surgical options, the largest problem that has still

not yet occurred in my view is the cultural shift of acceptance and acknowledgment of these diseases among the general population.

## **Section Two: Implementing Bioethical Principles to Enhance Patient Care**

Findings from this thesis show multiple ways in which we can increase facilitators and acknowledge barriers for urogynecologic care. When discussing provider related factors, I shared about many barriers in access to care including, but limited to, provider knowledge base, provider duration of practice, provider ability to screen and refer patients to appropriate care, and racism within provider practice. The length of practice of a physician and being a female provider was a facilitator for care for patients, as providers who were in practice for longer and providers who identified as female felt more comfortable screening and treating incontinence and prolapse (Wong et al., 2019; Dovey et al., 1996; Mazloomdoost & Westermann et al., 2017). The sexism and racism that is present from a provider standpoint, is partly embedded within the way physicians are trained and how the healthcare system does not actively aim to fix this. From an ethical standpoint, all providers should be adequately trained to at least screen for a disease that can so greatly affect one's mental and physical health. How do we ensure this happens? Providing additional lectures does not seem to be adequate enough (Eckhardt et al., 2022), and residents are constantly encouraged to learn and do more in a system that relies directly on their services at all times, leaving little free time to do such things. We need to encourage physicians currently practicing to screen more often. This could be done through social media campaigns, as it has been noted previously that social media has allowed a much further reach than regular media such as physical ads or TV. It would

also be something that could be started within one community by passionate physicians, ensuring that all clinics had a suite of appropriate information and expanded slowly to other surrounding communities (Eckhardt et al., 2022).

When investigating patient related factors to urogynecologic care, it was shown how knowledge of incontinence and prolapse as something abnormal was a key barrier in presenting for care (Shah et al., 2008). The effect of being unable to discuss incontinence or prolapse as is it related to anatomy that is often uncomfortable for patients to discuss with their friends, spouses and even providers makes it so that no care is provided for the issue, even if present. Unfortunately, too often a patient is unable to express their concerns due to language or cultural barriers, with many immigrant women feeling as though we perceive their disease differently than they do (Mehta et al., 2018; Alas et al., 2016). We must begin to use narrative medicine as a pathway into understanding the cultural attitudes of incontinence and prolapse, and to attempt to perceive a patient's story through their own lens. Too often providers change the story to a perception that fits into a specific model that healthcare has provided. We must allow for multiple voices to be present, with cultural understanding of what a certain disease means to a patient and the emotional and physical implications of a "embarrassing disease."

The structural and policy related factors to access of urogynecologic care, in my view, may be able to impact the community affected by incontinence and prolapse the most if change were implemented. Insurance is a difficult topic within healthcare, there is no current simple solution, but many patients and providers feel that insurance should not be the driver of treatment for patients. The most pertinent issue that affects patient care, is the racism, sexism, ableism, and ageism that perpetuates through all aspects of

healthcare. We must acknowledge that patients of different cultures, races, ages and sexes are treated differently, and data shows the effect of these disparities with minoritized patients receiving different treatments and experiencing different outcomes after surgery (Luchristt et al., 2023; Trowers-Cardenas et al., 2021; Kasey et al., 2020; Berkman et al., 2011). Patients must be able to access care and must be informed of the care available. Much of this relies on our society's duty to provide education to patients so that they may understand medical information. The healthcare system in the U.S. functions within a culture where the average level of understanding of basic health information is 36% (Mangnani et al., 2018) and yet I know that we as physicians do not always acknowledge this, as we are constrained by time of the visit and insurance liabilities. When we allow easy access to knowledge that can be understood at the level of education the patient has, the result is greater adherence to the treatment plan and greater patient satisfaction (Baryakova et al., 2023). Engaging our communities in healthcare classes, with specific topics of interest, may be one intervention that allows for time to really dissect and discuss uncomfortable medical issues. Ultimately, it is a combination of all these factors that would allow us to capture what I believe is a much larger true prevalence of incontinence and prolapse and encourage patients, providers and society to become more comfortable with this topic.

When applying these findings and data to my practice as a physician, there are multiple pertinent ethical principles; however, I believe the most pertinent is patient autonomy and patient agency. By encouraging more discussion around these topics of incontinence and prolapse, as suggested by Eckhardt et al. (2022), where a poster hung in the office encouraged more patients to ask about incontinence, we can provide more

appropriate screening for patients and offer possible treatment options. The agency we give patients by providing the baseline knowledge allows for an informed decision by the patient, and better their understanding of the significant life impact both incontinence and prolapse can have. This disparity in knowledge and access by race is also something that has to be acknowledged and actively fought against as the provider. We must ensure that all patients have equal opportunity to certain knowledge so that we are providing just care for all patients, without bias. Due to differing socioeconomic standing, certain patients have easier access to things such as transportation and child care, which can greatly impact one's ability to access care. Systems must adjust to incorporate social awareness and have options for these patients, such as vouchers for transportation or child care in the hospital, so that coming to a doctor's appointment is not something that seems unattainable. My goal in practice is to further elucidate reasons why presentation to care is so often delayed, and to adjust my practice to allow for increased visibility of these issues so that patients' can have the increased quality of life they deserve.

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