

**GENDER, RACE, CLASS AND THE NORMALIZATION OF WOMEN'S
PELVIC PAIN**

by

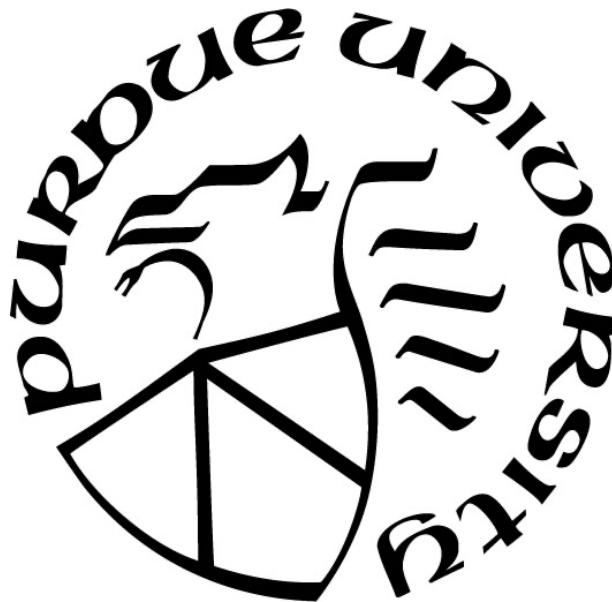
Stephanie N. Wilson

A Dissertation

Submitted to the Faculty of Purdue University

In Partial Fulfillment of the Requirements for the degree of

Doctor of Philosophy



Department of Sociology

West Lafayette, Indiana

August 2021

THE PURDUE UNIVERSITY GRADUATE SCHOOL
STATEMENT OF COMMITTEE APPROVAL

Dr. Brian C. Kelly, Chair

Department of Sociology

Dr. Christie Sennott

Department of Sociology

Dr. Trenton D. Mize

Department of Sociology

Dr. Andrea DeMaria

Department of Public Health

Approved by:

Dr. Shawn G. Bauldry

Dedicated to all the pelvic pain patients who are forced to endure

ACKNOWLEDGMENTS

This dissertation would not have been possible without the support and mentorship of the many colleagues and friends I have encountered during my time at Purdue University. First, to my committee chair and PhD advisor Dr. Brian Kelly, thank you for all the generous feedback, encouragement, and advisement throughout this process. You subtly pushed me to do more than what I was comfortable with for this dissertation, and in doing so helped me grow as a researcher in ways I did not know I could. I have learned a great deal from you not just about medical sociology, grant writing, and innovation in the research process, but about professionalism, decision-making, and networking—all of which I know will help carry me through my career as a medical sociologist with grace.

I also owe many thanks to my dissertation committee members who have offered insight, feedback, and guidance time and time again. To Dr. Trenton Mize, “thank you” does not do justice to the countless hours you spent guiding me through the process of experimental design, including the power analysis by simulation, programming in Qualtrics, and answering the *many* questions I had with patience and reassurance. For your time and dedication to my success as an experimentalist, thank you! To Dr. Christie Sennott, who gave me countless opportunities to hone my skills as a researcher from the moment I joined the Department of Sociology at Purdue, thank you for entrusting me with responsibilities that required me to grow as a researcher. And, lastly, I owe a huge thanks to Dr. Andrea DeMaria who was pivotal in offering support and guidance in the earliest stages of this dissertation. From connecting me with local patients and providers to offering insight on how best to recruit the niche sample of patients I hoped to interview, you constantly offered advice and shared a willingness to help me navigate this project in any way you could—thank you!

I cannot go without also acknowledging the funding sources that helped me complete this dissertation. First is the Dean Knudsen PhD Dissertation Award, which helped pay for a sample of healthcare workers for the survey experiment included in this research. Also helping secure the sample for the survey experiment was funding from the Walter Hirsch Dissertation Award and the Eichhorn Fellowship in Medical Sociology, both awarded from Purdue University. Without these funding sources, I would not have been able to secure the sample I did for the survey experiment portion of the dissertation. Thank you to the committees who deemed my research deserving of

these funds as well as the committee who awarded me the Bilsland Dissertation Fellowship for the 2020-2021 year. Not only did the fellowship allow me to dedicate full time to completing my dissertation over the past academic year, but in times of a deadly and uncertain pandemic it also allowed me the privilege of staying safely at home while many of colleagues were required to be back on campus. I am incredibly grateful for the opportunity to have had the funding and safety to complete this dissertation during such a devastating year for us all.

In addition to professional acknowledgments, I have many friends and family to thank for their support over the past five years. To my parents who never let the option of quitting before completion cross my mind, thank you for believing in my capabilities and for always showing pride in my accomplishments. I am forever grateful to have you both here to share my accolades with. To my incredibly patient and selfless partner Luke who was never short of his confidence in my abilities—even when I was—I cannot thank you enough for the hours you left me with space to analyze data and write; the moments of anxiety you not only gracefully witnessed but sat through with me; the numerous times you showed as much excitement about a milestone on this dissertation as I did; and the constant reinforcement you provided day in and out as I completed this goal. Thank you for your unwavering and supportive presence throughout this process. I also owe thanks to Abigail Nawrocki, Elle Rochford, Amy Petts, and Gülçin Con Wright, all of whom had many informal conversations with me about this project and about the dissertation process. Those informal conversations undoubtedly benefited the research presented in this dissertation and, just as important, motivated me to complete this degree. Finally, to Vasundhara Kaul, who not only helped me navigate some of the statistical roadblocks I encountered in this research, but who was never short on uplifting words of encouragement—thank you for your solidarity over the years!

TABLE OF CONTENTS

| | |
|--|----|
| LIST OF TABLES..... | 9 |
| LIST OF FIGURES | 10 |
| ABSTRACT..... | 11 |
| INTRODUCTION | 12 |
| Background and Historical Context..... | 14 |
| Historical Context..... | 15 |
| American Medicine and Pain Biases Today | 16 |
| Theoretical Relevance..... | 16 |
| Normalization of Pelvic Pain..... | 16 |
| The Role of Cultural Health Capital..... | 19 |
| Fundamental Cause Theory, Patient Resources, and Power..... | 20 |
| Power, Medical Authority, and the Medical Gaze | 22 |
| Standardization in Medicine | 22 |
| Construction and Institutionalization of Gender, Race, and Class | 24 |
| Overview of Empirical Chapters | 27 |
| EVIDENCE-BASED MEDICINE AND THE LIMITS OF STANDARDIZATION..... | 30 |
| The Case of Pelvic Pain Care..... | 30 |
| Background..... | 31 |
| The Medical Gaze and Biopower | 31 |
| Evidence-Based Medicine and Positivism..... | 32 |
| The Standard Human and Niche Standardization..... | 33 |
| The Limits of Dialectical Thinking | 35 |
| Methods..... | 37 |
| Analytical Technique..... | 39 |
| Findings | 39 |
| Evidence-based Medicine without the Evidence..... | 40 |
| Unnecessary lag in knowledge dissemination | 40 |
| Definitional dilemmas..... | 43 |

| | |
|--|-----|
| Fixing the unfixable | 45 |
| Pigeonholing Patients through Niche Standardization | 49 |
| Outdated standards of care..... | 49 |
| Unnecessary surgeries..... | 51 |
| It's the OBGYNs niche..... | 52 |
| The Limits of Niche Standardization..... | 53 |
| Shifting the Paradigm | 55 |
| Discussion | 58 |
| INTERSECTIONS OF PATIENT SES, GENDER, AND RACE AND CLINICAL | |
| EVALUATIONS OF PELVIC PAIN..... | 62 |
| Fundamental Cause Theory | 63 |
| Implicit Bias and Clinical Evaluations of Pain..... | 65 |
| Fundamental Causes and Evaluations of Women's Pelvic Pain..... | 67 |
| Socioeconomic Status | 68 |
| Race | 68 |
| Gender..... | 69 |
| Intersecting Fundamental Causes and Diminished Returns of SES | 70 |
| Methods..... | 72 |
| Design | 72 |
| Experimental manipulations | 76 |
| Sample | 78 |
| Procedure | 80 |
| Dependent measures | 85 |
| Analytical Strategy | 86 |
| Results..... | 88 |
| Patient SES | 88 |
| Patient SES, Gender, and Race..... | 90 |
| Endorsement of False Beliefs of Biological Difference and Gender and Race..... | 93 |
| Interactions between SES, Gender, and Race..... | 95 |
| Manipulation Check Failures..... | 103 |

| | |
|--|-----|
| Discussion | 105 |
| AN INVESTIGATION OF CULTURAL HEALTH CAPITAL IN THE CONTEXT OF A MEDICAL ANOMALY | 110 |
| Cultural Capital | 110 |
| Cultural Health Capital | 111 |
| Flexible Resources | 113 |
| Medical Authority | 115 |
| Pelvic Pain Care | 116 |
| Data and Methods | 117 |
| Sample | 117 |
| Recruitment | 118 |
| Analytical Approach | 119 |
| Findings | 121 |
| Experiencing Symptoms | 122 |
| Experiencing Dismissal from Medicine | 124 |
| Accumulating CHC and Successfully Negating Medical Authority | 127 |
| Accessing Care and Means | 131 |
| Overcoming Barriers to CHC | 132 |
| Discussion | 134 |
| CONCLUSION | 138 |
| Summary of Theoretical Insights | 138 |
| Implications for Medical Practice and Policy | 145 |
| Concluding Thoughts | 149 |
| REFERENCES | 150 |
| APPENDIX A. PATIENT INTAKE FORM EXAMPLES (WHITE MIDDLE-CLASS DECK) | 159 |
| APPENDIX B. INTERVIEW GUIDE FOR PROVIDER INTERVIEWS | 165 |
| APPENDIX C. INTERVIEW GUIDE FOR PATIENT INTERVIEWS | 166 |

LIST OF TABLES

| | |
|--|-----|
| Table 1. Patient Intake Form Decks..... | 74 |
| Table 2. 2(Gender) x 2(SES) x 2(Race) Experimental Conditions..... | 78 |
| Table 3. Sample Demographics (N = 453) | 80 |
| Table 4. False Beliefs of Biological Differences Based on Race Scale..... | 83 |
| Table 5. False Beliefs of Biological Differences Based on Gender Scale..... | 84 |
| Table 6. Descriptive Statistics for Dependent Variables (N = 453) | 86 |
| Table 7. Predicted Effect of Patient SES (and Participant Gender and Provider status when Included) across Outcomes Variables (N = 453)..... | 90 |
| Table 8. Predicted Effect of Patient SES, Gender, and Race (and Participant Gender when Included) across Outcomes Variables (N = 303)..... | 93 |
| Table 9. Predicted Effect of Endorsement of False Beliefs of Biological Difference based on Gender and Race (N = 303) | 95 |
| Table 10. Two-way Interactions Between Patient SES, Gender, and Race for Seriousness of Pain Ratings (N = 303) | 97 |
| Table 11. Three-way Interactions between Patient SES, Gender, and Race for Seriousness of Pain Ratings (N = 303) | 98 |
| Table 12. Two-way Interactions Between Patient SES, Gender, and Race for Perceptions of Importance of Medical Assessment (N = 303) | 100 |
| Table 13. Three-way Interactions Between Patient SES, Gender, and Race for Perceptions of Importance of Medical Assessment (N = 303) | 101 |
| Table 14. Pass Rate Percentages for Manipulation Checks by Gender/Race Condition Assigned | 104 |

LIST OF FIGURES

| | |
|---|-----|
| Figure 1. Dialectical Materialism of Medical Paradigms | 36 |
| Figure 2. Example of niche standardization based on race from e-poster | 54 |
| Figure 3. Wong-Baker FACES Pain Rating Scale with Numbers Omitted..... | 73 |
| Figure 4. Predicted Outcome Measures by Endorsement of False Beliefs of Biological Difference Based on Race..... | 94 |
| Figure 5. Ratings of Seriousness of Patients' Pelvic Pain by Patient SES, Gender, and Race..... | 99 |
| Figure 6. Perceived Importance of Medical Assessment for Patients Eliciting Concerns of Pelvic Pain by Patient SES, Gender, and Race..... | 103 |

ABSTRACT

This dissertation, broadly, examines how power dynamics manifest during clinical interactions related to vague and gendered medical symptoms, such as pelvic pain. To examine this issue, I approach my research questions through multiple methods including a critical discourse analysis of the medical discourse on pelvic pain, a survey experiment administered to healthcare workers in the US, and a narrative analysis of pelvic pain patient experiences. While the focus of this research is on pelvic pain, the analyses presented here reach far beyond ideas of power dynamics and pelvic pain. Rather, the findings from this research speak to theoretical discussions medical sociologists have been having for decades. Specifically, findings provide new insight on: 1) the limits of evidence-based medicine as a biomedical paradigm, 2) how fundamental causes of health inequality intersect with each other as well as other factors, such as gender, important in predicting health outcomes and 3) how discussions of metamechanisms in fundamental cause theory can inform our understanding of the accumulation of cultural health capital. In providing such insight, this dissertation uses the case of pelvic pain to integrate multiple perspectives and theories in medical sociology to drive the field forward in a way that acknowledges the many ways power is simultaneously constituted in the clinical interaction. From the role of gender, race, and class in power relations, to the ways medical knowledge, discourse, and authority dictate the clinical interaction, this research covers a wide range of sociological theories and concepts. In doing so, this dissertation sheds new light on current understandings of power in the clinical interaction and its relationship to inequitable health outcomes in the US.

INTRODUCTION

In 2015, Joe Fassler wrote an article for *The Atlantic* recounting his wife Rachel's experience of having her pelvic pain dismissed as an emergency-room patient in a US hospital. Fassler's (2015) article, titled "How Doctors Take Women's Pain Less Seriously," detailed their visit to the emergency room after Rachel woke up with agonizing pelvic pain. Fourteen and a half hours after arriving to the emergency room—and once Rachel's pain was finally assessed with adequate attention—Rachel and her doctor prepped for surgical removal of her ovary. Rachel was unknowingly suffering from excruciating pain that accompanies an ovarian torsion. While providers told Rachel she was "just feeling a little pain" and misdiagnosed her pain as kidney stones without any proper tests, her ovary was left to die (Fassler 2015).

Fassler's (2015) article sparked so much attention from other women with similar experiences that *The Atlantic* compiled women's stories for a follow-up piece four months later. The majority of women whose stories were published by *The Atlantic* discuss pelvic pain that was dismissed as normal. Some women were told their pain was due to anxiety, while others were urged to take a pregnancy test to rule out "normal" pains that accompany pregnancy (Bodenner 2016). As a result of having their pain silenced, these women experienced delayed diagnoses, limiting their treatment options once—and if—a diagnosis was given.

The stories showcased by *The Atlantic* are not exceptional. In fact, research demonstrates a consistent pattern of medicine taking women's pain less seriously (Hoffman and Tarzian 2001). Research has also exposed gendered biases related to women's *pelvic* pain in particular. Specifically, scholars demonstrate that providers regularly dismiss women's pelvic pain due to assumptions that such pain is "normal" for patients with female reproductive anatomy and therefore does not signal any underlying medical conditions (Ballard, Lowton, and Wright 2006; Huntington and Gilmour 2005; Markovic, Manderson, and Warren 2008; Seear 2009; Toye, Seers, and Barker 2014). For example, Markovic and colleagues (2008) find that women often endure severe pelvic pain accompanying endometriosis largely because of normality constructed around pelvic pain—and menstrual pain specifically.

The existing research provides clear arguments related to gender biases in pain assessment and treatment. Women's pain is taken less seriously than men's pain, and pelvic pain is often dismissed as normal for women. However, much of the literature in this area does not examine the

role of race or class in the assessment and treatment of women's pelvic pain. The lack of attention towards race in this line of research is concerning given the racial and ethnic biases in pain assessment and treatment that lead to minority patients having their pain taken less seriously than white patients (Anderson, Green, and Payne 2009). Additionally, there is ample evidence that social class impacts provider-patient interactions in various ways that disadvantage lower-income patients (Lutfey and Freese 2005; Verlinde et al. 2012). Lastly, research shows that gender, race, and class intersect to create unique experiences for different women during medical encounters related to reproductive health (Downing 2007).

Given the often-assumed relationship between pelvic pain and reproductive health, such findings are especially important to consider in explorations of pelvic pain bias. When it comes to pain more generally, intersectionality becomes a non-negotiable piece of the puzzle for understanding how patients of varying genders from varying racial and economic backgrounds are assessed and treated. In other words, because evidence shows gender, race, and social class all impact pain assessment and treatment, it is simply not sufficient to understand the individual impact of these social factors. Rather, we must analyze and understand how they work in tandem to impact patients in a stratified manner.

While there is research documenting the racial/ethnic bias and gender bias in pain assessment and treatment, there is limited exploration of the intersections between race and gender and its impact on biases related to pain (Hoffman et al. 2016; Hoffman and Tarzian 2011). Kempner's (2017) commentary on Pryma's (2017) research—which, broadly, explores the role of gender and race in fibromyalgia patients' narratives—articulates the significance of my research. In her commentary, Kempner (2017) calls for adopting an intersectional approach to research on pain. She uses Pryma's (2017) research as an example for why pain should be examined at the intersection of race and gender. By only understanding pain as a gendered *or* racialized experience—rather than gendered *and* racialized—women of color are rendered invisible in the research. This invisibility in the research, Kempner (2017) argues, reflects the invisibility of their claims of pain that leaves them without necessary medical treatment. Therefore, it is vital to explore how both race and gender, as well as class, impact experiences of pain simultaneously to bring visibility—and medical attention—to those rendered invisible.

Importantly, this dissertation explores gender, race, and class as *social structures*, rather than as identities, that impact interactions within our social institutions. In this way, this project is

an exploration of how social structures intersect to impact outcomes in our medical institutions. I first examine the role of medical discourse in constructing ideas around pelvic pain that may relate to the dismissal many women face. Next, I narrow my focus to the clinical interaction by examining how patients' gender, race, and socioeconomic status (SES) impact clinical evaluations of pelvic pain simultaneously through the use of a survey experiment. Lastly, I turn to the patient experience to investigate the way women from different SES positions navigate the medical system and experience pelvic pain as a result of potential barriers to diagnosis and treatment.

Background and Historical Context

Understanding the history of women's pelvic pain and the medical treatment of conditions causing pelvic pain in the U.S. is vital for contextualizing how women with pelvic pain are treated today. Therefore, this research takes a foundational intersectionality approach to understanding pelvic pain patient care. Wadsworth (2011) coined the term *foundational intersectionality* to refer to intersectional analyses that take historical context of a phenomenon, or group, into account. A foundational intersectionality approach, as it applies to this research, means understanding the gendered, racialized, and classed history of women's reproductive health and pelvic pain. Such understandings are important because "interlocking systems of subordination are constructed *across time*" (Wadsworth 2011: 204).

Wadsworth's (2011) concept of foundational intersectionality is not unlike Mills' (2000) *sociological imagination*, which also emphasizes the importance of historical context for understanding modern experiences. However, Wadsworth (2011) extends Mills' (2000) arguments to advocate for the importance of understanding historical formations of interlocking systems of domination and subordination. Roberts (1996), for example, demonstrates the importance of taking a foundational intersectionality approach by outlining how power exerted over black women's reproductive health in the U.S. has unfolded *across time*, starting with slavery and continuing through publicly funded birth control clinics in the 1930s and forced sterilization in the 1970s (Roberts 1996). Further, Feagin and Bennefield (2014), argue that acknowledging racialized history is vital for understanding the US healthcare system more generally. Therefore, I provide important historical context that informs this research below.

Historical Context

American gynecology emerged in the 19th century, marking a new era for women's reproductive health (McGregor 1998). This historical shift meant women's reproductive bodies were no longer treated and cared for by other women. Instead, men in the profession of gynecology were treating women's reproductive ailments and delivering their babies. The introduction of masculinized medicine into the realm of women's reproductive health arguably changed the way women were treated, understood, and assessed as reproducing humans. Further, as a result of this medicalization of reproduction, enslaved black women were forced to put their reproductive health in the hands of white male gynecologists (Owens 2017). In the historical context of slavery, such race and class relations of power lead to enslaved black women's bodies being exploited and manipulated in the name of gynecology.

Dr. James Marion Sims, who was deemed the “father of modern gynecology” and whose work was deemed a hallmark that led to modern gynecology, is the most well-known example of the control white men in medicine exerted over enslaved black women's bodies (McGregor 1998). By performing surgical experiments on enslaved women without anesthesia or consent, Sims left a dark legacy in the field of gynecology. In recent decades, however, his claim to fame has been doubted for his questionable ethics—especially because he did not operate on white women until anesthesia was more widely available (Wall 2006; Wanzo 2009).

In his autobiography, *The Story of My Life*, Sims (1884) wrote about Anarcha, Lucy, and Betsey—three of the enslaved women who endured the pain of his experimental surgeries during his years practicing medicine in Alabama. In his writings about the surgeries, Sims set a precedence for comparing black women's pain to white women's pain. He wrote that while “slave women could bear the ‘operation with great heroism and bravery’ ... a white ‘lady’ with her ‘keen sensibilities so afflicted’ would not have been able to handle the pain” (Wanzo 2009:152). In claiming such distinctions between black women and white women, Sims reproduced the false belief that differences exist between black and white patients' pain. The language of “slave” versus “lady” also indicates a social class comparison, illustrating the intersecting impact of race and class on Sims' interpretation. Sims, as “the father of modern gynecology,” institutionalized these false beliefs in women's reproductive health, arguably attaching it to pelvic pain in particular. Unfortunately, the false belief that black patients can endure more pain than white patients—although perhaps now less universally accepted—still exists in medicine (Hoffman et al. 2016).

American Medicine and Pain Biases Today

Not only do false beliefs around biology and race still exist today, but they are also linked to biases in pain assessment according to Hoffman and colleagues' (2016) study. Using a survey experiment, the researchers found that medical students and residents who endorse false beliefs of biological difference between black and white people also rate black patients' pain as less intense than white patients' (Hoffman et al. 2016). Hoffman and colleagues' (2016) study is just one of many other studies showing similar racial and ethnic biases in pain assessment and treatment (e.g., Anderson et al. 2009; Todd, Samaroo, and Hoffman 1993). Current research also outlines how gender biases unfold during pain assessment. For example, women's pain is more often assumed to result from psychological factors compared to men's resulting in stark differences in how men and women—and boys and girls—in pain are treated (Hoffman and Tarzian 2001).

With a history of blaming pain on hysteria, it may be unsurprising that women's pain is still often dismissed as psychological today. As a consequence of having their pain dismissed, women are often excluded from the benefits of a diagnosis, just as the women who wrote to *The Atlantic* were (Bodenner 2016). Taking Hoffman and colleagues (2016) findings into account, black women may be excluded from such benefits at even higher rates. Those benefits include anything from treatment options to legitimization of one's experience. Medical providers act as gatekeepers to the coveted diagnosis that, once given, allows a patient to move forward with treatment (Conrad 1992). Therefore, without a diagnosis, patients go untreated and their experiences may be delegitimized.

Theoretical Relevance

Normalization of Pelvic Pain

One condition accompanied by pelvic pain that is widely studied for its notorious diagnostic delays is endometriosis. Endometriosis is a reproductive health condition accompanied by pelvic pain, painful periods, and pain with sex (Markovic et al. 2008; Viganò et al. 2004). The research on endometriosis typically focuses on diagnoses experiences and particularly the diagnostic delays many women experience (Ballard et al. 2006; Huntington and Gilmour 2005; Markovic et al. 2008; Whelan 2007). The research in this area suggests that it is not uncommon for a woman to wait ten painful years before receiving a diagnosis (Huntington and Gilmour 2005).

Much of the literature attributes these diagnostic delays to the normalization of menstrual pain (Huntington and Gilmour 2005; Markovic et al. 2008; Whelan 2007). In other words, scholars argue that pelvic pain accompanying endometriosis is dismissed as normal because pain associated with menstruation has been normalized. More specifically, medical providers, as well as society in general, perceive pelvic pain as a normal or typical experience of being a woman with female reproductive anatomy (Markovic et al. 2008). Discussions in the literature about normalization of pelvic pain suggest it is a gendered phenomenon. In this way, providers may not normalize men's pelvic pain in the same way as women's because men are not expected to have any "normal" pain in the pelvic region. Markovic and colleagues (2008) also argue that young women with endometriosis endure their pain in the early stages of this condition and avoid seeking medical care because of this normalization, suggesting that normalization is not only occurring in medical contexts but in society more generally. Avoiding medical care further delays a diagnosis, subsequently hindering women's abilities to make sense of their pain, legitimize their pain, and manage their pain.

While endometriosis is perhaps the most widely studied condition causing pelvic pain in patients with female reproductive anatomy, other conditions causing pelvic pain also fit into this normalization process. For example, vulvodynia refers to "idiopathic, chronic vulvar pain" and is experienced by one in four women in the US (Goldstein et al. 2016:573; Hintz and Venetis 2019). While the condition is formally recognized in the medical literature, no clear etiology is discussed. In fact, part of the diagnosis criteria for vulvodynia includes pain without a "clear identifiable cause," making both diagnosis and treatment of the condition difficult for both patients and providers (Hintz and Venetis 2019:99). Another condition impacted by the normalization of pelvic pain includes persistent genital arousal disorder (PGAD), which is characterized by "recurrent, unwanted or intrusive, distressing feelings of genital arousal or being in the verge of orgasm not associated with concomitant sexual interest, thoughts or fantasies." PGAD is also often, though not always, accompanied by painful orgasms. The pudendal nerve is thought to play a role in the pain associated with this condition, though, as with most conditions causing persistent pelvic pain, no clear etiology has been identified (Komisaruk and Goldstein 2018). Sometimes discussed as related to PGAD and yet another condition impacted by the normalization of pelvic pain is pudendal neuralgia, understood broadly as irritation and, sometimes, entrapment of the pudendal nerve (Jackowich et al. 2017).

Still more conditions causing pelvic pain find themselves within the process of normalization of pelvic pain including: polycystic ovarian syndrome (PCOS)—the most common endocrine disorder among women of reproductive age—dyspareunia—or painful intercourse—irritable bowel syndrome (IBS), and pelvic floor dysfunction (Noroozzadeh et al. 2017). Some of these conditions, such as pelvic floor dysfunction—simply defined as muscular dysfunction in the pelvic floor—are musculoskeletal, while others, such as endometriosis and PCOS, are gynecological (Davila 2008). Other conditions, such as IBS, find themselves situated within the gastroenterology medical specialty, while interstitial cystitis (IC)—also known as painful bladder syndrome—is primarily treated by urologists (Homma et al. 2020; Moayyedi et al. 2019). While each of these conditions are somewhat unique in their symptomology, they all share the common thread of persistent pelvic pain, bringing with them the normalization process that goes along with persistent pelvic pain when it presents on bodies with female reproductive anatomy.

Importantly, research suggests that the normalization of pelvic pain may impact women differently depending on their relative positions of power in medical interactions. For example, Markovic and colleagues (2008) point out how women with different socio-demographic backgrounds have different experiences receiving diagnoses. The researchers found that older women from higher socio-demographic backgrounds were more likely to contest their doctors' dismissals of their pain. Alternatively, younger women from lower socio-demographic backgrounds typically endured the pain after being dismissed, likely because they did not have the same tendency to question authority (Markovic et al. 2008).

Markovic and colleague's (2008) research suggests that women in subordinated positions within relations of power (e.g., minority and low-income women) exert less authority in their interactions with providers (Markovic et al. 2008). This tendency to exert more or less power in medical interactions likely influences how women with pelvic pain are assessed and treated. Additionally, research illustrates that providers' communication depends on patients' relative positions of power. For example, physicians are more verbally dominant with black patients compared to white patients (Johnson et al. 2004). Research also shows that providers give less diagnostic and treatment information to lower income patients compared to their higher income patients (Verlinde et al. 2012).

Additionally, Viganò and colleagues (2004) make arguments about diagnostic biases specific to endometriosis. They argue that women in higher social class positions, as well as white

women, have higher rates of endometriosis because of diagnostic biases, explaining such biases as medical providers paying less attention to pelvic pain when it presents in minority and lower SES women (Viganò et al. 2004). These diagnostic biases lead to the façade that white women and women from higher social class positions are at higher risk for endometriosis. However, as Viganò and colleagues (2004) argue, it is more likely the case that women in subordinated positions of power have their pelvic pain dismissed by their providers at higher rates than women in more dominant positions. The lack of specificity in diagnostic testing for conditions such as endometriosis likely amplifies this bias. In other words, without readily available diagnostic testing that relies on (more) objective anatomical evidence, subjective bias may play a more influential role in diagnosing conditions causing pelvic pain.

The Role of Cultural Health Capital

Cultural Health Capital (CHC)—a framework developed from Bourdieu’s (1986) original ideas on cultural capital—helps explain differential communication patterns from both providers and patients. Shim (2010) conceptualized CHC as a specialized form of cultural capital that can facilitate effective communication and engagement during healthcare interactions. For example, one CHC patient characteristic useful in such interactions is “the ability to communicate social privilege and resources that can act as cues of favorable social and economic status” (Shim 2010:3). Importantly, Shim (2010) acknowledges that not all patients have access to CHC as a resource because systemic inequalities (e.g., race and class stratification) impact who can accumulate CHC and use it to one’s advantage. Further, not only is differential allocation of CHC a result of inequality, but it also works to reproduce varying forms of systemic inequality in that those not afforded CHC due to disadvantage will continue to be disadvantaged in healthcare contexts (Shim 2010).

Shim (2010) also emphasizes the role of providers in producing CHC, especially given the lack of agency that patients have in their abilities to accrue CHC. Providers play an important role in the production of CHC because of their unique abilities to educate patients and shape healthcare interactions. Therefore, although not all patients are afforded the advantage of CHC, providers can help mitigate those inequalities by interacting with patients in ways that encourage CHC. For example, providers may encourage women eliciting concerns about pelvic pain to keep a pain diary to bring to their next visit. While patients with CHC may already take this action without the

suggestion, providers can encourage those without the advantage of CHC to take this action. In doing so, providers are shaping their interactions with patients lacking CHC in a way that may promote the accumulation of CHC for those patients.

Taken together, the research suggests that minority and low-SES women do not receive the same medical attention when presenting pelvic pain as their white high-SES counterparts. Low-SES and minority women with pelvic pain also might contest their providers' dismissal of their pain less than women from more racially and economically privileged positions. Additionally, providers may give minority women less time to elicit their concerns about their pelvic pain during a visit (Johnson et al. 2004). Further, economically disadvantaged women may receive less diagnostic and treatment information about their pelvic pain during a medical encounter (Verlinde et al. 2012). Taking a CHC framework into account, providers in these examples have a responsibility to help patients accrue CHC through adapting their communication styles in ways that benefit, rather than disadvantage, minority and low-SES patients (Shim 2010).

Fundamental Cause Theory, Patient Resources, and Power

Fundamental cause theory provides another useful lens for synthesizing findings that demonstrate how race and class provide advantage and disadvantage to different patients during clinical interactions. Scholars first used this theory to discuss the link between SES and mortality that persisted across time, despite changing conditions that should eliminate that link (Link and Phelan 1995; Phelan and Link 2013). One important aspect of the theory posits fundamental social causes of disease “involve access to resources that can be used to avoid risks or to minimize the consequences of disease” (Phelan and Link 2013:106). CHC—also understood as a resource resulting in the accumulation of advantage—differs from fundamental cause theory in that fundamental cause theory argues that using certain resources to benefit certain groups is purposeful. Alternatively, CHC is understood as *habitus*, which is not enacted purposefully or consciously (Shim 2010). Research on SES as a fundamental cause offers additional insight into why the women from lower socio-demographic backgrounds in Markovic and colleagues (2008) study may not have contested their providers to the same extent as the women from higher socio-demographic backgrounds. Specifically, research shows how access to resources may provide more or less support for women's contestations.

Other evidence on SES as a fundamental cause that falls in line with Markovic and colleagues (2008) study comes from Lutfey and Freese (2005) who found that clinics serving higher-SES populations offer patients more continuity of care. That is, patients seeking care at these clinics are more likely to see the same provider visit after visit, as opposed to patients at clinics serving lower-SES populations who may see a new provider for every new visit. In the context of eliciting concerns about pelvic pain, higher-SES women experiencing greater continuity of care may only have to contest dismissal from one provider once. Alternatively, lower-SES women may not experience the same continuity of care, which means they may have to contest dismissals from multiple providers many times. In the absence of continuity of care, women essentially must start from scratch when eliciting their concerns, which could diminish their tendency to contest. Further, Lutfey and Freese (2005) demonstrate that continuity of care facilitates open provider-patient communication; and we would expect women to be more likely to contest providers' dismissal of their pelvic pain when provider-patient communication is open. In this example, continuity of care—as an SES-related resource—could facilitate women's ability to contest their providers' dismissal of their pain.

According to fundamental cause theory, *power* is a common resource driving the mechanisms linking low-SES populations to poorer health outcomes (Phelan and Link 2013). Markovic and colleague's (2008) research, although not in conversation with fundamental cause theory, demonstrates how power works as a resource enabling higher-status women to contest their providers' dismissals. Understanding power as a resource also helps us move beyond SES to include racism as a fundamental cause. Although a majority of the relationship between race and health works through SES, there are still unique resources associated with race that do not overlap with SES; and power is one of those resources (Phelan and Link 2015).

One study using fundamental cause theory to examine racial differences in diagnoses found a significant difference in age of diagnosis between white children and Latino children for autism spectrum disorders. Specifically, when controlling for the age parents noticed something different with their children and the age parents brought concerns to providers, Latino children were more likely to be diagnosed close to one year later than white children (Magaña et al. 2013). Such findings suggest that racism, as a fundamental cause, leads to diagnostic disparities. To summarize, research on race and class biases and fundamental causes suggests that race and class have unique

impacts on the care patients receive, partially due to how power—as a resource—impacts interactions.

Power, Medical Authority, and the Medical Gaze

Power, as a resource available to patients during clinical interactions, is complicated by both Freidson's (1970) writings on medical authority and Foucault's (1973) writings on the medical gaze. As a sociologist of professions, Freidson wrote about medical authority from an organizational and bureaucratic standpoint, particularly in regard to the title of "physician" and its professional dominance within medicine and the field of health services. In doing so, he conceptualized medical authority as stemming from the profession's formal ties to the state which grant it a legal monopoly over providing health services (Freidson 1970). In this way, power during the clinical interaction may be distinctive from power observed during other social interactions outside of our medical institutions.

Foucault's (1973) ideas on the medical gaze also suggest that power during the clinical interaction may be a unique case. That is, medical interactions comprise medical knowledge as a source of power that has authority over both patients *and* providers. Because providers have access to medical knowledge, they are afforded a great deal of power over the diagnostic and treatment trajectories of their patients. However, Foucault (1973) argues that the discourse determining that medical knowledge has power over providers and the gaze they use to assess patients. In other words, the medical gaze is determined by a power larger than the providers themselves: the medical discourse. Therefore, we must also think about the medical discourse as influencing power dynamics in clinical interactions.

Standardization in Medicine

Epstein's (2007) ideas on standardization in medicine are useful for understanding potential connections between medical discourse and the assessment and treatment of patients. Specifically, Epstein (2007) writes about the issues with standardizing patients—or treating all patients as if they belong to one homogenous group. For example, generalizing findings from a medical study on one group of people to all groups works off the assumption that all groups of people interact with the medical institution in the same way (Epstein 2007). However, research

shows that is simply not the case (e.g., Anderson et al. 2009; Feagin and Bennefield 2014; Hoffman and Tarzian 2001; Markovic et al. 2008; Phelan and Link 2015). Therefore, by ignoring the experiences of certain groups, standardized medical discourse may construct a medical gaze that overlooks many groups' experiences, leading to biases in assessment and treatment.

Arguments against the critiques of standardized patient care and research posit that treating every patient as an individual is simply not feasible. One potential solution to this argument is *niche standardization* (Epstein 2007). Epstein (2007) refers to niche standardization as the “biopolitical management (and redefinition) of population subgroups” (p. 136). For example, niche standardization may lead to treating women or patients of reproductive age as distinct subgroups. Although this change addresses some of the issues with standardized care, there is still the question of which groups are given a niche. For example, are women broken up into different racial/ethnic groups? If so, which racial groups are given their own subgroup and why?

Feagin and Bennefield's (2014) piece on systemic racism in U.S. medicine explains why standardizing patients can have many negative consequences. According to Feagin and Bennefield (2014), systemic racism in US medicine can be explained as white racial framing. For example, the language of “racial disparities” is framed in relation to and from the perspective of the majority white race. Their use of the phrase white racial framing signals a structural approach to understanding racism in US medicine. The authors use implicit racial biases as the most obvious example of white racial framing. However, they argue that simply discussing the issues as “bias” or “prejudice” reduce such problems to the individual level. This reduction presents issues because racism is not reproduced and reinforced only at the individual level. Instead, it is a *systemic* issue that structures individual attitudes like “bias” and “prejudice” (Feagin and Bennefield 2014).

Understanding how racism, as a systemic issue, operates in US medicine allows us to better understand how patient standardization plays a role in systemic racism. Implicit racial bias, for example, by definition tells us that patients are not treated as a standardized racial group (Feagin and Bennefield 2014). Therefore, when we do treat patients as a standardized group, certain groups' experiences are erased. For example, Kempner (2017) discusses how minority women's experiences with pain are erased through the niche standardization of pain patients into the subgroups of women patients *or* minority patients. That is, the research explores race and gender as separate niches that yield separate patient experiences, rather than as two potentially intersecting niches that yield unique patient experiences for minority women.

Construction and Institutionalization of Gender, Race, and Class

Similar to Kempner's (2017) argument, Glenn (2000) also argues that the experiences of minority women are erased when we understand race and gender as separate processes. Specifically, Glenn (2000) argues that we must understand gender and race not as "separate or additive" but as "simultaneous and linked" (p. 4). Given her critiques of the current work at the time, Glenn (2000) developed an integrative framework for understanding race and gender as simultaneously constructed and institutionalized. More specifically, she asserts that gender and race are "*relational* concepts whose construction involves *both representation and social structural processes* in which *power* is a constitutive element" (Glenn 2000:9). I argue that class can also be understood through Glenn's (2000) framework as simultaneously constructed and institutionalized alongside gender and race.

Understanding gender, race, and class as relational concepts means understanding how gender, race, and class categories gain meaning in relation to each other. Further, relationality assumes that subordinate categories of gender, race, and class are understood in relation to dominant categories. The dominant category is often constructed as the referent or "normal" category. This construction of the dominant category means white is often rendered "raceless" just as men and masculinity are "genderless" (Glenn 2000:10). This relational construction mimics Acker's (2006) arguments about gender-neutral discourse on class in that seemingly gender-neutral discourse is actually referring to men.

Relationality is important for understanding the consequences of patient standardization in medical discourse because of the sometimes seemingly raceless, genderless, and classless discourse that such research produces. By taking a relational approach to understanding medical discourse that standardizes patients, we can better understand what racial, gender, and economic groups the discourse represents. In doing so, we can problematize that discourse for normalizing dominant groups (e.g., white, middle-class women) as the standard patient. Additionally, we can understand comparisons between racial groups in such discourse as socially constructed in relation to the dominant group. For example, if the medical discourse on pelvic pain makes comparisons between white women and black women, we can better understand why black women's experiences may be problematized and seen as particular in comparison to the "normal" or general experiences of white women.

The second notion in Glenn's (2000) framework introduces the interplay between social structure and cultural representation. By interplay, Glenn (2000) means that cultural representations of race and gender have consequences for different racial and gender groups because of social structure. According to Glenn (2000), this phenomenon takes place because "race and gender are features of social structures" (p. 11). For example, cultural representations of women as hysterical were institutionalized in the medical treatment of women's pain because of the gendered (i.e., masculine and male-dominated) structure of medicine. Further, I argue that cultural representations of racial minorities lead to perceptions that minority patients have higher pain tolerances or "thicker skin" than their white counterparts (Hoffman et al. 2016; Kempner 2017). This perception was then institutionalized into the racialized structure of US medicine, impacting how racial minority patients in pain are treated by their providers (Feagin and Bennefield 2014). Glenn's (2000) ideas can apply to representations of different social class positions as well, where gendered and racialized representations of low-income women become imbedded in the social structure of medical care through institutionalization. For example, Downing's (2007) research demonstrates that low-income minority women were more likely to have providers advise them to limit their childbearing and discourage them from having children compared to middle-class white women. Glenn (2000) might argue that this institutionalized difference in patient care results from cultural representations of low-income minority women.

The last concept in Glenn's (2000) integrative framework is power. Gender scholars have long argued that gender is a primary way of signifying relations of power. Additionally, race scholars make similar claims about race signifying relations of power (Glenn 2000). Therefore, when theorizing about the role of power in the context of pelvic pain, or any other medical symptom, both gender and race must inherently—and simultaneously—be a part of that theorization alongside social class. Also important is Glenn's (2000) argument that power is not limited to spaces or institutions conventionally thought of as political. For example, many may consider medicine an apolitical space. Yet, research shows that gender, race, and class relations of power have been, and remain to be, at play during seemingly apolitical clinical interactions (Downing 2007; Feagin and Bennefield 2014; Hoffman and Tarzian 2001; Hoffman et al. 2016; Phelan and Link 2015; Wall 2006). Additionally, Foucault's (1973) work highlights medicine as a unique site for relations of power. In bringing various social theorists' ideas on power together—

including Glenn's (2000), Foucault's (1973), and others'—we are better able to specify the ways power influences certain social situations, such as clinical interactions around pelvic pain.

Glenn's (2000) framework for understanding the construction and institutionalization of gender and race is also an important tool for problematizing ideas around patient standardization (Epstein 2007). In fact, the idea of standardizing patients is inherently incompatible with Glenn's (2000) framework. That is, to use Glenn's (2000) framework for understanding the construction and institutionalization of gender, race, and class, means to understand relations between groups. Such understandings require acknowledging more than one group, as well as differences between those groups as systematically related. Additionally, power infers the presence of at least two groups—a dominant group and a subordinate group. Although we may be able to understand relations of power between providers and patients within the standardized patient approach, we are unable to understand relations of power between particular groups of patients and providers (e.g., black providers and white patients or men providers and women patients). Lastly, structure and representation help us to further critique the standardized patient approach. Specifically, we can use Glenn's (2000) framework to understand how representation, or a lack-there-of, for certain groups becomes imbedded in the structure of patient care.

The theoretical and empirical evidence reviewed here reveals a much-needed effort to better integrate the intersectionality literature with the health inequality literature, while also integrating both with the medical and social science literature on pain assessment, treatment, and management. For example, adapting Glenn's (2000) integrative framework requires understanding the simultaneous influence of multiple fundamental causes of health, rather than focusing only on racism or only on SES. Similarly, addressing both Freidson's (1970) and Foucault's (1973) distinct yet complimentary ideas on power within our medical institutions means a more holistic understanding of medical authority. Lastly, integrating such ideas on medical authority with those of intersectionality and health inequality only further develops an understanding of how these processes occur simultaneously during clinical interactions on pain. In an attempt to utilize the vast theoretical tools available in the literature, I combine the ideas and evidence presented in this introductory chapter to investigate pelvic pain patient care in a somewhat sequential process starting with the construction of pelvic pain in the medical discourse, moving to the institutionalization of gender, race, and class in clinical evaluations of pelvic pain, and, lastly,

ending with an analysis of the impact of that construction and institutionalization on the patient experience. In doing so I pose three distinct, yet connected, research questions:

- 1) *How are gender, race, and class constructed in the pelvic pain discourse, and how is pelvic pain differentially constructed as a medical symptom?*
- 2) *How are gender, race, and class simultaneously institutionalized in clinical evaluations of pelvic pain and what is the impact of that institutionalization on disparities in patient assessment?*
- 3) *How does the construction and institutionalization of gender, race, and class in pelvic pain care impact the patient experience in ways that may advantage some patients while disadvantaging others?*

Overview of Empirical Chapters

In the chapters that follow, the theoretical ideas discussed above guide the holistic analysis of pelvic pain patient care in the US. While the three research questions above guided the data collection and analysis for each empirical chapter that follows, the literature also guided those processes and in doing so answered more precise questions that are outlined in detail in each corresponding chapter. In the first empirical chapter, I present a critical discourse analysis of the medical discourse on pelvic pain to reveal a link between evidenced-based medicine and the limits of standardization in medicine. In doing so, I rely heavily on Epstein's (2007) ideas on patient standardization and niche standardization in my analysis. I also introduce classical sociological theory into the analysis driven by Epstein's (2007) ideas with my argument on the dialectical nature of the emergence of new biomedical paradigms, such as niche standardization. The findings in the chapter drive my critique of that dialectical process through the support of Theodor Adorno's (1973) ideas on negative dialectics. In short, I argue for a process of negating standardization to allow new biomedical paradigms to emerge that are more inherently tapered to individualized patient care, leaving minority and low-income patients needs more likely to be met, especially when presenting with conditions such as pelvic pain that lack adequate standards of care.

Next, I assess the intersections of patient gender, race, and SES and biases related to pelvic pain assessment using a survey experience administered to healthcare workers. Through the guidance of fundamental cause theorists, I test for a causal effect of institutional mechanisms—and specifically implicit biases—linking low-SES and racism to less favorable outcomes for pelvic

pain patients. I also use the guidance of Glenn's (2000) integrative framework to test how gender combines with fundamental causes to impact outcomes for patients from varying backgrounds. In doing so, I join others in making a case for more research exploring the intersections of fundamental causes of disease to better understand the simultaneous impact of various social factors on health inequality.

Lastly, I provide evidence from a narrative analysis of pelvic pain patient experiences to discuss the ways patients from different socioeconomic positions navigate care and treatment. Through the analysis, theoretical insight on both CHC and fundamental causes of health broaden current sociological understandings of the usefulness of CHC in cases of medical anomalies, or conditions for which medical knowledge and effective standards of care are lacking. In making use of ideas related to the intentional *and* unintentional use of flexible resources to improve one's health, the analysis brings ideas on habitus and socioeconomic means into discussion with CHC. The findings from the analysis also shed light on how CHC may be best utilized to successfully challenge medical authority when patients present conditions that medicine does not have answers for. In this way, the research presented in this empirical chapter expands current perceptions on how CHC may be accumulated and utilized to benefit patient outcomes.

In using pelvic pain as a case for examining the theoretical ideas discussed here, findings become relevant to a variety of medical conditions that relate to both women's sexual and reproductive health as well as pain medicine. Therefore, while this research focuses on pelvic pain as a medical symptom, it speaks to a much broader line of research concerned with gender, race, and class inequality in sexual and reproductive health. In a similar vein, this research also informs the larger literature on pain medicine and the social forces that both shape and are shaped by pain medicine. With that said, this research uses pelvic pain as a case for both testing and building theories that apply well beyond the narrow scope of pelvic pain, and in doing so speaks to a variety of theoretical literatures in the field of medical sociology.

For example, the critical discourse analysis presented in the first empirical chapter is as much about sociological insights on biomedical paradigms as it is about pelvic pain. Additionally, the second empirical chapter assessing clinical evaluations of pelvic pain speaks perhaps even more to the medical sociology literature on implicit bias in clinical evaluations than to the specific literature on pelvic pain. Finally, the narrative analysis of patient experiences, although focused on a sample of pelvic pain patients, reaches far beyond the scope of pelvic pain—and even pain

more generally—to provide applicable theoretical implications for both sociological and health services research on the utilization of CHC in the US healthcare system. In making the broad theoretical arguments I do, I bring this research out of the small niche of pelvic pain and into the larger realm of medical sociology to advance concepts and theory driving research on all sorts of health conditions and topics within the subfield.

EVIDENCE-BASED MEDICINE AND THE LIMITS OF STANDARDIZATION

The relationship between medical knowledge and practice continues to be an important area of inquiry in medical sociology. From Foucault's (1973) writings on the medical gaze to Epstein's (2007) ideas on standardization in medical research, social theorists have consistently been critical of not only the production of medical knowledge, but also the clinical implications of that knowledge. That connection between medical knowledge and practice can be understood as the *medical gaze* (Foucault 1973). With the understanding that medical decision-making is influenced by medical knowledge, as a source of power over clinical interactions, medical discourse becomes an important site for analysis.

In many ways, much of the sociological knowledge in this branch of research is concerned with the same process: how medical knowledge is produced, and the clinical implications of that knowledge production. The examination of medical discourse in this chapter falls in line with previous work concerned with that very process, and particularly how that process plays out within the confines of evidence-based medicine (EBM). However, I use the case of pelvic pain to examine how this relationship between medical knowledge and practice plays out in the context of a medical symptom and area of medical specialization that both relies on subjective experience and lacks much of the "objective" evidence necessary to align with EBM. Theoretically, I ask, how does evidence matter, what does it mean in the context of a lack of "objective" evidence, and how does it constitute power in the clinical interaction? More specifically, I ask, how is pelvic pain patient care constructed within the EBM paradigm and what are the unintended consequences of such constructions?

The Case of Pelvic Pain Care

Pelvic pain care serves as an interesting and necessary case for examining the limits and consequences of the standardization involved in EBM for three reasons (Timmermans and Epstein 2010). First, pain in general has a long and complicated history in medicine, primarily because of its subjective nature. Medicine still lacks any clear biomarkers that objectively measure pain, and in the context of EBM this lack of evidence creates barriers for both patients in pain and their

providers (Rubin et al. 2018). Second, pelvic pain in particular appears at the intersection of a lack of medical knowledge on: 1) pain, 2) women's health, and 3) sexual health (Rubin et al. 2018; Criniti et al. 2014; Kirschstein 1991). By appearing at this intersection, pelvic pain becomes somewhat of a medical anomaly when it comes to EBM. Yet, the research does not provide a clear understanding of what that means for providers practicing EBM. Lastly, pelvic pain is a unique condition in that a clear definition is not developed in the medical literature and it often has multiple underlying causes that cross medical specialties (e.g., gynecology and gastroenterology). Despite the lack of a clear medical definition and evidence-based treatments for conditions causing pelvic pain, standardized, comprehensive guidelines have been developed for assessment and treatment of pelvic pain (Speer et al. 2016). Therefore, it's necessary to understand not only how medical knowledge around pelvic pain care is constructed, but also the consequences of that construction in the context of the current paradigm for medical practice.

Background

The Medical Gaze and Biopower

Foucault outlined the genesis and evolution of what he termed the medical gaze, in his 1973 book, *The Birth of the Clinic*. His analysis provides an overview of the history of the medical profession and the production of medical knowledge. Over that history, medical knowledge became more and more focused on the visible components of disease. As technology improved and different instruments were introduced—for example, the stethoscope—what was embraced as “visible” multiplied. Medical professionals were increasingly able to use not only sight, but also touch and hearing to guide their medical gaze. This shift allowed them to visualize the “invisible” aspects of disease. With these advances, the gaze shifted toward visible *disease* and away from patients and their subjectively reported symptoms (Foucault 1973). Consequently, the medical gaze increasingly relied on “objective” measurements of health, bringing the power of medical knowledge to the forefront of clinical interactions.

Foucault referred to such growing bodies of knowledge as a form of *biopower*, specifically discussing them as a *biopolitics of the population* (Foucault 1978). As opposed to older conceptions of power that focus on sovereignty and obedience, biopower allows us to analyze the

relationship between dominance and subjugation that occurs in a myriad of relationships in life, including the provider-patient relationship. Rather than focusing on power as the right to “*take* life or *let* live,” biopower focuses on the power over life. It is “a power bent on generating forces, making them grow, and ordering them, rather than one dedicated to impeding them, making them submit, or destroying them” (Foucault 1978:136). The ability to monitor population health through data collected using the ever-evolving technology in the field of medicine introduced this disciplinary form of power to the clinical interaction. Therefore, rather than observing power in the clinical interaction as simply the relational dynamic between providers and their patients, the concept of biopower allows us to understand medical knowledge and discourse as a hugely influential source of power over such interactions.

Evidence-Based Medicine and Positivism

One important topic of interest to medical sociologists studying the production and clinical implications of medical knowledge is the shift to EBM in the US, which took place in the 1990s. EBM can be understood as “a social movement aimed to strengthen the scientific base of health care and determine the effectiveness of clinical interventions” (Timmermans and Kolker 2004:177). The movement gained traction due to speculation over varying practice patterns in medicine, which undermined the credibility of medical professions and raised concern about unnecessary medical expenses. The shift to EBM is often discussed as epistemological, but I argue that it was not only epistemological, but rather a complete paradigmatic shift towards positivism and “objectivity” in medicine. In other words, there was a shift in epistemology *and* ontology, axiology, and methodology in terms of how medical knowledge was produced and applied. This idea is alluded to by Timmermans and Kolker (2004), but not explicitly discussed in the sociological literature on EBM. Using Mertens (2010) definitions of these philosophical assumptions, we can understand *epistemology* as the nature of knowledge and the relationship between the knower and the would-be-know, *ontology* as the nature of reality, *axiology* as the nature of ethical behavior, and *methodology* as the approach to systematic inquiry.

Within the positivist paradigm, we assume objective knowledge that is not influenced by the relationship between the provider or researcher and medical knowledge; we ethically value the suppression of personal bias and minimizing harm to patients; we assume a single, tangible reality,

and in doing so assume all bodies can be assessed and treated in the same way; and we use quantitative data and methods to systematically assess patients' symptoms based on standards of care developed through quantitative research (Mertens 2010). In EBM, these assumptions are all active. Clinical trials using quantitative methods of design, data collection, and analyses are the end all be all to producing medical knowledge. Those quantitative approaches to producing knowledge presumably generate objective knowledge that is not tainted by personal bias. That same knowledge production also leads to the assumption of a single, tangible reality which manifests as standard clinical guidelines. EBM assumes that those clinical guidelines can be applied in the same way across patient cases, yet we know—from evidence—that interactions between providers and patients vary based on patient characteristics like gender, race, and SES (Hoffman and Tarzian 2001; Hoffman et al. 2016; Lutfey and Freese 2005). The shift to EBM was also characterized by the emergence of two major ethical concerns: 1) quality of healthcare and 2) cutting costs, aligning with axiological assumptions of positivism that prioritize minimizing harm to patients (Mertens 2010; Timmermans and Kolker 2004).

Perhaps unsurprisingly, EBM has been critiqued across many disciplines since its conception, including, but certainly not limited to, sociology. For example, Medical Doctor and professor of primary healthcare Trisha Greenhalgh (1999) discussed EBM as having “tenuous assumptions” about diagnostic decision-making. She even argued that EBM supports the idea that “discovery of ‘facts’ about a patient’s illness is equivalent to the discovery of new scientific truths about the universe” (Greenhalgh 1999:323). However, Greenhalgh (1999) contests this claim given the fact that illness does not manifest identically across patients, as well as evidence that providers do not simply assess patients objectively. Rather, they assess patients based on evidence of what symptoms, conditions, and diseases look like in *typical* patients (Greenhalgh 1999).

The Standard Human and Niche Standardization

The idea of assessing patients using evidence based on a *typical* patient is what connects theoretical and philosophical ideas on EBM to theoretical ideas on standardization (Epstein 2007; Timmermans and Epstein 2010). In his 2007 book, Epstein discusses the ways medical research was largely lacking diverse bodies in that it almost entirely relied on middle-aged white male bodies to produce medical knowledge. Despite the lack of minority bodies in medical research, the

evidence resulting from such research was considered standard and often translated into clinical guidelines (Epstein 2007). Those guidelines, although built on findings specific to the middle-aged white male body, were then used to assess and treat a diverse set of patients whose bodies and experiences that knowledge may not be applicable to.

A new biomedical paradigm emerged as a critique to this standardization, which Epstein (2007) terms the “inclusion-and-difference” paradigm. The inclusion-and-difference paradigm is “the research and policy focus on including diverse groups as participants in medical studies and in measuring differences across those groups” (Epstein 2007:17). In some ways, this paradigm is comparable to constructionism which assumes multiple, socially constructed realities, as opposed to the single reality assumed by positivism (Mertens 2010). Importantly, Epstein (2007) stresses that the inclusion-and-difference paradigm is not a paradigm in the traditional philosophical sense because it lacks a full set of assumptions that such paradigms espouse. However, its assumption of multiple realities certainly takes it out of the positivist paradigm where EBM resides, creating a somewhat contradictory perspective to EBM and its assumptions.

Women’s health activists and feminist groups were perhaps the most influential in translating the inclusion-and-difference paradigm into policy changes requiring the inclusion of female bodies in medical research. Feminist critiques of medicine as a patriarchal institution, which emerged in the 1970s, had a lasting impact on the state of both medical research and the medical profession. For example, more women were taking up space in medicine and the National Institutes of Health appointed its first female director in 1991 (Epstein 2007). This long-overdue introduction of more women to medicine helped prioritize women’s health in medicine. Following critiques from feminist groups and women’s health activists, racial minorities began to push back against medicine as an institution that had perpetually violated their human rights both in medical research and practice. As such, regulatory guidelines emerged that required researchers to include racial minorities in clinical trials and other medical research. As medical research began including women and minorities in their study samples—often due to legal requirements—the process of niche standardization emerged (Epstein 2007).

Niche Standardization is the process by which human populations are transformed “into standardized objects available for scientific scrutiny, political administration, marketing, or other purposes that eschews both universalism and individualism and instead standardizes at the level of the social group” (Epstein 2007:135). When it comes to EBM, niche standardization is helpful

for understanding different clinical guidelines based on sex, age, and other social or biological characteristics. For example, research on sex differences in symptom presentation associated with acute myocardial infarction, or heart attack, began emerging in the late 1990s (Goldberg et al. 1998). This emergence presumably led to sex-based clinical guidelines for assessing heart attack symptoms.

At the same time the inclusion-and-difference paradigm was on the rise, the EBM movement was also gaining popularity. I argue that these movements, or paradigms, conveniently converged in a dialectical manner synthesizing into niche standardization. The convergence of these paradigms likely occurred because they emerged historically at similar times. At the time, folks were increasingly worried about the credibility of medicine (Timmermans and Kolker 2004), as well as the inclusion of minority groups in medical research (Epstein 2007). Niche standardization, as a medical paradigm with potential to address both concerns of credibility and inclusion, therefore materialized as a seemingly obvious direction forward for the field of medicine.

The Limits of Dialectical Thinking

Dialectics have been a common way of theorizing about the world, in both ideal and material forms, for centuries. Although originating from Hegel, Marx brought the idea of dialectical materialism to sociology. In short, dialectical materialism posits that all contradictions eventually resolve themselves through the synthesis of a new level or concept (Freistadt 1956). For example, Marxists might argue that feudalism and mercantilism—as contradicting economic systems—synthesized into capitalism. The same idea can be applied to paradigms for medical practice. For example, EBM takes a positivist approach to medical knowledge contradicting the inclusion-and-difference paradigm which takes a more constructionist approach by acknowledging multiple realities. Applying dialectical materialism to this scenario we can understand this contradiction as having synthesized to form a new level: niche standardization (see Figure 1).

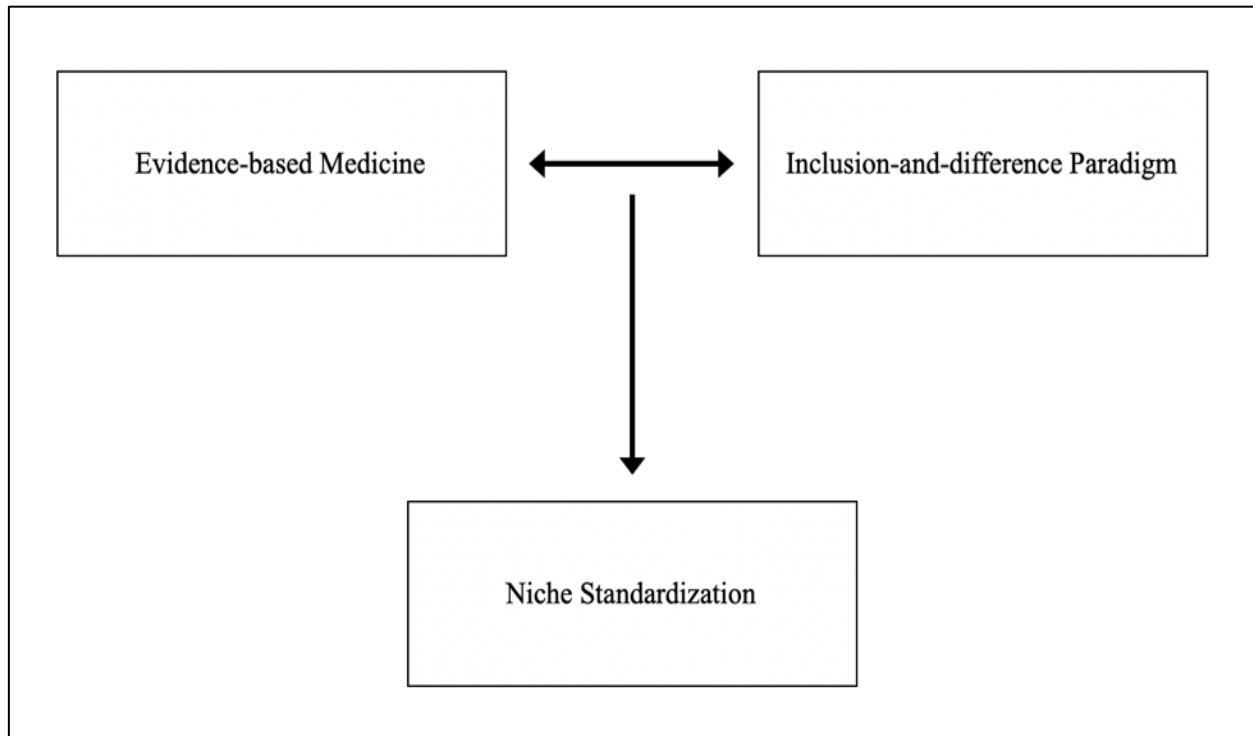


Figure 1. Dialectical Materialism of Medical Paradigms

However, just because the synthesis of these paradigms is new, does not necessarily mean it is *improved*. In fact, by design, the contradicting ideas always leave remains behind within the synthesized concept in dialectical materialism (Adorno 1973; Bonefeld 2012). Hence, “that which is denied in the [synthesized] concept has no separate existence from the concept. It lives within and through the concept” (Bonefeld 2012:130). In this case, niche standardization includes elements from both the inclusion-and-difference paradigm and EBM, and even the elements from each that are lost in the synthesis still define niche standardization. This property of dialectical materialism is why niche standardization is still a form of standardization, likely bringing with it, the limits of that standardization.

The analysis here unpacks this process in the context of pelvic pain care to understand the limits of this synthesis and, more generally, how thinking outside of dialectics may offer a path out of standards of care for conditions that lack necessary evidence to reach acceptable standards. As a medical symptom that is highly gendered, pelvic pain care may find itself within the “niche” of women’s health, where the standards of care are focused on women. However, this idea begs

the question, along which lines are those standards built and which women might benefit from them? By turning to the medical discourse—the process of the production of medical knowledge and, therefore, the medical gaze—the limits of that standardization may reveal themselves (Foucault 1973).

Methods

Foucault's (1973; 1978) ideas on power largely drive the methodology behind this research. In *The Birth of the Clinic*, Foucault (1973) outlines the rise of medical authority, the power of the medical gaze, and the evolution of the medical gaze over time. One prominent shift in the medical gaze occurred when language and description was introduced into the gaze. Specifically, Foucault (1973) writes:

To describe is...to see and to know at the same time, because by saying what one sees, one integrates it spontaneously into knowledge; it is also to learn to see, because it means giving the key of a language that masters the visible. (p. 114)

In this excerpt, Foucault (1973) is introducing the power of discourse in constituting the medical gaze. Specifically, he argues that by using language to describe what one sees through the medical gaze, the medical gaze is transformed into medical knowledge. This process of describing what one sees also alters the medical gaze through this construction of knowledge (Foucault 1973). Foucault's (1973) ideas suggest medical discourse is an important site for analysis when asking questions regarding medical knowledge and practice. Therefore, I turn to the medical discourse to answer my research questions.

Data for the discourse analysis come from two sources: 1) fieldnotes from observations at two annual meetings for OBGYN- and pelvic pain-specific organizations, and 2) qualitative interviews with medical providers. I originally planned to attend two OBGYN association conferences but was only able to gain access to one: the American College of Obstetricians and Gynecologists (ACOG). ACOG is associated with one of the two highest impact factor OBGYN journals in the US, *Obstetrics & Gynecology*, making it an authority over medical discourse on women's health. It was founded in 1951 and began publishing *Obstetrics & Gynecology* in 1953 (The American College of Obstetrics and Gynecology 2017). The ACOG conference took place in Nashville, TN in May of 2019 and lasted three days.

The second conference I attended was held by the International Pelvic Pain Society (IPPS). According to its members, it is the only professional medical society dedicated to pelvic pain in the world, making it a leader in the production of medical knowledge on pelvic pain. The IPPS meeting took place in Chicago, IL in October 2018. It lasted four days, including pre-conference and post-conference events, both of which I attended. Unlike ACOG, which is primarily attended by OBGYNs and medical students, IPPS was highly attended by Physical Therapists (PTs), psychologists, and psychiatrists, in addition to MDs, most of whom specialized in OBGYN. It was at IPPS where the important role of PT in pelvic pain care became apparent. With that knowledge, I decided to include PTs in my interviews with providers to grasp a more holistic picture of the medical discourse on pelvic pain, given that PTs play a large role in producing that discourse.

To capture the pelvic pain discourse generated by medical providers, I conducted semi-structured interviews with 17 providers. The interview sample consists of 15 women, and 2 men, including 12 providers who identify as white, two who identify as Middle Eastern, one who identifies as Black, one who identifies as Latinx, and one who identifies as non-white. The age range of providers was 28-59 at the time of their interviews, with the average age of providers being 39. The sample consists of 11 OBGYNs, five PTs, and one nurse practitioner (NP). Interviews took place between October 2018 and November 2019, and 12 of the interviews were conducted over the phone, while the remaining five were conducted in person at the medical conferences. To recruit providers for interviews I approached them at appropriate times during the meetings (e.g., before or after a presentation), introduced myself, and explained my research to them. I also advertised a recruitment flyer for providers with permission from each association. Lastly, I also advertised the recruitment flyer on social media, including Twitter and Facebook. In the end, seven providers were recruited at ACOG, eight were recruited at IPPS, and the remaining two were recruited from a Facebook group specific to pelvic health. All providers I interviewed reported the US as their nationality/country of birth, and they were all currently practicing in the US at the time of the interviews. If providers I spoke with, or emailed with, were interested in participating in an interview, I supplied them with a consent form and upon receiving informed consent, we set a time for the interview.

Analytical Technique

Critical discourse analysis (CDA) is the technique used to analyze both sources of data. According to Van Dijk (2015), CDA primarily focuses on the relationship between social issues and discourse, rather than understanding discourse outside of its social context. In this way, CDA focuses not only on describing discourse structures, but also on explaining discourse in terms of social structures. CDA is unique in the critical perspective it requires a researcher to take when analyzing discourse, leaving many tenets in line with ideas originating from critical theorists of the Frankfurt School. Relatedly, it is often discussed as a reaction against dominant paradigms, such as positivism, making it an ideal method for examining the limits of positivist assumptions within EBM (Van Dijk 2015). The eight basic tenets of CDA are as follows: “1) addresses social problems, 2) power relations are discursive, 3) discourse constitutes society and culture, 4) discourse does ideological work, 5) discourse is historical, 6) the link between text and society is mediated, 7) discourse analysis is interpretive and explanatory, and 8) discourse is a form of social action” (Van Dijk 2015:467).

Using CDA as an analytical technique, I approached the data with previous concepts from the literature in mind. For example, analysis began by coding for instances where EBM, patient standardization, and niche standardization were alluded to or explicitly mentioned. I also coded for examples that did not fit these concepts, and instead negated them, requiring me to take a critical lens during analysis. For instance, the code “negating positivism” emerged through analysis. Lastly, I looked for instances where EBM, standardization, and niche standardization were connected to unintended consequences to better understand the limits of these medical paradigms. In doing so, the code “pigeonholing patients” emerged, which is discussed in depth in the findings section below.

Findings

Analysis of interviews with providers and fieldnotes from the two medical conferences reveal a process by which standards of care for pelvic pain patients may only benefit patients with certain conditions that include the tangible evidence necessary to fit the standards of care within EBM. Theoretically, I argue that practicing EBM in the context of a lack of evidence leads to pigeonholing patients into evidence that does not adequately explain their case or experience. This

somewhat process-oriented phenomenon is unpacked below in two major themes: 1) *evidence-based medicine without the evidence*, and 2) *pigeonholing patients through niche standardization*. Within the two major themes lie subthemes that help explain the process of how these phenomena play out within the confines of EBM. In addition to these two major themes, the *limits of niche standardization* as a product of dialectical materialism also emerged in the data. I discuss this theme through evidence of niche standardization, and then present two outlier cases from fieldnotes that demonstrate the valuable paradigm shift that can occur when we resist dialectical thinking.

Evidence-based Medicine without the Evidence

Unnecessary lag in knowledge dissemination

The discourse I analyzed, first and foremost, revealed that medicine constructs pelvic pain care through an EBM framework, even though individuals and organizations are well aware that the evidence for assessing and treating these patients is lacking. In the context of this medical symptom that is both stigmatized and normalized, this lack of knowledge exacerbates the barriers that patients with pelvic pain might face. These barriers arise particularly because pelvic pain patient care follows a similar evidence-based model as other medical specialties yet lacks much of the evidence necessary to properly treat patients through EBM. Even when the necessary evidence exists somewhere in the peer-reviewed medical literature, the usefulness of that evidence is not always clear. For example, one MD told me:

Even if there's knowledge about pelvic pain, I think that there's just not a practice of how to diagnose and manage these patients...So, I think there's just generally not much training in how to actually handle these patients. So, I think that's probably where the deficiency comes in. And that probably is from lack of experience and lack of having an algorithm or a treatment of care plan.

One reason that evidence may not make its way into the treatment “algorithms” for pelvic pain is the slow dissemination process of that knowledge from the literature to clinical practice. One MD explained this dissemination lag in the following quote:

There's a significant lag, okay?...You had people on the cutting edge and they would develop ideas, and then they would develop studies to try to test those ideas,

and about five or ten years after they had the idea, they would publish a paper, and then about five or ten years after the paper was published, it would be common knowledge and get in text books, and then a couple years after that, it would be taught to students. By necessity, there's a significant lag time in when the knowledge is kind of begun and when it's common knowledge and disseminated to others. And, of course, along the way some knowledge is refuted. So, people think this is the way it is, and a couple studies come out that say no, this disproves that theory, and that's just the way knowledge is pushed forward. But you know, the students who are being trained to be the future are generally not getting the cutting-edge knowledge because it's still being formulated.

Another MD shared a similar statement through a specific example she remembered from a professional meeting:

[An OBGYN] was [giving a talk] about [vulvar pain] along with her other research about the biopsychosocial model...and it was like foreign to [the audience]. Even though it had been in the literature for some time, it was foreign to them...It's up to...our professional societies...It's kind of their duty to put it in the publications that go out to all the community providers. Like we have ACOG's community opinion—it's a practice bulletin. [General OBGYNs] have to know everything in those documents because that is the standard of care...but usually there's a very long lag of time between evidence being put into the journals and then something being put into the community opinion. So, in the interim...[care] is very variable.

Again, even if the evidence exists somewhere in the peer-reviewed literature, it can take years or even decades to actually make its way to clinicians who, by the nature of the EBM paradigm they practice in, will use it to assess and treat their patients.

This knowledge that is lacking due to an unnecessary lag in its dissemination exerts power over providers and their abilities to assess and treat patients. The very idea that providers must wait for knowledge to be adequately “proven” before they apply it to their medical gaze illustrates Foucault's (1978) concept of biopower. Not only does this form of biopower restrict providers in their abilities to care for patients, but it also leaves female bodies without proper “evidence” to warrant treatment of their symptoms. The lack of evidence on women's pelvic pain is not a coincidence. It reflects a larger phenomenon of lacking evidence on women's health and, particularly, women's sexual and reproductive health (Criniti et al. 2014; Kirschstein 1991). If there is no definitive, visible “disease” based on medical knowledge for providers to direct their gaze towards, symptoms like pelvic pain become essentially meaningless for assessment. For in

the era of biopower, disease, rather than symptoms, are measured for knowledge production, which means it is disease, rather than symptoms, that dictate the medical gaze (Foucault 1973).

Physical therapists also, somewhat unexpectedly, play a large role in the production of medical knowledge around pelvic pain. Although their role in pelvic pain care is different than medically trained providers such as MDs or NPs, they share the same opinions about a dissemination lag of knowledge to practice. The PTs I interviewed had similar observations about not only the lack of evidence, but the slow process of that evidence making its way to practice. For example, one PT told me:

The research is...increasing. I think in the beginning of me starting to do this there was some, just not a lot. And now it's slowly [increasing] because it takes so long to do research and it's expensive...Each year it's like a couple more articles are coming out about pelvic health, about GI issues that are related to pelvic pain, and bladder issues, sexual function issues. So...It's definitely evolving.

The following fieldnote excerpt is another example of PTs recognizing a similar lag in dissemination of knowledge to practice:

This morning I sat down at a table with two PTs. I asked one about how long PTs have been involved in pelvic pain care and she said it has been growing for maybe about a decade. She said she thinks PTs started getting involved because MDs didn't know what else to do for patients, so they just started sending them to PTs to see if it would help. Now the evidence is there, at least somewhat, but she thinks that it started less intentionally based on evidence.

Once again, another PT shared, "I think that every year it continues to get better. As the studies come out and more physical therapists start treating it and more doctors start knowing about it, it's getting better."

This discourse not only tells us that this dissemination lag exists, but that providers are well aware of it. Despite their awareness of this lag, they still aim to practice based on evidence, and in doing so project an objectifying gaze onto their patients. For example, one MD described the "workup" for pelvic pain as "anatomical," or relating to tangible evidence in the patient's anatomy. Assessments and workups relying on patient anatomy alone neglect the patient as a person with opinions, feelings, and subjective experiences, and instead attend only the patients' body as an object. Also, as I will discuss further in later themes, only certain conditions provide such tangible,

anatomical evidence for providers to use in a workup, leaving many conditions undetectable by this medical gaze.

Another MD told me, “I don’t do things just because a patient wants me to. I do things based on evidence.” She added the caveat, “but I talk about it, you know? And my patient satisfaction scores are really good!” Additionally, one PT at one of the medical conferences shared an example of why, even if students are learning the newest evidence, it might not translate into the way they practice in the following quote discussing some new research from “about a year ago” in the “PT Education journal.” She said the research explains:

You can take students that have been taught much more updated evidence, they’ll go into clinics and the clinician may be like in the old evidence and not brought up—70% of the students will revert to their clinical instructor’s point of view in clinic despite the fact that they were taught something [newer] and know it’s better.

Interestingly, this research, as interpreted by the PT, tells us that an institution based on an evidence-based paradigm introduces systemic flaws that work against that very paradigm it prescribes to.

Definitional dilemmas

Given the lack of evidence on pelvic pain, and the lag in the dissemination of the small amount of evidence that does exist, is not surprising that both care and definitions used to care for patients are variable. I use the sub-theme “definitional dilemmas” to explain the inconsistent definitions used in pelvic pain care. One MD discussed the lack of consensus around definitions involved in pelvic pain care explicitly when she said, “when people talk about like chronic pelvic pain sometimes vulvar pain gets lumped into it, but then some people talk about it separately.” She went on to say, “a lot of that though is driven by the fact that the subsets of pain—like the sub-types—are not well-defined yet.” She then mentioned that “identifying those sub-types” to make them “clinically applicable” was part of the work she did as a research coordinator early in her career. This MD continued to provide evidence for definitional dilemmas, and her awareness of them, as she stated:

The names for vulvar pain have changed so many times. Like when I was a research coordinator it was called vulvar vestibulitis syndrome. And now...people generally say vulvodynia or vestibulodynia or—focusing more on the anatomical aspect of

where there's pain. But there's—as you learned in the conference—there's just so many sub-types of pain that we don't actually have a phenotype for yet.

This quote shows that not only are there numerous inconsistent definitions in the medical literature related to pelvic pain, but there are also many undefined symptoms and sub-types of pain that would potentially be helpful for treating pelvic pain patients via EBM. Once again, we see how the lack of institutionalized knowledge dictates the medical gaze, inherently impacting the treatment of patients with pelvic pain. A PT shared yet a slightly different definition of vulvodynia in the following quote:

There's a specific condition called vulvodynia. It literally just means pain in the vulvar area...that's only one condition of pelvic pain and we're even trying to define that. And it is very complex. Just to give you an example, we have vulvodynia as generalized/localized, provoked/unprovoked, uh, sorry I'm—this is off the top of my head, but provoked/unprovoked, generalized/localized, uh, I'm totally missing another category here.

As definitions shift and become more or less specific, it may be increasingly hard to keep up with the latest definitions, leaving providers to rely on outdated definitions and standards of care. In such cases, it is not clear which definitions count as legitimate. For example, if the latest definition of vulvodynia has yet to be disseminated from the research to practice, is it considered legitimate? Based on my conversations with providers, as long as they have some form of evidence from the literature to back up the definitions they use, regardless of how outdated they are, those definitions are legitimate. This process ironically defeats the purpose of EBM by allowing varying practice patterns to persist in medicine, despite efforts to standardize, highlighting the connection between the unnecessary lag of knowledge dissemination and definitional dilemmas (Timmermans and Kolker 2004).

Another MD shared evidence of more definitional dilemmas in pelvic pain care when she told me:

Persistent pain used to be defined by pain that has been present for more than six months and then people really felt it should be three months. And now there's a movement to make that definition longer than expected time of healing.

This quote also shows a unique language choice of “persistent pain” rather than “chronic.” Only a few providers used the language of persistent pain, while the majority used the more common “chronic” versus “acute” pain definitions to discuss definitions and conditions involving pelvic pain. One MD shared an example of how even definitions of acute and chronic pelvic pain can be inconsistent:

Acute pelvic pain is pain lasting less than six weeks for the most part. I mean everybody divvies out this, but I would say less than six weeks of an acute type nature. Usually accompanied by autonomic symptoms. For instance, nausea, vomiting, headaches. Typically, it’s something that is related to an organic cause. For instance, they have appendicitis. Or they have a ruptured ovarian cyst or something that is typically a little easier to fix and find. It would also include stuff like your urinary tract infections and acute gastroenteritis. Those are all things that would cause acute pelvic pain. As far as chronic pelvic pain, chronic pelvic pain has a little bit more of—it’s a little bit more nebulous as to how it is defined. Most people will define chronic pelvic pain as regular pain in the pelvis lasting for more than six months without a definitive organic cause.

The MD describes the definition of chronic pelvic pain as “nebulous,” and adds the caveat that “most” people define it in the same way she does. When another PT used the term persistent pain in our interview, I asked her why she opted for that language, and she shared the following:

It’s all in the language. You know and I think the term chronic just seems like you are never ever going to get out of it, so chronic is, I don’t know, inflammatory language in my mind where persistent just kind of talks about how you have dealt with your pain up until this point in time because it’s been persistent. It really doesn’t give that [inflammatory] outlook to your pain.

Fixing the unfixable

These types of language choices can impact not only the experience of receiving care for patients, but also the experience of providing care for clinicians. If they prescribe to the idea that a patient’s pain is chronic and therefore perpetual and untreatable, perhaps providers will “give up” on treating those patients. This may be especially true for OBGYNs, who according to one MD go into their specialty because they want to be able to “fix” patients:

I mean one of the reasons I went into OBGYN was I felt like I could generally fix most things, and [pelvic pain] is the one thing—the one thing that as a generalist

OBGYN you [can't necessarily] fix. And that is the god to honest truth. I don't know what else you can't fix...There's pelvic organ prolapse. Sometimes you can't fix it because it's not fixable. Somebody's pregnant. They have a baby, or they have an abortion, or they have a miscarriage, or they have an ectopic pregnancy. It's all very finite. So, people who tend to go into OBGYN want to fix stuff. And generally speaking, they absolutely can, and [pelvic pain] is the one thing [they can't fix]...[It] is their little albatross [laughs].

Another MD similarly noted that gynecologists take a “black and white” approach to treating patients, where they can either fix the problem, or they can't.

As gynecologists we're very—we're surgeons, right? So...we're a little bit black and white in how we get trained. We're like “there's a problem, and we're going to fix it. And it's in this part of the body. And that's what we're going to do.” Hence, we do surgery a lot of times.

This gynecologist is emphasizing the role her training, and other gynecologists' training, plays in the approach to assessing patients. They are trained to “fix” things as “surgeons,” yet pelvic pain is perhaps the one thing they can rarely, if ever, “fix.” One NP mentioned her perception that people who go into the OBGYN specialty do so because of the surgical skills involved when she said:

[OBGYN] is a surgical specialty, so you have a lot of people who want to be surgeons, and so they go to medical school because they want to be surgeons...There aren't a lot of physicians who go to medical school because they want to do routine gynecological care. It's not the fun part.

The fact that OBGYN is a surgical specialty, according to the providers I talked with, is related to a certain way of thinking about and viewing the body. Based on the discussions I had with providers, it is likely that other surgical specialties reinforce a similar medical gaze that may be slightly more objectifying than is typical in American medicine. However, that speculation is beyond the scope of this analysis. What this analysis does tell us is the OBGYN specialty fosters an idea that the successful treatment is one that “fixes” a patient. Yet, when it comes to pelvic pain, a symptom not likely to be “fixable,” their training may fall short.

A quote from one MD exemplifies the idea that although pelvic pain is not necessarily “fixable” it can be managed. He said:

If someone says “I want to be pain free,” that may not be realistic. And if that’s still what they want after you’ve talked to them—yeah that’s not going to happen. Nobody’s pain free. But, be able to function, not interfering with your life, be able to be intimate—like those are realistic expectations for most patients.

As a reputable pelvic pain specialist, this MD has treated enough pelvic pain patients to know that he cannot necessarily “fix” them by taking away their pain completely. However, he can help them manage the pain enough for them to improve their quality of life in various ways. Importantly, this MD works in a pelvic pain clinic affiliated with an academic institution where the patients he treats have seen “five, six, ten doctors” who may be trying to “fix” them before they land in his office for more realistic care. From years of working with this population of patients, his medical gaze has adapted based on knowledge he has produced himself in the medical literature as well as knowledge he has access to through his academic affiliations. However, most providers do not have such access to hot-off-the-press knowledge and evidence to hone their gaze to specific patient populations such as pelvic pain patients.

For example, another MD mentioned how a lack of training in pain science for gynecologists may also contribute to a lack of guidelines for treating pelvic pain patients. She shared:

We’re not trained in pain science as OBGYNs, which is really disturbing because about 40%—I think it’s 40% was the last statistic that I read—of patients come to the GYN because they’re having issues with pain. Now some of that is acute pain, obviously, and some of it’s like vaginitis-related pain or yeast-related pain or whatever, but it’s a really alarmingly high number of patients that are coming in...because of pain...And we don’t know what to do with these patients. We’re not taught in residence how pain science works.

Despite evidence that around 40% of OBGYN patients elicit concerns of pain to their gynecologists, pain science has yet to make its way into OBGYN training. Unless an OBGYN takes a career path similar to the pelvic pain specialist quoted above, pain science is unlikely to influence their medical gaze in a way that improves their assessment and treatment of pelvic pain patients. Therefore, in most cases, this lack of training leaves gynecologists unequipped to handle pelvic pain patients, unless their cases conveniently fit the standards of care they have been taught to follow.

The desire to “fix” in the context of definitional dilemmas and a lag in the dissemination of pelvic pain knowledge can be a frustrating combination for providers. In fact, a majority of the providers I interviewed discussed how pelvic pain patients are often labeled as “difficult” due to this frustration. For example, one MD said:

Let’s put it this way, when I interviewed for the job that I have now, I told one of the practitioners there...“send me the people with pelvic pain, I like pelvic pain”...at the dinner that they took me out to when I was interviewing...they [groaned] and that groan tells me that people really don’t like to deal with it...It’s one of the diagnoses like “oh groan, I don’t even want to—I don’t want to deal with that.” And I think [that is] because it is so complex and it is so time intensive, you know?

In general, what providers alluded to is that a lag in the dissemination of medical knowledge to practice and definitional dilemmas leads to a frustrating process of care that leaves providers scrambling to practice EBM without the necessary evidence and tools. Another MD similarly shared:

I think when you say the word pelvic pain, initially my heart sinks a little bit because it’s just...such a challenging disease to treat... I do see a fair amount of people that are coming in for pelvic pain, and it’s frustrating, unfortunately, because I feel often that it is a very wide range of things that could be causing it and often it’s a lot of trial and error that is frustrating for patients as well as clinicians just trying to find what works best for them. So, it’s something that we need to do more research and like learn more about different types of pelvic pain to treat. But, in the meantime it’s just a very frustrating process.

This quote in particular demonstrates the understanding that this frustrating process is directly related to a lack of evidence on pelvic pain. Given the frustration that results from such contextual factors, it is not surprising that providers, and OBGYNs in particular, may resort to following outdated or irrelevant standards of care to try to help their patients with pelvic pain. Together, the slow dissemination process of knowledge into practice guidelines, definitional dilemmas both in the formal medical literature and the medical discourse on pelvic pain, and training that leaves gynecologists unable to “fix” pelvic pain, leaves providers without clear guidelines for assessment and treatment of pelvic pain.

Pigeonholing Patients through Niche Standardization

Much of the discourse on pelvic pain is specific to “women’s health.” As such, pelvic pain care ends up conflated with OBGYN, the medical specialty focused on women’s health. A nurse practitioner went as far as to say, “I think anytime you’re practicing in women’s health, you’re practicing in pelvic pain because there’s such a high rate of pelvic pain.” This conflation of pelvic pain care and women’s health leaves pelvic pain care fixed within the niche of women’s health, leaving many providers relying on the standards of care developed within the OBGYN specialty. In the context of a profession that has a consistent goal to “fix,” it is unsurprising that providers may resort to using a single method to try to fix an often-multifaceted problem.

Importantly, pelvic pain does not always have a gynecologic cause and, according to one MD, patients “can have different types of pelvic pain caused by different systems, [making it] hard to tease out what pain is caused by which system.” So, even if there is a gynecologic cause to the patient’s pain, there is likely to be another cause outside of the patient’s gynecologic anatomy. This process of conflating pelvic pain with OBGYN standards of care leaves many providers without guidelines for patients who do not neatly fit within the box of gynecologic pain. In such instances, the data reveal that providers often resort to the set of knowledge they are sure about. Specifically, pelvic pain often automatically signals endometriosis to many gynecologists, given their training to automatically make such assumptions.

Outdated standards of care

According to multiple MDs, the standard of care for assessing pelvic pain in the past was performing a laparoscopy, a form of minimally invasive surgery that allows gynecologists to check for tangible evidence of endometriosis. One MD shared:

I can tell you when I started my career in the early 90s, the standard of care for evaluating chronic pelvic pain was basically doing a laparoscopy, seeing if the woman had endometriosis or pelvic adhesions, and if neither one was present, send her to a psychiatrist. That was basically the standard of care and there were articles in the literature...that said that.

Yet another MD shared her memory of what the standard of care was before laparoscopies became routine. She said.

[Standards of care have] changed a lot because there used to be kind of a thinking that a lot of these things were almost imaginary or psychiatric. And...I think that's gone by the wayside now. People don't jump to that so quickly. And they kind of do more of a physical exam and more now we have ultrasound being used more aggressively and laparoscopy is a more routine procedure...I think usually if somebody presents with pelvic pain, you're usually going to find something. It's just a matter of looking.

This gynecologist's quote reveals not only that there was a shift in standard of care to rely more heavily on laparoscopies to diagnose pelvic pain, but also that she is under the impression a provider will "usually" find the cause of the pain with this procedure. Another MD shared a similar idea, which she based on the medical literature and evidence:

If you go read like books that were written in the 50s and 60s about pelvic pain, they're mostly about psychological problems... And then when laparoscopy came up, people actually researched laparoscopy, like diagnostic laparoscopy for pelvic pain and very famously [it] was discovered that...teenagers coming into the ER with pelvic pain, you actually find a problem in more than two thirds of those people if you did a laparoscopy on all of them. So that kind of changed everybody's thinking...And we started looking more aggressively for other causes. And I think now at this point, the whole focus on psychological issues causing pelvic pain has really been completely eclipsed by the many physical things that cause pelvic pain. And it turns out we were probably misleading people all those years and...we just didn't know. We didn't have laparoscopy. We didn't have ultrasound.

The discourse around laparoscopies was rampant in my interviews. Still another MD shared, "laparoscopy is just way more common, you know...I mean now it's considered very standard to do a laparoscopy for pain." These providers are not simply performing surgeries on patients without reason. They have been trained to respond to a patient's pain with surgery, and the medical research tells them that they should find the cause of the patients pain via laparoscopy "more than two thirds" of the time. One MD also shared evidence from "studies on...the placebo effect of surgery." She said "you do a diagnostic laparoscopy, you don't find much, yet they're a lot better after you do that. And I don't know if they've done it on pelvic pain, but they've done it on orthoscopic surgery." They are following the standards of care, and practicing EBM using the evidence that does exist. Yet, in doing so, they are also ignoring a majority of the potential causes of pelvic pain, such as pelvic floor dysfunction, vulvodynia, irritable bowel syndrome, interstitial cystitis, and pudendal neuralgia, all of which cannot be diagnosed via laparoscopy.

Unnecessary surgeries

The lack of updated standards of care that encompass the multitude of conditions causing pelvic pain can, and do, lead to unnecessary surgeries from well-meaning physicians who assume pelvic pain equates to endometriosis. For example, one gynecologist told me:

Historically...[providers] have generally just done surgery to help people with these pains. But...surgery...is only part of treatment. It sometimes makes pain worse. Sometimes it doesn't help at all...A lot of the patients that get referred to us...they've had like ten laparoscopies. I'm not kidding. I had a patient once who had fifteen laparoscopies. That was doing nothing for her. But when she saw someone else for her pain, they didn't know what else to do.

Another MD similarly told me:

People get unnecessary surgeries all the time by well-meaning physicians who have only been trained to take them to the operating room which is what happens with the training that we get from [gynecology]. Because pretty much if somebody shows up on your doorstep as a [gynecologist] and says they have pelvic pain, either I don't know what it is, or it's endometriosis. And if the only thing you know how to hit is a nail, you're going to be a hammer.

Both MDs quoted here emphasize the role of training in the unnecessary surgeries performed on patients with pelvic pain. These physicians are “well-meaning” but have only been trained to, as one provider put it, hit a nail. And when providers are only trained to address symptoms in one way, their toolsets become extremely limited. In the context of a profession full of providers who want to “fix” their patients, it is not surprising that they use the only tool they have to try to fix the patient.

Another piece of training that leads to such unnecessary surgeries is the lack of knowledge around pelvic floor exams. The following excerpt from an interview with one MD demonstrates that connection:

Provider: Unfortunately, as we were talking about earlier, without knowing how to do a pelvic floor exam, everybody has endometriosis, which is completely nonsense, right? So—

Interviewer: So, do you see a lot of misdiagnoses of—

P: Regularly.

I: And unnecessary laparoscopies pretty regularly?

P: Yeah. Regularly.

Further, while sitting in a session on pelvic girdle pain at IPPS, another MD mentioned she is “a gynecologist and [learning about the pelvic floor] is one of the reasons” she was at the session. She said OBGYNs are taught to treat endometriosis and mentioned that in her group of gynecologists she is the only who knows about the pelvic floor. To drill this OBGYNs point further, another OBGYN I interviewed told me “We don’t usually use pelvic floor physical therapy for pelvic pain. Usually pelvic floor physical therapy has to do with you know, do you have like pelvic relaxation, are you losing urine if you cough or sneeze?” This provider’s response demonstrates the lack of knowledge surrounding the pelvic floor, which, according to the PTs I spoke with, often plays a role in patients’ pelvic pain even when there is also a gynecologic cause for the pain, such as endometriosis.

It’s the OBGYNs niche

Constructing pelvic pain care through an EBM framework in the context of a lack of evidence leads to pigeonholing patients into certain assessment and treatment methods, and sometimes even certain diagnoses. Most providers were aware that pelvic pain does not always have a gynecological cause. They are also aware that patients end up in the OBGYN office because pelvic pain is often equated with gynecologic issues, even though that is not always the case. One provider shared:

The reason people land in the gynecologist office is because they have a menstrual cycle every goddamn month...There’s something about their uterus and ovaries that reminds them every month that they are there and it has to be that, right? And so that’s why they land typically in the GYN office—understandably so. It has to be that. And it might be—but it might not be.

In addition to pelvic pain not always having a gynecological cause, one provider noted, “it’s very rare when [there’s] just one cause of their pain.” With that said, even when there’s a gynecological cause, there is likely another component to the patients’ pain as well. For example, one presenter mentioned comorbidity of irritable bowel syndrome and endometriosis, and a case of an

endometriosis patient who saw him after four or five other doctors. None of those providers had asked about her bowel activities. After focusing on bowels and getting a GI doctor involved, that patient was pain free. Without having her non-gynecologic symptoms addressed, that patient's chronic pelvic pain was likely to persist.

When I asked yet another OBGYN about referring patients to other specialists she said, “We don’t usually do that. I mean they get referred to us for that. So, like who would we send them to [laughing]? You know, we’re kind of the end of the line.” Overall, there seemed to be a consensus across OBGYNs I interviewed and observed at the meetings that pelvic pain is left to OBGYNs, even when the cause is not gynecologic. In this sense, these MDs are aware that they are the go-to source for patients with pelvic pain, and they know that they do not have all the training necessary to adequately assess all the possible causes of those patients’ pain. Yet, rather than referring to other specialists they use the tools they have available to do their best to identify a treatable cause. However, when that cause is either invisible, ambiguous, or untreatable, these same providers have no clear route forward for those patients. In these cases, well-meaning providers may attempt to “fix” those patients through laparoscopy and hope for the best.

The Limits of Niche Standardization

Although women’s health was the general “niche” present in the pelvic pain discourse, there were plenty of examples of niche standardization based on both age and race as well. The majority of examples of niche standardization based on race appeared on e-posters at the ACOG conference and were referring to demographic characteristics of research participants (see Figure 2 for an example). Instances of niche standardization based on age appeared in patient case examples in presentations at both conferences. For example, many patient cases presented at the “Pre-conference Clinical Foundations Course” at IPPS were specified as “reproductive age.” Each presenter during this pre-conference course ended their presentation with questions for the audience that attendees could answer through the conference’s mobile application. These questions were usually in reference to patient cases that specified sex—although, all were female—and age. If that patients’ age fell within the reproductive age range, that was also usually, though not always, specified.

Although this type of niche standardization may be helpful for tracking health trends by race, age, or sex, it is not necessarily helpful for understanding how to assess or treat patients. In

fact, it may actually exacerbate biases when it comes to medical decision-making. One MD actually alluded to the bias of health statistics in her interview when she said:

...women are much more likely by the statistics to have chronic pelvic pain. Now I say by the statistics because that is operative. A lot of men will not admit that they have chronic pelvic pain, so the statistics may be very skewed just by reporting bias. Women are more likely to report pelvic pain in which case the statistics skew that you know the good predominance—I can't remember the most recent statistics, but it's probably somewhere around the neighborhood of about 70% of chronic pelvic pain sufferers are female.

Researchers have suggested that bias statistics create the façade that high-SES white women suffer from endometriosis more than low-SES and minority women, when these diagnostic differences are more likely due to diagnostic biases (Viganò et al. 2004). Given that medical evidence based on demographic characteristics is often bias, it stands to argue that using such evidence to construct standards of care will introduce (more) bias. Hence, the limits of this kind of niche standardization in the construction and application of medical knowledge.

Table 1. Participant characteristics

| | |
|---|--------------|
| n=672 | |
| Age in years (median) | 53 (41, 64)* |
| Time since IC/BPS diagnosis in years (median) | 7 (3, 14)* |
| Gender | |
| Female | 98% |
| Male or Other | 2% |
| Ethnicity | |
| Hispanic | 3% |
| Non-Hispanic | 96% |
| Unknown | 1% |
| Race | |
| Asian/Pacific Islander | 1% |
| Black | 1% |
| Native American | 0.1% |
| White | 94% |
| More than one race | 3% |
| Unknown | 0.7% |

*Interquartile range

Figure 2. Example of niche standardization based on race from e-poster

Shifting the Paradigm

The alternative to niche standardization that breaks free from the restraints of dialectical materialism, and therefore standardization, can be understood through the two outlier examples discussed here. These examples come from two sessions at ACOG and they consider both evidence and medical practice differently than the examples outlined above. They discuss evidence as patient stories and recognize medical practice through the act of storytelling. In doing so, they reject the ontology inherent in EBM that assumes one, tangible reality; they reject the epistemology that assumes objectivity and a process of knowledge production and medical practice that is never influenced by personal bias; they expand the axiological assumptions to include increasing social justice; and they expand their systematic approach of inquiry to support the value of narrative. They are the product of what Adorno (1973) called *negative dialectics*.

The sessions that demonstrated this alternative approach to niche standardization acknowledged race not as a demographic category, but as a social structure that influences patients, providers, and their interactions, which subsequently influences the practice of medicine. The first session was titled “Maternal Health Crisis: Rethinking our approach to Safety, Support, and Racism.” This session included a small panel made up of one black woman who nearly lost her life during childbirth, and one black man who lost his wife and the mother of his two children just after she gave birth to their second child. In addition to the two guest speakers, the panel included a moderator who was a provider of color. At one point the moderator brought light to racism and provider bias in practice when he mentioned there’s a very fine line between intuition and racism, saying “When our intuition works out, we celebrate it, but when it doesn’t, it may just be racism.” One of the panelists took this idea even further when she said, “some doctors don’t even think black people feel pain...When it comes to physicians, I always go back the oath...do no harm. But is it do no harm unless they’re black or they’re brown?”

The paradigm shift in this session, however, was not just about looking at racism as a social structure rather than race as a demographic category. It also presented patient experiences in a new light—as important and reliable evidence. Before the first speaker began, the moderator said “the first thing people need to know is what happened to you. So, let’s start with your story.” Here, the moderator, a reputable and well-known MD, was emphasizing the importance of her story. First, and foremost, folks needed to hear about her experience as a patient who nearly died after postpartum hemorrhage. The moderator later said, “there [are] so many things that only a woman in

labor can tell you.” Although this example is not specific to pelvic pain care, it shows a paradigm shift in thinking about evidence used in patient care. For example, we can take that last statement from the moderator and imagine a presenter telling the audience at IPPS that “there are so many things that only a woman with pelvic pain can tell you.” With that thinking, perhaps providers can start to rely more on subjective experience, and less on “objective” evidence that may rarely be accessed in cases of pelvic pain. Towards the end of the panel, the moderator emphasized these ideas again when he said, “you’re not experts on their lived experience...The people who live through those experiences are [the experts.]”

The second session showcasing the possible paradigm shift that can move medical practice past the limits of standardization was a session titled, “Prioritizing Racial Justice and Equity in Women’s Healthcare.” This session was led by folks associated with a group of “family planning” OBGYNs, which often, though not always, was used in interviews as a proxy for “abortion care.” Based on the title, folks may assume this session took a social justice approach to women’s health care, and they would not be wrong. Although, the social justice approach was only one thing that made this session incredibly unique at ACOG. I ended up interviewing four out of five OBGYNs who organized this session, and through those interviews it became clear that this was the first time they were granted space for this type of session at the annual ACOG conference.

The session had a three-hour time slot in the program and took place in a room much smaller than many I had occupied for other sessions. Many times, attendees were standing in the back for presentations because seats were full. However, this session had plenty of empty seats, making the attendance obviously low compared to other sessions I attended that aligned more with an evidence-based framework. The first half of the session was a presentation by the MDs who organized the session. They went over everything from critical race theory to reproductive justice as a framework that could, and should, apply to medical practice. The presenters discussed race as both socially constructed and a social structure and one presenter explicitly said, “we need to name racism explicitly as the cause of these poor health outcomes.” This statement subscribes to ideas similar in fundamental cause theory, which instead of viewing race as a demographic characteristic associated with varying health outcomes views *racism* as a fundamental cause of poor health and disease (Phelan and Link 2015).

The second half of the session was built around a story-telling activity. However, instead of the stories coming from patients as they did in the first session I discussed in this section, they were stories from providers. The following fieldnote excerpt explains the activity that took place:

The chairs were set up in two circles—one larger outer circle, and one slightly smaller inner circle. The outer circle was designated for those who wished to observe, while the inner circle was meant for those willing to share stories. I took a seat in the outer circle. The session organizers started off the exercise describing why they put the chairs in the circle. One organizer showed a diagram on the screen of systems of oppression with the outer circle being societal, the next being institutional, the next being interpersonal, and the smallest inner circle being individual. They noted that this exercise would tap into those inner circles at the individual and interpersonal levels.

The organizer speaking said the hierarchical space of the room was dismantled by putting the chairs in a circle. She compared this hierarchical structure to that of the exam room ... They had five chairs in the center of the inner circle where they started with a demonstration of a circle they had done in the past. The prompt for that circle was names. They each told stories about their names. The language they used for this exercise was storytelling. The five session organizers all told their name stories. Before moving onto the actual exercise, one of the speakers pointed out that they weren't going to use the same prompt for us because it was perhaps too deeply personal for the people of color in the room. To give us a prompt they started with a visualization activity. They told us to close our eyes, if we wanted, and visualize a difficult patient. One that no one wants to see. Now think about the race of that patient, they said, and how their race played into that categorization of them.

After giving us all time to visualize this difficult patient, the organizers began asking folks to go around in the circle and share their stories one at a time. The stories told ranged from those of residents dealing with microaggressions from authority figures who stereotyped patients they identified with, to those of bilingual providers able to make a breakthrough with a “difficult patient” by stepping in as a translator. The following fieldnote excerpt is a specific example of one attendees’ story.

One woman talked about a “skinny white woman” who was a transplant surgeon and was her patient. She said that patient made her feel small. “I felt so small” she said. She even said, “I was afraid of her.” At one point she mentioned “she had too much knowledge, but not enough knowledge, if you know what I mean.” There was agreement from those listening through nodding and verbal “mmhms.”

The stories told in that session lead to the examination of power dynamics and personal biases both on the provider side and the patient side. Providers realized they are not necessarily always the person with the most power when interacting with their patients, with one participant saying “power dynamics ebb and flow depending on what spaces we’re in.” This reflects Foucault’s ideas on biopower as power that is “exercised through networks...[where] individuals...are in a position to both submit to and exercise this power” (Cisney and Morar 2015:3). They confronted the discomfort of recognizing their own racial biases, whether those biases are against minority women or “skinny white women.” What both of these outlier cases show is a new *and* improved alternative to the dialectical materialism that led to niche standardization.

Unlike earlier themes and subthemes explaining how providers are extremely limited through both an EBM framework and standards of care developed within the niche of women’s health, these outlier cases present an alternative approach to care. This alternative approach allows for subjective patient and provider experiences to shed light on clinical assessment and medical practice. Such inclusion of subjective experience is desperately needed in pain medicine, where more often than not, patients do not present any tangible, “objective” evidence for assessment. Further, treating subjective experience as a legitimate form of knowledge and evidence may help providers avoid the unnecessary surgeries discussed here. Not only could this allow patients to avoid potentially diminished quality of life post-surgery, but it may also allow healthcare systems to avoid unnecessary expenditures that come with such surgeries. Together, the findings discussed here illuminate the limits of standardization that are inherent in EBM, while presenting an alternative approach to medical practice that exists beyond those limits.

Discussion

Theodor Adorno, a voice of influence in the development of critical theory in the Frankfurt School, critiqued dialectical thought for the very reasons made apparent through the analysis here (McLaughlin 1999). He argued that concepts derived from dialectical materialism were “afflicted with the same injustice under which they are conceived.” (as cited in Bonefeld 2012). Therefore, this type of synthesis of “new” ideas or practices cannot actually lead to new ideas or practices. For new ideas or practices to emerge, the process of generating those new ideas or practices must negate the injustices present in the concepts that precede them. That process of negation is critical

for moving past the limits of standardization in the production of medical knowledge. Niche standardization may standardize at a different level, allowing for attention to demographic characteristics, but as a product of EBM it does not allow for the production of medical knowledge to move past the limits of standardization.

As an alternative to the limits of dialectical materialism, Adorno (1973) introduced negative dialectics. In short, negative dialectics challenge us to think about what it means to say “no” and what new ideas or practices might emerge if we negate dialectical thought (Bonefeld 2012). What would medicine look like if it said “no” to standards of care based on “objective” evidence? What might pelvic pain care entail if medicine negated the philosophical assumptions present in EBM that not only enforce, but require, standardization? Perhaps it would look something like the two outlier sessions at ACOG that turn the idea of evidence on its head to endorse the power of narrative.

The analysis here also provides insight on how the concept of biopower relates to pain management and women’s health. Specifically, analyzing pelvic pain—which lies at the intersection of these two medical specialties—allows us to better understand how biopower works through medicine to regulate the female body. As many providers alluded to, pelvic pain is extremely common. Yet, there is a general lack of evidence on pelvic pain in the medical research. The absence of such evidence exerts power over the life of patients with pelvic pain. When relevant medical knowledge is expected to emerge in only way—as “objective” evidence from medical research—and that relevant knowledge is not available, the female body with pelvic pain becomes easily overlooked and tossed aside. Patients in such circumstances may be convinced that their pain is normal because a lack of tangible evidence may mistakenly suggest a lack of disease or anatomical abnormality. In this way, biopower works in a disciplinary way to ensure that patients feel it is them, and not the medical system, that is flawed. This process upholds a system that leaves female bodies in pain undiagnosed, untreated, and unable to understand why they are both.

This lack of ability to properly assess female bodies in pain, then, is not necessarily the fault of individual providers, but rather a system that is set up to fail these patients by ignoring the limits of standardization present in the paradigm that dictates medical practice. The ways in which this paradigm guides the medical gaze relies heavily on the objectification of patients to view them simply as a body, and, as such, a vessel for disease. As Foucault (1973) puts it, the body becomes an “object of science” and “of positive knowledge” (p. 197). However, this medical gaze leaves

no room for subjectivity or lived experience, and therefore does not allow for the possibility of multiple experiences at once. For only one reality can exist at a time within positivist knowledge. This narrow view of reality leaves bodies with multiple factors contributing to their pain—which is more often than not the case with pelvic pain due to the convergence of multiple organ system in the pelvic region of the body—incapable of existing within the current medical paradigm.

The analysis presented here suggests that instead of relying on a “natural” evolution of EBM resulting in the equally limited niche standardization approach, we must instead negate the limits of EBM through negative dialectics (Adorno 1973). This process would allow medical providers to see past the limits of standardization, permitting their medical gazes to reach beyond “objective” knowledge of the body to include subjective experiences of patients’ symptoms in their assessments. In doing so, a biomedical paradigm resulting from negative dialectics may push providers to rely less on how standards of care apply to the “typical patient” in cases of pain and more on how patients experience their pain. In relying less on the established standards of care, this new and improved biomedical paradigm may not even need the inclusion-and-difference paradigm to adequately assess minority patients. Instead, minority patient experiences would influence the medical gaze in a way that allows the unique circumstances of their health, both socially and biologically, to be brought to the forefront of the clinical interaction. For example, the racism a black mother faces during childbirth that leaves her dismissed and unattended to would count as relevant knowledge; the numerical measurement of pain intensity may become less important, allowing the impact of pain on quality of life to matter more, or at least equally as much; and the medical gaze may eventually begin to break free from the grips of biopower, all of which may improve the quality of treatment afforded to patients with pelvic pain.

With pelvic pain at the important intersection of pain management, women’s health, and sexual health, the ideas discussed here have implications not only for pelvic pain patients, but also for patients dealing with conditions that fall within any three of those medical specialties. With that said, male bodies with pain may equally benefit from a shifting paradigm that breaks through the limits of standardization, just as pregnant patients receiving care from specialists in the niche of women’s health would. The analysis here does not definitely argue that we must leave EBM behind completely in order to adequately treat patients in pain, women, and minority patients. Rather, my argument here is meant to expose how EBM has limits that allow biopower to dictate

what knowledge matters and for whom, with a goal to bring new *and* improved ideas to the ever-evolving biomedical paradigms that constitute the medical gaze.

INTERSECTIONS OF PATIENT SES, GENDER, AND RACE AND CLINICAL EVALUATIONS OF PELVIC PAIN

Intersectionality, a term first coined by Kimberlé Crenshaw (1989), was originally used to highlight the lack of available legal frameworks for acknowledging the impact of both race *and* sex discrimination against black women. The idea of intersectionality is now used to encompass a collection of related ideas discussed by sociologists, such as Hill Collins' (1990) matrix of domination. These ideas not only take black women's experiences into account by acknowledging positions of marginality, but they also emphasize the importance of recognizing positions of privilege and the impact of those positions on social interactions. In other words, certain social positions come with certain resources, or the lack-there-of, and intersectionality theory allows us to understand how those social positions and their accompanying resources impact social interactions. The focus on intersecting positions of power and oppression and their impact on social interactions is what makes intersectionality theory imperative to research on clinical interactions.

One way medical sociologists can quantitatively analyze intersectionality as it applies to clinical interactions is through fundamental cause theory, which by definition deals with social processes involved in producing and maintaining health inequalities across social lines (Evans 2019; Link and Phelan 1995). In doing so, fundamental cause theory, although “not originally articulated in intersectional terms is nevertheless highly suitable for adaptation” (Evans 2019: 250). Specifically, in focusing on social class and race—two major social structures discussed in classic intersectional work by sociologists (e.g., Acker 2006; Hill-Collins 1990)—and often the overlap between them (e.g., Link and Phelan 2015), fundamental cause theory is set up to appreciate how that overlap is organized in ways that may simultaneously and differentially impact individuals' health.

Just as particular theories may be useful for untangling social inequalities related to health, certain medical conditions may offer more insight than others into intersectional social processes. Pain, for example, is a highly gendered and racialized medical symptom that affects tens of millions of Americans (Dahlhamer et al. 2018; Kempner 2017). In fact, dating to the late 20th century, there has been a significant increase in the experience of pain—in a variety of forms—among American adults (Case and Deaton 2015). Further, research tells us that pain is both gendered and racialized in that the way a patient's pain is both perceived and treated by healthcare

providers depends on that patient's race and gender (e.g., Hoffman and Tarzian 2001; Hoffman et al. 2016). As a highly prevalent and highly gendered and racialized medical symptom, pain becomes an important site for analyzing intersections of gender and race in clinical interactions. That is, analyses of pain assessment and treatment may amplify the effects of gender and race on clinical interactions, allowing us to better identify and comprehend them in the research.

Clinical interactions in *pelvic* pain care in particular have kept the attention of sociologists for more than a decade due to the gendered dynamics of such interactions (Huntington and Gilmour 2005; Markovic et al. 2008; Whelan 2007). Specifically, evidence shows providers often dismiss women's claims of pelvic pain because they assume it is a normal, or typical, experience for patients with female reproductive anatomy and therefore does not signify any underlying medical conditions. Gender biases in pain assessment and treatment likely play a role in the dismissal of women's pelvic pain in clinical interactions and have been acknowledged as doing so (Hoffman and Tarzian 2001). Racial biases in pain assessment and treatment however, despite remaining impactful in clinical interactions, have not been acknowledged in sociological analyses of pelvic pain care (Hoffman et al. 2016). Acknowledging such racial biases, as Kempner (2017) argues, may allow us to better understand how our medical institutions "make some individuals visible, while rendering others invisible" (p. 1). Still more, another piece of the pelvic pain puzzle is missing without clear assessment of the role of socioeconomic status (SES) in such clinical interactions.

A plethora of sociological research on health inequalities shows social class and race impact health outcomes as fundamental causes of disease through a variety of mechanisms—including provider bias (Link and Phelan 1995; Lutfey and Freese 2005; Phelan and Link 2015). Yet, the research on pelvic pain currently lacks a clear understanding of how both are imbedded within clinical interactions alongside gender. Employing an experimental design, I use fundamental cause theory to understand if—and how—patient gender, race, and SES intersect to impact clinical evaluations of pelvic pain. In doing so, this research informs the growing literature on intersecting fundamental causes of disease (Evans 2019).

Fundamental Cause Theory

The theory of fundamental causes includes four basic tenets, each of which make fundamental causes distinct from what scholars may typically identify as "causes" of health. First,

fundamental causes are not linked to only a few disease outcomes; rather, they influence a wide range of health outcomes. Second, fundamental causes influence many disease outcomes through multiple risk factors and mechanisms. Third, a fundamental cause must always involve access to flexible resources that can be used—intentionally or not—to minimize the risk or consequences of disease. Lastly, fundamental causes persist over time despite changing mechanisms that are expected to ameliorate them (Link and Phelan 1995; Phelan and Link 2013).

Freese and Lutfey (2010) expand on Link and Phelan’s (1995) original discussion of mechanisms in the second tenet to include what they call *metamechanisms*. Their extension introduces four metamechanisms with hopes of moving the theoretical framework forward in a fruitful way. Those metamechanisms are 1) means, 2) spillovers, 3) habitus, and 4) institutions. *Means* refer to when individuals purposefully utilize resources to improve their health status. This metamechanism represents Link and Phelan’s (1995) original argument about access to and use of flexible resources. For pelvic pain, disparities in health via differences in means may manifest as different levels of knowledge on obscure conditions causing pelvic pain. Differences in means may also relate to use of monetary resources and access to specialists who treat those obscure conditions not known to the majority of providers.

Spillovers occur when an individual’s social connections allow resources to improve that individual’s health, subsequently enabling the health benefits of their social networks to “spill over” and positively influence their health. One example Freese and Lutfey (2010) provide is higher-SES neighborhoods’ vigilance against environmental hazards, creating healthier neighborhoods for higher-SES folks. If higher-SES women tend to have a similar vigilance against undiagnosed pain because they have encountered research on gender biases in pain treatment, that may provide a positive spillover effect on their health and experiences of pain—regardless of any agency exercised to utilize those resources.

Habitus refers to our unconscious cultural choices that positively impact our health. Importantly, however, behaviors that fall under habitus are not purposeful behaviors aimed at improving one’s health. This metamechanism allows sociologists to embrace the disciplines “openness to the malleability of preferences to differential experiences and influence” without “blaming the victim” (Freese and Lutfey 2010:73-74). Perhaps higher-SES women are more likely to know someone who had the monetary and educational resources to successfully treat and manage their pelvic pain, making them more likely to “choose” to seek medical assessment and

treatment having seen multiple success stories. Alternatively, lower-SES women may know more women who have spent time and money on assessment and treatment only to continue to deal with the same—or worse—level of pelvic pain, deterring them from investing their resources into seeking treatment. Such differential experiences and influence help us understand divergent “preferences” when it comes to seeking healthcare for pain.

Finally, *institutions* refers to how organizations differentially treat individuals in ways that impact their health. For example, providers’ implicit biases within a healthcare organization and the application of those biases during patient evaluations would fall under this metamechanism (Freese and Lutfey 2010). This research focuses specifically on this fourth metamechanism discussed by Freese and Lutfey (2010) to better understand the role of providers’ implicit biases on clinical evaluations of pelvic pain.

Implicit Bias and Clinical Evaluations of Pain

Implicit bias during all forms of social interactions has been a topic of inquiry for social and behavioral scientists for decades. The research generally discusses implicit bias as resulting from learned stereotypes that are often engrained into our judgements of others in early life. Importantly, even when explicit beliefs about a group evolve over time, implicit bias persists. For example, those who report egalitarian attitudes may still display implicit biases related to racial and gender minorities (Chapman, Kaatz, and Carnes 2013). While stereotypes may help people process information more quickly, they often also lead to misjudgment of individuals based on group-level perceptions. Because physicians are trained to understand health and medicine at the group level, they may easily rely on stereotypes for decision-making, bringing implicit bias into their medical practice (Chapman et al. 2013).

Hoffman and colleagues’ (2016) study may be the most well-known piece of research demonstrating implicit racial biases in clinical evaluations of pain. Through an experimental survey design manipulating the race of patients to be either white or black, the authors reveal that medical students and residents who endorse false beliefs of biological difference between black and white people also rate black patients’ pain as less intense than white patients’ (Hoffman et al. 2016). Other researchers have noted similar differences between other minority patients and white patients. For example, Todd, Samaroo, and Hoffman (1993) found that Hispanic patients had higher odds—by a factor of 7.56—of *not* receiving pain medication for long-bone fractures

compared to non-Hispanic white patients in the UCLA Emergency Medical Center. Further, Anderson and colleague's (2009) review on the racial and ethnic disparities in pain literature shows Asian patients also received significantly lower opioid doses for their post-operative pain compared to white patients.

In a review of a separate line of literature on gender biases in pain assessment and treatment, Hoffman and Tarzian (2001) demonstrate a gender bias in how pain is assessed and treated during medical encounters. For example, compared to men, women are more likely to be given sedatives, rather than pain medication, for their pain. This difference in medication distribution suggests that women's pain is often assumed to result from psychological factors, rather than somatic conditions. Men and boys are also more likely to receive pain medication post-operatively, compared to women and girls. Additionally, one study reviewed demonstrates that women endure pain longer than men before being referred to specialty pain clinics (Hoffman and Tarzian 2001).

The review by Hoffman and Tarzian (2001) also outlines divergent perceptions about women and men in regard to pain. For example, the authors relay research findings demonstrating that women are perceived to have higher pain tolerances than men, perhaps because of the pain many women endure during childbirth. The medical literature also portrays women as hysterical and irrational (Hoffman and Tarzian 2001). This gendered portrayal likely leads to the idea that women's pain is often a psychosomatic symptom—or rather, all in their head. These findings suggest that false beliefs of biological differences between men and women, as they relate to pain, may have a similar moderating effect on gender biases, just as false beliefs of biological difference based on race is shown to have a moderating effect on racial biases in pain assessment (Hoffman et al. 2016).

Although less evidence specific to social class biases and pain exists in the literature on implicit biases and pain assessment, sociology, public health, and medical research suggests a patients' SES may play a similarly important role as gender and race in clinical interactions on pelvic pain. For example, Downing and colleagues (2007) found that low-income Latina patients received significantly different reproductive advice from providers compared to middle-income white women patients. Importantly, although pelvic pain may not always be related to reproductive health, many conditions causing pelvic pain may be related to these systems (e.g., endometriosis, ovarian cysts, uterine fibroids, etc.). This is important because the same social class biases that

impact the reproductive advice providers give to women, may play a role in evaluating their pain, and specifically, their pelvic pain. Further, given evidence that social class is a fundamental cause of health inequality, we would expect it to operate similarly for most, if not all, pelvic pain conditions because fundamental causes influence multiple disease outcomes.

We also see similar patterns that disadvantage lower income patients when looking at provider-patient communication and patient SES in that research shows providers give less diagnostic and treatment information to lower income patients (Verlinde et al. 2012). Additionally, Viganò and colleagues (2004) make arguments about diagnostic biases specific to endometriosis, one condition causing pelvic pain. They argue that women in higher social class positions, as well as white women, have higher rates of endometriosis because of diagnostic biases. The authors explain such biases as medical providers paying less attention to pelvic pain when it presents in women from lower class positions and non-white women (Viganò et al. 2004). In other words, the literature speculates that patient SES plays a significant role in diagnostic biases for conditions causing pelvic pain, yet clear evidence has yet to confirm this speculation.

Fundamental Causes and Evaluations of Women's Pelvic Pain

Beyond the literature on implicit biases and pain, understanding the role of SES, race, and gender in evaluations of women's pelvic pain becomes sociologically relevant under the guidance of fundamental cause theory. SES, as the original fundamental cause of disease laid out by Link and Phelan in 1995, may operate as such in pelvic pain patient care through implicit provider bias. We might also expect racism to operate similarly through implicit bias to impact clinical evaluations of pelvic pain. In these ways, we can see the metamechanism of institutions potentially playing a role in divergent clinical evaluations of pelvic pain. Sociological perspectives are unique in that they focus on systems and institutions and their influence on individual behavior, rather than solely focusing on individual behavior. Using fundamental causes and the metamechanisms involved allows us to see how the *institution* of medicine lays the groundwork for provider bias in clinical evaluations. As Freese and Lutfey (2010) argue, medicine is “a dynamic institution that may respond directly to a patient's efforts to mobilize resources for health, but may also either amplify or mitigate those same efforts” (p. 74). In this way, even if patients mobilize resources for health with equal effort, institutional agency may intervene via provider bias to produce differential outcomes for patients.

Gender, on the other hand, has a complex relationship with health outcomes that makes the application of fundamental causes theory to that relationship difficult. In fact, scholars argue that a fundamental cause theory framework may be counterintuitive to understanding the relationship between gender and health, given the widely documented gender health paradox (Bird and Rieker 2008). Therefore, although gender itself cannot be understood as a fundamental cause of health, including it in these analyses allows us to understand how gender—a complex, though impactful, social factor for health outcomes—may interact with fundamental causes, such as SES and race.

Socioeconomic Status

SES is likely to play a role in clinical evaluations of pelvic pain because of its role as a fundamental cause of disease. Specifically, we would expect low-SES patients to have their pain dismissed at higher rates than high-SES patients. Because high-SES patients are afforded more flexible resources (i.e., knowledge, money, power, prestige, and beneficial social connections), we might also expect providers to suggest different treatment trajectories for low-SES pelvic pain patients compared to higher-SES patients. Conversely, high-SES patients may have their pelvic pain taken more seriously by providers than low-SES patients, which may also indicate a different treatment approach for those patients.

***Hypothesis 1:** Participants will evaluate low-SES patients' pelvic pain as significantly: a) less painful, b) more typical, c) less serious, d) less in need of medical attention, e) less in need of a specialist's attention, f) less in need of pain medication, and g) less credible than high-SES patients' pelvic pain.*

Race

Racism, as a fundamental cause, is also highly likely to impact pelvic pain evaluations. Given evidence of racial biases in pain assessment and treatment (e.g., Anderson et al. 2009), we might expect racism to operate similarly to patient SES through provider bias. Evidence from Hoffman and colleagues' (2016) findings identifying false beliefs of biological differences based on race as a moderator in the relationship between patient race and providers' pain assessments suggest this is the case. If we understand endorsement of such false beliefs as a form of racial bias, the study shows that, overall, medical students with higher levels of racial bias rated black patients' pain as less intense compared to white patients' pain. Using the same scale to measure endorsement

of false beliefs of biological difference, we may expect similar results in regard to patient race and pelvic pain.

Hypothesis 2: *Participants will evaluate black patients' pelvic pain as significantly: a) less painful, b) more typical, c) less serious, d) less in need of medical attention, e) less in need of a specialist's attention, f) less in need of pain medication, and g) less credible than white patients' pelvic pain.*

Hypothesis 3: *The relationship between race and the seven outcome variables will be moderated by level of endorsement of false beliefs of biological difference based on race in that a higher level of endorsement will coincide with less serious evaluations for black patients.*

Gender

Although gender cannot be analyzed as a fundamental cause of health, its inclusion in this analysis is nonetheless important for two reasons. First, analyses of pelvic pain have historically been focused on the gendered interactions that leave women with pelvic pain, and pain in general, dismissed and untreated (e.g., Werner and Malterud 2003). Those analyses demonstrate a clear narrative that women are indeed disadvantaged during clinical interactions dealing with pain. Secondly, although gender's relationship with health is complex, the literature on gender and pain assessment is quite straightforward: women and girls receive less adequate treatment for their pain compared to men and boys (Hoffman and Tarzian 2001).

The question of whether or not women and men seek care for their pain at equal rates is also important but is not the focus of analyses presented here. Rather, these analyses focus on what happens to those who seek medical counsel for their pelvic pain. Regardless of whether or not women and men seek medical care for their pain at equal rates, the research shows women are systematically disadvantaged by our medical institutions when they do. This disadvantage is at least partially due to gendered perceptions of credibility that lead providers to question and often outright dismiss women's claims of pain (Toye, Seers, and Barker 2014; Werner and Maltrud 2003). Therefore, we may expect the following:

Hypothesis 4: *Participants will evaluate women's pelvic pain as significantly: a) less painful, b) more typical, c) less serious, d) less in need of medical attention, e) less in need of a specialist's attention, f) less in need of pain medication, and g) less credible than men's pelvic pain.*

Additionally, we might expect the effect of patient gender to operate similarly to patient race in that it is moderated by level of endorsement of false beliefs of biological difference based on gender. This relationship would further indicate that the effect of gender is operating through providers' implicit bias. In this case, we would expect:

Hypothesis 5: *The relationship between gender and the seven outcome variables will be moderated by level of endorsement of false beliefs of biological difference based on gender in that a higher level of endorsement will coincide with less serious evaluations for women.*

Intersecting Fundamental Causes and Diminished Returns of SES

Although research suggests gender, race, and SES all impact clinical evaluations of pelvic pain (Viagnó et al. 2004), there is no clear empirical evidence as to how they impact clinical evaluations when combined. That is, the simultaneous impact of all three patient characteristics may be either intersectional—or multiplicative—or additive. However, evidence in favor of what has been termed the “diminished returns hypothesis” suggests intersectional rather than additive effects of race, SES, and—sometimes—gender on health outcomes and trajectories. Researchers have typically found two explanations for interactive effects between race and SES. First, health inequality is greater between black and white Americans living in poverty and that gap decreases for those in higher SES positions. Second, health inequality between black and white Americans is greater for those in higher SES positions because black Americans experience diminished health returns as their SES increases.

Farmer and Ferraro's (2005) research tested each of these explanations using both cross-sectional and longitudinal data, and in doing so found support for the later. Specifically, the racial gap in self-rated health was largest at the highest levels of income and occupational prestige, suggesting that black adults do not receive the same returns in self-rated health for increasing SES as their white counterparts. Interestingly, when examining interactions between race and education, the gap did not just widen but actually reversed somewhat with increasing education. That is, black adults at the lowest education levels actually reported better self-rated health than white adults with the same level of education; however, as education increases, self-rated health only improves for white adults (Farmer and Ferraro 2005).

Assari (2018a) extends the previous work on diminished health returns for SES by testing for interactions between race, SES, *and* gender. The research shows that not only does race limit how individuals benefit from SES resources, but so does gender. The article does not claim that race, SES, and gender do not have additive effects, rather it argues that the effects are not *just* additive—they are also multiplicative. More specifically, the results suggest diminished health gains of employment for black Americans, women, and those with lower education. Further, findings demonstrate the largest health gains of employment for men with high levels of education, white men, and white Americans with high levels of education (Assari 2018a).

Overall, the research supporting the diminished returns hypothesis shows that SES, as a protector against poor health and mortality, does not provide the same benefits to individuals based on race and gender and—sometimes—an interaction between the two (Assari 2018a; Boen 2016; Farmer and Ferraro 2005). Although this research is not directly related to pelvic pain evaluations, it shows that gender, race, and SES often have intersectional effects—in addition to their sometimes-additive effects—on health outcomes.

Fundamental cause theory provides explanations for why SES may protect certain groups from poor health outcomes (Link and Phelan 1995). For example, access to resources impacts care received, which subsequently impacts health. However, Assari (2018b) outlines the difference between “differential exposure” and “differential effects” to explain that the relationship between SES and health is not simply about differential exposure—or access—to resources. As the research outlined above indicates, differential effects of SES-related resources explain diminished health returns for racial minorities (Assari 2018b). Ideas about racism as a fundamental cause that is not fully explained by SES supports this idea (Phelan and Link 2015)

Given the evidence suggesting SES, race, and gender intersect due to differential effects of SES for different racial and gender groups, Assari (2018b) argues that researchers must consider the use of an intersectionality framework for understanding the multiplicative effects of gender, race, and class on health. Support for diminished returns—in combination with research suggesting that provider bias may be one mechanism through which fundamental causes operate (Lutfey and Freese 2005)—suggests that provider biases could mirror the intersectional effects of gender, race, and class that are outlined here. Put another way, the evidence for diminished returns suggests fundamental causes (i.e., SES and race) are intersectional and not simply additive. Based on this evidence, I predict:

Hypothesis 6: *There will be a significant interaction between patient race and SES on all outcomes in that patient SES will have a protective effect for white patients, but not black patients.*

Hypothesis 7: *There will be a significant interaction between patient gender and SES on all outcomes in that patient SES will have a significantly larger protective effect for men patients than for women patients.*

Hypothesis 8: *There will be a significant interaction between patient gender and race on all outcomes in that gender (i.e., being a man) will have a significantly larger protective effect for white patients than for black patients.*

Methods

According to Lutfey and Freese (2005), the best way to detect provider bias—as it relates to fundamental cause theory—is to use audit studies or vignette experiments to isolate patient characteristics. By holding all factors constant with the exception of experimental conditions, experimental designs allow researchers to make *causal* claims about the independent variables of interest. Further, *factorial* survey experiments allow researchers to vary multiple experimental conditions at once. For example, patient gender, race, and SES can all vary at once in a factorial survey experiment, allowing researchers to better mimic real-world evaluations that may take place (Auspurg and Hinz 2015). In allowing for multiple factors to vary at once, factorial survey experiments create the ideal situation for evaluating interactions between independent variables. Using this approach allowed for testing for interaction effects between gender, race, and SES on pelvic pain assessment. Therefore, this approach allows for testing theories about intersectionality as they relate to pelvic pain assessment.

Design

I employed a 2 x 2 x 2 factorial design that included two gender conditions (men and women), two SES conditions (high-SES and low-SES), and two race conditions (black and white), yielding a total of eight experimental conditions (Auspurg and Hinz 2015). Additionally, the experimental design was mixed both between- and within-subjects. I maximized the sample I was able to obtain by evaluating the effect of patient gender within-subjects. Patient race and SES were

evaluated between-subjects as I expected them both to produce more social desirability bias than gender (see Correll, Benard, and Paik 2007 for a similar approach). If the argument that pelvic pain is normalized for women is correct, participants could fairly easily evaluate both men and women with pelvic pain without risking social desirability bias. This combination of between- and within-subject designs means that each respondent evaluated one “male” and one “female” patient of the same race and SES who were both presenting pelvic pain.

The survey experiment was designed to mimic real-world evaluations that may take place. I used new patient intake forms as vignettes to create patient profiles for evaluation. The patient intake forms were created based on real patient intake forms distributed at various health clinics in the US. However, all the information on the intake forms was fabricated for the purposes of the study. Additionally, I referenced patient intake forms specifically from pain clinics in the US (e.g., Carolina Pain Center) to include questions addressing patient pain on the intake forms (see Appendix A for example of patient intake forms used in survey). I also gained permission to utilize the Wong-Baker FACES Pain Rating Scale with numbers omitted on the intake forms to signify pain levels without numerical measurements. See Figure 3 for an example of the FACES Scale.



Figure 3. Wong-Baker FACES Pain Rating Scale with Numbers Omitted

In addition to the two experimental intake forms, each respondent received a third patient intake form between the two experimental intake forms that acted as a filler to distract respondents from the purpose of the study (Correll, Benard, and Paik 2007). This filler intake form presented a patient eliciting concerns of knee pain. Adding a filler patient intake form supported the cover story by creating a more realistic pool of patients for evaluation. Additionally, presenting a patient

with knee pain, as opposed to pelvic pain, made it less likely for respondents to guess that the study is specifically examining evaluations of pelvic pain. This filler intake form only served the purpose of distracting participants from the real purpose of the study. Respondents' evaluations of the filler patients were not included in analyses testing any hypotheses.

To use Auspurg and Hinz's (2015) term, respondents received one of eight "decks" of patient intake forms. As shown in Table 1, half of participants received a "male" filler patient while the other half received a "female" filler patient. The assignment of filler patients was randomly distributed among participants. Distributing the filler intake forms in this way controls for any effects that the filler patient gender may have within-subjects. Additionally, to control for order effects—or what survey researchers sometimes call "halo effects"—some participants evaluated "patient 1" first while others evaluated "patient 3" first (Auspurg and Hinz 2015). In other words, half of participants evaluated a female patient first, while the other half evaluated a male patient first. Random assignment was also used to determine which respondents evaluated male patients first and which respondents evaluated female patients first. However, the position of "patient 2" (i.e., the filler patient), as the second patient evaluated, remained constant across all respondents' decks.

Table 1. Patient Intake Form Decks

| | Patient 1 | Patient 2 | Patient 3 |
|--------|-------------------------|---------------|---------------------------|
| Deck 1 | Male / White / Low-SES | Filler Male | Female / White / Low-SES |
| Deck 2 | Male / White / High-SES | Filler Male | Female / White / High-SES |
| Deck 3 | Male / Black / Low-SES | Filler Male | Female / Black / Low-SES |
| Deck 4 | Male / Black / High-SES | Filler Male | Female / Black / High-SES |
| Deck 5 | Male / White / Low-SES | Filler Female | Female / White / Low-SES |
| Deck 6 | Male / White / High-SES | Filler Female | Female / White / High-SES |
| Deck 7 | Male / Black / Low-SES | Filler Female | Female / Black / Low-SES |
| Deck 8 | Male / Black / High-SES | Filler Female | Female / Black / High-SES |

Note: Patient 1 and Patient 3 were randomly assigned to be presented first and third.

Decks were assigned to participants through random assignment. When random assignment is administered properly, unobserved heterogeneity due to participant characteristics is neutralized (Auspurg and Hinz 2015). Therefore, it is not necessary to include control variables

in models used for analysis. However, to test for evaluator effects, I collected basic demographic information from all participants at the end of the survey. Doing so allowed me to analyze whether participant gender, for example, significantly impacted pelvic pain evaluations.

Because I am interested in the effect of patient gender, race, and SES on pelvic pain assessment, only those three variables changed across patient profiles. However, for face validity, other information on the intake forms varied slightly to support the idea that the patients were real patients with real symptoms and unique cases. For example, the last piece of information on the intake form asked patients to describe their pain in their own words. Because identical descriptions could lead respondents to guess that the patients are fictional—which could impact their evaluations—the descriptions vary slightly while alluding to the same experience. These written descriptions were counterbalanced across intake forms and decks to ensure they would not impact participants' evaluations. The last precaution I took to ensure face validity was providing unique hand-written responses on each intake form. In doing so, each participant evaluated three unique patient intake forms with unique handwriting for each patient.

This study, in a broad sense, is testing how participants use certain patient characteristics to evaluate patient symptoms. Specifically, it is testing how individuals in healthcare settings use patient gender, race, and/or SES to evaluate patient pelvic pain. How patient characteristics activate stereotypes and implicit biases to impact patient evaluations is another way to think about the study. If we think about the study in terms of how activated stereotypes and implicit biases are applied in evaluations, it is important to encourage such activation as to examine the impact of that activation. Therefore, the patient intake forms were designed to provide limited information on patient conditions as to activate stereotypes about gender, race, and SES and assess if and how those activated stereotypes are applied during pelvic pain assessment (Kunda and Spencer 2003).

In addition to limited information, I also provided time limits for providers' evaluations. Respondents had two minutes to view each patient intake form *and* answer all seven evaluation questions. This time limit is in accordance with social psychologists' suggestions that stereotype activation may fade after 15 minutes (Kunda and Spencer 2003). Given the two-minute time-limit, respondents had to evaluate all three patients within six minutes, keeping their evaluations well within the stereotype activation time. Scholars also argue that time pressure can activate stereotypes because the stress associated with it can deplete cognitive energy, leading those under time pressure to rely on stereotypes (Macrae, Milne, and Bodenhausen 1994). Further, the decision

to include a two-minute time limit for each patient evaluation mimics common time pressure that physicians and other medical providers work under (Stepanikova 2012). Specifically, Stepanikova's (2012) research showed that physicians reported high stress from time-pressure when required to read two vignettes and answer three questions for each vignette within three minutes. Therefore, the time limit of two minutes to review each intake form and answer the seven questions for each patient further activates stereotypes due to time pressure.

Experimental manipulations

The experimental manipulation of race and gender on the intake forms were straightforward. The intake form asked patients to report their race/ethnicity as well as their sex. The intake forms either read "white" or "black" to indicate patient race. While the research on racial and ethnic biases in pain assessment and treatment identify a significant gap in assessment and treatment favoring white patients over Black, Hispanic, *and* Asian patients, most of the research focuses on the difference in assessment and treatment between Black and white patients (Anderson et al. 2009). With that in mind and because introducing more categories to nominal independent variables such as race—especially when evaluated *between* subjects—often reduces statistical power for factorial survey experiments, I simplify my measurement of race to include only two categories: Black and white.

I chose to specify gender through sex terminology because it aligns better with typical medical terminology. Additionally, patient intake forms typically only provide two gender choices—although this may be changing with efforts to increase trans- and non-binary-inclusive healthcare in the US. Therefore, the intake forms read either "male" or "female" to specify patient gender. While this terminology may not be ideal when referring to gender, this choice was also made to explicitly encourage the conflation between gender and sex among participants because that conflation is an important component of the normalization process examined throughout this dissertation. For example, a woman patient with male reproductive anatomy may not be subjected to dismissal of their pain through the same normalization process that leads to dismissal for a woman patient with female reproductive anatomy. Therefore, the language of "male" and "female" also strategically infers specific patient reproductive anatomy, ensuring that the gender and sex are conflated and that the gender manipulation was perceived consistently across participants.

Patient SES was signaled through gender-neutral occupations listed on the intake forms which were identified through a small pretest with a postgraduate-educated sample (N = 63). The postgraduate-educated sample ensured that education levels were more closely aligned with my ideal provider sample, who would all have postgraduate degrees. Gender-neutrality was determined based on percentage of women in that occupation reported by the U.S Bureau of Labor Statistics as of 2019. I also asked pretest participants to identify what percent of employees in the U.S. they think are women for each occupation listed to determine the perceived gender-neutrality of occupations.

In signaling SES through occupations, this latent variable is operationalized through the more easily observed variables of education and income. For example, low-SES occupations were identified through the pretest to signal both lower income and lower education levels compared to high-SES occupations which signaled higher incomes and higher education levels to pretest participants. In doing so, this research joins other scholars in measuring the variable of SES through income, education, and—as a result of both—social standing (Fujishiro, Xu, and Gong 2010). The complicated relationship between occupation and health in that occupations can involve both “health-enhancing resources and health-damaging exposures” was also considered (Fujishiro et al. 2010:2106). Specifically, occupations presenting potential relationships to development of pelvic pain (e.g., occupations involving heavy lifting or sitting for long periods of time) were not considered in the pretest.

Because participants viewed two experimental patients of the same SES, I identified two low-SES occupations and two high-SES occupations to list on the intake forms. Through the pretest I found “food prep worker” and “telemarketer” to signal lower SES based on interpretations of annual income and educational requirements. Higher SES gender neutral occupations identified via the pretest were “veterinarian” and “physical therapist.” Low-SES filler patients indicated “US postal clerk” as their occupation, while high-SES filler patients indicated “education administrator.” To check whether occupations accurately signaled SES, I used the widely used question from Add Health that asks participants to place themselves on a ten-step ladder of stratification (Harris et al. 2009). I reworded the question to ask the following:

Think of this ladder as representing where people stand in the United States. At the top of the ladder (step 10) are the people who have the most money and education,

and the most respected jobs. At the bottom of the ladder (step 1) are the people who have the least money and education, and the least respected jobs or no job.

*Where would you place **Patient 1/2/3** on this ladder?*

*Pick the number for the step that shows where you think **Patient 1/2/3** stands, relative to other people in the United States.*

A two-sample t-tests of this continuous measure of SES by the binary SES condition indicates that this manipulation worked as intended. On average, participants placed low-SES patients significantly lower on the social class ladder compared to high-SES patients ($p < .001$). See Table 2 for an overview of all eight experimental manipulations included in the survey design.

Table 2. 2(Gender) x 2(SES) x 2(Race) Experimental Conditions

| | High-SES | | Low-SES | |
|---------------|----------------|----------------|---------------|---------------|
| | Black | White | Black | White |
| Male | Black High-SES | White High-SES | Black Low-SES | White Low-SES |
| | Male | Male | Male | Male |
| Female | Black High-SES | White High-SES | Black Low-SES | White Low-SES |
| | Female | Female | Female | Male |

Note: Again, sex terminology is used for gender to correspond with medical terminology.

Sample

After running a power analysis by simulation in Stata, I identified 800 subjects as my ideal sample size for analyses with this data. The program I used accounted for the multi-level structure of the data (i.e., the within- and between-subjects design). The program also modeled an interaction term between race and gender, as well as a three-way interaction term between gender, race, and class. According to the power analysis, a sample of 800 participants would have allowed me to detect both two-way interactions and a three-way interaction, should they exist in the data. Specifically, with reasonable effect sizes for gender, race, and class, a sample of 800 would have provided adequate power ($\beta = 0.80$) to detect a significant three-way interaction if it exists and if that effect is a difference of one unit or more on the 11-point outcome measures.

Although the ideal sample was 800 providers, I was only able to secure a sample of 453 healthcare workers for analyses with the data after accounting for failed attention checks and

missing data on outcomes variables via listwise deletion. This final sample size also only includes participants with complete responses for all three patients who passed the attention checks. Of the healthcare workers included in the full sample, I was able to secure 225 MDs, PAs, and NPs. Of those 225 providers, 148 were recruited through SurveyHealthcareGlobus, 69 were recruited on Amazon Mechanical Turk (MTurk), and eight were recruited through Medical Marketing Service's email list. Among the remaining 228 participants, a majority reported having healthcare roles that would put them in direct contact with patients in a clinical setting including: 50 medical assistants and medical technicians, 47 registered nurses (RNs), 17 certified nursing assistants (CNAs), 15 social and behavioral health specialists (e.g., counselors, psychologists, speech therapists, social workers), five physical therapists, three medical students, two home health aides, and two dentists. The remaining 87 participants either did not indicate their healthcare role or indicated something not directly tied to patient care (e.g., receptionist, food service worker, IT specialist, billing, etc.). Because theoretical assumptions of the analyses here are related to *clinical* interactions—and not just interactions with any healthcare workers—an indicator for clinical providers (i.e., MDs, PAs, and NPs) is included in each model for analyses. Table 3 details demographic information collected from participants.

Table 3. Sample Demographics (N = 453)

| Demographic Variables | Mean/Proportion | SD | Range |
|---|-----------------|-------|-------|
| Age | 40.68 | 12.62 | 18-85 |
| Gender | | | |
| Men | 38.04 | | |
| Women | 59.99 | | |
| Non-binary | 0.22 | | |
| Race | | | |
| White | 80.38 | | |
| Black/African American | 5.73 | | |
| Other | 13.89 | | |
| Indicator for Latinx | 8.84 | | |
| Indicator for OBGYN training | 22.82 | | |
| Indicator for Pain Management training | 24.95 | | |
| Years Practicing (for MDs, PAs, and NPs only) | 15.78 | 10.98 | 0-60 |

Note: “Other” for race includes those who indicated their racial identity as South Asian, East Asian, Southeast Asian, mixed race, Native American or Alaskan Native, or Native Hawaiian or Pacific Islander.

Procedure

Participants opted in to taking the survey after being presented with an IRB-approved informed consent statement. They were then given the following information:

You are being asked to evaluate three clinical case files based on information provided on new patient intake forms. You will be presented with three different patient cases.

In compliance with HIPAA, we have redacted all identifying information on the patient intake forms.

The following statement was also provided to participants recruited on MTurk because not all participants recruited on this platform were healthcare providers. The sample and recruitment strategy are outlined in more detail below.

Importantly, you do not need to be a healthcare provider to participate in this survey. The only requirement is that you work in a healthcare setting in the U.S. Regardless of your role in that healthcare setting, please evaluate the patient cases to the best of your abilities. We understand that you may not have training in diagnosing or evaluating patient symptoms, and that is okay.

Directly following this information, participants were given the following instructions:

In this study, we are interested in learning more about how providers evaluate certain symptoms at intake. We ask that you assess these cases as real patients whose symptoms have not yet been addressed—as if you were the first provider to be asked to address these patients' symptoms.

You will have two minutes to evaluate each patient intake form and answer seven questions about the patient's condition. *Once you begin your evaluations, the first patient intake form will be displayed on your screen. You will automatically advance to the next screen with the seven questions after 30 seconds of viewing the intake form, but you will have the option to view the intake form again on the second screen as well.*

Remember, you will have two minutes to both: (1) read over the intake form and (2) answer seven questions. *When you are ready to begin your evaluations, please click the forward button below*

Once participants moved forward in the survey, they were presented with the first patient intake form in the deck randomly assigned to them through the programmed survey. After 30 seconds passed, participants were automatically directed to the next page of the survey where they had the option to view the patient intake form again and were prompted to answer questions about the patient. After another 90 seconds, participants were automatically directed to the second patient in their deck—the filler patient. Participants went through the same steps for the second and third patient within the first six minutes of the survey.

Directly after answering questions about each of the three patients based on symptoms presented on the intake forms, participants were presented with an attention check question, and then manipulation checks to determine if participants were mindful of experimental manipulations during their evaluations. Participants were prompted to answer manipulation checks with the following statement.

*A secondary interest of this research is learning more about what information is available based only on patient intake forms. To help us assess this, **please answer the questions below regarding which patient characteristics you were able to observe based on the forms you evaluated.***

Following the manipulation checks, participants moved on to the false beliefs of biological difference scales, first answering questions about race, and next about gender. Participants were prompted to rate each statement presented to them on a 1-6 scale from “definitely true” to “definitely untrue” with the following statement:

Below is a list of statements regarding race/gender and health. Some of these statements are true, while others are not. Please read each statement and rate the extent to which you believe it is true, from Definitely Untrue to Definitely True.

Endorsement of false beliefs of biological differences based on *race* was measured using a scale developed by Hoffman and colleagues (2016). The scale consists of twelve statements, including four true statements and eight false statements. Through pretesting the survey instrument, I determined that two of the statements could be dropped to shorten the survey while keeping a relatively high Cronbach’s α (0.85). See Table 4 for statements and descriptive statistics for scale responses.

Table 4. False Beliefs of Biological Differences Based on Race Scale
Descriptive Statistics (N = 453)

| Statements | Percent | Mean (SD) | Range |
|--|---------|-------------|--------|
| Black people's nerve-endings are less sensitive than white people's nerve-endings. | 49.23 | | |
| *White people are less susceptible to heart disease like hypertension than black people. | 53.99 | | |
| *Black people are less likely to contract spinal cord diseases like multiple sclerosis. | 40.23 | | |
| White people have a better sense of hearing compared with black people. | 48.52 | | |
| Black people's skin has more collagen (i.e., it's thicker) than white people's skin. | 50.99 | | |
| *Black people, on average, have denser, stronger bones than white people. | 45.35 | | |
| Black people have a more sensitive sense of smell than white people; they can differentiate odors and detect faint smells better than white people. | 21.43 | | |
| White people have more efficient respiratory systems than black people. | 21.51 | | |
| Black couples are significantly more fertile than white couples | 25.24 | | |
| *White people are less likely to have a stroke than black people. | 41.92 | | |
| Black people are better at detecting movement than white people. | 21.14 | | |
| Black people have stronger immune systems than white people and are less likely to contract colds. | 21.21 | | |
| False Beliefs Scale | | 2.62 (1.13) | 1-5.75 |

*Note: For easier interpretation and presentation, I binarized scale items by coding responses marked as possibly, probably, or definitely untrue as 0 and possibly, probably, or definitely true, as 1, resulting in percentages of participants who endorsed each item. Bold statements are those in the false beliefs about biological differences based on race summated scale. *Items that are factual or true*

False beliefs of biological differences based on *gender*, on the other hand, was created using a mixture of true and false statements related to pain medicine and gender and sex differences. The scale contains fourteen total statements, including four true statement and ten false statements. False statements were used to generate a summated rating scale to measure endorsement of false beliefs of biological differences based on gender (Cronbach's $\alpha = 0.87$). See Table 5 for statements and descriptive statistics for scale responses.

Table 5. False Beliefs of Biological Differences Based on Gender Scale
Descriptive Statistics (N = 453)

| Statements | Percent | Mean (SD) | Range |
|---|---------|-------------|-------|
| On average, women respond better to non-pharmacological pain interventions than men do. | 58.23 | | |
| On average, dysmenorrhea (menstrual cramps) makes women less susceptible to central sensitization (a condition of the nervous system associated with the development of chronic pain) compared to men. | 41.92 | | |
| On average, women can tolerate more pain than men. | 72.64 | | |
| Childhood trauma is more closely associated with chronic pain conditions for men compared to women. | 46.82 | | |
| * Prior to menopause, women experience major depression at roughly twice the rate of men. | 69.13 | | |
| * Women and men metabolize medications differently. | 79.96 | | |
| Comorbidity of mood disorders and chronic pain is more common in women compared to men. | 67.52 | | |
| * On average, women catastrophize (e.g., ruminate in, worry excessively about, and feel helpless about) their pain more than men. | 54.06 | | |
| Men have higher risk than women for developing painful bladder syndrome. | 54.06 | | |
| In general, there is greater pain prevalence among men compared to women. | 32.70 | | |
| Women are more susceptible to psychosomatic pain compared to men. | 52.74 | | |
| * Comorbidity of irritable bowel syndrome (IBS) and chronic pelvic pain is more common in women than men. | 70.81 | | |
| Fluctuating hormones across women's menstrual cycles puts them at higher risk for acute pain compared to men. | 62.03 | | |
| Men are more likely to experience chronic widespread pain compared to women. | 30.07 | | |
| False Beliefs Scale | | 3.43 (0.95) | 1-5.5 |

*Note: For easier interpretation and presentation, I binarized scale items by coding responses marked as possibly, probably, or definitely untrue as 0 and possibly, probably, or definitely true, as 1, resulting percentages of participants who endorsed each item. Bold statements are those in the false beliefs about biological differences based on gender summated scale. *Items that are factual or true*

After answering questions to measure endorsement of false beliefs of biological differences based on race and then gender, participants were asked to report demographics including their: age, race, ethnicity, gender, years practicing if they reported also being a MD, PA, or NP, their

role in healthcare if not one of those three, the zip code of their primary workplace, whether or not they have any specialized training in obstetrics and gynecology, and whether or not they have any specialized training in pain medicine. Finally, after reporting demographics, participants were presented with a link to an information page upon completing the survey that provided more information about the study's goals.

Dependent measures

To assess evaluations of patient pelvic pain, I included seven outcome questions for each patient in the following order:

1. *What level of pain do you think the patient is experiencing? Please answer on a scale from 0-10, with **0 being no pain at all** and **10 being the worst pain possible**.*
2. *How typical do you think this patient's pain is? Please answer on a scale from 0-10, with **0 being not at all typical** and **10 being completely typical**.*
3. *How serious do you think this patient's pain is? Please answer on a scale from 0-10, with **0 being not at all serious** and **10 being extremely serious**.*
4. *How important do you think it is that this patient has their symptoms assessed by a medical provider? Please answer on a scale from 0-10, with **0 being not at all important** and **10 being extremely important**.*
5. *How likely would you be to refer this patient to a specialist? Please answer on a scale from 0-10, with **0 being not likely at all** and **10 being extremely likely**.*
6. *How likely would you be to prescribe this patient medication for pain? Please answer on a scale from 0-10, with **0 being not likely at all** and **10 being extremely likely**.*
7. *How do you think this patient's reported pain compares to their objective level of pain? Imagine that the middle of the sliding scale is the level of pain the patient is actually experiencing—it is the objective measure of the patient's pain. **Please indicate how much more or less pain you think the patient reported compared to their objective level of pain** by sliding to the right to indicate over-reporting of pain and sliding to the left to indicate under-reporting of pain.*

In asking these questions, I aimed to assess: 1) participants' assessments of the intensity of the patient's pain, 2) participants' normalization of the patient's pelvic pain, 3) participants' assessments of the seriousness of the patient's condition, 4) participants' opinions about the

necessity of medical care given the patient's condition, 5) the likelihood that participants would refer the patient to a specialist to further assess their symptoms, 6) the likelihood that participants would prescribe the patient medication for their pain, and 7) participants' evaluations of the credibility of the patient's claims. Given the experimental design of the survey, each question assessed the direct impact of patient gender, race, and SES on participants' evaluations.

I asked the questions in the order outlined to help guide respondents in a sequential thought process about each patient's condition. I wanted participants to report their initial reactions about the patient's level of pain first to encourage them to contextualize their remaining responses. Therefore, when participants answered the second question, they did so with their response to the first question in mind. Participants' responses to the third question then took their answer to the second question into account, and so on. For example, once participants reached the fifth question, they would have theoretically responded based on their attitudes about the patient's pain intensity, the typicality of the patient's pain, the seriousness of the patient's condition, and the importance of medical assessment given the patient's condition. Descriptive statistics for all seven dependent variables are outlined in Table 6.

Table 6. Descriptive Statistics for Dependent Variables (N = 453)

| Dependent Variables | Mean (SD) | Range |
|---------------------------------------|-------------|-------|
| Pain Level | 5.80 (1.89) | 0-10 |
| Pain Typicality | 5.44 (2.65) | 0-10 |
| Seriousness of Pain | 5.66 (2.23) | 0-10 |
| Importance of Medical Assessment | 7.44 (2.11) | 0-10 |
| Likelihood of Referring to Specialist | 5.96 (2.75) | 0-10 |
| Likelihood of Prescribing Medication | 5.57 (2.72) | 0-10 |
| Credibility of Claims of Pain | 5.77 (1.94) | 0-10 |

Analytical Strategy

Because all outcome variables were measured on a continuous scale, I analyzed the data using linear regression. Given the within- and between-subject design of the study, I also accounted for clustering of the data. Patient gender was evaluated within-subjects, while patient

race and SES were evaluated between-subjects. Because each respondent evaluated three patients, including one male and one female experimental patient, each participant is included in the data three times, therefore requiring a modeling approach that accounts for this clustering of the data. To do so, I use a random intercept model for all analyses. I estimated all regression analyses using Stata 16.1 and assessed significance at $p < .05$ unless otherwise specified.

Based on results from two-sample t-tests of the continuous class manipulation checks by patient SES category (low-SES vs. high-SES), the patient SES manipulations were successful showing a significant difference between placement of low-SES and high-SES patients on the social class ladder across all three patients presented to participants ($p < .001$). Specifically, on average, participants placed low-SES patients significantly lower on the social class ladder compared to high-SES patients. Given the success of the SES manipulation across the sample, I analyzed the causal impact of patient SES on all seven continuous outcome variables utilizing the full sample of those who passed the attention check ($N = 453$). To do so, I employed linear regression using a random intercept model. Importantly, I also limited analyses to experimental conditions only to ensure I was measuring evaluations of pelvic pain only—filler patient evaluations were not included in the analyses. The full sample was only utilized to test hypotheses 1a-1f.

In total, only 66% of the sample passed both gender and race manipulation checks across all three patients. When assessing the percentage who passed both gender and race manipulation checks for experimental patients only (i.e., excluding filler patient conditions), that number increases slightly to 67%. Given this low percentage of passing across the sample, I analyzed the effects of patient gender and race using a limited sample that includes only those who passed both the gender and race manipulation checks for both experimental patients presented to them ($N = 303$). I used the limited sample to test the remaining hypotheses (2a-2f, 3, 4a-4f, 5, 6, 7, and 8). Although I do not have a hypothesis related to interactions between all three patient characteristics, I also use this sample to test for a three-way interaction between patient SES, gender, and race.

When dropping a significant percent of the sample, testing for covariate balance is advised to ensure that passing or failing the manipulation checks was not systematically distributed across participants demographics. To check for covariate balance, I predicted the odds of passing both the gender and race manipulation checks for experimental using logistic regression and included all demographic variables as predictors. Results suggested overall covariate balance based on the

non-significant likelihood-ratio test, meaning participant demographics were not collectively predictive of passing or failing both the gender and race manipulation checks for experimental patients.

Because random assignment was applied, and doing so neutralizes heterogeneity in the sample, it was not necessary to include control variables in the models. Not only are control variables theoretically unnecessary when applied to experimental data using random assignment, but they also may increase the risk of Type II errors. Following advice from Mutz (2011), I do not include control variables unless there is a compelling theoretical case for doing so, such as the case for indicating participants who are clinical providers. Unless otherwise specified, an indicator for providers—denoting participants who are MDs, PAs, or NPs—was the only control variable included in the models presented below.

Results

Patient SES

Overall, results support hypothesis 1 for all outcome variables with the exception of typicality of patient pain and likelihood of referring to a specialist (i.e., hypotheses 1b and 1e were *not* supported). Table 7 summarizes regression coefficients for all models. Results show that on average, participants rated high-SES patients' pain levels as .387 points higher than low-SES patients' pain on the 0-10 pain scale where zero indicates no pain at all and ten indicates the worst pain possible ($p < .01$). This result indicates that providers, other health professionals, and administrative and support staff¹ in healthcare settings assume patients from lower-SES backgrounds have lower pain levels than higher-SES patients even when presenting identical symptoms on paper. Although there was no significant difference in typicality ratings of patient pain based on patient SES, providers did rate patients' pelvic pain as significantly more typical on the 0-10 scale compared to other healthcare workers, regardless of patient SES ($\beta = .415, p < .05$).

Participants' ratings of the seriousness of patients' pain also differed based on patient SES. On average, participants rated high-SES patients' pain as significantly more serious than low-SES

¹ When the models ran to test hypotheses 1a-1f exclude administrative and support staff from the sample—which is 16.57% of the total sample—results remain significant unless otherwise noted. Also important, there was no significant difference between administrative and support staff and other healthcare workers who routinely have clinical interactions with patients when analyzing manipulation check pass and fail rates.

patients by .428 points on a scale of 0-10 ($p < .001$). These results confirm class biases related to how serious healthcare workers take patient's pelvic pain—something not yet discussed in the sociological research on pelvic pain and evaluation bias.

Results also show a significant difference in participants' perceptions of the importance of patients having their symptoms assessed by a medical provider based on patient SES. Specifically, participants rated importance of assessment as significantly higher for high-SES patients compared to low-SES patients ($\beta = 0.344, p < .01$). This measurement may be related to how serious participants rated patients' pain in that less serious pain would warrant lower importance of medical assessment. Women participants also indicated significantly higher perceptions of importance of medical assessment for patients, regardless of patient SES ($\beta = 0.450, p < .01$). Clinical providers also rated need for medical assessment as significantly more important compared to other healthcare workers ($\beta = 0.310, p < .05$).

Although there was no significant difference in likelihood of referring the patient to a specialist based on patient SES, including the control for participant gender indicated women participants reported a significantly higher likelihood of referring patients to specialists compared to men, regardless of patient SES ($\beta = .483, p < .05$). This result may be related to the fact that it is typical for women to visit gynecologists, especially when dealing with pain in the pelvic region. Women participants may therefore be more likely to think about the relevance of assessment from a gynecologist when presented with pelvic pain patients compared to men. However, the model also shows that clinical providers reported a significantly lower likelihood of referral to a specialist ($\beta = -.779, p < .001$). When examining the gender composition of providers in the sample, I found that roughly 62% of men in the sample were MDs, PAs, or NPs compared to only 40% only women in the sample. In other words, what appears to be a gender difference in likelihood of referral may be more of indication of perceptions of expertise, where clinical providers are less likely to see a need for referral to a specialist compared to other healthcare workers—especially given that the effect of being a provider is larger.

Likelihood of prescribing medication for patient pain also differed across SES-lines. Participants, on average, reported a significantly higher likelihood of .378 points on a 0-10 scale of prescribing medication to high-SES patients compared to low-SES patients based on identical symptoms presented on the intake forms ($p < .05$). This class bias related to prescription medication for pain may be related to class biases in opioid use (Wood and Elliot 2020).

Lastly, when asked whether patients were over- or under-reporting their pain symptoms in comparison to their objective pain level, participants, on average, rated high-SES patients as significantly less likely to *over-report* their pain symptoms compared to low-SES patients ($\beta = -.305, p < .05$). In other words, low-SES patients were perceived as over-reporting their pain at a significantly higher rate than high-SES patients. Importantly, when running this model excluding administrative and support staff from the sample, this effect size decreased slightly and moved from significant to marginally significant ($\beta = -.287, p = .051$). Similar to prescribing likelihood, the tendency to believe high-SES patients' claims of pelvic pain more than low-SES patients' claims may be related to class biases and opioid use (Wood and Elliot 2020). For example, providers and other healthcare workers may assume lower-SES patients are exaggerating their claims of pain because of drug-seeking goals, whereas the same stigma may not be applied to higher-SES patients reporting pain.

Table 7. Predicted Effect of Patient SES (and Participant Gender and Provider status when Included) across Outcomes Variables (N = 453)

| Outcome Measure | Effect of Patient SES | Effect of Participant Gender (Reference is men) | Effect of Being a Clinical Provider |
|---------------------------------------|-----------------------|--|-------------------------------------|
| Pain Level | 0.387** | | - 0.054 |
| Pain Typicality | - 0.114 | | 0.415* |
| Seriousness of Pain | 0.428** | | - 0.178 |
| Importance of Medical Assessment | 0.344* | 0.450** | 0.310* |
| Likelihood of Referring to Specialist | 0.243 | 0.483* | - 0.779*** |
| Likelihood of Prescribing Medication | 0.378* | | - 0.140 |
| Credibility of Claims of Pain | - 0.305* | | 0.115 |

Note: An indicator variable for participant gender was included when it independently predicted the outcome and reduced the standard error for the effect of patient SES. The effect shown is for women, in comparison to men.

** $p < .05$, ** $p < .01$, *** $p < .001$*

Patient SES, Gender, and Race

When accounting for patient gender and race in the model, the sample size is reduced to 303 participants. I used a chi-square test to examine whether or not certain participants had higher fail rates for manipulation checks determining this limited sample based on demographics

collected. Upon doing so I found that those with specialized training in pain management failed manipulation checks for patient gender and race at a significantly higher rate than those without such training ($p < .01$). Participants who indicated specialized training in OBYGN also failed manipulation checks for patient gender and race at significantly higher rates ($p < .01$). Importantly, however, when examining this limited sample further, we can see that the proportion of clinical providers in the sample drops a miniscule amount from roughly 50% to roughly 47%, closely mirroring the proportion of providers—including MDs, PAs, and NPs—in the full sample used for analyzing the effect of SES.

The effect of patient SES decreases slightly for pain level ratings and moves from significant to marginally significant ($\beta = 0.298$, $p = 0.053$). The effect of patient SES also decreases for perceptions of the seriousness of patient pain ($\beta = 0.412$, $p < .05$), and perceptions about importance of medical assessment ($\beta = 0.358$, $p < .05$) when accounting for patient gender and race. Patient SES is no longer a significant predictor of likelihood of prescribing medication or perceptions of credibility of claims of pain when patient gender and race are added to the model.

The effects of patient gender and race are not significant for a majority of outcomes. Specifically, hypotheses 2a, 2b, 2c, 2d, 2e, 2f, and 2g were not supported. Additionally, hypothesis 4a, 4c, 4d, 4e, 4f, and 4g were not supported. In other words, patient gender and race were not shown to have a significant impact on: pain level ratings, seriousness of pain, importance of medical assessment, likelihood of referring to a specialist, likelihood of prescribing medication, or credibility of claims of pain. However, hypothesis 4b is supported for the pain typicality outcome measure ($\beta = 0.423$, $p < .05$). Specifically, participants rated female patients' pelvic pain as significantly more "typical" than male patients' pelvic pain. This finding suggests that women's pelvic pain is perceived as a typical, or normal, experience for patients with female reproductive anatomy, supporting much of the qualitative research suggesting a "normalization" of women's pelvic pain.

Although hypothesis 2 overall was not supported in that white patients were not afforded more favorable evaluations than black patients, there is a marginally significant effect of patient race for perceptions of importance of medical assessment ($\beta = 0.284$, $p = .059$). The effect of patient race on ratings of seriousness of pain also approaches significance at $p = .078$ ($\beta = 0.287$). However, the direction of these effects is the opposite of what was predicted based on theory and evidence of racial biases and pain assessment and treatment. Participants actually reported a higher

importance of medical assessment for black patients' pelvic pain compared to white patients' pelvic pain. This surprising and unexpected finding may be related to increasing discourse around racial health inequality and implicit racial bias among providers, perhaps making healthcare workers more aware of their potential biases. I do not perceive this finding as solely a result of social desirability bias since participants evaluated either all white patients or all black patients. However, social desirability bias is still a potential explanation for this result. It is also important to recognize that these effects are small, and not quite significant at the $p < .05$ level.

The models including patient gender and race also show continued significance of participant gender as a predictor of perceptions of importance of medical assessment ($\beta = 0.609, p < .001$) and marginal significance of participant gender as a predictor of likelihood of referring to a specialist ($\beta = 0.422, p = .064$). See Table 8 for a full summary of results from models including all three experimental conditions. We also see significant effects of being a provider for pain typicality ratings ($\beta = 0.434, p < .05$), importance of medical assessment ($\beta = 0.466, p < .01$), likelihood of prescribing pain medication ($\beta = -0.587, p < .01$).

Table 8. Predicted Effect of Patient SES, Gender, and Race (and Participant Gender when Included) across Outcomes Variables (N = 303)

| Outcome Measure | Effect of Patient SES (Ref. High-SES) | Effect of Patient Gender (Ref. Male) | Effect of Patient Race (Ref. White) | Effect of Gender (Ref. Men) | Effect of Being a Provider |
|---------------------------------------|---------------------------------------|--------------------------------------|-------------------------------------|-----------------------------|----------------------------|
| Pain Level | 0.298 [†] | - 0.168 | 0.173 | | 0.020 |
| Pain Typicality | - 0.118 | 0.423* | 0.071 | | 0.434* |
| Seriousness of Pain | 0.412* | - 0.152 | 0.287 [†] | | - 0.001 |
| Importance of Medical Assessment | 0.358* | - 0.197 | 0.284 [†] | 0.609*** | 0.466** |
| Likelihood of Referring to Specialist | 0.208 | 0.081 | - 0.031 | 0.422 [†] | - 0.587** |
| Likelihood of Prescribing Medication | 0.072 | 0.018 | 0.073 | | - 0.017 |
| Credibility of Claims of Pain | - 0.206 | - 0.150 | - 0.080 | | 0.143 |

Note: An indicator variable for participant gender was included when it independently predicted the outcome and reduced the standard error for the effect of patient SES. The effect shown is for women, in comparison to men.

p < .05, **p < .01, *p < .001, [†] Marginally Significant*

Endorsement of False Beliefs of Biological Difference and Gender and Race

Hypothesis 5—which predicted that endorsement of false beliefs of biological differences based on gender would moderate the relationship between patient gender and all seven outcome measures—was not supported by analyses. Therefore, I do not include coefficients for these non-significant interactions in the tables. However, endorsement of false beliefs based on gender did significantly predict perceptions of importance of medical assessment. Specifically, an increase in endorsement of false beliefs based on gender is associated with a decrease in perceptions of importance of medical assessment, regardless of patient SES, gender, or race ($\beta = -0.265, p < .01$). Endorsement of false beliefs of biological differences based on gender was not significantly associated with any other outcome measures.

Additionally, hypothesis 3—which predicted that endorsement of false beliefs of biological differences based on race would moderate the relationship between patient race and all seven outcome measures—was also not supported by analyses. As such, coefficients for these non-significant interactions are not reported. Although, endorsement of false beliefs based on race was significantly associated with all outcome measures except for perception of importance of medical assessment. Coefficients are reported in Table 9 for the effect of each false beliefs scale. Upon including a quadratic term for the endorsement of false beliefs based on race scale, I found that

higher endorsement of false beliefs had a significant, nonlinear, and positive association with higher pain level ratings ($\beta = 0.202, p < .01$), pain typicality ratings ($\beta = 0.448, p < .001$), seriousness of pain ($\beta = 0.335, p < .001$), likelihood of referring to a specialist ($\beta = 0.232, p < .05$), and higher likelihood of perceiving the patient as over-reporting their pain ($\beta = 0.232, p < .01$) regardless of patient race, gender, or SES. Additionally, endorsement of false beliefs of biological difference was significantly, positively, and *linearly*, associated with likelihood of prescribing medication ($\beta = 0.467, p < .01$). Significant nonlinear and linear effects of endorsement of false beliefs of biological difference based on race are depicted in Figure 4.

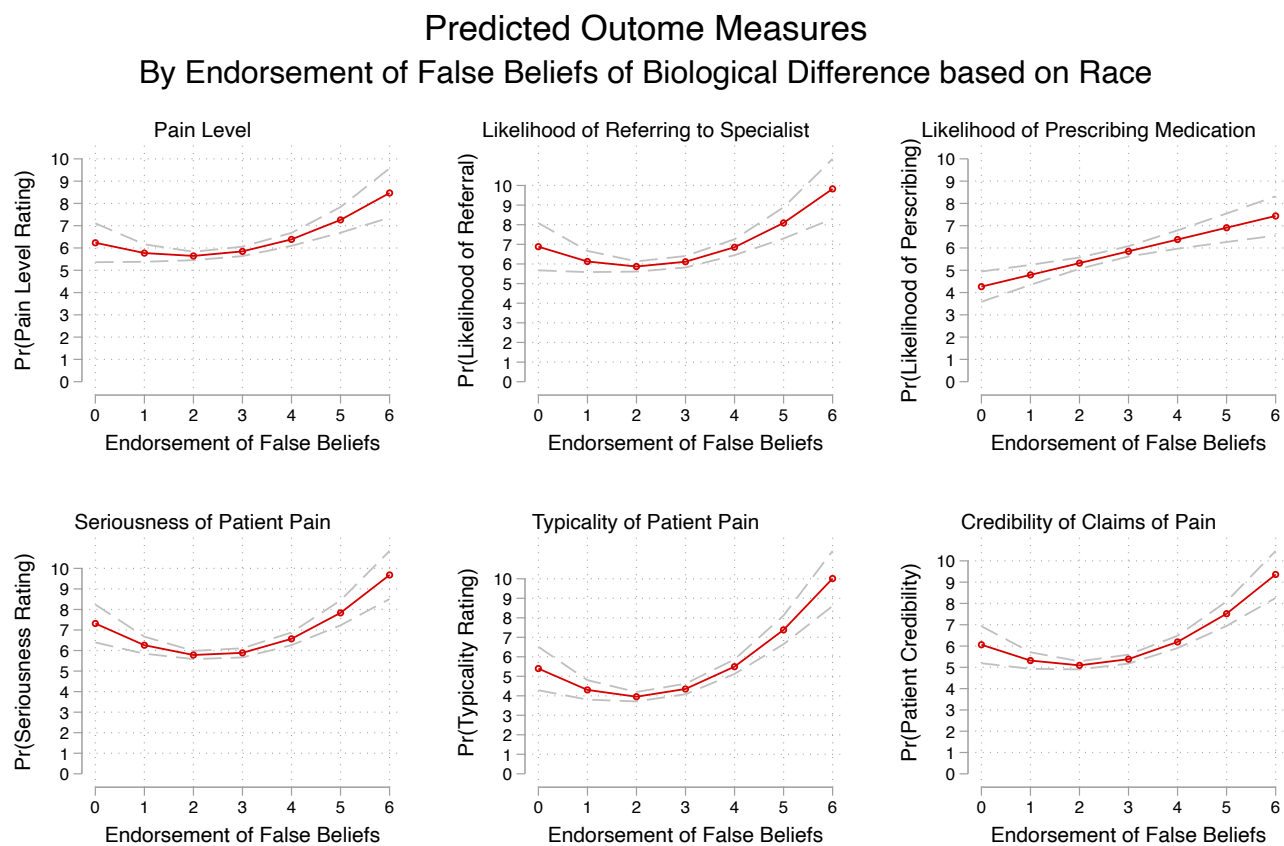


Figure 4. Predicted Outcome Measures by Endorsement of False Beliefs of Biological Difference Based on Race

These findings are somewhat contradictory in that they suggest healthcare workers and providers with high endorsement of false beliefs based on race would rate a patient's pain more seriously than healthcare workers and providers with lower endorsement of false beliefs while also

being more likely to perceive the patient as over-reporting their pain compared to those with lower endorsement of false beliefs. Similarly, the model predicts those same healthcare workers with higher endorsement of false beliefs also rate the patient's pain level as significantly higher than those with lower endorsement of false beliefs would. The nonlinear relationships depicted in Figure 4 tell us that high endorsement of false beliefs seems to be associated with the most extreme evaluations, in either direction. However, these findings remain difficult to explain theoretically and require future research to fully understand the relationship between endorsement of false beliefs of biological differences based on race and clinical evaluations of pelvic pain. However, based on previous research (Hoffman et al. 2016), one likely explanation is that evaluations from those who endorse false beliefs based on race were more susceptible to social desirability bias, again perhaps due to heightened discourse around implicit racial biases.

Table 9. Predicted Effect of Endorsement of False Beliefs of Biological Difference based on Gender and Race (N = 303)

| Outcome Measure | Effect of Patient | False Beliefs | Effect of Patient | False Beliefs |
|---------------------------------------|-----------------------|--------------------|----------------------|------------------|
| | Gender (Ref. Male) | based on Gender | Race (Ref. White) | based on Race |
| Pain Level | 0.343 | 0.019 | 0.287 | 0.202** |
| Pain Typicality | 1.595* | 0.069 | - 1.311 | 0.448*** |
| Seriousness of Pain | 0.413 | - 0.118 | 0.222 | 0.335*** |
| Importance of Medical Assessment | 0.024 | - 0.265* | 1.424 [†] | 0.236 |
| Likelihood of Referring to Specialist | 0.838 | - 0.165 | 0.650 | 0.232* |
| Likelihood of Prescribing Medication | - 0.559 | - 0.165 | - 0.244 | 0.467** |
| Credibility of Claims of Pain | - 0.008 | 0.065 | 0.632 | 0.232** |

Note: An interaction term for patient gender X false beliefs based on gender as well as an interaction term for patient race X false beliefs based on race were included in the model. However, none of the interaction terms were significant. Therefore, I do not provide coefficients for those interaction terms in the table.

p < .05, **p < .01, *p < .001, [†] Marginally Significant*

Interactions between SES, Gender, and Race

Two-way interaction terms for gender by SES, race by SES, and gender by race were all included in the models testing for interactions between patient characteristics. I also included a

three-way interaction term to test for an interaction between SES, race, and gender on all seven models. Hypotheses 6, 7, and 8 were not supported for all outcome measures. However, there was a significant interaction between gender and SES ($p < .05$) and race and SES ($p < .05$) in the models predicting rating of seriousness of patient pain. The interaction between race and gender was marginally significant in this model ($p = .06$). There was also a significant three-way interaction in the model ($p < .05$). To interpret the interactions, I reference marginal effects using pairwise comparisons to test for significant differences across all possible combinations and comparisons of patient SES, gender, and race. Table 10 reports those contrasts for all possible two-way interactions while Table 11 reports contrasts for all possible three-way interactions.

Table 10. Two-way Interactions Between Patient SES, Gender, and Race for Seriousness of Pain Ratings (N = 303)

| Interaction | Comparison | Contrast | SE |
|---------------|------------------------------------|----------------------|-------|
| Gender x SES | | | |
| | Low-SES Female vs. High-SES Male | - 0.574* | 0.232 |
| | Low-SES Female vs. Low-SES Male | - 0.226 | 0.240 |
| | High-SES Female vs. High-SES Male | - 0.077 | 0.221 |
| | High-SES Female vs. Low-SES Male | 0.271 | 0.230 |
| | High-SES Male vs. Low-SES Male | 0.348 | 0.227 |
| | High-SES Female vs. Low-SES Female | 0.497* | 0.234 |
| Gender x Race | | | |
| | White Female vs. Black Male | - 0.438 [†] | 0.231 |
| | White Female vs. White Male | - 0.157 | 0.237 |
| | Black Female vs. Black Male | - 0.134 | 0.223 |
| | Black Female vs. White Male | 0.147 | 0.229 |
| | Black Male vs. White Male | 0.280 | 0.227 |
| | Black Female vs. White Female | 0.304 | 0.234 |
| Race x SES | | | |
| | High-SES White vs. Low-SES Black | 0.131 | 0.233 |
| | Low-SES Black vs. Low-SES White | 0.192 | 0.241 |
| | High-SES White vs. Low-SES White | 0.322 | 0.238 |
| | High-SES Black vs. Low-SES Black | 0.507* | 0.225 |
| | High-SES Black vs. Low-SES White | 0.699** | 0.231 |
| | High-SES Black vs. High-SES White | 0.377 [†] | 0.221 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, [†] Marginally Significant

Results in Table 10 suggest participants rated low-SES female patients' pelvic pain as significantly *less* serious than high-SES male patients' pelvic pain ($p < .05$) and high-SES female patients' pelvic pain as significantly *more* serious than low-SES female patients' pelvic pain ($p < .05$). Pairwise comparisons also show that white female patients' pelvic pain was taken *less* seriously than black male patients' pelvic pain at a marginally significant level ($p = .06$). Lastly, participants rated high-SES black patients' as more serious than low-SES black patients' pain ($p < .05$), low-SES white patients' pain ($p < .01$), and high-SES white patients' pain ($p = .09$).

Table 11. Three-way Interactions between Patient SES, Gender, and Race for Seriousness of Pain Ratings (N = 303)

| Comparison | Contrast | SE |
|---|----------------------|-------|
| White Low-SES Female vs. Black High-SES Male | - 1.264*** | 0.331 |
| White Low-SES Female vs. White Low-SES Male | - 0.706* | 0.349 |
| Black Low-SES Female vs. Black High-SES Male | - 0.606 [†] | 0.310 |
| White Low-SES Female vs. White High-SES Male | - 0.536 | 0.345 |
| White Low-SES Female vs. Black Low-SES Male | - 0.458 | 0.351 |
| White High-SES Female vs. Black High-SES Male | - 0.422 | 0.308 |
| Black High-SES Female vs. Black High-SES Male | - 0.416 | 0.302 |
| Black Low-SES Male vs. White Low-SES Male | - 0.248 | 0.335 |
| Black Low-SES Female vs. White High-SES Female | - 0.186 | 0.326 |
| White High-SES Male vs. White Low-SES Male | - 0.169 | 0.329 |
| Black Low-SES Male vs. White High-SES Male | - 0.078 | 0.331 |
| Black Low-SES Female vs. White Low-SES Male | - 0.049 | 0.331 |
| Black High-SES Female vs. White High-SES Female | 0.006 | 0.316 |
| Black Low-SES Female vs. White High-SES Male | 0.120 | 0.327 |
| White High-SES Female vs. White Low-SES Male | 0.136 | 0.328 |
| Black High-SES Female vs. White Low-SES Male | 0.143 | 0.322 |
| Black High-SES Female vs. Black Low-SES Female | 0.192 | 0.320 |
| Black Low-SES Female vs. Black Low-SES Male | 0.199 | 0.331 |
| White High-SES Female vs. White High-SES Male | 0.306 | 0.323 |
| Black High-SES Female vs. White High-SES Male | 0.312 | 0.317 |
| White High-SES Female vs. Black Low-SES Male | 0.384 | 0.330 |
| Black High-SES Female vs. Black Low-SES Male | 0.390 | 0.324 |
| Black High-SES Male vs. White Low-SES Male | 0.558 [†] | 0.314 |
| Black Low-SES Female vs. White Low-SES Female | 0.657 [†] | 0.346 |
| Black High-SES Male vs. White High-SES Male | 0.728* | 0.309 |
| Black High-SES Male vs. Black Low-SES Male | 0.806* | 0.316 |
| White High-SES Female vs. White Low-SES Female | 0.842* | 0.344 |
| Black High-SES Female vs. White Low-SES Female | 0.848* | 0.339 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, [†] Marginally Significant

Pairwise comparisons for three-way interactions show significant—or marginally significant—differences in participants' evaluations of the seriousness of patient pain between nine

out of 28 possible combinations of patient SES, gender, and race. For example, white low-SES female patients' pelvic pain was taken significantly *less* serious than black high-SES male patients' pelvic pain ($p < .001$). Participants, however, also rated black high-SES male patients' pelvic pain as significantly *more* serious than white high-SES male patients' pain ($p < .05$). As Figure 5 shows white low-SES female patients' pelvic pain was rated as the least serious overall, whereas black high-SES male patients' pelvic pain was rated as the most serious overall. Additionally, black patients' pelvic pain was rated as more serious across all gender and SES combination with the exception of low-SES male patients where white low-SES male patients' pelvic pain was rated as more serious than black low-SES male patients' pelvic pain, although this difference is not significant

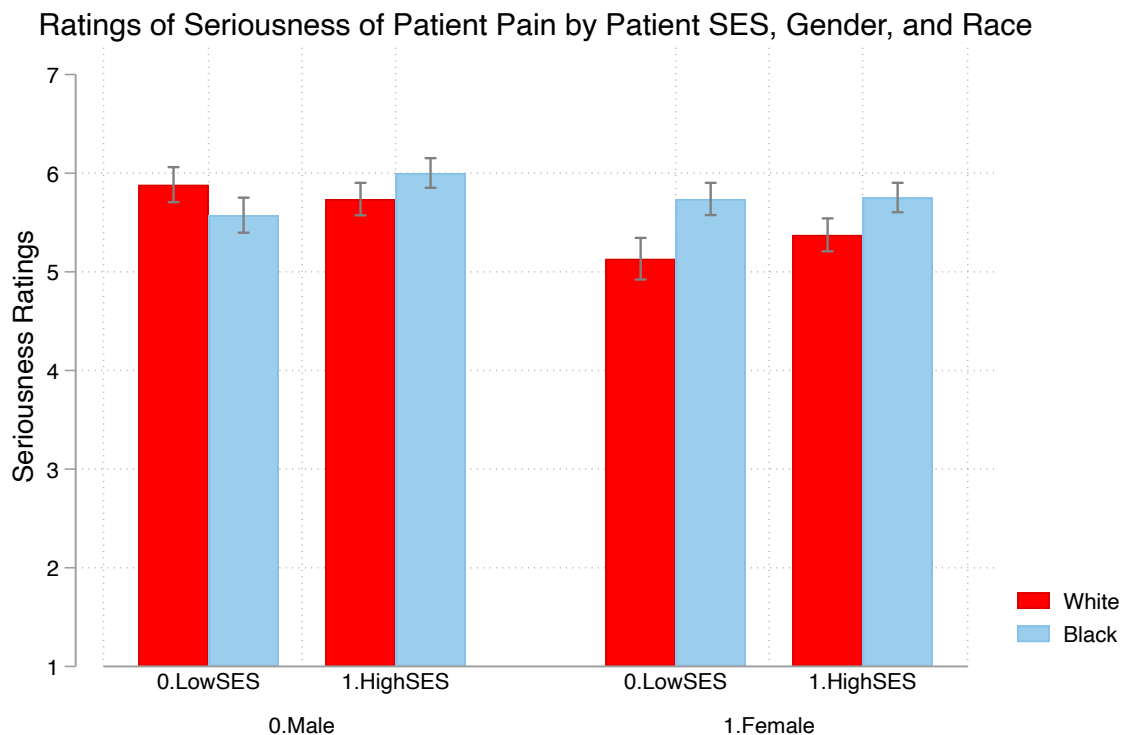


Figure 5. Ratings of Seriousness of Patients' Pelvic Pain by Patient SES, Gender, and Race

The model predicting perceptions of importance of assessment also showed a significant three-way interaction ($p < .05$). Interaction terms for race and SES ($p = .059$) and race and gender ($p = .055$) were also marginally significant. Again, I use pairwise comparisons of marginal effects

to test for significant differences across all possible combinations and comparisons of patient SES, gender, and race. Tables 12 and 13 provide estimates for those comparisons.

As shown in Table 12, participants reported perceiving a significantly lower importance of medical assessment for white female patients with pelvic pain compared to black male patients ($p < .05$). Participants also reported a significantly higher importance of medical assessment for high-SES black patients with pelvic pain compared to low-SES white patients ($p < .01$) and low-SES black patients ($p < .05$).

Table 12. Two-way Interactions Between Patient SES, Gender, and Race for Perceptions of Importance of Medical Assessment (N = 303)

| Interaction | Comparison | Contrast | SE |
|---------------|-----------------------------------|----------|-------|
| Gender x Race | | | |
| | White Female vs. Black Male | - 0.479* | 0.213 |
| | White Female vs. White Male | - 0.229 | 0.217 |
| | Black Female vs. Black Male | - 0.161 | 0.204 |
| | Black Female vs. White Male | 0.089 | 0.210 |
| | Black Male vs. White Male | 0.250 | 0.208 |
| | Black Female vs. White Female | 0.317 | 0.215 |
| Race x SES | | | |
| | High-SES White vs. Low-SES Black | 0.084 | 0.214 |
| | Low-SES Black vs. Low-SES White | 0.234 | 0.222 |
| | High-SES White vs. Low-SES White | 0.318 | 0.219 |
| | High-SES Black vs. High-SES White | 0.325 | 0.203 |
| | High-SES Black vs. Low-SES Black | 0.409* | 0.206 |
| | High-SES Black vs. Low-SES White | 0.643** | 0.212 |

Note: * $p < .05$, ** $p < .01$, *** $p < .001$, † Marginally Significant

Pairwise comparisons for the three-way interaction between patient SES, gender, and race showed significant, or marginally significant, contrasts for 12 of the 28 possible combinations and comparisons for perceived importance of medical assessment. The largest significant difference is between white low-SES female patients and black high-SES male patients. Specifically, participants reported significantly lower importance of medical assessment for white low-SES

female patients with pelvic pain compared to black high-SES male patients ($p < .001$). Participants also reported marginally significant lower importance of medical assessment for white high-SES female patients compared to black high-SES male patients ($p = .06$). Further, black high-SES male patients with pelvic pain were perceived as having a significantly higher importance of medical assessment compared to both black low-SES male patients and white high-SES male patients ($p < .05$). Participants also perceived significantly higher importance of medical assessment for black high-SES *female* patients with pelvic pain compared to white low-SES male and female patients ($p < .05$). Again, we see more favorable evaluations for black patients compared to white patients in many cases—a surprising finding given previous evidence that black patients receive *less* favorable evaluations when presenting pain in clinical settings (Anderson et al. 2009; Hoffman et al. 2016).

Table 13. Three-way Interactions Between Patient SES, Gender, and Race for Perceptions of Importance of Medical Assessment (N = 303)

| Comparison | Contrast | SE |
|---|----------------------|-------|
| White Low-SES Female vs. Black High-SES Male | - 1.195*** | 0.303 |
| White Low-SES Female vs. White Low-SES Male | - 0.594 [†] | 0.319 |
| White Low-SES Female vs. White High-SES Male | - 0.584 [†] | 0.316 |
| White High-SES Female vs. Black High-SES Male | - 0.530 [†] | 0.283 |
| Black Low-SES Female vs. Black High-SES Male | - 0.528 [†] | 0.284 |
| Black High-SES Female vs. Black High-SES Male | - 0.507 [†] | 0.276 |
| White Low-SES Female vs. Black Low-SES Male | - 0.419 | 0.321 |
| Black Low-SES Male vs. White Low-SES Male | - 0.175 | 0.307 |
| Black Low-SES Male vs. White High-SES Male | - 0.166 | 0.302 |
| White High-SES Male vs. White Low-SES Male | - 0.010 | 0.301 |
| Black Low-SES Female vs. White High-SES Female | 0.002 | 0.230 |
| Black High-SES Female vs. Black Low-SES Female | 0.214 | 0.292 |
| Black High-SES Female vs. White High-SES Female | 0.023 | 0.291 |
| White High-SES Female vs. White Low-SES Male | 0.070 | 0.301 |
| Black Low-SES Female vs. White Low-SES Male | 0.072 | 0.303 |
| White High-SES Female vs. White High-SES Male | 0.080 | 0.296 |
| Black Low-SES Female vs. White High-SES Male | 0.082 | 0.299 |
| Black High-SES Female vs. White Low-SES Male | 0.094 | 0.295 |

Table 13 Continued

| | | |
|--|--------|-------|
| Black High-SES Female vs. White High-SES Male | 0.104 | 0.290 |
| White High-SES Female vs. Black Low-SES Male | 0.246 | 0.303 |
| Black Low-SES Female vs. Black Low-SES Male | 0.248 | 0.302 |
| Black High-SES Female vs. Black Low-SES Male | 0.269 | 0.296 |
| Black High-SES Male vs. White Low-SES Male | 0.601* | 0.287 |
| Black High-SES Male vs. White High-SES Male | 0.610* | 0.283 |
| White High-SES Female vs. White Low-SES Female | 0.664* | 0.316 |
| Black High-SES Female vs. White Low-SES Female | 0.688* | 0.310 |
| Black High-SES Male vs. Black Low-SES Male | 0.776* | 0.288 |
| Black Low-SES Female vs. White Low-SES Female | 0.666* | 0.318 |

*Note: * $p < .05$, ** $p < .01$, *** $p < .001$, † Marginally Significant*

Figure 6 provides predictions of average perceived importance of medical assessment for patients based on their SES, gender, and race. As shown, low-SES white female patients with pelvic pain were perceived having the lowest importance of medical assessment among all conditions presented to participants. Participants perceived high-SES black male patients as having the highest importance of medical assessment. These findings mirror those of the three-way interaction for ratings of seriousness of patient pain. Additionally, similar patterns to those revealed in seriousness ratings show that black patients have more favorable evaluations when it comes to importance of medical assessment for all gender and SES combinations with the exception of low-SES male patients. Although, again, the difference in perceived importance of medical assessment between black and white low-SES male patients is not significant.

Percieved Importance of Medical Assessment by Patient SES, Gender, and Race

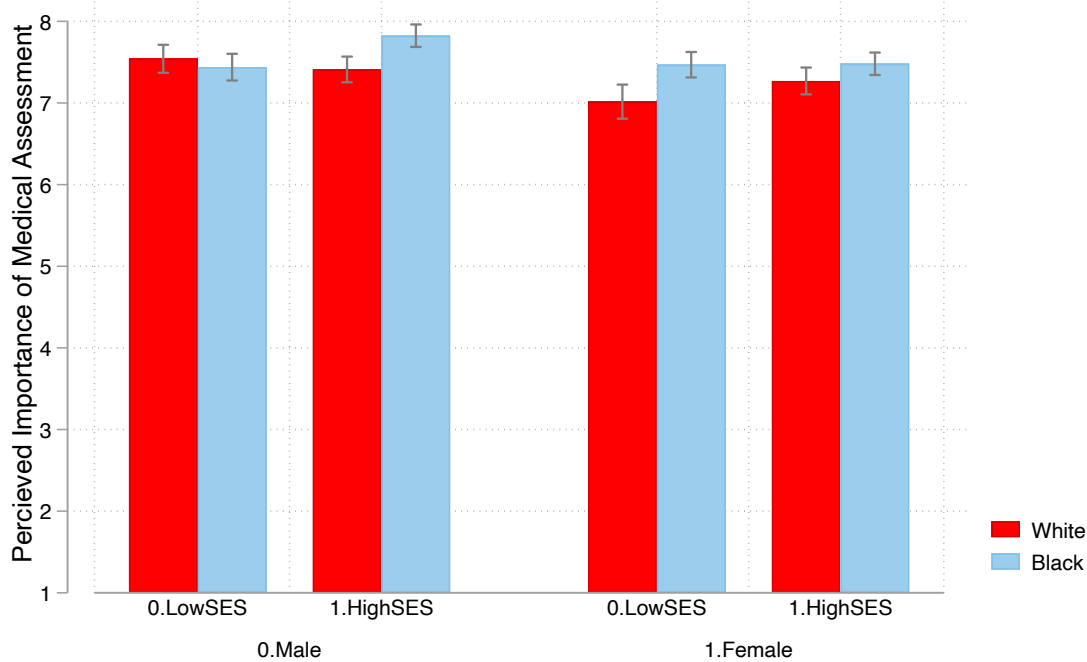


Figure 6. Perceived Importance of Medical Assessment for Patients Eliciting Concerns of Pelvic Pain by Patient SES, Gender, and Race

Manipulation Check Failures

Given the high failure rate for gender and race manipulation checks, I also analyzed whether or not manipulation check failure was associated with certain experimental conditions. For example, were participants who received black patient conditions more likely to fail race manipulation checks compared to those who received white patient conditions? To test for these associations, I ran chi-squared tests to determine any significant relationships between gender manipulation check failures and gender condition assigned, and race manipulation check failures and race condition assigned. Results show marginally significant differences for passing both all manipulation checks ($p = .059$) and gender manipulation checks only ($p = .052$), where participants passed both gender manipulation checks as well as all manipulation checks at a higher rate when assigned male patient conditions compared to female patient conditions. Similar patterns are observed for race conditions where participants who received white patient conditions passed both all manipulation checks ($p < .05$) as well as race manipulation checks only ($p < .001$) at

significantly higher rates than those who received black patient conditions. See Table 14 for pass rates among the full sample.

Table 14. Pass Rate Percentages for Manipulation Checks by Gender/Race Condition Assigned

| Condition Assigned | Passed All Manipulation Checks (%) | Passed Gender Manipulation Check (%) | Passed Race Manipulation Check (%) |
|--------------------|------------------------------------|--------------------------------------|------------------------------------|
| White Patient | 50.49 | | 88.31 |
| Black Patient | 43.28 | | 75.63 |
| Female Patient | 43.58 | 74.17 | |
| Male Patient | 48.66 | 78.64 | |

Note: N = 453 for analysis of passing all manipulation checks. N = 303 for analysis of passing gender and race manipulation checks.

These findings suggest that when participants were not paying attention to the race and gender of patients presented, they may have automatically assumed those patients were both white and male. Theoretically, these results support the literature on patient standardization which argues that the standard patient is often assumed to be both white and male (Epstein 2007). Results from the chi-square tests also support ideas from Glenn’s (2000) theoretical writings on the construction and institutionalization of race and gender. Glenn argues that dominant categories of race and gender (i.e., white and male) are often constructed, and subsequently institutionalized, as the referent or neutral category. Within this line of thought, participants likely guessed that patients were white and male if they had not actively observed those characteristics given how both “white” and “male” become the default race and gender categories. If they were assigned white and male patients, those guesses became passes, whereas if they were assigned black and female patients those guesses became failures on manipulation checks. It is also possible that the two-minute time limit for evaluating each patient did not provide adequate time for participants to fully grasp the demographic profile of each patient, exposing a potential flaw in the design. In other words, a slightly longer time limit such as five minutes per patient may have provided participants with a more realistic amount of time to view demographic information on the patient intake forms, more accurately ensuring the activation of stereotypes. This slightly longer time limit would also have kept patient evaluations within the suggested 15-minute stereotype activation time (Kunda and Spencer 2003).

Discussion

Although not all hypotheses presented were supported, the analyses here do support the main argument that fundamental causes of poor health should be applied with intersectionality theory in mind (Evans 2019). The significant three-way interactions between patient SES, gender, and race for two of the seven outcome measures suggest that interpretations of main effects of these patient characteristics on pain evaluations, and pelvic pain evaluations in particular, do not tell the full story. Further, results suggest that high-SES black men may receive more favorable pain evaluations than all other patients incorporated in the analyses, including high-SES white men. This finding contradicts much of the literature on racial biases in pain assessment, as well as the literature in support of the diminished returns hypothesis (Farmer and Ferraro 2005). According to evidence supporting the diminished returns hypothesis, black patients should receive less favorable outcomes compared to their white counterparts as both patients' SES increase. However, we see the opposite pattern in the data presented here where low-SES white men have more favorable evaluations than low-SES black men, while high-SES black men have more favorable evaluations compared to high-SES white men. These patterns tell us that SES has a favorable effect on pain evaluations for black men while having a negative effect for white men, suggesting diminished returns for white men in this case. Importantly, however, there is no significant difference in pain evaluations between low-SES and high-SES white men, whereas a significant difference between low-SES and high-SES black men was observed in the data. Therefore, rather than challenging the diminished returns hypothesis, the results presented here show a protective effect of SES for black men during clinical interactions—a protective effect not afforded to black women. In other words, a higher-class status may outweigh the effects of racism during clinical interactions for black men, but not for black women.

The same pattern, however, does not hold true for women. Instead, we see the effect of SES having virtually no impact on evaluations for black women and only a slight positive effect on evaluations for white women. One overarching argument that these results support is that assessing intersectional effects of fundamental causes is not only favorable, but necessary—for without doing so, we miss important nuance in the relationships we analyze. Additionally, despite gender not being a fundamental cause of disease (Bird and Rieker 2008), it is vital to understand the effect of gender on fundamental causes, such as SES and race, to fully grasp the effect of those fundamental causes themselves.

Although findings presented here are not all as expected—and sometimes even contradict the existing evidence as is the case with race—it is important to interpret them within the existing literature. The contradictory findings regarding race, once again, remind us of the significance of intersectional analyses. Importantly, the individual effect of race on all outcomes measured here never quite reached significance. When we combine the effect of race with the effect of gender and SES, however, we are able to see that race is significant for pelvic pain evaluations. However, the way in which it matters when combined with the effects of gender and SES still contradicts the existing literature that documents less favorable clinical evaluations for black patients compared to white patients. Regardless, the research here provides evidence for pushing the agenda of an intersectional fundamental causes framework forward by showcasing the intricacies of how patient gender, race, and SES simultaneously impact clinical evaluations of pain (Evans 2019).

As discussed in the results section, it may be the case that the unexpected findings on race are the outcome of social desirability bias. When we look at the relationship between endorsement of false beliefs of biological difference and many of the evaluation questions, this explanation becomes clearer. Participants with the highest racial biases in regard to false beliefs of biological differences also gave the most favorable evaluations, suggesting that those with high levels of bias may have evaluated all patients, regardless of race, more favorable than they might in a real clinical interaction to present themselves as more desirable evaluators on paper. Whether or not social desirability would have similar favorable effects for minority patients in the exam room is not clear from this analysis, but future research should explore the possible positive impact of social desirability bias on clinical interactions and patient evaluations.

Alternatively, these findings also reveal important limitations for this study: how participants evaluated patients on paper may not translate to how they evaluate patients during in-persons, or even telehealth, clinical interactions. Although I took steps to ensure face validity with the intake forms, it is reasonable to expect evaluations to differ when patients and providers are face-to-face. It is also reasonable that racial stereotypes were not activated in the same way through patient chart reviews as they may be in person. In this way, because the context of this experiment differs heavily from the context of a face-to-face visit with a patient, it is possible that race did not actually matter for evaluations in the context of this experiment. That is not to say that race does not matter for evaluations of pelvic pain, but rather that a thoughtfully designed audit study taking

place in an exam room may be more equipped to reveal the ways in which race and implicit racial bias matters for such evaluations (see Gaddis 2018).

Additionally, patient SES, which had an independent effect for most outcomes measured, is likely to have a larger effect during clinical interactions where patients can signal their SES via mannerisms, dress, language use, and more. The metamechanism of habitus, which can largely affect the ways in which we interact with others, is likely to play a role here (Freese and Lutfey 2010). The concept of cultural health capital—"a specialized form of cultural capital that can be leveraged in health care contexts to effectively engage with medical providers"—may also be important for understanding the limitations of this study and expanding it to provide more accurate results for what may happen during real-life clinical interaction (Shim 2010:3). I would expect future research in this area to show an even more influential effect of patient SES on evaluations because SES is signaled in a variety of ways during face-to-face interactions, compared to the single manipulation used to signal SES in this experiment. In this way, the SES results here are likely conservative compared to what we might observe in real-world evaluations.

The effect of SES on clinical evaluations may also be explained through status characteristics and their relationship to evaluations of patient competence and reliability. Evaluations of competence are part of an extensive lineage of research using status characteristics theory (SCT). SCT, a sub-theory of expectation states theory, works to explain how status characteristics—such as gender, race, and SES—impact performance expectations to influence an individual's evaluation of others (Correll and Ridgeway 2003). Applied to provider-patient interactions, we can think about SCT as providing a framework for understanding how status characteristics such as SES impact providers evaluations of patients' competence and therefore their evaluations of the patient symptoms based on patient reports. With evaluations of competence in mind, the findings presented in this chapter suggest that higher SES patients may be viewed as more competent and reliable reporters of their pain compared to lower SES patients. Therefore, research addressing the issue of biased clinical evaluations based on patient SES from the perspective of SCT and evaluations of competence would be advised to explore this idea further.

Returning to the patterns related to who passed or failed manipulation checks for gender and race based on gender and race condition assigned, it is worth exploring the idea that black patients were evaluated in comparison to a hypothetical white patient despite race being evaluated between-subjects. In other words, because the standard, or referent, patient is often constructed at

white, participants may implicitly be comparing their evaluations to their hypothetical evaluations of white patients (Epstein 2007). In this way, social desirability bias would easily occur despite efforts to reduce it by having participants evaluate either all white patients or all black patients. For clinical interactions, these findings have implications for the possible positive impact of social desirability bias for minority patients in pain. However, given the large proportion of manipulation check failures in the sample, it is also worth exploring the possibility that a two-minute time limit for evaluating patients was not sufficient. Future research should keep this potential design flaw in mind when including time limits for survey participants, especially if participants are meant to capture all the information presented to them.

Another important limitation in this study is the statistical power of the sample. As discussed, power analyses by simulation revealed 800 as the necessary sample for finding significant three-interactions between patient gender, race, and SES if those significant interactions exist. Given the small sample used to test hypotheses 6, 7, and 8 presented here, it is possible that patient gender, race, and SES significantly interact for other outcomes measured but that these interactions were not detectable with a sample size of 453. With that said, results presented here should be interpreted as modest. With a more statistically powerful sample, insignificant results presented here may prove significant, and such possibilities should be explored in future research.

Despite limitations discussed here, it is important to emphasize that Figures 3 and 4 paint consistent pictures on how patient gender, race, and SES intersect to impact clinical evaluations of pelvic pain. The consistency reported here suggests that although findings may be amplified or altered in real-world scenarios, what we see here is likely to accurately guide future research in this area and perhaps help researchers make sense of that future data. The consistency in this data also makes it ideal for informing policy related to ameliorating health disparities.

One suggestion Link and Phelan (1995) provide for those working to ameliorate health disparities resulting from fundamental causes involves skepticism of overly ambitious policies and interventions. Policymakers should be wary of interventions that focus on mechanisms but claim to address broader social factors contributing to disease. These interventions present false claims because addressing the mechanisms will *always* fail long-term since doing so does not confront the underlying causes of those mechanisms (i.e., the fundamental causes). For example, we cannot ameliorate socioeconomic disparities in pelvic pain evaluation by addressing implicit class biases in medicine because such biases are only one of many mechanisms linking SES to poor health

outcomes. Therefore, it is overly optimistic and misleading to claim that policies directed at implicit bias will ameliorate health disparities. Importantly, although implicit bias is the mechanism of focus on this study, it is certainly not the only mechanism linking fundamental causes to poor health outcomes for pelvic pain patients.

To avoid false promises with policy, Phelan and Link (2013) suggest that we redistribute flexible resources more equitably. According to this suggestion, interventions that target health disparities may not appear health-related at first glance. For example, policies that tackle housing inequality, parental leave, education inequalities in early childhood, and more all work to redistribute flexible resources that, when lacking, put people at risk for a multitude of diseases. Therefore, interventions that acknowledge fundamental causes of health may come from evidence in research on many forms of inequality and may even appear to be unrelated to the health condition of concern. Because fundamental causes impact multiple disease outcomes, interventions aimed at improving disparities for one condition should also be implicitly, if not explicitly, aimed at improving disparities for other conditions. Such interventions, therefore, should not be limited by evidence specific to certain health conditions or even health inequities more generally. Meaning, research beyond what is presented here should inform policy decisions to improve pelvic health disparities alongside this work.

Overall, ameliorating health disparities that result from fundamental causes is complex, and applying intersectionality theory to those fundamental causes can make this task even more complex. However, the application of intersectionality theory may also paint a clearer picture of how disparities are organized across different groups, allowing policies informed by such work to be more precise and perhaps more effective. Such a task requires that policymakers understand the role of different metamechanisms, such as institutions and habitus, in perpetuating health inequities. Despite the difficulties in developing successful interventions that address health disparities long-term, if policymakers want to improve health disparities across the entire population—and not just for the most advantaged groups—they must take an intersectional fundamental cause framework to the table.

AN INVESTIGATION OF CULTURAL HEALTH CAPITAL IN THE CONTEXT OF A MEDICAL ANOMALY

Cultural Health Capital—a concept developed by Shim (2010) to account for clinical interactions and the ways they contribute to health disparities—has been widely referenced in both the medical sociology literature as well as the health services literature since its conception. Throughout these literatures, the concept has proven useful for understanding the complex dynamics of clinical interactions for a variety of health conditions and contexts (Chang, Dubbin and Shim 2016; Madden 2015; Rubin et al. 2018). However, upon applying the concept to the case of pelvic pain, it becomes clear that new insights are necessary for moving the concept forward as an applicable tool for analyzing the clinical interaction.

Cultural health capital (CHC) makes the implicit assumption that medicine, as an institution, has the tools required to adequately treat the patients it comes in contact with. This assumption falls in line with Barker's (2005) argument that biomedical methods and treatments are best suited for acute illnesses with "discrete pathogens" that can be identified and treated with similarly discrete technical solutions (p. 70). However, not all illnesses are acute, and not all illnesses are treatable—with discrete technical solutions or otherwise—under the gaze of modern medicine. That leaves us with the question: what is the role of CHC in the context of health conditions that medicine cannot readily identify through current biomedical methods and currently does not have treatment for? In this chapter, I use the case of pelvic pain care in the US to argue for the expansion of our current understandings of CHC to account for such conditions.

Cultural Capital

Cultural capital was first introduced by Bourdieu in his 1986 essay titled, "The Forms of Capital." Bourdieu's (1986) discussion on forms of capital other than economic capital was meant to challenge and expand the way sociologists and other social scientists understood the accumulation and exchange of capital in society. While economic capital in its material form certainly impacts interactions between individuals, organizations, and institutions, Bourdieu (1986) argued for recognition of immaterial forms of capital and their equally impactful influence on interactions. Cultural capital, as both a material and immaterial form of capital, allows us to

understand how things like interests, art, literature, and educational qualification may be accumulated and exchanged as a form of capital.

While cultural capital may directly convert to economic capital—as can be the case with educational qualifications that lead to higher-paying occupations—Bourdieu (1986) provides important distinctions that make cultural capital unique from economic capital. First is the way cultural capital can be *embodied*. Bourdieu (1986) uses the term *habitus*—or “long-lasting dispositions of the mind and body”—to describe the embodied state of cultural capital (p. 17). Examples of embodied cultural capital might include regional accents, bodily posture, and the unconscious use of certain phrases or words that signify an individual’s location in a social hierarchy. Bourdieu (1986) also discusses cultural capital as *objectified* when it is presented in material forms such as art and other cultural goods. While cultural goods are material forms of capital that may be directly converted into economic capital, they are also symbolic in that they signal possession of cultural capital in its embodied state. For example, one might acquire a collection of art through economic capital, but the socially acceptable consumption of that art requires a habitus of appreciation, knowledge, and understanding that goes beyond what money can buy—i.e., it’s symbolic in addition to material. Lastly, cultural capital can also be observed in its *institutionalized* state. In this state, cultural capital may take the form of educational or professional qualification. Once again, although cultural capital in this form is material, it is also symbolic in the way certain material qualifications signal social status symbolically.

Cultural Health Capital

Cultural *health* capital was introduced as a way of applying Bourdieu’s (1986) concept cultural capital to clinical interactions. CHC is best understood in the medical sociology literature as a specialized form of cultural capital that is beneficial for patients during the clinical interaction (Shim 2010). As such, it may also appear both materialistically—in the form of cultural goods and services related to health such as a gym membership or private insurance coverage—or symbolically in its embodied state of habitus (Bourdieu 1986). As a theoretical concept, it allows researchers to evaluate the micro-level interactions between patients and providers as processes and practices that are imbedded in our macro-level social structures (e.g., social class). Applied to the case of pelvic pain care, CHC offers insight into the ways pelvic pain patients interact with individual providers at the micro-level—as well as medicine more broadly at the macro-level—to

find relief from conditions causing their pain. Moreover, the concept encourages the investigation of variance across pelvic pain patient experiences, while facilitating an understanding of why some patients find success and others do not.

In her introduction of CHC, Shim (2010) focused on particular patient characteristics that allow for success in the clinical encounter. For example, patients with knowledge of medical topics and vocabulary may more efficiently communicate with their healthcare providers. The ability to adapt one's interactional style as well as the ability to successfully signal social positions of privilege may also help patients fare well in their interactions with providers (Shim 2010). Scholars utilizing the concept as a tool in their research have continued discussions of CHC with a similar focus on patient characteristics leading to theoretical advancements. One of those theoretical advancements emphasizes that CHC is highly contextual (Rubin et al. 2018).

In an examination of chronic pain management for low-income patients, Rubin and colleagues (2018) found that which patient characteristics are deemed useful depends on the context of the clinical encounter. In other words, not all resources, skills, or assets, are useful across social, medical, and political contexts. For example, what is a useful skill for patients seeking care in a private healthcare system may not prove as useful for those seeking care in a public healthcare system, given the organizational and bureaucratic differences between the two systems. Similarly, what constitutes necessary skills for pelvic pain patients likely differs from the skills necessary for cancer patients. The CHC research focused on patient characteristics exposes the idea that CHC likely does not operate the same across contexts, partly because of variations in culture and structure across spaces, but also because of variation across health conditions.

Importantly, Shim's (2010) introduction to the concept does not stop at a list of patient characteristics that may constitute CHC symbolically. Despite the clear connection of CHC to Bourdieu's (1986) theoretical lineage, Shim (2010) was also inspired by the long line of literature on fundamental causes of disease (Link and Phelan 1995). Specifically, Shim's (2010) concept of CHC problematizes the assumption that resources—including cultural resources—are *purposefully* used to benefit one's health. This critique falls closely in line with Freese and Lutfey's (2010) expansion of Link and Phelan's (1995) original articulation of flexible resources to include the metamechanism of habitus.

In the same way CHC acknowledges the unintentional ways privilege positively impacts patients during clinical interactions, habitus acknowledges the unintentional ways privilege

positively impact individuals' health more generally (Freese and Lutfey 2010; Shim 2010). In this way, we can understand CHC as the manifestation of habitus in the clinical interaction. As such, it may be particularly useful to use CHC in conjunction with ideas from fundamental cause theory to grasp how habitus operates within and beyond the clinical interaction to advantage some patients over others. Further, in turning our attention to the case of pelvic pain care, we are able to analyze these social processes within the context of a medical symptom that has been deemed the “little albatross” of medicine².

Flexible Resources

Fundamental cause theory conceptualizes flexible resources as the “‘risks of risk’ that shape individual health behaviors by influencing whether people know about, have access to, can afford, and receive social support for their efforts to engage in health-enhancing or health-protective behaviors” (Link and Phelan 2013:107). Examples of flexible resources in the literature include money, knowledge, and prestige among other resources often associated with socioeconomic status (SES). Given the broad spectrum of ways flexible resources can be defined and measured, Freese and Lutfey (2010) introduced more specific metamechanisms, such as habitus, to clarify the role of flexible resources in determining health disparities between different SES groups.

The relevance of the metamechanism of habitus in analyses of CHC requires thorough explanation. As previously discussed, habitus is the embodied state of cultural capital—it is the habitual and unconscious dispositions that are rooted in an individual's life experiences. By focusing on both habitus and CHC simultaneously, we are able to analyze how the larger habitual and unconscious dispositions of patients impact the clinical interaction. Habitus can impact health outcomes in a variety of ways, from sedentary habits engrained in an individual's daily life from childhood, to the phrases, words, and body language an individual uses to communicate health concerns to a provider. In this way, habitus allows for a broader scope of analysis on how embodied cultural capital impacts health outcomes, while CHC narrows that scope to how cultural capital impacts outcomes in the clinical interaction.

² This quote comes from an OBYGYN interviewed for the critical discourse analysis chapter

A second metamechanism introduced by Freese and Lutfey (2010) highly relevant to analyses of CHC is the metamechanism of *means*, which according to fundamental cause theorists refers to the *purposeful* use of socioeconomic resources to improve one's health (Link and Phelan 2013). Although cultural capital is distinct from economic capital, which may seem more closely related to means than other forms of capital, CHC and means are interrelated—most obviously in their material forms—and therefore require consideration together. The importance of analyzing means, habitus, and CHC all at once is particularly important in the context of US healthcare—a primarily private system that requires an abundance of socioeconomic resources to receive its intended benefits. Although US healthcare is jointly funded through both public and private sources, the majority of Americans are enrolled in employer-based private health insurance (Berchick, Barnett, and Upton 2018). Hence, access to healthcare in the US is closely tied to one's occupation and, therefore, their SES.

For those enrolled in public healthcare plans (i.e., Medicaid), access to healthcare services is still a concern due to an estimated 25% of physicians declining to accept patients covered through Medicaid. This lack of participation in public healthcare from a quarter of physicians threatens the access of patients enrolled in those public services (Neprash et al. 2018). Also important, patients in the US typically qualify for a public option based on income or ability, directly linking this option to lower-SES patients and those with disabilities that hinder their ability to work. Together, these patterns tell us that access to healthcare in the US is closely tied to, if not dependent on, access to socioeconomic resources related to one's occupation.

Lower-SES patients already lack many of the necessary socioeconomic resources for improving their health based on means. Insurance coverage certainly poses a potential barrier as well as the ability or inability to pay out-of-pocket for specialists or treatments not covered by insurance—something particularly pertinent for pelvic pain patients who frequently rely on a small network of specialists for proper assessment and treatment options not recognized as “medically necessary” by insurance companies (e.g., Botox injections for vulvodynia). Understanding the context of means as a metamechanism in the patient experience is important in accounting for socioeconomic factors that influence clinical interactions outside of the exam room. Similarly, a focus on the metamechanism of habitus in addition to CHC in analyses allows for acknowledgement of *unintentional* use of norms, dispositions, and lifestyles in patients' lives more generally that impact clinical interactions.

Medical Authority

While means, habitus and CHC allow for a thorough investigation of *patient* resources for successful clinical interactions, patients are only half that interaction. To fully understand the clinical interaction, we must also take account of social forces working from the provider's side of that interaction. One such force is *medical authority*. In his book *Professional Dominance: The Social Structure of Medical Care*, Freidson (1970) wrote extensively about the social origins of physician authority in the medical profession and society more broadly. His analyses emphasize the organizational structure of medicine, its "special form of legal 'powers,'" and its "special position of dominance in the set of occupations that provide healthcare" (Freidson 1970:77). As a profession that has "gained monopoly over the right to offer" health services, medicine attracts clients (i.e., patients) that have "few alternatives for action" (Freidson 1970:118). Generally, patients only seek out medical consultation after having tried to solve their problems themselves. Therefore, patients are immediately placed in subordinated positions of power during clinical interactions with providers who they legally and bureaucratically rely on to solve their problems. In short, medicine maintains its authority and dominance through its formal ties to the state that grants the profession continuous sole legal rights to offer health services. This monopoly problematizes power dynamics between providers and their patients.

One way medical authority, in its conceptualization by Freidson (1970), problematizes power dynamics in the clinical interaction is through the formal process of diagnosis. In her introduction to a sociology of diagnosis, Jutel (2009) drew important connections between the social process of diagnosis and the organizational structure of medicine when she wrote:

Diagnosis is integral to the system of medicine and the way it creates social order. It organizes illness: identifying treatment options, predicting outcomes, and providing an explanatory framework. Diagnosis also serves an administrative purpose as it enables access to services and status, from insurance reimbursement to restricted-access medication, sick leave and support group membership and so on. (p. 278)

According to this explanation, diagnosis not only provides patients with a validating label (Barker 2005), but also a bureaucratic pathway to treatment options. Therefore, if a patient seeking health services presents symptoms not likely to lead to diagnosis—or if their condition has yet to be formally recognized in the scientific literature—their pathway to treatment is essentially

obstructed. That obstruction might occur despite accumulation of CHC, or it may be navigated more successfully because of the accumulation of CHC. When it comes to pelvic pain, however, there is also the question of whether or not a diagnosis leads to any clear treatment options, as evidence-based treatment options are limited for many conditions causing pelvic pain (e.g., PGAD, vulvodynia, and endometriosis). The analysis presented here provides insight into how patient resources such as CHC and means combine with medical authority and the social process of diagnosis in the face of a notoriously difficult to diagnosis and tough to treat medical symptom: pelvic pain.

Pelvic Pain Care

Pelvic pain is a medical symptom that falls at the intersection of women's health, sexual and reproductive health, and pain science—three medical specialties that arguably lack acceptable standards of medical knowledge (Rubin et al. 2018; Criniti et al. 2014; Kirschstein 1991). For example, Criniti and colleagues (2014) argue “the current medical education system, from medical education to residency and continuing medical education for attending physicians, lacks standardization regarding sexual health education” (p. 76). Additionally, the lack of any formally agreed-upon biomarkers for pain only adds to the lack of medical knowledge on conditions causing pelvic pain (Rubin et al. 2018). While formal diagnoses related to conditions causing pelvic pain do exist within the biomedical paradigm (e.g., polycystic ovarian syndrome, endometriosis, pelvic inflammatory disease), clear etiology for pelvic pain is often lacking (Speer et al. 2016).

When presented with a lack of evidence, providers assessing pelvic pain patients often respond with a lack of answers, which also often means a lack of diagnosis, treatment, and, sometimes, referral. When a provider has no answers, diagnosis, treatment, or referral to give, a patient's ability to exercise CHC in the way that it is currently understood may not matter. Instead, the ability to negate medical authority may be most helpful, allowing patients to move beyond the biomedical paradigm that lacks the knowledge to help them to find relief. Further, the ability to negate medical authority may be linked to socioeconomic resources identified through both means and habitus, as discussed by fundamental cause theorists (Freese and Lutfey 2010; Link and Phelan 2013)

Data and Methods

To analyze the ways in which patients with pelvic pain utilize CHC, means, and habitus to find relief from their pain, I interviewed 43 pelvic pain patients. More specially, the data analyzed for this project includes patient narratives collected through semi-structured, in-depth interviews with pelvic pain patients. Those who qualified as a “pelvic pain patients” were patients with female reproductive anatomy who were 18 years of age or older and sought medical advice for their pelvic pain in the US. In crafting the inclusion criteria in this way, I hoped to collect of sample that included both positive and negative experiences, which proved successful. While almost all patients interviewed shared stories of having their symptoms dismissed by providers, some patients’ stories of dismissal ended with relief of their symptoms. This variation allowed me to analyze the fundamental differences between narratives of relief and stories of perpetual pain.

Sample

Further variation within the sample of patients allowed for an analysis of how those differences are tied to CHC, means, and habitus. Twelve patients reported an annual household income (AHHI) of \$40,000 or less, while 16 patients reported an AHHI of \$100,000 or more. The remaining 15 participants either did not report or reported AHHIs somewhere between \$40,000 and \$100,000. Education provided less variation with seventeen participants reporting having earned graduate degrees while 14 reported earning bachelor’s degrees, and 12 reported having some college education. While this sample is not representative as far as the distribution of educational attainment across the US population, Freidson’s (1970) ideas on the professional dominance of medicine provide insight into how this work may still be generalizable to a degree.

According to Freidson (1970), “where status differences between client and practitioner are so great as to require deference in interaction, the client may be so uncomfortable and fearful as to avoid consultation in the first place” (p. 114). In other words, potential pelvic pain patients with the lowest levels of education may never transition into the formal patient role because of their anticipation of deference to the higher status provider. Under these theoretical assumptions, by limiting my sample to those who consulted with medical providers about their pain, I also limited my sample to relatively high-status patients. This limitation is particularly evident when it comes to education level in the sample. Therefore, while this analysis cannot speak to the

experiences of the patient who avoids consultation in the first place, it can and does speak to the patient whose social status encourages seeking consultation from medical professionals. While a deeper analysis of why lower-status patients avoid consultation is both important and necessary, it is beyond the scope of this research, which focuses on the consultation itself.

In terms of race and ethnicity, of the 43 patients, 35 identified as white, two as Black, two as Middle Eastern, one as South Asian, and one as Latina. Given that the sample I was able to secure is mostly white, the analyses here focus on differences across socioeconomic groups, rather than racial groups. These data do allow me to hone the experiences of white pelvic pain patients, but not necessarily in comparison to other racial groups. While the sample is not ideal for comparisons across racial groups, it does closely reflect the population of Indiana where recruitment took place (U.S. Census Bureau 2019). A small variation in sexuality also exists among participants with five bisexual participants, one queer participant, one asexual participant, and one gay participant. The remaining 35 participants identified as heterosexual. All patients but one identified as women with one transmasculine patient included in the data. Roughly half of the sample reported being religious or spiritual, with 22 patients reporting some form of religiosity. Religions reported by participants included Taoism, Catholicism, Judaism, and denominational and non-denominational Christianity. Majority of those who reported religion reported Christianity. Participants ages ranged from 21 to 68 with an average age of roughly 38 at the time of the interviews.

Recruitment

Patients were recruited for participation in the research through two methods, both of which employed purposive sampling techniques while also relying on snowball sampling. First, I used online resources to recruit patients by creating a project webpage that included the Purdue IRB approved recruitment flyer and a short bio about me and my research. I also shared the page and the recruitment flyer on various social media outlets (e.g., Facebook and Twitter) to reach a wide audience of women. Additionally, I reached out to administrators of online support groups for women living with pelvic pain and ask for permission to post the link to the project webpage or the flyer where members could see it. If the online group was not public, an administrator was often willing to share the flyer with the members for me.

The second method utilized low-income health clinics in the Greater Lafayette, Indianapolis, and surrounding areas to advertise the recruitment flyer. This method of recruitment was employed to ensure the sample of patients was economically diverse. I reached out to a total of 17 free and low-income health clinics in Indianapolis and surrounding rural areas. While most clinics were able and willing to allow me to hang the recruitment flyer, a few had policies against such activities and therefore denied my request to recruit patients at their clinic. Upon a stunt in recruitment, I also reached out to ten low-income clinics around Chicago and was able to advertise the recruitment flyer at a couple of clinics in the area. However, no participants were recruited as a result of my efforts in the Chicago area.

Analytical Approach

The analytical approach I used to examine the interview data was narrative analysis. In following this approach, I was able to investigate the connections between patient narratives, sense-making processes, and interactions with providers, all while keeping social structural context in mind. One sociological example of the connections between illness narratives, sense-making processes, and interactions with providers comes from Barker's (2005) book, *The Fibromyalgia Story: Medical Authority and Women's Worlds of Pain*. In her book, Barker (2005) discusses the legitimizing experiences of receiving diagnoses as diagnostic transformations. Specifically, she details the experiences of women with fibromyalgia symptoms, arguing that the women she interviewed underwent transformations once they received a formal medical diagnosis. After a diagnosis, women could *make sense* of their illnesses within the legitimate and accepted medical framework. Such findings exemplify how illness narratives facilitate the ability to understand the connection between interactions with providers and sense-making processes related to illness.

Werner, Isaksen, and Malterud (2004), on the other hand, found that women with medically unexplained—or undiagnosed—pain still organize their illness experiences within the frameworks provided by medical discourses. However, without the legitimacy of a diagnosis, women's stories of pain are built around justifying their experiences as somatic, rather than psychological (Werner et al. 2004). That is, women make sense of their pain within the available medical frameworks with or without a diagnosis. Yet, *how* they make sense through storytelling depends on the presence or absence of a diagnosis. Both Barker's (2005) and Werner and colleagues' (2004)

analyses provide examples of how sense-making processes can inform an understanding of women's illness experiences in light of their interactions with providers.

Williams (2004) describes illness narratives as a way to examine “how people make sense of social forces that shape their experiences of health and ill health” (p. 280). Using this definition, my approach to interviewing patients with pelvic pain allowed me to examine how they make sense of social forces—such as social class—that shape their interactions with providers and subsequently their experiences with pelvic pain. Williams (2004) also importantly calls attention to the role of interpretation in narratives when he argues:

The point is that their stories *are* interpretive. They are not merely descriptions waiting for social scientists to interpret them, and they invite us to acknowledge the ability of people to turn routine, taken-for-granted knowledge into discourse or narrative, and the need to find ways of interpreting the relationship between structure, context, and experience through a reading of people's own stories. (p. 285)

Through narrative analysis, interviews can reveal a person's interpretations of how social forces shape their experiences. Narratives are also described as providing insight on the connections between experience and structure (Williams 2004). If we think about medicine and social class as structures that impact patient experiences—and illness experiences more broadly—then narratives become a way to understand how those structures impact those experiences. When patients told me their stories of encounters with providers, those stories revealed the connections between those structures and their experiences in a way that allowed me to examine those connections through a sociological lens. Thus, although women's narratives are subjective interpretations of their individual experiences, they also reveal the role that social structures play in a collection of individual experiences.

The ability of narratives to reveal the link between structure and experience is partially because narrative analysis relies on researchers' abilities to see an interview as a whole, rather than fragmented pieces of text (Holloway 2001). In seeing each interview as it exists in its entirety, the structure shaping that narrative becomes available for analysis. For example, Riessman (1993) argues that, importantly, narrative analysis challenges researchers to ask, “why was the story told that way?” (p. 2). When we start to ask these questions as researchers, the narratives under examination become so much more than a collection of responses to prompted questions and

follow-ups; they become insight into how experiences unfold at varying positions within social structures.

With that said, the interviews with patients were not analyzed merely as interviews. Rather, they were analyzed as narratives that unfold to reveal experiences that are embedded in the structures that shape them—including the structure of their interactions with providers which were influenced by their SES, including the dispositions of their minds, or rather, their *habitus*. To be clear, in using narrative analysis as a method I investigated the ways patients tell their stories of pain and of interactions with providers. The differences in how patients from varied social positions told their stories allowed me to draw conclusions about how social positions impacted their-sense making processes related to their pain, and therefore their illness experiences. In this way, patient narratives afforded insight into the roles of means, *habitus*, and CHC in the experiences of patients across varying socioeconomic positions.

Findings

Findings from the analysis reveal how CHC and means, as patient resources, collide with medical authority to impact patient experiences in the context of a medical symptom that rarely presents a clear path to treatment, even with a diagnosis. In general, patients' narratives unfolded in three phases: 1) experiencing symptoms, 2) experiencing dismissal from medicine, and 3) accumulating the necessary CHC to successfully negate medical authority. Given the relatively highly educated sample of patients, it is not surprising that patients seemed to share a relatively high accumulation of CHC. However, they also shared a similar experience of having to accumulate new skills and knowledge to successfully negate medical authority in ways that still allowed them access to medicine and potentially helpful medical treatments.

Importantly, means also played a significant role in patients' abilities to harness their newly accrued CHC. In other words, patients may successfully challenge the medical authority they encounter during their clinical interaction, but if the treatment they are pushing for is not recognized as medically necessary, which was common, they may be stuck having to either pass on that treatment or pay out-of-pocket. Without an overabundance of socioeconomic resources, patients often had to make the difficult choice of succumbing to medical authority and continuing to let their provider dictate their care plan. For patients who had the means, they often chose to seek consultation from out-of-state specialists who did not accept their insurance. Other patients

with the means were able to try experimental treatments not deemed “medically necessary” and therefore not covered by insurance. Below, I elaborate on the three phases as they unfolded in patient narratives and end with a discussion on the impact of means as a metamechanism in the process of seeking care for symptoms that medicine often lacks the knowledge to treat.

Experiencing Symptoms

Each patient interview allowed patients to tell their pelvic pain stories starting from when they first began experiencing symptoms. For some patients, this occurred in adolescence, while others made it past 50-years-old before experiencing symptoms. Other patients yet experienced multiple causes of various forms of pelvic pain throughout their lives. However, among the variation in patients’ stories one common thread at the onset of their symptoms was their general reluctance to immediately seek medical consultation. That reluctance was sometimes due to thinking their pain was normal and did not indicate an underlying medical condition, and it was sometimes due to anticipation of dismissal.

Kim, a 30-year-old white heterosexual woman with a graduate degree and an annual household income (AHHI) of \$100,000, for example, shared an important perspective on uterus pain when she told me:

If I'm not trying to get pregnant does it matter if my ovary is messed up? Which it does, but like in my head it only mattered if I was trying to get pregnant and couldn't. You know, like uterus pain is uterus pain, and it doesn't really matter until like it does.

Kim’s quote here demonstrates the common theme of patients thinking their pelvic pain “doesn’t really matter” in a medical context. Other patients similarly mentioned not seeking treatment because they did not see a path forward. For instance, Olivia, a 24-year-old white heterosexual woman with a graduate degree and AHHI of \$40,000, told me:

I would love to tell you that I thought it was normal because that's a good like sound bite, you know. But I don't know if I thought it was normal. I just never sought help for it. I think I don't know if I thought it was acceptable or okay. But I definitely didn't think that there was anything that could be done about it.

Elise, a 38-year-old white heterosexual woman with a graduate degree and undisclosed AHHI, on the other hand, avoided seeking treatment for her pain because those around her, including medical providers, suggested it would go away on its own. Elise first started experiencing pelvic pain when she started menstruating and decided to try using tampons. Her mom had given her a tampon to try for the first time and she told me:

I tried and it was like a knife going in. It was just so bad. And I don't think I got very far I think it was just the tip, but it was like terrible burning pain... Later when I was like 17, almost 18 I decided to have intercourse and it was just terrible... I told my mom and she, she's like, Oh, yeah. She said it hurts for everyone.

Later, Elise told me about when she went to a gynecologist to get a birth control prescription at 16. She told me, "I mentioned to them that I was I was having pain. And they were just like, oh, it'll go away." She continued,

And I again went to the gynecologist for like a yearly checkup. And they use the speculum and oh my god, I almost fell off the table...I just felt like on the verge of tears, I said to him, like, it really hurts especially with intercourse, it's terrible. And he was like, oh, it'll go away after you have kids. And I just started crying. And I'm like, that doesn't even make sense.

The gynecologists' comments suggested that the only thing Elise could do about her pain was either wait for it to go away or have kids. Before Elise even had the chance to decide to formally seek medical consultation for her pain outside of briefly mentioning it in her yearly checkup, she was convinced by those with authority—her mother and gynecologist—that there were few, if any, options for finding relief.

Another patient shared her fears with seeking medical advice about her symptoms seemingly due to her social status at the time of the onset of her symptoms. Brianna, a 64-year-old white heterosexual woman with a college degree and no income, began experiencing symptoms of persistent genital arousal disorder (PGAD) while she was homeless. When discussing the onset of her symptoms, Brianna told me:

I've always been a real private person, and I have also observed that depending upon what you say and to whom you could be misunderstood as being mentally unbalanced and might be reported...So, I knew that if I tried to explain something

like this to somebody, even if it was the medical professional, I knew that I would be viewed—well I wouldn't say *I knew* that I would be—I *was afraid* that I would be viewed as mentally ill, so I didn't reach out for help.

While Brianna's story is an outlier in her experience of being homeless at the onset of her symptoms, her internal dialogue around avoiding medical consultation because she may be viewed as mentally ill mirrored the avoidance from a majority of patients interviewed. Briana's quote also shows the awareness patients have around the authority of medicine, although the way they understand their relationship to that authority tended to change over time as they continued to seek help for their pain.

The avoidance demonstrated by Brianna also speaks to Freidson's (1970) discussions on potential patients from lower-status positions never fully becoming patients due to avoiding consultation in the first place. Also in line with Freidson's (1970) ideas, the patients I interviewed ultimately ended up seeking the same consultation they avoided once they felt they had exhausted all other options for relief. Unfortunately, those consultations often played out in the exact way patients feared they would: dismissal.

Experiencing Dismissal from Medicine

What makes pelvic pain care a unique and useful case for building theory is the universal patient experience of dismissal. All 43 patients shared stories of having their pain dismissed by providers who were undereducated about conditions causing pelvic pain. For example, Tina—a 29-year-old white bisexual woman with a graduate degree and undisclosed AHHI who has lived with pelvic pain for 11—years told me:

I remember very specifically the very first time going into my doctor and being like “this hurts, help.” And her being like “sometimes vaginas hurt”—or like “just use more lube. I don't really know what to tell you.” I remember this like very deep feeling of like okay this is some bullshit though. Like this is bullshit because this hurts and you haven't given me a solution and like you're a gynecologist and like every time that I have talked to a doctor about it since and I've gotten basically the same answer it's just like—it just feels very deeply unfair.

Tina's story revealed that she has yet to receive any formal diagnosis to explain her pain. She followed up with a story about another interaction when she told me,

She's a good doctor and she follows up on things that afterwards I'm like maybe I didn't need to go that far into this...but...this is just the one thing that it was like "I don't know what to tell you."

Even when she interacted with providers who she deemed to be "good," Tina was still unable to find any answers from medicine on how to manage or treat her pain. Tina's story reveals both the complexity of pelvic pain as a medical symptom as well as the structural limitations of medicine that go beyond "good" or "bad" providers.

Cori is another patient who has yet to receive any formal diagnoses. She is a 25-year-old white heterosexual woman with some college education, an AHHI of \$40,000 and has dealt with pelvic pain for roughly five years following an emergency c-section to deliver her son. When I asked her if any providers have validated her pain over the years she replied with:

Cori: No. No not one.

I: Wow. And over five years. And how many providers would you say you see in a year?

Cori: Uh at minimum, three.

I: Wow that's like at least fifteen probably? Is that somewhat accurate?

Cori: Yeah at least. It's probably even more than that. I know in the first month I went to three different doctors...Like the beginning years I was in the hospital every two to three months...I was constantly going back and constantly going back. After about two and a half years is when I started to give in and like give up on going back.

Cori constantly referenced the lack of compassionate doctors in her area, which she described as rural. Later, she told me that the lack of validation from providers "makes [her] feel like they'll never find out what's wrong with [her]." She added "it's just like yeah we've confirmed that there is, again, nothing wrong with me. That's basically how it goes every time I go in," and "I would be super shocked if I actually had a different response from a doctor."

Cori's and Tina's stories of invalidation and dismissal are not outliers. In fact, nearly every patient narrative included codes for feelings of dismissal or a lack of validation from providers. However, it wasn't always that providers did not care to help, but sometimes that they felt they

could not help. Whether providers were constrained by knowledge, time, or other factors, that lack of resources combined with the complexity of assessing and treating pelvic pain led to many providers “giving up” on patients. Alana—a 38-year-old white heterosexual woman with a college degree and an undisclosed AHHI who has lived with pelvic pain for roughly three years—demonstrated this common occurrence with her story. In regard to one interaction she had with a provider, she said:

I just felt like he was just rushing to move on to the next patient and he doesn't have enough time for me and every other—not every, but the majority of the doctors after him have always been with that demeanor [of] I don't have enough time to figure out what's wrong with you, so we just need to move on.

Another example of medicine's lack of ability to help pelvic pain patients comes from Jemma's story. Jemma is a 28-year-old white asexual woman with a college degree and an AHHI of roughly \$18,000. She's been living with pelvic pain for 16 years and although she's been diagnosed with vaginismus, vestibulitis, pelvic congestion syndrome, possible endometriosis, and pelvic floor dysfunction, she has yet to find a path to successfully managing her pain through medicine. During our discussion about a clinical interaction where providers told her to “just go to pain management” for medication, she told me, “it just made me feel like because my issues weren't an easy fix and because it was a complex case, they didn't really want to give me the time of day.” Even with a set of diagnoses, Jemma felt dismissed by an institution whose only answer was a set of diagnoses with little to no evidence-based options for treatment.

The lack of investment and validation from providers who could not seem to give pelvic pain patients “the time of day” due to the complexity of their symptoms creates a unique circumstance for evaluating the role of CHC. As alluded to by fundamental cause theorists (Freese and Lutfey 2013), *habitus*—the macro-level manifestation of CHC—undoubtedly plays a role in the production of health inequalities. But, how does *habitus* manifest as CHC when providers—and medicine more broadly—fail to have answers for the patients they interact with, whether those answers are diagnoses or pathways to treatment for those diagnoses?

Accumulating CHC and Successfully Negating Medical Authority

Before delving into examples of accumulation of CHC and successful negation of medical authority, it is important to provide context for why that negation is important for patients in this context. Although patient compliance is typically touted as a good thing, in the context where compliance means acceptance of a life of pain, it actually leads to undesirable patient outcomes. An acceptance of medical authority in this case means accepting medicine as the dominant profession afforded the ability to offer health service and treat patient ailments.

One example of accepting medical authority as the determinant of one's health comes from an interview with Tina. Tina hasn't seen a provider specifically for her pelvic pain since the first provider she saw who simply suggested more lubrication during penetrative sex to offset the pain. When I asked her why she told me:

Because she didn't have an answer for it, and she was like the head of gynecology. She really seemed like she knew what she was doing, weirdly, even though she kind of didn't. I mean not didn't, but like—I just I mean—I—I—I feel like the times that I've brought it up...as a secondary reason or as a like "oh by the way also sex hurts sometimes," the answers that I've gotten have been uniform in that they have been like unhelpful...Not like a oh here's why this is happening. Like no one has ever been able to tell me why this is happening. And I mean that's why I haven't specifically gone, because it's like why would I? Why would I go to a doctor for [something] that they don't have an answer to?

Tina felt there was no reason to continue looking for a management or treatment plan for her pain during sex because the head of gynecology at her health clinic told her there was nothing medicine could do for her other than suggest she use lube or try new positions during penetrative sex. To Tina, this meant medicine did not offer hope for her or her future of painless sex. At this point in her pain journey, she had yet to accrue the CHC necessary to successfully negate the medical authority that left her without any answers and in pain.

When speaking about earlier years in pain, another patient, Gloria, shared a similar acceptance of medical authority. Gloria is a 48-year-old white heterosexual woman with a college degree and an AHHI of \$72,384 who was diagnosed with possible polycystic ovarian syndrome (PCOS), interstitial cystitis (IC), vulvodynia, and desquamative inflammatory vaginitis and has lived with pelvic pain for 16 years. When I asked her how she felt about the treatment options she came across earlier in her pain journey she told me

...at that stage in my life I just accepted that if a doctor said something that of course, as an authority...they were right and I trusted them. So I just, you know, followed through with the instructions they gave me and I wasn't particularly crazy about going for my six month checkups, because they were painful, but I just sort of accepted that that was the way things were. And you know, now I feel really stupid, especially since I work as a physical therapist in pelvic health. I actually didn't know that wasn't normal. Nobody bothered to mention that it wasn't normal for the exam to be painful. I just thought that was how, how things were for everybody else too.

In Gloria's case, accepting medical authority without question meant being subjected to painful pelvic exams every six months. She later told me that those six-month check-ups may have gone on for ten years, although she could not remember exactly how long she continued to comply with that medical advice.

The most helpful examples of CHC across patient narratives were those that aided in a patient's ability to *successfully* negate medical authority. Examples of successful negation ranged from insisting that the provider's diagnosis is wrong and bringing research articles to appointments, to fully turning away from western medicine as the authority over health services. The process of accumulating that CHC generally began after experiences of dismissal. Similar to ideas discussed by Freidson (1970), patients did not end up in medical consultations about their pelvic pain unless they felt they had no other options to move forward toward relief. With that said, once patients reached the point of consulting a medical provider, they generally *knew* something was not right. As Ruby—a 28-year-old Latina bisexual woman with a graduate degree and AHHI of \$34,000 put it, "I *know* my body, and [this provider was] not listening to me." This insistence on being the authority over what is happening to one's body uniformly came up after discussing stories of dismissal within the patient narratives. In other words, after facing dismissal, patients grappled with that dismissal—whether through finding online resources, patient stories that mirrored their own, or receiving external validation from friends and family—to often end up in the position of believing in their own pain enough to seek medical consultation again. For example, Blaire, whose story came up earlier, told me:

We still had just kind of reached a point where there wasn't really an answer why I was having pain with intercourse. And at that point I was like trying to do research

on my own, you know, like trying to look and see like what could it be? What exactly am I experiencing and are there other people having these experiences?

After facing dismissal and a lack of answers, Blaire began to grapple with that dismissal by looking for validation of her pain elsewhere.

Having decided that their ailments were worth consultation with a medical professional, patients were often determined to show up to that consultation with enough information to convince a provider that their pain was legitimate and warranted a formal medical diagnosis accompanied by treatment. The accumulation of CHC, in this case, often happened between clinical interactions. For example, Sally, a 67-year-old white heterosexual woman with a graduate degree and AHHI of \$60,000 living with PGAD, took time prior to appointments to find research she could bring into her appointment. She told me she is “terrified of going into a strange doctor’s office,” so she always takes “one of the briefer, less-jargony pieces of research, and then also something written by a woman who has had PGAD for a long time.” She “goes in with some educational materials” in hopes that she can provide expert advice for the expert professional who acts as a gatekeeper to treatment options. Sally also spoke about bringing a nurse she knows from her church with her to the first appointment with a new provider to act as an advocate on her behalf. She had learned enough about how medical authority works to suggest “there might be some more authority based on” the nurse’s status. Rather than blindly accepting authority from an institution that lacks the resources to help her, she strategically uses her CHC to find common ground with providers who she assumes will dismiss her.

Alana, a clinical research associate whose case came up earlier when she discussed feeling like providers didn’t have time for her, also accrued the necessary CHC overtime to successfully negate medical authority. When she told me she did a lot of research and googling on her own to try to understand her pain and possible treatment routes, I asked her if she would bring what she found to her providers. Her response was as follows:

Yeah, I always would tell them that with the risk to sound like, you know, like, I know it all...which I didn't, right? I only know what I know and what I've read and that's...again one more person that is just like getting their medical degree online through google [laughs]. I just have to, I have to let [my providers] know what I know. And thank God I did! Without that I would not be here right now.

Her background in clinical research certainly afforded her a base level of CHC that was undoubtedly useful in her ability to challenge medical authority when necessary; and doing so lead her down a path to finding pelvic floor PTs who helped her manage her pain long term. Later in our interview when I asked Alana for advice she might give to other patients dealing with pelvic pain, she told me:

I guess my advice would be like to be your own advocate. Keep digging for the right answers and finding the right professional. But don't pay attention to all the negative and distressing stories because everybody should keep in mind that those bad and depressing stories are probably the result, majority of time of professionals that don't know how to help you. So hopefully all these bad stories can one day be a success stories by turning to the right professionals. And hopefully one day professionals will be getting much more education.

Here, Alana's is encouraging others to "be [their] own advocate" and to "keep digging for the right answers," or, rather, to accumulate CHC to help them negate unhelpful medical advice.

Another example of accumulating CHC to successfully negate medical authority comes from Daniela's story. Daniela is a 37-year-old white heterosexual woman with a graduate degree and an AHHI of \$150,000 who dealt with undiagnosed pudendal neuralgia symptoms prior to our interview. She was able to find an out-of-state, and out-of-network, specialist who she has had luck with as far as negotiating a mutually agreed upon plan of action. But, in reference to that specialist—and closely mirroring Alana's words, she told me:

I guess I've learned that you really have to advocate for yourself. Because if I would not have—I mean, I wouldn't be anywhere if I hadn't, you know, tried to figure out where to go and who could help me. You know, I came across [that specialist] myself. No one referred me to them.

Daniela had to learn about her symptoms, and about the limited specialists trained to address them, herself. She spent time outside of her clinical encounters doing the work to find someone who could address her symptoms in the way she wanted. Through doing that research and accruing that CHC, she was able to successfully challenge the medical authority of providers who misdiagnosed her pudendal neuralgia as interstitial cystitis. Rather than using her energy to challenge the individual doctors whose diagnoses she did not trust, she spent time accumulating the CHC

necessary to challenge the authority of the medical profession more broadly through choosing her own provider.

Accessing Care and Means

Importantly, Daniela's ability to successfully challenge medical authority relied heavily on her means. In addition to seeing an out-of-network and out-of-state provider for which she had to travel for, she also was able to negate medical authority by having the economic resources to pay for out-of-pocket treatment that was deemed "medically unnecessary." In other words, medicine, as an institution, refused her treatment through their bureaucratic system because they deemed that treatment unnecessary. Thankfully, Daniela had the proper economic means to access that treatment despite medical authority acting as a gatekeeper.

In comparison to Daniela's experience, a lack of access to necessary specialists who sometimes do not take insurance was a reoccurring barrier for patients, sometimes regardless of accumulated CHC. Tina and I, for example, shared the following exchange about accessing pelvic pain specialists:

I: So, do you feel like if you were in a different area you might try and reach out to other providers who seem more equipped to handle this issue? If they were around at least?

Tina: Oh absolutely. I mean if I lived in New Jersey where that one doctor is, hell yeah! I mean also if he was in my network because like I'm not made of money and he sounds expensive.

As a reminder, Tina has a graduate degree, but did not report her AHHI. With that said, even with a graduate degree—which affords her a higher SES—she still has to pick and choose providers based on who is in her network due to cost. Unlike other patients who happily traveled out of state for treatment, it was not realistic for Tina to travel out of state to see a provider—even if that provider is likely to be able to help her or offer answers about her pain.

Amara, who is a 24-year-old, South Asian, heterosexual graduate student with an AHHI of \$60,000, also shared stories of socioeconomic barriers. She has lived with pelvic pain for four years and was diagnosed with a "football-sized ovarian cyst" that required surgical removal and

inflammatory bowel disease (IBD). After having “another colonoscopy and endoscopy” to assess the pelvic pain caused by her IBD, she said,

[The doctor] did suggest a medication, but it was \$400 a month. So, I was like, no. Who can afford to pay for that? [Laughs] Not going to do that. Thank you. And that was like after the insurance like...that was with my co-pay.

Amara also mentioned she “was holding off on getting any more tests until [she] went home [to India] because [health services are] cheaper,” once again demonstrating the ways in which socioeconomic barriers shape the decisions that patients make when it comes to their care.

Overcoming Barriers to CHC

While providers may not have the individual authority to cut the cost of healthcare for patients who lack the means to access it, providers do have the authority to help patients accumulate CHC. As Shim (2010) discusses, providers play an important role in the production of CHC in their patients. One patient who provided insight into how providers may help patients accrue the necessary CHC for successfully negating medical authority is Elise. Elise is a 38-year-old white heterosexual woman with an undisclosed AHHI and a graduate degree. She has lived with pelvic pain for 26 years out of her life and has been diagnosed with early onset vulvar vestibulitis, clitorodynia, IC, and possible PCOS. When I asked her about both good and bad experiences with providers, she told me:

I feel like they could have been a little more open about it being like a trial and error because as a patient you don't realize that. You think you go there and they have this answer...they say, we will do this because that's going to help, but the reality of the situation is they don't know that it's going to help you, they have all these things to try. And every person is different, and you have to keep going through different things to get there. And I know that really wasn't clear the first time around. So, when things aren't working, you're starting to feel like it's not going to work, or there's nothing out there.

Elise would have appreciated insight into the trial-and-error process that providers earlier in her pain journey put her through. She had not yet accrued the CHC at that time to successfully challenge medical authority. Had she known about the trial-and-error process, she may have begun

her accumulation of CHC earlier through researching possible causes, treatments, and more on her own. The combination of a lack of communication from her doctor, her acceptance of medical authority, and her lack of experience at that point in her journey created a feeling that there was “nothing out there” to help her manage her pain.

Another patient shared similar sentiments about wishing she had more open communication from her doctor about the limits of their knowledge around pelvic pain. Stacy is a 34-year-old Black bisexual woman with a college degree and AHHI of \$80,000. She was diagnosed with endometriosis by ultrasound after living with undiagnosed pelvic pain for two years. When I asked Stacy what might make the process of trying to figure out her pain and receive treatment for it better, she said:

Stacy: I guess if people had more answers. But I am happier with them, rather than trying to blow smoke up my ass, they’re saying I don’t know rather than telling me it’s one thing and it’s not. I do appreciate that.

I: So like you wish they knew more but you’d rather they tell you they don’t know if they don’t know?

Stacy: Yeah.

Stacy is reiterating the point made by Tina that insight into the trail-and-error process of treating pelvic pain, and other conditions that may lack necessary evidence to streamline treatment, would be helpful for patients. Stacy eventually learned that just because medicine holds the authority to offer health services does not mean they have the adequate knowledge to offer those services. Later in our interview when I asked her how her experiences have impacted the way she views the healthcare system, she told me:

I feel like I’m more—I questions anybody’s actions more. So like if a doctor likes a new medication—why? Are we sure this is the right way to go? Are there other things we could do? How much do you know about this medication? Like are you just—like a doctor wrote me a prescription for a new drug. I went home to do research to find out the drug’s been out for 20 years. So like what are you doing? I question their motives. Like you’re lying to me or you’re trying to mislead me. Either way it’s a lie. If you mislead me, or try to deceive me it’s a lie. So I catch on to people’s bullshit more. I don’t know [laughs].

Had providers been more open with her about the limitations of their training and knowledge around pelvic pain, Stacy may have begun questioning their medical advice earlier. This quote also demonstrates Stacy's use of CHC to successfully negate the authority of medicine. Instead of being combative about the new drug her doctor prescribed, she waited to question that authority in a more palatable way by doing the research on her own at home before deciding to follow her doctor's advice.

Discussion

The analysis presented here investigated the role of CHC in the context of medical anomalies through examining pelvic pain patient narratives. The findings suggest that patients with medical symptoms not easily linked to diagnoses with clear etiology and pathways to treatment use CHC in a specific way that allows them to successfully negate medical authority. First, patients experiencing pelvic pain often avoided consultation for months and sometimes years due to anticipation of having their pain invalidated by providers. In line with Freidson's (1970) theories, patients generally sought medical consultation when they had exhausted all other options for relief from their pain. Upon seeking consultation, patients were more often than not met with the dismissal that kept them from seeking help in the first place. Their use of CHC became clear in their narratives after experiencing dismissal from medicine. In this way, the accumulation of CHC in this patient population is guided by the universal experience of dismissal from medical professionals. While dismissal was a near universal experience for the pelvic patients interviewed for this study, the accumulation of CHC was not.

Patients who were able to accumulate the necessary CHC to receive proper treatment to help manage their pain did so through the use of socioeconomic resources including habitus, knowledge, and monetary resources. Once such patients experienced that dismissal, they grappled with it in similar ways by looking for evidence to validate their symptoms. Sometimes that evidence came from peer-reviewed research in medical journals, while other times it came from other patients' stories that mirrored their own. In either case, patients who took the route of gathering their own evidence did so with previous knowledge and experience in mind. For example, even knowing to go to the peer reviewed-medical literature requires a certain level of education that not all patients had. Similarly, knowing that sharing such evidence may be an effective way to communicate with providers requires a certain habitus that, again, not all patients

possessed. When habitus and SES combined in favorable ways for patients researching their own ailments, these patients accrued the necessary CHC to challenge the medical authority that left them undiagnosed, untreated, or both.

That successful challenge of medical authority often also required the socioeconomic means to access providers and treatment options outside of the bureaucratically organized healthcare system. Patients who had the means to, traveled out of their home states to receive care from a limited number of specialists. Those with the means to do so also opted for experimental treatments not yet recognized in the current medical institutions as “medically necessary.” Their ability to access those treatments generally relied upon their overabundance of socioeconomic resources as well as their accumulation of CHC, which allowed them to bring evidence of those treatments to their medical consultations. Patients without the means to access those treatments were left with the option to either forgo a potentially pain-reducing treatment or go into debt trying something that *might* reduce their pain.

While the combination of both abundant SES resources—including education, financial resources, and habitus—and accumulation of CHC made for the most advantageous patient outcomes, it is important to discuss how these two factors do not always go hand in hand. For example, low-income patients with a college education, or even specialized education in health, often accrued the CHC necessary to navigate their treatment. However, without the necessary financial means to travel to specialists or pay out-of-pocket for care from providers not in their network, that navigation was halted. On the other hand, a patient with abundant financial resources who has not accrued the necessary CHC to successfully challenge medical authority may also have their treatment navigation halted. Based on the data analyzed here, in the case of pelvic pain—and perhaps other medical anomalies—effective patient outcomes are the result of both CHC *and* socioeconomic means being used in tandem, which may not always be the case. Theoretically, this quandary reveals how CHC must be investigated and understood alongside other social factors impactful for health, such as financial resources, to produce meaningful and applicable knowledge on the relationship between CHC and patient outcomes.

In general, the findings presented here join others in demonstrating how the usefulness of CHC is highly contextual (Rubin et al. 2018). In this study, the evidence shows how CHC is still a useful patient resource even when a patient’s symptoms fall outside the lines of what modern medicine can fix. In this context, CHC is most useful for helping patients successfully negate

medical authority in a way that provides them with more control over their treatment options. Rather than blindly accepting the authority of an institution that dismisses their symptoms, patients challenged that authority in strategic ways in addition to utilizing their means to gain access to diagnoses and treatment options that otherwise may not have been accessible.

Theoretically, the findings here solidify the important ties between CHC and fundamental causes of health. Shim's (2010) initial introduction of CHC relied heavily on ideas about fundamental causes of health (Link and Phelan 1995), particularly critiques around a missing explanation for *unintentional* use of resources to improve one's health. Yet, the literature on CHC has yet to use empirical evidence to make those connections. Here, I show how CHC, as a micro-level manifestation of habitus, and means work together and simultaneously to help patients find relief from conditions that medicine typically cannot readily identify and treat. Additionally, by also examining the role of medical authority in this process, the study here advances ideas around how patient resources work in tandem with resources that uphold our medical institutions and their monopoly over health services. In other words, the findings of this study show the importance of analyzing power on both the provider and patient side of the interactions when analyzing the clinical interaction. While medical authority may not always work against a patient's interest, in the instances it does, it is important to understand how patients use resources on their side of the clinical interaction to manipulate medical authority to work for them. In this way, when that medical authority leaves patients dismissed, the connection between CHC and expert fallibility becomes clear. Having a base level understanding that experts can and do make mistakes and can and do lack knowledge on certain aspects within their expertise, was pivotal in patients' abilities to continue to accumulate CHC. Without the assumption of expert fallibility, patients may be much less likely to take steps to negate medical authority, leaving them at the mercy of the institutions that dismissed them.

While the theoretical implications documented here are important, they are not without limitations. The most obvious limitation present in this research is the sample. While this sample allowed for insight into how relatively highly educated patients use CHC and means to negate medical authority, it does not allow for insight into how the lowest status patients deal with medically unexplainable symptoms and ailments. This limitation is likely due to my approach to participant recruitment, which required that participants consulted with at least one medical professional about their pelvic pain. According to Freidson (1970), this recruitment strategy

excluded the lowest-status patients who are not likely to seek medical consultation at all due to their anticipation of subjugation by medicine. With that said, future research interested in how these processes unfold for low-status patients should not limit participants to those seeking medical consultation, even if the research is focused on that medical consultation. By limiting my sample in this way, I missed the opportunity to compare the narratives of relatively high-status patients who sought consultation to lower-status patients who experience the same symptoms, yet never seek help from medical professionals.

Despite limitations in the sample, the findings derived from the sample are promising when it comes to understanding how CHC and fundamental cause theory should be analyzed in tandem as well as the importance of medical authority in the context of patients dealing with difficult to diagnose and tough to treat symptoms. In addition to the theoretical implications of this research, the findings also provide insight into how medicine, as an institution, might improve the experiences of patients dealing with pelvic pain and other medical anomalies. For example, providing patients with insight into the limits of medical knowledge when it comes to medical anomalies may be key in getting them the help they need to successfully manage their symptoms. Even if those symptoms cannot be addressed medically, exposing the limits of medicine to patients in such situations allows them to move beyond medical authority on their journey's to finding relief from their symptoms. While whether patients continue to rely on medical authority or not may be determined by their means to access other routes to relief, providers can still be the starting point for helping patients explore alternative health services that they may not otherwise turn to out of acceptance of medical authority. Simply put, even when providers cannot diagnose or treat a patient's symptoms based on their training and knowledge in medicine, they can still help that patient through encouraging the accumulation of CHC that may lead to more helpful providers, treatments, or alternative health services.

CONCLUSION

I began this dissertation by sharing an account from Joe Fassler (2015), who wrote an article in *The Atlantic* about his wife having her pelvic pain dismissed in a US emergency room. The publication sparked countless other women to write to *The Atlantic* detailing their similar experiences (Bodenner 2016). Some discuss this gendered phenomenon as doctor's gaslighting women (e.g., Northwell Health 2021) while others describe it more matter-of-factly as doctors dismissing women's pain due to gendered assumptions about women and patients with female reproductive anatomy (Hoffman and Tarzian 2001). Regardless of semantics we use to discuss this issue, the issue of medicine dismissing women's pain persists, requiring investigation of the many predictive factors involved in that persistence. While the precise issue of women's pelvic pain remains important, the research presented in preceding chapters reveals how this investigation of pelvic pain actually speaks more generally to *imprecise* conditions and the ways power dynamics unfold when patients present with them.

In other words, this dissertation, broadly, examined how power dynamics manifest during clinical interactions related to vague medical symptoms, such as pelvic pain. To examine this issue, I approached my research questions through multiple methods including a critical discourse analysis of the medical discourse on pelvic pain, a survey experiment administered to healthcare workers in the US, and a narrative analysis of pelvic pain patient experiences. While the focus of this research is on pelvic pain, the analyses presented here reach far beyond ideas of power dynamics and pelvic pain. Rather, the findings from this research speak to theoretical discussions medical sociologists have been having for decades. Specifically, findings provide new insight on: 1) the limits of evidence-based medicine as a biomedical paradigm, 2) how fundamental causes of health inequality intersect with each other as well as other factors, such as gender, important in predicting health outcomes and 3) how discussions of metamechanisms in fundamental cause theory can inform our understanding of the accumulation of CHC.

Summary of Theoretical Insights

The first empirical chapter of this dissertation examined power dynamics within the clinical interaction through a Foucauldian lens (Foucault 1973; 1978). In doing so, I directed attention

towards medical discourse and knowledge as sources of power available to providers evaluating patients. Foucault's (1973; 1978) ideas on power provide complex yet important nuance to conversations on power during clinical interactions because his ideas expand beyond the status characteristics of individuals in any given interaction. Instead, Foucault (1973; 1978) focuses on what he termed *biopower*, turning our attention to the increasingly dominant force of medical knowledge and the process of generating that knowledge—i.e., discourse. Ideas on biopower tell us discourse plays a hugely important role in power dynamics, especially when those power dynamics are unfolding in a circumstance where some actors are experts who hold knowledge while others are consulting those experts for their knowledge.

In taking a Foucauldian approach to understanding the role of power in pelvic pain care, themes around biopower and its role in regulating the female body emerged in the chapter. Specifically, through analyzing the medical discourse, it became clear that pelvic pain is often conflated with the niche of women's health, making the knowledge produced around it directly influential on the way female bodies are treated by medicine. While the data presented does not definitively demonstrate a lack of attention to women's health by our medical institutions, it certainly does suggest that pelvic pain, as a symptom conflated with women's health, is deemed too complex to understand largely because of its connection to the female body. Further, because of its connection to the female body, it fails to be a priority for innovative research on etiology and treatment. This lack of prioritizing women's health in the production of medical knowledge demonstrates the link between biopower and the regulation of female bodies in pain, showcasing the gendered power dynamics that constitute our medical institutions and the biomedical paradigms that guide them.

As discussed in the empirical chapter, the main purpose of the critical discourse analysis was to understand how medical knowledge is applied to clinical practice. With a focus on pelvic pain, the analysis provided insight into how medical knowledge is applied to clinical practice when a lack of relevant knowledge readily exists. With the current biomedical paradigm for clinical practice in the US being evidence-based medicine (EBM), findings exposed the limits of such standardized care for pelvic pain patients while presenting alternatives to the EBM approach through outlier cases in the data. In doing so, findings suggest that breaking away from the limits of standardization inherent in EBM may require a process introduced by critical theorist Theodor Adorno (1973) called *negative dialectics*.

Overall, the purpose of negative dialectics is to allow new *and* improved paradigms to emerge. This idea was introduced in opposition to Karl Marx's theory of dialectical materialism, which posits that all contradictions eventually resolve themselves through the synthesis of a new level or concept (Freistadt 1956). Rather than viewing contradicting paradigms as converging into a new level, bringing with them both the useful and potentially detrimental components, Adorno (1978) suggested negating those contradicting paradigms and allowing a new paradigm to emerge through that process of negation. Using theories on standardization in medicine from Timmermans and Epstein (2010) I argued that two biomedical paradigms, EBM and the inclusion-and-difference paradigm, converged to form what Epstein (2007) called *niche standardization*. While this new paradigm allows for standardization at the group level, it still relies on standardization, which in medicine relies on an agreed upon collection of evidence and knowledge translated into standards of care.

Standards of care may be useful—and even necessary—for conditions for which medicine has produced an ample amount of knowledge. However, applying standards of care to medically imprecise symptoms, such as pelvic pain, may do more harm than good given the lack of knowledge and evidence produced on the etiology and treatment of those symptoms. The harm of standards of care for pelvic pain patients came through in the data as pigeonholing patients into diagnoses, which often led to unnecessary laparoscopic surgeries. These unnecessary surgeries took place under the assumption that pelvic pain always indicates endometriosis unless other objective evidence is observed to contradict that assumption—which is rarely the case with pelvic pain.

In contrast to the data presenting a compliance with EBM and standards of care present in obstetrical and gynecological practice, two outlier cases presented alternative approaches to clinical care. Both cases incorporated storytelling as a way of providing subjective evidence in the nearly always objective world of medicine. One case focused on patients' stories and the role of those stories in combating racism in obstetrics and gynecology, while the other focused on providers' stories and the inevitable ebb and flow of power dynamics that is dependent on the status characteristics of both a provider and their patient. In both cases, the emphasis on storytelling may seem similar to what's been discussed as *narrative medicine*, defined by Charon (2006) as "clinical practice informed by the theory and practice of reading, writing, telling, and receiving of stories" (p. vii). I discuss the incorporation of storytelling in these cases as shifting our perception

of what counts as evidence in the exam room. Rather than relying on visual, objective evidence—as Foucault (1973) argued was increasingly the case in clinical practice—providers practicing narrative medicine allow patients’ subjective experiences of their symptoms, and the impact of those symptoms on their overall well-being, to guide the clinical interaction. In doing so, narrative medicine is arguably better suited for evaluating and treating conditions and symptoms lacking traditional objective evidence.

To assess how power dynamics play out during clinical evaluations of pelvic pain, I turned to the literature on fundamental causes of health inequality with a focus on metamechanisms linking those fundamental causes to health outcomes (Link and Phelan 1995; Freese and Lutfey 2010). Using a survey experiment to assess the impact of patient SES, gender, and race on clinical evaluations of pelvic pain I examined the extent to which providers’ implicit biases related to SES, race, and gender intersect to impact their evaluations. In doing so, I evaluated the metamachanism of institutions, or ways organizations differentially treat individuals to impact their health—including implicit provider bias. To focus on the role of implicit bias in evaluations, I also gauged the extent to which participants endorsed false beliefs of biological differences based both on race as well as gender.

While hypotheses that false beliefs of biological difference based on race and gender would moderate the relationship between patients race and gender and evaluations of their pain were not supported, results from the false belief scales showed surprisingly high endorsement of false beliefs among the sample of healthcare workers. For example, roughly 73% of the sample endorsed the false belief that on average, women can tolerate more pain than men. Additionally, roughly half the sample endorsed the false statement that Black people’s nerve-endings are less sensitive than white people’s nerve-endings. Also notable was the overall higher endorsement of false beliefs of biological difference based on gender compared to race. I explained this as potential social desirability bias when assessing statements related to racial differences that may not be present when assessing similar statements related to gender differences. The reality of biological differences between males and females along with the conflation of sex and gender in medical settings may have made false statements related to gender more believable and less susceptible to social desirability bias.

I also argued that this same social desirability bias may have come into play in how black patients were evaluated. While I made attempts to avoid social desirability bias by having

participants evaluate either all white or all Black patients, theoretical arguments suggest participants may have still evaluated Black patients in comparison to an imaginary standard white patient. As Glenn's (2000) ideas on the social construction and institutionalization of gender and race speculate, minority racial categories are constructed *in relation* to the referent majority racial category: white. In other words, because racial categories are social constructed in relation to one another, we can never really evaluate Blackness without acknowledging its relation to whiteness (Glenn 2000).

When evaluating patient SES, gender, and race separately, findings provided evidence for significant impact of patient SES on ratings of the seriousness of patient pain as well as perceived importance of medical assessment in that lower-SES patient pain was viewed as less serious and less in need of medical assessment compared to higher-SES patients. Additionally, patient gender was related to ratings of pain typicality in that women's pelvic pain was viewed as more typical than men's, providing evidence for the normalization of women's pelvic pain. Patient race, on the other hand, was not significantly related to any of the seven outcome measures for pain evaluation, again, pointing towards social desirability bias given the clear evidence on racial biases in pain assessment and treatment that favor white patients (e.g., Hoffman et al. 2016).

When accounting for the ways patient SES, gender, and race might intersect to impact evaluations of pelvic pain, the findings provide evidence for the argument that intersectionality theory is important in the assessment of fundamental causes of health. A test for three-way interactions between SES, gender, and race provided a clear and consistent pattern on how these patient characteristics simultaneously impact evaluations. Notably, high-SES Black men received the most favorable evaluations regarding the seriousness of their pain and the importance of medical assessment, while low-SES white women received the least favorable evaluations for those outcomes. While social desirability may be at play here again, another explanation for such favorable ratings for high-SES Black men could be perceptions of hypermasculinity.

Studies on masculinity and health show that identification with traits coded masculine—such as strength and independence—may be related to health seeking behaviors (Keogh 2015). Given this set of knowledge, it's possible that Black men, who are often perceived to be hypermasculine, may also be perceived as avoiding medical consultation due to their adoption of such masculine behaviors. With this assumption in mind, providers may perceive black men as only seeking consultation for pain when absolutely necessary, increasing perceptions of

seriousness of patient pain. Importantly, however, research also shows that hypermasculinity is closely associated with *working-class* Black men, whereas results from my study would associate high-SES Black men with hypermasculinity when relying on this explanation (Chun 2011). Given such evidence, future research may be interested in teasing apart classed and racialized gendered perceptions when it comes to patients in pain. Overall, the results from the survey experiment support Evans' (2019) argument that while fundamental cause theory may not have been originally intended for intersectional analyses, it can and should be adapted to push the research on fundamental causes forward.

The third empirical chapter of this dissertation attempted to understand how the construction of medical knowledge on pelvic pain and institutionalization of gender, race, and class biases in pelvic pain evaluations impact the pelvic pain patient experience. In other words, how do the power dynamics at play during clinical evaluations of pelvic pain impact the subjugated patient experience of navigating care? The analysis for this chapter relied on macro-level ideas of power in the form of medical authority as it is conceptualized by Freidson (1970) and fundamental causes of health, as well as micro-level ideas of power in the form of CHC as a form of cultural capital useful in healthcare contexts (Shim 2010). Through narrative analysis of interviews with pelvic pain patients with female reproductive anatomy, I demonstrated that while accumulating CHC is important, it must work in tandem with socioeconomic resources—or means—to produce desirable outcomes for patients in the context of symptoms, such as pelvic pain, which may be deemed medical anomalies.

Pelvic pain, as a widely misunderstood medical symptom, made for a theoretically interesting case for expanding ideas on CHC. Specifically, it allowed for an examination of the usefulness of CHC when medicine does not have diagnoses or treatment options for the symptoms a patient is presenting. If the institution tasked with fixing a medical problem does not have the answers, then what is the role of CHC in favorable patient outcomes? Findings from the analysis showed patients used their CHC in combination with socioeconomic means to successfully negate medical authority. After the universal experience of having their pain dismissed by medicine, patients lacking CHC accepted that dismissal along with medicine's monopoly over health services and essentially gave up on finding relief. The same patients who lacked the necessary CHC to successfully negate medical authority were often the ones without access to means that might help them with that negation.

Patients who successfully negated medical authority using their CHC, on the other hand, did so through supplying evidence from peer-reviewed medical research and even turning away from medicine completely as an authority over health services. Instead, those patients used their means to seek alternative treatments and healing modalities outside of traditional medicine, such as yoga and acupuncture. Those same patients also negated medical authority by using their means to receive treatment outside of the bureaucratically organized healthcare system by finding their own specialists outside of their insurance networks and states of residence. Having the socioeconomic means to do so, these patients also often opted for “experimental treatments” not yet identified by insurance companies as medically necessary.

In addition to providing intriguing nuance on the usefulness of CHC in the context of medical anomalies, the narrative analysis also informed our understanding of how CHC and fundamental cause theory can be used in combination to better understand the difficulties and successes patients face when navigating healthcare. I discussed CHC as the micro-level manifestation of Bourdieu’s (1986) macro-level concept of *habitus*, which is also one of the metamechanisms Freese and Lutfey (2010) introduced in their expansion of fundamental cause theory. Through the narrative analysis, it became clear that different metamechanisms related to fundamental causes, such as *habitus* and means, work together to shape patient experiences and outcomes; and while CHC is an important concept in and of itself, our understanding of it can be improved through considering its connection to fundamental causes of health inequality. For example, in their examination of CHC in chronic pain management, Rubin and colleagues (2018) conclude there is a widening gap between those who possess CHC and those who do not.

While this conclusion is important, bringing ideas about CHC’s relationship to macro-level forces identified by fundamental cause theorists (e.g., means and *habitus*) allows us to begin grappling with why that widening gap exists and how we might narrow it. In doing so, the findings from the narrative analysis necessarily complicate current understandings of CHC by showcasing the limits of this patient resource. Patient narratives revealed that while more CHC is generally useful for negating medical authority—a process shown through analysis to be beneficial for these patients—more CHC may not necessarily be beneficial without the socioeconomic means to pursue the negation that comes along with that accumulation of CHC. In other words, CHC may not always be an effective patient resource in and of itself, especially in the privatized US healthcare system that often requires disposable income to receive appropriate and high-quality

care. Without understanding CHC as part of a larger web of social factors that influence patient outcomes at various levels, we risk missing—as fundamental cause theorists call them—the “causes of the causes” (Link and Phelan 1995).

Implications for Medical Practice and Policy

Overall, the findings of the research presented in this dissertation problematize the power dynamics within our medical institutions that leave patients with pelvic pain in precarious positions. When it comes to improving outcomes for pelvic pain patients, and patients with other medically ambiguous symptoms, the evidence presented here suggests institutions, organizations, and individuals in power hold that responsibility. Medicine, as a social institution monopolizing the right to provide healthcare services in the US, has the responsibility of understanding, acknowledging, and communicating the limits of its role in fixing the unfixable (Freidson 1970). Hospitals, health clinics, and providers—as organizations and individuals that uphold the institution of medicine—have the same responsibility. In owning that responsibility, these powerful actors can redistribute some of that power back to the patients they come in contact with, granting patients more agency in their healing journeys.

One way this redistribution of power might occur is through clear communication about what knowledge does and does not exist for certain medical symptoms. For example, if part of the training within our medical institutions encouraged future providers to transparently share what they do and do not know regarding certain symptoms, unnecessary surgeries for pelvic pain patients may be avoided. If an OBGYN who has been taught to only see endometriosis when patients elicit concerns of pelvic pain is transparent about that narrow training, a patient contemplating surgery may decide to try other paths to relief before relying on a surgical procedure that only addresses one of many potential causes of their pain. That same patient, depending on their CHC and SES, may not have seen an option outside of the suggested surgery had the provider not been transparent about those limitations.

Medical schools and continuing education programs might encourage providers to recognize the limitations of their knowledge by approaching medical education in a way that emphasizes both what is known as well as what is *not* known. In other words, the research here shows that the knowledge providers do *not* have is equally as impactful on patients as the knowledge they do have. Bringing awareness of the inevitable fallibility in the production and

application of medical knowledge to medical education is key. Similarly, while keeping up with the latest research is necessary and important for providing quality healthcare to patients, learning the history and evolution of certain standards of care would be similarly important for providing high-quality care. For example, a few providers interviewed for the critical discourse analysis shared their knowledge of how pelvic pain was assessed in the past compared to how it is currently assessed today. Knowing how and why standards of care have changed may provide a more open-minded perspective on the approach to standards of care, especially for symptoms such as pelvic pain where standards of care have drastically changed over time. Those changes in standards of care signal the inevitable fallibility of the scientific process that should be included in medical education throughout providers' careers.

Transparency about the limits of standards of care may also help patients accrue the necessary CHC to successfully negate medical authority should medicine leave them undiagnosed and untreated. The idea that providers play an important role in the accrual of CHC for patients is not new (Shim 2010), but what may be new is the specific approach that evidence from this research suggests. As the evidence demonstrated, patients who may not have the necessary CHC to see medicine as the flawed institution it is are likely to accept the authority of medicine despite the harm such acceptance could bring to their healing. However, despite a lack of CHC, patients may be able to avoid harmful acceptance of medical authority through conversations with providers that acknowledge the scope of their expertise. For example, providers who lack training in pain management should communicate that with their pain patients. Those same providers could also help their pain patients accrue CHC by knowing some alternative treatments to suggest, giving patients permission—as a professional authority—to seek those alternative paths to healing.

As an alternative to placing all the responsibility on individual providers, healthcare organizations may consider referral systems for pain patients, especially if those organization do not have the necessary, specialized knowledge to assess and treat pain patients. While evidence from the discourse analysis showed the power of referrals in directing pelvic pain patients to specialists, findings from the narrative analysis showed patients often had to do the work themselves to find those specialists outside of any formal referral from medicine. With that said, having a program in place to provide a path to healing beyond the dead end often presented to pain patients by medicine could be crucial in improving outcomes for those patients.

One actionable step toward implementing a referral system for pelvic pain patients may be the creation of a resource list for pelvic pain specialists. Through collaboration with the International Pelvic Pain Society (IPPS), creating such a list would be reasonable. In fact, something similar already exists through the organization on their “Find a Provider” webpage. This resource allows patients and providers to search the IPPS database of pelvic pain specialists based on city, state, country, and/or medical specialty to find providers near them. However, there seems to be barriers to knowledge of this database among both patients and providers based on the analyses conducted for this dissertation; and a resource is only as useful as it is accessible to those who need it. In this sense, an important first step may be to simply amplify knowledge around this existing resource, primarily for providers who may be referring their pelvic pain patients to specialists such as OBGYNs.

To take this step, I suggest a public health campaign that uses social media, provider networks, professional medical organizations, and patient networks to advocate for the use of this resource. While I argue that providers—who hold more power than their patients in medical settings—should be held responsible for providing better options for their pelvic pain patients, they also can only be as helpful as the resources available allow. In other words, they face barriers, just as their patients do, when it comes to pelvic pain due to a lack of awareness around existing resources like the “Find a Provider” service through IPPS. A public health campaign would work to increase awareness of: 1) conditions causing pelvic pain, 2) obscure modes of treatment for pelvic pain patients (e.g., pelvic floor therapy), and 3) resources such as IPPS’ “Find a Provider” service. Only once the resources available are utilized more fully can we assess what other resources may be vital for getting pelvic pain patients the necessary care they deserve.

Outside of medical institutions and healthcare organizations, the research here suggests that a shift in the culture and discourse around women and pain may be an important place to start. Many patients interviewed who were eventually diagnosed with hereditary conditions such as endometriosis mentioned that painful periods run in their family. They often learned from their mothers that women in their family simply have painful periods. Patients attributed part of this normalization to the fact that endometriosis was not widely understood when their mothers were dealing with symptoms. Similarly, their grandmothers who dealt with painful symptoms were living in a time where pelvic pain was highly conflated with mental illness in the medical literature, leaving patients seeking care at that time even more dismissed than patients today. As medical

knowledge evolves and expands to provide more accurate assessments of pelvic pain etiology, it is important to disseminate that information to the general public.

This point of multiplying the public discourse around pelvic pain to change the cultural representation of women with pelvic pain brings us back to Glenn's (2000) integrative framework. To briefly review, Glenn (2000) argued that cultural representations of race and gender have consequences for different racial and gender groups because of social structure. When women in pain, and particularly minority women in pain, are represented as hysterical and dramatic, that cultural representation undoubtedly impacts their care-seeking behaviors as well as their own sense-making processes around their pain. In the same vein, encouraging and validating public discourse on women's pelvic pain may similarly impact care-seeking behaviors and sense-making process, but in a way that benefits patients rather than dismisses them. If most discourse around patients is telling them their experience is valid and deserving of quality healthcare, they may be more equipped to accumulate CHC in a way that helps them navigate care for their misunderstood symptoms.

In addition to the suggestions presented for individual providers and organizations, a top-down approach of disrupting power dynamics at the macro-level with the intention of redistributing power in micro-level interactions, such as the clinical encounter, are worth discussing. One example of macro-level policy based on the evidence presented here may be revisiting how medical research funding is allocated and what professionals have access to it. As the discourse analysis demonstrated, and as other scholars have noted (McCartney et al. 2021), the production of medical knowledge through research hugely impacts communication about and within our medical institutions, including communication between providers and their patients. While approaching patient care outside the confines of EBM would be ideal when it comes to imprecise conditions and symptoms such as pelvic pain, the reality is that EBM is the standard of practice for most, if not all, practicing providers in the US. With that said, the allocation of funding for medical research related to ambiguous medical symptoms is necessary to make sure patients presenting with those symptoms are not so easily tossed aside by our medical institutions. Even if the knowledge production around such symptoms does not lead to standardized approaches to care—which we would ideally move beyond for such symptoms anyways—simply producing a discourse in the medical literature around the issue of a lack of evidence or standards of care for certain conditions would be helpful. However, for this discourse to emerge in the formal literature,

funding sources, such as the National Institutes of Health (NIH), must encourage it through specified funding opportunities.

In general, to center the patient experience and encourage a critical analysis of the way medicine treats patients with imprecise symptoms, funding agencies should consider a shift in how they define evidence as it relates to research. Are clinical trials really the be-all and end-all for conditions that largely exist outside of the objectifying medical gaze of such trials? A cultural shift in our understanding of what evidence means when practicing EBM is not only important, but necessary, for adequately treating patients whose ambiguous symptoms are overlooked. Community-based participatory research, for example, allows community members and other stakeholders to take an active role in the research process (Cross, Pickering, and Hickey 2015). Similar research that not only centers the patient experience but allows patients to have an active role in shaping the research agenda for conditions that impact their lives could provide the type of evidence necessary for better treatment of such conditions. As Cross and colleagues (2015) argue, “[cultures] and communities are de-objectified when they are treated as co-equal players in an inclusive research process,” allowing the medical gaze to move beyond objective—and objectifying—evidence for conditions that require such a shift (p.1022). But again, for this shift to occur in a meaningful way, funding agencies such as the NIH must not only support it, but also encourage it.

Concluding Thoughts

There are many ways to conceptualize power dynamics in medicine. Through this dissertation, I was able to examine power through a variety of levels and perspectives to holistically capture the ways it infiltrates the clinical interaction to impact patient outcomes. The many conceptualizations of power throughout this dissertation showcased the complexity of factors associated with health inequality. Those diverse theoretical perspectives on power also allowed for an in depth look into how different ideas of power can inform one another. For example, understanding CHC as existing within a larger system of professional authority in medicine meant contextualizing micro-level power dynamics (CHC) within macro-level systems (medical authority). As research on health inequality pushes forward, I encourage medical sociologists to continue analyzing power at various levels and through various theoretical perspectives to create a more complete picture of the forces driving health inequality in the US.

REFERENCES

- Acker, Joan. 2006. *Class Questions: Feminist Answers*. Lanham, MD: Rowman & Littlefield Publishers, Inc.
- Adorno, Theodor W. 1973. *Negative Dialectics*. The Continuum Publishing Company
- Anderson, Karen O., Carmen R. Green, and Richard Payne. 2009. "Racial and Ethnic Disparities in Pain: Causes and Consequences of Unequal Care." *The Journal of Pain* 10(12): 1187-1204.
- Assari, Shervin. 2018a. "Life Expectancy Gain Due to Employment Status Depends on Race, Gender, Education, and Their Intersections." *Journal of Racial and Ethnic Health Disparities* 5:375–86.
- Assari, Shervin. 2018b. "Health Disparities Due to Diminished Return among Black Americans: Public Policy Solutions." *Social Issues and Policy Review* 12(1):112–45.
- Auspurg, Katrin and Thomas Hinz. 2015. *Factorial Survey Experiments*. SAGE Publications, Inc.
- Ballard, Karen, Karen Lowton, and Jeremy Wright. 2006. "What's the Delay? A Qualitative Study of Women's Experiences of Reaching a Diagnosis of Endometriosis." *Fertility and Sterility* 86(5):1296–1301.
- Barker, Kristin K. 2005. *The Fibromyalgia Story: Medical Authority & Women's Worlds of Pain*. Philadelphia: Temple University Press.
- Berchick, Edward R., Jessica C. Barnett, and Rachel D. Upton. 2018. "Health Insurance Coverage in The United States: 2017." *Current Population Reports*. Washington DC: US Government Printing Office.
- Bird, Chloe E., and Patricia P. Rieker. 2008. *Gender and Health: The Effects of Constrained Choices and Social Policies*. New York, NY: Cambridge University Press.
- Bodenner, Chris. 2016. "Stories of Misunderstanding Women's Pain." *The Atlantic*, February 19. Retrieved May 10, 2021 (<https://www.theatlantic.com/notes/2016/02/stories-of-misunderstanding-womens-pain-contd/470202/>).
- Boen, Courtney. 2016. "The Role of Socioeconomic Factors in Black-White Health Inequities across the Life Course: Point-in-Time Measures, Long-Term Exposures, and Differential Health Returns." *Social Science & Medicine* 170:63–76.

- Bonefeld, Werner. 2012. "Negative Dialectics in Miserable Times: Notes on Adorno and Social Praxis." *Journal of Classical Sociology* 12(1):122–134.
- Bourdieu, Pierre. 1986. "The Forms of Capital" Pp. 241-258 in *Handbook of Theory and Research of the Sociology of Education*, edited by J. Richardson.
- Case, Anne, and Angus Deaton. 2015. "Rising Morbidity and Mortality in Midlife among White non-Hispanic Americans in the 21st century." *Proceedings of the National Academy of Sciences* 112(49):15078-15083.
- Chapman, Elizabeth N., Anna Kaatz, and Molly Carnes. 2013. "Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities." *Journal of General Internal Medicine* 28(11):1504-10.
- Chun, Elaine. 2011. "Reading Race Beyond Black and White." *Discourse & Society* 22(4):403-421.
- Cisney, Vernon W., and Nicolae Morar. 2015. *Biopower: Foucault and Beyond*. Chicago, IL: University of Chicago Press.
- Collins, Patricia Hill. 1990. "Black Feminist Thought in the Matrix of Domination." Pp. 221–38 in *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. Boston: Unwin Hyman.
- Conrad, Peter. 1992. "Medicalization and Social Control." *Annual Review of Sociology* 18:209–32.
- Correll, Shelley J. and Cecilia L. Ridgeway. 2003. "Expectation States Theory" Pp. 29–51 in *Handbook of Social Psychology*, edited by J. Delamater. Kluwer Academic/Plenum Publishers.
- Crenshaw, Kimberlé. 1989. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics." *The University of Chicago Legal Forum* 139–168.
- Criniti, S., M. Andelloux, M. B. Woodland, O. C. Montgomery, and S. U. Hartmann. 2014. "The State of Sexual Health Education in U.S. Medicine." *American Journal of Sexuality Education* 9(1):65–80.
- Cross, Jennifer E., Kathleen Pickering, and Matthew Hickey. 2015. "Community-Based Participatory Research, Ethics, and Institutional Review Boards: Untying a Gordian Knot." *Critical Sociology* 41(7-8):1007-1026.

- Dahlhamer, James M., Jacqueline Lucas, Carla Zelaya, Richard Nahin, Sean Mackey, Lynn Debar, Robert Kerns, Michael Von Korff, Linda Porter, and Charles Helmick. 2018.
- Davila, Willy G. 2008. "Concept of the Pelvic Floor as a Unit" Pp. 3-6 in *Pelvic Floor Dysfunction: A Multidisciplinary Approach*, edited by G. W. Davila, G. M. Ghoniem, and S. D. Wexner. London: Springer.
- "Prevalence of Chronic Pain and High-impact Chronic Pain Among Adults — United States, 2016." *Morbidity and Mortality Weekly Report* 67(36):1001–1006.
- Downing, Roberta A., Thomas A. LaVeist, and Heather E. Bullock. 2007. "Intersections of Ethnicity and Social Class in Provider Advice Regarding Reproductive Health." *American Journal of Public Health* 97(10):1803–7.
- Epstein, Steven. 2007. *Inclusion: The Politics of Difference in Medical Research*. University of Chicago Press.
- Evans, Clare R. 2019. "Modeling the Intersectionality of Processes in the Social Production of Health Inequalities." *Social Science and Medicine* 226(December 2018):249–253.
- Farmer, Melissa M. and Kenneth F. Ferraro. 2005. "Are Racial Disparities in Health Conditional on Socioeconomic Status?" *Social Science & Medicine* 60(1):191–204.
- Fassler, Joe. 2015. "How Doctors Take Women's Pain Less Seriously." *The Atlantic*, October 15, 1–11. Retrieved May 10, 2021 (<https://www.theatlantic.com/health/archive/2015/10/emergency-room-wait-times-sexism/410515/>).
- Feagin, Joe and Zinobia Bennefield. 2014. "Systemic Racism and U.S. Health Care." *Social Science & Medicine* 103:7–14.
- Foucault, Michel. 1973. *The Birth of the Clinic*. NY: Travistock Publications, Ltd.
- Foucault, Michel. 1978. *The History of Sexuality Volume. 1: An Introduction*. NY: Random House, Inc.
- Freese, Jeremy, and Karen Lutfey. 2010. "Fundamental Causality: Challenges of an Animating Concept for Medical Sociology" Pp. 67–83 in *The Handbook of the Sociology of Health, Illness, and Healing*, edited by B. A. Pescosolido, J. K. Martin, J. McLeod, and A. Rogers. New York: Springer.
- Freidson, Eliot. 1970. *Professional Dominance: The Social Structure of Medical Care*. New York: Routledge.

- Freistadt, Hans. 1956. "Dialectical Materialism: A Friendly Interpretation." *Philosophy of Science* 23(2):97–110.
- Fujishiro, Kaori, Jun Xu, and Fang Gong. 2010. "What does 'Occupation' Represent as an Indicator of Socioeconomic Status?: Exploring Occupation Prestige and Health." *Social Science & Medicine* 71:2100-2107.
- Gaddis, S. Michael. 2018. "An Introduction to Audit Studies in the Social Sciences" Pp. 3-44 in *Audit Studies: Behind the Scenes with Theory, Method, and Nuance*, edited by S. M. Gaddis. Cham, Switzerland: Springer International Publishing.
- Glenn, Evelyn Nakano. 2000 "The Social Construction and Institutionalization of Gender and Race" Pp. 3-43 in *Revisioning Gender*, edited by M. M. Ferree, J. Lorber, and B. B. Hess. Walnut Creek, CA: AltaMira Press.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York, NY: Simon and Schuster Inc.
- Goldberg, Robert J., Caitlin O'Donnell, Jorge Yarzebski, Carol Bigelow, Judith Savageau, and Joel M. Gore. (1998). "Sex Differences in Symptom Presentation Associated with Acute Myocardial Infarction: A Population-based Perspective." *American Heart Journal* 136(2):189-195.
- Goldstein, Andrew T., Caroline F. Pukall, Candace Brown, Sophie Bergeron, Amy Stein, and Susan Kellogg-Spadt. 2016. "Vulvodynia: Assessment and Treatment." *The Journal of Sexual Medicine* 2016(13):572-590.
- Greenhalgh, Trisha. 1999. Narrative Based Medicine: Narrative Based Medicine in an Evidence Based World. *British Medical Journal* 318(7179):323–325.
- Harris, K.M., C.T. Halpern, E. Whitsel, J. Hussey, J. Tabor, P. Entzel, and J.R. Udry. 2009. The National Longitudinal Study of Adolescent to Adult Health: Research Design.
- Hintz, Elizabeth A., and Maria K. Venetis. 2019. "Exploring the Effects of Patient-Provider Communication on the Lives of Women with Vulvodynia" Pp. 99-115 in *Narrating Patienthood: Engaging Diverse Voices on Health, Communication, and the Patient Experience*, edited by P. M. Kellet. New York, NY: Lexington Books.
- Hoffman, Diane E., and Anita J. Tarzian. 2001. "The Girl Who Cried Pain: A Bias against Women in the Treatment of Pain." *Journal of Law, Medicine, & Ethics* 29(1): 13-27.

- Hoffman, Kelly M., Sophie Trawalter, Jordan R. Axt, and M. Norman Oliver. 2016. "Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites." *Proceedings of the National Academy of Sciences* 113(16): 4296-4301.
- Holloway, Royal. 2001. "Illness Narratives: Fact or Fiction?" *Sociology of Health & Illness* 23(3):263–85.
- Homma, Yukio, Yoshiyuki Akiyama, Hikaru Tomoe, Akira Furuta, Tomohiro Ueda, Daichi Maeda, Alex TL Lin, Hann-Chorng Kuo, Ming-Huei Lee, Seung-June Oh, Joon Chul Kim, and Kui-Sung Lee. 2020. "Clinical Guidelines for Interstitial Cystitis/Bladder Pain Syndrome" *International Journal of Urology* 2020(27):578-589.
- Huntington, Annette, and Jean A. Gilmour. 2005. "A Life Shaped by Pain: Women and Endometriosis." *Journal of Clinical Nursing* 14(9):1124-1132.
- Jackowich, Robyn, Leah Pink, Allan Gordon, Évéline Poirier, and Caroline F. Pukall. 2017. *Journal of Sex & Marital Therapy* 0(0):1-16.
- Johnson, Rachel L., Debra Roter, Neil R. Powe, and Lisa A. Cooper. 2004. "Patient Race/Ethnicity and Quality of Patient-Physician Communication during Medical Visits." *American Journal of Public Health* 94(12):2084–90.
- Jutel, Annemarie. 2009). Sociology of Diagnosis: A Preliminary Review. *Sociology of Health and Illness* 31(2):278–299.
- Kempner, Joanna. 2017. "Invisible People with Invisible Pain: A Commentary on 'Even My Sister Says I'm Acting like a Crazy to Get a Check': Race, Gender, and Moral Boundary-Work in Women's Claims of Disabling Chronic Pain." *Social Science & Medicine* 189:152–54.
- Keogh, Edmund. 2015. "Men, Masculinity and Pain." *Pain* 156(12):2408-2412.
- Kirschstein, Ruth L. 1990. "Public Health Policy Forum: Research on Women's Health." *American Journal of Public Health* 81(3):291–293.
- Komisaruk, Barry R., and Irwin Goldstein. 2018. "Pathophysiology and Medical Management of Persistent Genital Arousal Disorder" Pp. 161-171 in *Textbook of Female Sexual Function and Dysfunction: Diagnosis and Treatment*, edited by I. Goldstein, A. H. Clayton, A. T. Goldstein, N. N. Kim, and S. A. Kingsberg. John Wiley & Sons Ltd.

- Kunda, Ziva and Steven J. Spencer. 2003. "When Do Stereotypes Come to Mind and When Do They Color Judgment? A Goal-Based Theoretical Framework for Stereotype Activation and Application." *Psychological Bulletin* 129(4):522–44.
- Link, Bruce G. and Jo Phelan. 1995. "Social Conditions as Fundamental Causes of Disease." *Journal of Health and Social Behavior* 35:80-94.
- Lutfey, Karen and Jeremy Freese. 2005. "Toward Some Fundamentals of Fundamental Causality: Socioeconomic Status and Health in the Routine Clinic Visit for Diabetes." *American Journal of Sociology* 110(5):1326–72.
- Macrae, C. Neil, Alan B. Milne, and Galen V. Bodenhausen. 1994. "Stereotypes as Energy-Saving Devices: A Peek Inside the Cognitive Toolbox." *Journal of Personality and Social Psychology* 66(1):37–47.
- Magaña, Sandra, Kristina Lopez, Arellys Aguinaga, and Holly Morton. 2013. "Access to Diagnosis and Treatment Services Among Latino Children With Autism Spectrum Disorders." *Intellectual and Developmental Disabilities* 51(3):141–53.
- Markovic, Milica, Lenore Manderson, and Narelle Warren. 2008. "Endurance and Contest: Women's Narratives of Endometriosis." *Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine* 12(3): 349-367.
- McCartney, Gerry, Elinor Dickie, Oliver Escobar, and Chik Collins. 2021. "Health Inequalities, Fundamental Causes and Power: Towards the practice of good theory." *Sociology of Health & Illness* 43(1):20-39.
- McGregor, Deborah Kuhn. 1998. *From Midwives to Medicine: The Birth of American Gynecology*. Rutgers University Press.
- Mertens, Donna M. 2010. *Research and Evaluation in Education and Psychology*. Thousand Oaks, CA: SAGE Publications, Inc.
- Mills, C. Wright. 2000. *The Sociological Imagination*. NY: Oxford University Press.
- Moayyedi, Paul, Christopher N Andrews, Glenda MacQueen, Christina Korownyk, Megan Marsiglio, Lesley Graff, Brent Kvern, Adriana Lazarescu, Louis Liu, William G Paterson, Sacha Sidani, and Stephen Vanner. 2019. "Canadian Association of Gastroenterology Clinical Practice Guideline for the Management of Irritable Bowel Syndrome (IBS)." *Journal of the Canadian Association of Gastroenterology* 2(1):6-29.
- Mutz, Diana C. 2011. *Population-Based Survey Experiments*. Princeton University Press.

- Neprash, Hannah T., Anna Zink, Joshua Gray, and Katherine Hempstead. 2018. "Physician Participation in Medicaid Increased only Slightly Following Expansion." *Health Affairs* 37(7):1087-91.
- Noroozzadeh, Mahsa, Fahimeh Ramezani Tehrani, Mahnaz Bahri Khomami, and Fereidoun Azizi. 2017. "A Comparison of Sexual Function in Women with Polycystic Ovary Syndrome (PCOS) Whose Mothers Had PCOS During Their Pregnancy period with Those Without PCOS." *Archives of Sexual Behavior* 2017(46):2033-2042.
- Northwell Health. 2021. "Gaslighting in Women's Health: No, it's not just in your head." Katz Institute for Women's Health. Retrieved May 10, 2021 (<https://www.northwell.edu/katz-institute-for-womens-health/articles/gaslighting-in-womens-health>).
- Owens, Deirdre Cooper. 2017. *Medical Bondage: Race, Gender, and the Origins of American Gynecology*. Athens, GA: University of Georgia Press.
- Phelan, Jo C. and Bruce G. Link. 2013. "Fundamental Cause Theory." Pp. 1–267 in *Medical Sociology on the Move: New Directions in Theory*, edited by W. C. Cockerham. New York: Springer.
- Phelan, Jo C. and Bruce G. Link. 2015. "Is Racism a Fundamental Cause of Inequalities in Health?" *Annual Review of Sociology* 41:311–30.
- Riessman, Catherine Kohler. (1993) *Narrative Analysis*. Newbury Park: Sage.
- Roberts, Dorothy. 1996. "Reconstructing the Patient Starting with Women of Color." Pp. 117–43 in *Feminism & Bioethics: Beyond Reproduction*, edited by S. M. Wolf. Oxford University Press.
- Rubin, Sara, Nancy Burke, Meredith Van Natta, Irene Yen, and Janet K. Shim. 2018. "Like a Fish out of Water: Managing Chronic Pain in the Urban Safety Net." *Journal of Health and Social Behavior* 59(4):487–500.
- The American College of Obstetricians and Gynecologists. 2017. "About Us." Retrieved April 25, 2018 (<https://www.acog.org/About-ACOG/About-Us>).
- Seear, Kate. 2009. "The Etiquette of Endometriosis: Stigmatisation, Menstrual Concealment, and the Diagnostic Delay." *Social Science & Medicine* 69(2009):1220-1227.
- Shim, Janet K. 2010. "Cultural Health Capital: A Theoretical Approach to Understanding Health Care Interactions and the Dynamics of Unequal Treatment." *Journal of Health and Social Behavior* 51(1):1–15.

- Sims, James Marion. 1884. *The Story of My Life*. NY: D. Appleton and Company.
- Speer, Linda M., Saudia Mushkbar, and Tara Erbele. 2016. "Chronic Pelvic Pain in Women." *American Family Physician* 93(5):380–387.
- Stepanikova, Irena. 2012. "Racial-Ethnic Biases, Time Pressure, and Medical Decisions." *Journal of Health and Social Behavior* 53(3):329–43.
- The American College of Obstetricians and Gynecologists. 2017. "About Us." Retrieved April 25, 2018 (<https://www.acog.org/About-ACOG/About-Us>).
- Timmermans, Stefan, and Emily S. Kolker. 2004. "Evidence-based Medicine and the Reconfiguration of Medical Knowledge." *Journal of Health and Social Behavior* 45(Extra):177–193.
- Timmermans, Stefan., and Steven Epstein. 2010. "A World of Standards but not a Standard World: Toward a Sociology of Standards and Standardization." *Annual Review of Sociology* 36(1):69–89.
- Todd, Knox H., Nigel Samaroo, and Jerome R. Hoffman. 1993. "Ethnicity as a Risk Factor for Inadequate Emergency Department Analgesia" *JAMA: The Journal of the American Medical Association* 269(12):1537–39.
- Toye, Francine, Kate Seers, and Karen Barker. 2014. A Meta-ethnography of Patients' Experiences of Chronic Pelvic Pain: Struggling to Construct Chronic Pelvic Pain as "Real." *Journal of Advanced Nursing* 70(12):2713–2727.
- U.S. Census Bureau. (2019, July 1). *QuickFacts: Indiana, Population Estimates*. Retrieved from <https://www.census.gov/quickfacts/IN>.
- Viganò, Paola, Fabio Parazzini, Edgardo Somigliana, and Paolo Vercellini. 2004. "Endometriosis: Epidemiology and Aetiological Factors." *Best Practice and Research: Clinical Obstetrics and Gynaecology* 18(2):177–200.
- Van Dijk, Teun A. 2015. "Critical Discourse Analysis" Pp. 466-485 in *The Handbook of Discourse Analysis*, 2nd edition, edited by D. Tannen, H. E. Hamilton, and D. Schiffrin. West Sussex, UK: John Wiley & Sons, Inc.
- Wadsworth, Nancy D. 2011. "Intersectionality in California's Same-Sex Marriage Battles: A Complex Proposition." *Political Research Quarterly* 64(1):200–216.
- Wall, Lewis L. 2006. "The Medical Ethics of Dr. J. Marion Sims: A Fresh Look at the Historical Record." *Journal of Medical Ethics* 32(6): 346-350.

- Wanzo, Rebecca. 2009. "In the Shadow of Anarcha: Race, Pain, and Medical Storytelling" Pp. 145-183 in *The Suffering will not be Televised: African American Women and Sentimental Political Storytelling*. Albany, NY: SUNY Press.
- Werner, Anne and Kirsti Malterud. 2003. "It Is Hard Work Behaving as a Credible Patient: Encounters between Women with Chronic Pain and Their Doctors." *Social Science & Medicine* 57(8):1409–19.
- Werner, Anne, Lise Widding Isaksen, and Kirsti Malterud. 2004. "'I Am Not the Kind of Woman Who Complains of Everything': Illness Stories on Self and Shame in Women with Chronic Pain." *Social Science & Medicine* 59:1035–45.
- Whelan, Emma. 2007. "'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community." *Sociology of Health & Illness* 29(7): 957-982.
- Williams, Gareth. 2004. "Narratives of Health Inequality: Interpreting the Determinants of Health." Pp. 279–91 in *Narrative Research in Health and Illness*, edited by B. Hurwitz, T. Greenhalgh, and V. Skultans. Oxford: Blackwell Publishing.
- Wood, Emily, and Marta Elliott. 2020. "Opioid Addiction Stigma: The Intersection of Race, Social Class, and Gender." *Substance Use and Misuse* 55(5):818–827.

APPENDIX A. PATIENT INTAKE FORM EXAMPLES (WHITE MIDDLE-CLASS DECK)

[REDACTED]
NEW PATIENT INTAKE FORM

Date: **[REDACTED]**

First Name: **[REDACTED]** Last Name: **[REDACTED]**

Address: **[REDACTED]**

City: **[REDACTED]** State: IL Zip Code: **[REDACTED]**

Race (select all that apply):

☒ White or Caucasian ☐ Black or African American ☐ Asian or Asian-American

☐ Native Hawaiian or Other Pacific Islander ☐ Native American or Alaskan Native

☐ Middle Eastern ☐ Other (Please Specify): _____

Ethnicity (select one): ☐ Hispanic/Latino(a) ☒ Non-Hispanic/Latino(a)

Sex: ☐ Male ☒ Female

Home Phone: **[REDACTED]** Cell Phone: **[REDACTED]**

Email: **[REDACTED]** Age: 31

Social Security: **[REDACTED]** Date of Birth: **[REDACTED]**

Emergency Contact: **[REDACTED]**

Relationship to Patient: **[REDACTED]** Phone: **[REDACTED]**

Marital Status (select one): ☒ Single ☐ Married ☐ Widowed ☐ Divorced

Occupation: Food prep worker

Insurance type (select one): ☒ Private ☐ Medicaid

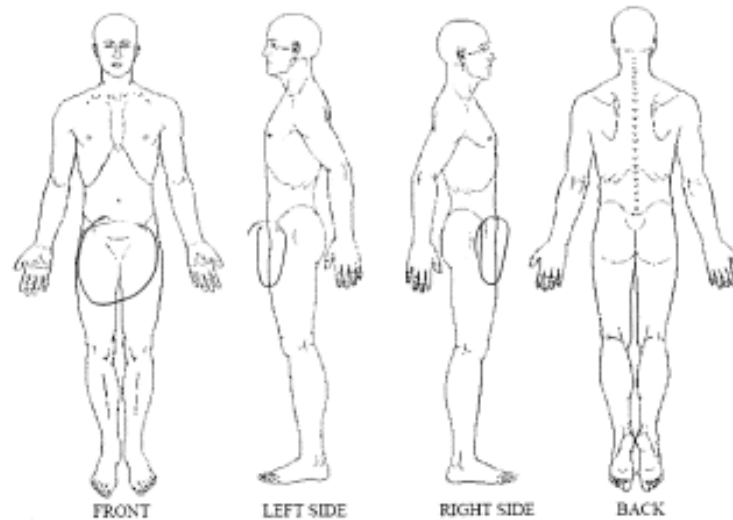
Please list any allergies to drugs or medications: N/A

Current Medical Problems (e.g., diabetes, heart disease, hypertension, etc.):
N/A

Past Medical History: List any major past illnesses/hospitalizations
N/A

Current Medications/Supplements: Multi-Vitamin + Omega-3
Supplement + ibuprofen

Please circle all areas of pain:



Please circle the face that best describes the pain you are experiencing:

Wong-Baker FACES® Pain Rating Scale



©1993 Wong-Baker FACES Foundation. www.WongBakerFACES.org
Used with permission.

In your own words, please describe your pain and how it is impacting your life:

It has increasingly gotten more severe & is
interfering with my social life because I can't
focus on anything but my pain.

NEW PATIENT INTAKE FORM

Date: [REDACTED]

First Name: [REDACTED] Last Name: [REDACTED]

Address: [REDACTED]

City: [REDACTED] State: IN Zip Code: [REDACTED]

Race (select all that apply):

☐ White or Caucasian ☒ Black or African American ☐ Asian or Asian-American

☐ Native Hawaiian or Other Pacific Islander ☐ Native American or Alaskan Native

☐ Middle Eastern ☐ Other (Please Specify): _____

Ethnicity (select one): ☐ Hispanic/Latino(a) ☒ Non-Hispanic/Latino(a)

Sex: ☐ Male ☒ Female

Home Phone: [REDACTED] Cell Phone: [REDACTED]

Email: [REDACTED] Age: 35

Social Security: [REDACTED] Date of Birth: [REDACTED]

Emergency Contact: [REDACTED]

Relationship to Patient: [REDACTED] Phone: [REDACTED]

Marital Status (select one): ☒ Single ☐ Married ☐ Widowed ☐ Divorced

Occupation: US Postal Service Clerk

Insurance type (select one): ☒ Private ☐ Medicaid

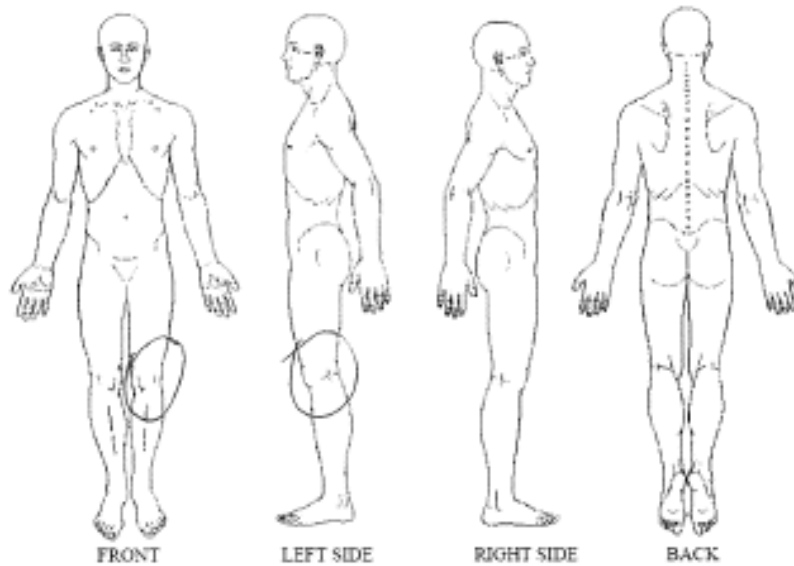
Please list any allergies to drugs or medications: Penicillin

Current Medical Problems (e.g., diabetes, heart disease, hypertension, etc.):
No current medical problems

Past Medical History: List any major past illnesses/hospitalizations
No major past illnesses/hospitalizations

Current Medications/Supplements: Advil

Please circle all areas of pain:



Please circle the face that best describes the pain you are experiencing:

Wong-Baker FACES® Pain Rating Scale



©1993 Wong-Baker FACES Foundation. www.WongBakerFACES.org
Used with permission.

In your own words, please describe your pain and how it is impacting your life:

My knee has been in pain for a little over a month.
It mostly hurts when I am walking up stairs or doing
physical activities, but it also hurts when I sit for
long periods of time.

ADVANCED PAIN MANAGEMENT

NEW PATIENT INTAKE FORM

Date: [REDACTED]
First Name: [REDACTED] Last Name: [REDACTED]
Address: [REDACTED]
City: [REDACTED] State: IN Zip Code: [REDACTED]

Race (select all that apply):

- ☒ White or Caucasian ☐ Black or African American ☐ Asian or Asian-American
☐ Native Hawaiian or Other Pacific Islander ☐ Native American or Alaskan Native
☐ Middle Eastern ☐ Other (Please Specify): _____

Ethnicity (select one): ☐ Hispanic/Latino(a) ☒ Non-Hispanic/Latino(a)

Sex: ☐ Male ☒ Female

Home Phone: [REDACTED] Cell Phone: [REDACTED]
Email: [REDACTED] Age: 30
Social Security: [REDACTED] Date of Birth: [REDACTED]
Emergency Contact: [REDACTED]
Relationship to Patient: [REDACTED] Phone: [REDACTED]

Marital Status (select one): ☒ Single ☐ Married ☐ Widowed ☐ Divorced

Occupation: Telemarketer

Insurance type (select one): ☒ Private ☐ Medicaid

Please list any allergies to drugs or medications: none

Current Medical Problems (e.g., diabetes, heart disease, hypertension, etc.):

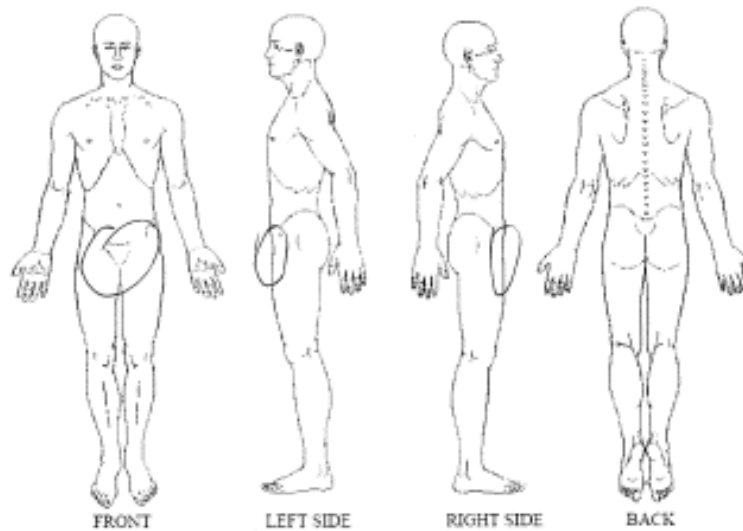
none

Past Medical History: List any major past illnesses/hospitalizations

none

Current Medications/Supplements: Daily Vitamin, fish oil, advil

Please circle all areas of pain:



Please circle the face that best describes the pain you are experiencing:

Wong-Baker FACES® Pain Rating Scale



©1993 Wong-Baker FACES Foundation. www.WongBakerFACES.org
Used with permission.

In your own words, please describe your pain and how it is impacting your life:

The pain around my pelvis has gotten so bad that it hurts keeps me up at night. It is also interfering with my ability to continue my regular workouts, but it doesn't just hurt when I am working out.

APPENDIX B. INTERVIEW GUIDE FOR PROVIDER INTERVIEWS

Building rapport and background:

1. How long have you been practicing medicine/nursing/etc.?
2. Where did you go to school?
3. Why did decide to go into this profession?
4. Do you have a specialty area?
 - a. Why this area?
5. How long have you been involved in this organization?
 - a. What is your role in this organization?
6. Do you go to this meeting every year?

Pelvic pain questions:

1. In general, what are your thoughts on pelvic pain? Feel free to expand on both medical and personal opinions.
2. If you had to medically define pelvic pain, what would the definition be?
3. In your opinion, is pelvic pain a relatively simple or complex symptom to assess? Why?
4. From your knowledge and experience, what conditions generally cause pelvic pain?
5. What are your thoughts specific to female pelvic pain?
6. Do you ever treat, or have you ever treated, female patients with severe pelvic pain?
 - a. If YES:
 - i. What are your general thoughts when female patients elicit concerns about pelvic pain?
 - ii. How do you typically go about assessing and treating such patients?

Wrap-up:

1. Is there anything you would change about the way pelvic pain is currently assessed or treated? Why/Why not?
 - a. What about female pelvic pain specifically? Why/Why not?
2. Do you have any other thoughts related to pelvic pain more generally or female pelvic pain specifically that you would like to share?

APPENDIX C. INTERVIEW GUIDE FOR PATIENT INTERVIEWS

Building Rapport:

1. Can you tell me a bit about yourself and the things you enjoy doing?
 - Hobbies? Occupation? Family?

Reproductive health history (Adolescence):

1. Can you tell me about your first period?
 - How old were you?
 - Did you know about menstruation before starting?
 - What is your memory of your first period?
 - How did you feel about starting your period?
 - Was this a negative or positive experience for you? Why?
2. Were your periods painful in adolescence?
 - YES:
 - Can you tell me about your painful periods?
 - How did you know that your periods were “painful”?
 - Did you think this pain was normal at the time? Why or why not?
 - Looking back, would you still say the pain was/was not normal?
 - Did your painful periods interfere with your life (e.g., school, sports, activities, social life, etc.)?
 - How so?
 - Did you tell anyone about your pain? Why/why not?
 - What did others think about your painful periods?
 - Did other people think your pain was normal?
 - How did you feel about other people’s opinions of your pain?
 - Did you ever see a medical provider for your pain?
 - What was that experience like?
 - Who did you see?
 - What was the outcome?
 - How did you feel about the outcome?
 - NO:
 - Did you have any friends who had painful periods?
 - How did you know they had painful periods?
 - What were your thoughts about that friend’s pain?
 - Did you think it was normal?

If diagnosed with reproductive health condition in adolescence:

3. What symptoms lead you to seek treatment, and why?

- Did anyone have influence over your choice to seek treatment for your symptoms? Who? How so?
 - What role did your parents or other legal guardians play in this process?
- 4. What providers did you see and what were your experiences with those providers?
 - Why that provider/those providers?
 - How long did it take to receive a diagnosis after first seeking treatment?
 - What treatment options did your provider(s) give you?
 - Were you happy with the options provided?
- 5. What were your reactions to being diagnosed?

Pelvic pain experiences:

Personal experiences:

1. Can you tell me about the first experience you had with pelvic pain? *(if relevant)*
 - How old were you?
 - What does/did the pain feel like?
 - When did you first consider your pelvic pain to be a persistent issue?
 - What were some of your initial reactions to the pain you were experiencing?
 - Were you worried about it?
 - Does your pain interfere with your daily life in any way?
 - How so?
2. Who knows about your pain, if anyone?
 - How long after your pain started did you tell someone?
 - Why have you told these people?
 - What was their reaction?
 - Did you find their reactions helpful in anyway?
 - Did you find their reactions hurtful in anyway?
 - IF THEY TOLD NO ONE:
 - Why haven't you told anyone about your pain?

Medical experiences:

1. When did you first see a medical provider about your pain?
 - What made you decide to seek treatment at that time?
 - IF DELAYED:
 - Why do you think you waited to seek treatment?
 - How do you feel about that delay now?
 - What kind of provider did you see and why (e.g., GP, OBGYN, other specialists, PT, etc.)?
 - Can you tell me about this provider?
 - Man/woman?
 - Was this your first visit with him/her?
 - What was this experience with your provider like?
 - Did you feel comfortable expressing your concerns during the appointment? Why/why not?

- Did your provider help you express your concerns related to your pain? How so?
 - Did you feel like your experience was validated by the provider? Why/why not?
 - Was this a positive or negative experience? Why?
 - What was the outcome (e.g., diagnosis, treatment, recommendations, referred to specialist, etc.)?
 - Were you happy with this outcome? Why/why not?
 - Do you remember any other specifics of your interaction with this provider that you would like to share?
- 2. How many providers have you seen throughout the process of trying to treat/understand your pain?
 - Can you tell me about that journey with each provider?
 - *SAME QUESTIONS AS ABOVE FOR EACH PROVIDER*
 - Did you feel that you had a wide range of choices over how you were treated for your pain throughout this process? Why/why not?
 - Did your providers communicate with each other about your case?
- 3. Have you run into any complications receiving medical care for your pain?
 - Health insurance-related issues?
 - Other issues?
- 4. Did you ever try any “alternative” treatments throughout this process?
 - What did you try and why?
 - What was your experience with the treatments you tried?
 - Did you tell any of your medical providers about these treatments? Why/why not?
- 8. How did you end up where you are today with your pelvic pain/treatment/diagnosis/provider/etc.?
 - Looking back, is there anything you would have done differently throughout this journey? Why/why not?

Impacts:

1. How has your experience with pelvic pain impacted these aspects of your life?
 - *Fertility:*
 - **[IF RELEVANT]** What was it like when you found out your condition impacted your ability to conceive children?
 - Given the connection between many conditions that cause pelvic pain and fertility, has your pelvic pain impacted how you think about your fertility?
 - Are you more aware of it? Do you worry about it at all?
 - *Family and Family planning*
 - *Dating*
 - *Intimacy with partners*
 - *Work/School*
 - *Physical Activities*
 - *Social Life*
 - *Hobbies*

2. Are there other aspects of your life that have been impacted by your pelvic pain that we have not discussed?
3. What aspects of your life have been impacted the most by your pelvic pain?
 - How does your pain impact those aspects of your life?
4. Are there aspects of your life that have **not** been disrupted by your pelvic pain experience?
 - What are those aspects?
 - Why do you think they were not impacted?
5. How have your interactions with medical providers throughout this process impacted your life?

Wrap up:

1. Is there anything I did not touch on that is important for me to know?
2. What have been some positive experiences throughout this process?
3. Is there anything you can think of that would have made this process better for you?
4. What advice would you give to other women or girls experiencing pelvic pain?