A GENDER ANALYSIS OF MILD TRAUMATIC BRAIN INJURY PATIENTS' EXPERIENCES

By

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ABSTRACT

Head injuries, such as concussions, have garnered increased public awareness and clinical research attention. However, such attention has not been equally productive for all patient populations and has had the unfortunate consequence of silencing alternative illness experiences, particularly those of women. Whereas other conditions lack medical authority (e.g., Barker 2005) or the power of the diagnosis is undermined by its feminization (e.g., Kempner 2014), the case of mild traumatic brain injury (mTBI) is unique in that it both has medical legitimacy and a masculine disease frame. The insufficiency only becomes evident in the case of gender incongruence between the diagnosis and the patients who embody it. This research indicates that women, more so than men, face a legitimacy deficit in every stage of the mTBI disease process. I draw on interviews with 52 women and men who have had diagnosed mTBIs to examine the fluid authority of the mTBI diagnosis and the gendered pathways of patient resilience that drive the observed gender disparities. I discuss patients' experiences in the diagnostic search, during illness and recovery, and when navigating a new "normal" as a person with permanent impairment. My analysis finds that women face more barriers to getting diagnosed, accessing treatment, and reintegrating due to gendered legitimacy deficits but that men also face barriers pertaining to masculinity. This research contributes to our understandings of gender, health disparities, and the production of medical knowledge.

For those who experience brain injury; for the people who love and support them; and for the exceptional healthcare professionals who treat them.

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CHAPTER 1

INTRODUCTION

Violet is a 27-year-old single mother of two children under the ages of three. While in her final year of college as a biology major, she was in a car accident. She incurred a mild traumatic brain injury (mTBI) and received no follow-up care after her treatment at the emergency department. She was not able to complete her college courses that term and did not return the following term. Over the next two years she found herself misusing substances. When she became pregnant with her first child, she tried to “go straight” but had trouble managing a conventional job due to her lingering mTBI symptoms. Fast forward to today, Violet is now the proud single mother of two young children with whom she recently moved into a domestic violence shelter for safety and shelter. She worries about how she will care for her children once their temporary housing ends because she been unable to find work she can succeed in with her symptoms.

Violet’s experiences contrast with those of William, a 56-year-old former doctor who is married with three adult children. After his fall, William received extensive treatment through an outpatient program at a traumatic brain injury (TBI) treatment center. While he is no longer able to practice medicine due to an mTBI, he continues to work as a writer, consultant, and brain injury advocate. These two cases illustrate two starkly contrasting outcomes of mTBI moderated in part by the preexisting protective factors and flexible resources. As a young woman with virtually no social support system, like family, and a college student with minimal income, Violet had few flexible resources to draw from to mediate the effects of a medical crisis. William on the other hand was well versed in the healthcare system and had ample social and economic resources from which to rely. This dissertation builds on and expands the concept of *legitimacy deficits*, which “highlights the complex, contingent, and contested character of the process of legitimating disease” (Kempner 2014: 10) to understand how the legitimating process unfolds across the disease course to produce disparate outcomes both across and within genders.

This dissertation examines how mTBI can simultaneously be widely recognized in society with a large and diverse patient population, and yet still be distrusted and minimized. In today’s age of football and awareness of brain injuries such as chronic traumatic encephalopathy (CTE)[1], why is it that some mTBIs garner extensive cultural attention and profound compassion while others are treated as lesser? The clinical discovery of CTE has in some ways helped to recast concussion as a significant neurologic condition. But with it comes the persisting stigma and unequal recognition of patient subpopulations that exposes the social contests that surround the social legitimacy and cultural significance of the concussion diagnosis.

The effects of mTBI can be difficult for others to understand because it often leaves no visible markers and at present has no consistent diagnostic tests, leaving diagnosis dependent on an expansive symptom cluster. In this dissertation, I focus on how gender becomes a default framework for interpreting health and disability when other visible and clinical markers are absent. I argue that gender is implicitly written into the concussion/mTBI diagnosis – both clinically and culturally – ultimately affecting patients’ quality of life and prognosis. Through interviews with patients, I uncover the hidden legacy of the 19th century gendered concept of the nervous temperament. I also show the extensive impression management and self-advocacy work women patients engage in to pursue diagnosis, treatment, and recognition as a legitimate patient,

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[1] A condition of brain degeneration that is believed to be caused by a history of repeated head traumas.

as well as the barriers to return to play, learn, and work. By examining gender differences in diagnosis and treatment, I parse out the importance of flexible resources to explain the disparities within and between gender categories. In brief, this dissertation explores the role gender has in the decisive legitimating processes of mTBIs, its subsequent effects across the disease process, and the mediating role of flexible resources.

BRAIN INJURY EPIDEMIOLOGY

Brain Injury Basics

It is important for the purposes of this study to define traumatic brain injuries (TBI). An acquired brain injury (ABI) is one that is not congenitally linked (Zasler, Katz, and Zafonte 2013). ABIs can be either traumatic or non-traumatic. When we refer to a TBI, we are talking about a specific subset of ABIs characterized by a sudden physical impact on the brain caused by an *external force* (rather than some internally occurring physiological dysregulation, e.g., infection, stroke, and hypoxia) that results in damage or deficit. Thus, TBI is clinically distinct from conditions caused by internally occurring physiological dysregulations, like strokes and brain tumors.

To understand the full scope of mild traumatic brain injury (mTBI) as a major public health issue, we must frame it within the broader context of TBI. TBI is a major cause of death and disability within the U.S. and globally (Hyder et al. 2007). Each year, an estimated 10 million people around the globe are affected by TBI, making TBI a pressing public health issue. In 2010, in the U.S. alone, the total combined rates of TBI-related hospitalizations, ED visits, and deaths was 823.7 per 100,000. This rate does not even include the number of people who do not recognize the symptoms and seek professional care, or those who are not seen in the hospital or emergency department. The annual incidence rate has also been on the rise since the turn of the millennium. This trend may be explained by an actual increase in cases, but it may also be due, at least in part, to increased awareness of concussions. Brain injury broadly has caught the media's attention, but especially concussions among young athletes and chronic traumatic encephalopathy[2] (CTE) among veteran professional athletes, which may contribute to increased awareness among the public.

TBI is the leading cause of injury-related deaths in the U.S. (approximately one-third) (Faul et al. 2010; Taylor et al. 2017). Among those for whom the injury is not fatal, an estimated 43.3% have residual disability one year after injury (Corrigan et al. 2010). The World Health Organization (WHO) estimates that 70% to 90% of treated head injuries are "mild," what is colloquially referred to as *concussion*. The NIH estimates that the observed rates of concussion incidence are likely to be underestimated due to underreporting with upwards of a quarter of all concussion sufferers who do not seek medical care. Concussion has a hospital treatment rate of 0.001 – 0.003 but given that not all concussions are treated in the hospital setting, a more accurate estimate is that six in one thousand people each year incur a concussion. According to the CDC, current data sources may only be capturing one in every nine concussions. Young adults (15-24 years old) make up the highest proportion of patients for ED visits. Older adults (over 55 years old) had the highest rates of hospitalization. The 75 years old and older category had the highest overall rates of death. For those who survive a TBI, symptoms can last from only a few days to the rest of their lives. Effects of TBI can include cognitive, physiological, psychological, and motor coordination impairments. These issues cause significant challenges for individual sufferers, but the effects extend beyond—to their families, communities, and

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[2] CTE is a neurodegenerative disease caused by repeated head injuries.

society generally. For example, many sufferers are unable to hold employment post-injury, or "return to work," resulting in economic, social, familial, and psychological problems (Zasler, Katz, and Zafonte 2013). For example, the economic impact of TBI in the U.S. for the year 2010 alone was approximated to be $76.5 billion.

There are three main categories of TBI diagnoses based on severity: mild, moderate, and severe. However, universally accepted definitions of these categories do not exist as each brain injury presents uniquely, making it difficult to assess a strict threshold between mild to moderate or moderate to severe. The field of medicine has long debated this; however, practitioners today rely primarily on three severity indicators: duration of unconsciousness, the Glasgow Coma Scale (GCS) score[3], and the duration of post-traumatic amnesia (PTA). The most widely used definition of mTBI is from the World Health Organization (WHO) Collaborating Center Task Force on Mild Traumatic Brain Injury which states:

> mTBI is an acute brain injury resulting from mechanical energy to the head from external physical forces. Operational criteria for clinical identification include: (*a*) one or more of the following: confusion or disorientation, loss of consciousness for 30 minutes or less, posttraumatic amnesia for less than 24 hours, and/or other transient neurological abnormalities such as focal signs, seizure, and intracranial lesion not requiring surgery; (*b*) Glasgow Coma Scale score of 13 to 15 after 30 minutes postinjury or later upon presentation for health care. These manifestations of mTBI must not be due to drugs, alcohol, medications; caused by other injuries or treatment for other injuries (e.g., systemic injuries, facial injuries, or intubation); caused by other problems (e.g., psychological trauma, language barrier or coexisting medical conditions); or caused by penetrating craniocerebral injury (Carroll et al. 2004: 115).

This definition is quite similar to two other dominant definitions developed by the Mild Traumatic Brain Injury Committee of the Head Injury Interdisciplinary Special Interest Group of the American Congress of Rehabilitation Medicine and the Center for Disease Control (CDC) and has been endorsed for use in clinical practice and research.

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[3] The Glasgow Coma Scale (GCS) is based off a patient's eye opening response, verbal response, and motor response.

While most mTBIs resolve on their own within a couple days or weeks, persistent damage is less common. This subgroup of mTBIs that experience such poor recovery outcomes is often referred to as the “miserable minority” (Zasler, Katz, and Zafonte 2013: 44). The miserable minority is “poorly understood despite decades of research” (p. 234), leading medical researchers to believe that they may still have the potential for improved recovery with more research that focuses on the psychosocial aspects of resiliency: maladaptive beliefs, coping behaviors, and environmental influences (p. 488). Symptoms of mTBI vary, and it is said that no two brain injuries are alike, but there are symptom clusters that dominate the literature: visual disturbance, headache/migraine, vestibular issues, motor functioning impairment, emotional disturbances (associated with impulsivity, aggression, depression, anxiety, erratic behavior, etc.), personality changes, cognitive impairments, light and sound sensitivity, and insomnia. This list is not exhaustive and only includes some of the most cited symptoms in mTBI symptomology. The varied presentation of mTBI along with soft guidelines for classifying severities demonstrates the variation in understandings of mTBI, suggesting that biomedical explanations for patient symptoms are incomplete.

Pink Concussions

Concussion scholars today widely accept that both sex and gender may be risks for incidence, severity, and prognosis (McCrory et al. 2013). While concussion had largely been viewed as an issue for males, recent research suggests that females sustain concussions more frequently than males, as well as have more resulting neurologic deficits, a different symptom cluster, and delayed recoveries (Covassin, Swanik, and Sachs 2003; Broshek et al. 2005; Covassin et al. 2006; Covassin, Schatz, and Swanik 2007; Covassin et al. 2010; Covassin, Moran and Elbin 2016). One commonly proposed explanation for such disparities includes differences in neck musculature and head/neck stability, with that of females being weaker and, therefore, more vulnerable to injury. Another common biological explanation offered in clinical research is that females have lower biomechanical thresholds, which makes them more susceptible to injury. Hormones have also been offered as an explanation for the differences in pain response. Within only the last couple years, emerging research has indicated that the timing of menstrual cycles may impact recovery (Wunderle et al. 2013). Finally, because females are more likely to have pre-existing symptoms that are also concussion symptoms - like headache - scholars suggest that the rate of persistent concussion symptoms among females may be inflated (Brown et al. 2015). It is important to note that much of this research requires significant refinement, as studies continue to fail to disaggregate by sex (Mollayeva, El-Khechen-Richandi, and Colantonio 2018).

Furthermore, even as such biological research attempts to explain the different ways TBI manifests among males and females, it does not currently offer sufficient explanations for the observed disparities in concussion, suggesting that there is something else going on. A great deal of emerging evidence supports the argument that sociocultural processes wield a strong influence on the gender gap in concussion. Given what is known across health and illness profiles about not only the interconnectedness of sex and gender, but also the direct effects of gender, this is not surprising. A review conducted by Mollayeva, El-Khechen-Richandi, and Colantonio (2018) concluded that "social roles driv[e] or modif[y] variances between men or women in traumatic brain injury (TBI) rates, recovery course and outcomes" (p. 6). While the data shows that females experience higher symptom loads long-term after work-related concussions, their community integration and perceived disability were less adversely affected. Research also finds that sex-gender interactions determine rates and severity of TBI, in part, through gendered health practices such as help-seeking behaviors and healthcare system use.

Emerging research highlights gender influences in the epidemiology of brain injury. Such findings provide strong evidence that traditional gender roles and activities – such as risk-taking behaviors – contribute to gender differences in concussion rates and outcomes (Love et al. 2009; Ilie et al. 2015). Covassin et al. (2003) found a 1.4 times greater incidence of reported concussion among girls and women when considering only sex-comparable National Collegiate Athletic Association (NCAA) sports (e.g., baseball and softball; soccer; basketball; tennis). The reason for this disparity is not well understood with explanations ranging from a difference in seeking medical attention because of increased symptoms to gendered health-seeking behaviors or gender influences.

> It is hypothesized that girls/women may report more symptoms as it is more socially acceptable for women to admit vulnerability than for men (Kroshus et al. 2017). At the same time, research reported that girls/women who display more traditional 'masculine' traits are more prone to risk-taking behaviors and may continue playing despite concussive symptoms. Other gender-related factors that may affect differential rates in seeking medical care are the quality of coaching and support for concussion care that may not be at the same level of that of boys/men (Mollayeva, El-Khechen-Richandi, and Colantonio 2018: 2).

According to the University of Pittsburgh's Sports Medicine Concussion Program, girls' soccer and basketball have the second- and third-highest rates of concussions across all high school sports following only behind football (UPMC Sports Medicine Concussion Program 2020). A meta-analysis by Mollayeva, El-Khechen-Richandi, and Colantonio (2018) offers compelling evidence that gender affects both the rates and prognosis of concussion through socio-cultural processes associated with risk taking behavior, stress, and coping. They provide a convincing argument for the necessity of future research to address the "very real contextual challenges of sex and gender in concussive injury which is critical for the prevention and management of this injury at the population level, and among vulnerable populations" (p. 5). The Centers for Disease Control and Prevention (CDC) labeled mTBI a "silent epidemic" because it had largely been unnoticed. While reports show increasing awareness and research dedicated to mTBI, women continue to be marginalized in the discourse. Historically, the majority of TBI cases have been men with age-adjusted TBI-related hospitalization rates being consistently higher (Langlois et al. 2003; Taylor, Bell, and Breiding 2017).

The gender gap in concussion research and practice had gone largely unnoticed by the public until recently. Among researchers, practitioners, and advocacy organizations, sex differences are increasingly being recognized as a critical factor in injury vulnerability, post-injury experience, and extent of recovery (Mollayeva and Colantonio 2019). For example, the Defense and Veterans Brain Injury Center (DVBIC) recently published findings that both female and male service members and veterans experience and recover from concussion differently (Military Health Systems Communications Office 2020). Most of the research in this body of literature, however, falls just short of the mark as it largely assumes the alignment of binary sex and gender categories and use these distinctly different terms interchangeably. As such, it makes it difficult to parse out whether studies are concerned with the sexed body or the gender identity of the individuals. The DVBIC has formally stated a need for more research to examine whether differences in TBI are due to gender (social) or sex (biology). The Brain Injury Association of America released a special edition of their newspaper, *The Challenge,* in March 2019 on “Women and Brain Injury”; a call to improve science and practice through increased attention to sex and gender in concussion research and treatment. The topic even gained airtime in February 2018 when Founder and Executive Director of PINKConcussions, Katherine Snedaker, discussed the organization’s partnership with several of the top global brain banks in the #PINKBrainPledge on Good Morning America (GMA). Through the #PINKBrainPledge, individuals may donate their brains to science to expand research on women with brain injury.

Just two months earlier in December 2017, the National Institute for Health (NIH) hosted its first workshop on "Understanding TBI in Women" to outline the state of our current knowledge. I attended this workshop, and as a sociologist, what most profoundly stood out to me was the interchangeable usage of female and woman – a confusion of sex category and gender or, alternatively, the assumption of their alignment. Even the few researchers studying sex or gender differences in brain injury are doing a disservice to the production of knowledge by failing to differentiate the two given current understandings in medicine, public health, and social sciences that identify some sex characteristics (e.g., hormones) as being risk or protective factors of incidence and prognosis. Gender has also been found to influence incidence and prognosis, but significantly less medical attention has been dedicated to this issue. Furthermore, when it is addressed, medicine largely discusses gender as a binary.

This paucity of sex and gender in the field of brain injury research is confirmed in the meta-analysis by Mollayeva, El-Khechen-Richandi, and Colantonio (2018) of the special issue "Sex, Gender and Traumatic Brain Injury" from the Archives of Physical Medicine and Rehabilitation found that "among the 200 studies of prognosis after mTBI, only 7% of studies provided sex-stratified data" (p. 5). The absence of girls and women in research follows the historical precedence within sciences (medical as well as social) to "add women and stir" that fails to consider the import of the specificity of men's and women's social locations and consequent gendered experiences. For example, women are at a greater risk for intimate partner violence (IPV), and there is an elevated rate of TBI among women survivors of IPV, estimated at about 80%. This is compounded by an increased likelihood to become a victim of IPV after sustaining a TBI. Glynnis Zieman, a Phoenix, Arizona area neurologist, spoke to the changing landscape of concussion patients stating, "The domestic violence patients are the next chapter of brain injury." Gender affects health after brain injury directly through paths not dissimilar from other health issues. In the context of TBI, men more often engage in higher risk behaviors that can be the cause of injury, make an injury worse, or increase the risk of repetitive injury (Mollayeva and Colantonio 2019). The chart below outlines the observed differences between men and women with TBI by four dimensions: hospitalizations (a proxy for severity of injury), work-related injuries, sports-related injuries, and life after injury (recovery). The World Health Organization's (WHO) Disability and Rehabilitation Action Plan 2014–2021 also calls for gender disaggregated data in policy documents.

Table 1. Gender Differences in Severity, Etiology and Recovery

Hospitalizations	Work-Related	Sports-Related	Life after Injury
Men have a higher incidence of TBI than women, particularly during young adulthood. Hospitalization rates between men and women even out in older adulthood as injury rates become more similar. Men more often leave hospital after admission against medical advice. The highest rates for concussion, or mild TBI, among older adults are among women.	Most work-related TBI fatalities occur in men; the jobs and workplaces of men are associated with more severe injuries. Women are at a greater risk of sustaining work-related TBI due to assault, often in the healthcare, social services, and education sectors. Men experience higher rates of work-related TBI in law enforcement and public administration. Women are more proactive in seeking medical and	In a study of young adults who sustained sports-related concussions, young women expressed greater intention to report than men. Men more often exhibit on-field markers of injury such as amnesia and disorientation. Women more frequently report headache, drowsiness, and nausea/vomiting.	Being a man is associated with greater likelihood of aggression after TBI relative to women. Women are significantly more likely to dies from a head injury than men. Women are more likely to die from a head injury by assault. Women experiencing intimate partner violence (IPV) are at a high risk of brain injury, with up to 90% of incidents of IPV involving hits to the head or strangulation.

Girls and women with a concussion-related emergency department visit have a higher reported rate of concurrent neck injury than boys and men. This is true across injury causes, including motor vehicle collisions, assault, and sports-related injury.	rehabilitation services. Women report more positive return-to-work outcomes if coming from a traditionally “feminine” environment (i.e., healthcare, social care) relative to those in more “masculine” environments.		

* Adapted from Mollayeva, Tatyana and Angela Colantonio. 2019. “Sex, Gender, and Traumatic Brain Injury: Implications for Better Science and Practice” in *The Challenge* 13(1): 4-6. Brain Injury Association of America, Vienna, VA.

There are also indirect pathways through which gender can affect TBI risk and resilience. The traditional family structure is still alive and well today, manifesting different home and work stressors for men and women. Consequently, men and women tend to have varied amounts of time or flexibility to dedicate to their health pursuits. Gender also influences whether individuals are able to take the first step towards health and recognize or accept their health issues. Lastly, there is a multitude of ways in which social aspects of health are affected by gender after brain injury; society creates standards and associated pressures with respect to rate and extent of recovery and return to previous roles based on gender. The chart above outlined the significant sex and gender differences that have been found in brain injury research for four main areas: hospitalization, work, sports, and post-injury life. However, it is important to note that medical knowledge – including that regarding brain injury – is dominated by male sample populations, which means that we have less data and, therefore, likely an incomplete understanding of other sexes’ experiences. Add gender to this and our medical knowledge falls even shorter; either by not addressing gender, by conflating it with sex, or by assuming binary systems of sex and gender always align.

In this study, I examine gender as an identity, a process, and a structure that influence medical diagnosis and treatment. For this study, I am conceptualizing gender in the interactionist tradition that conceives of gender as a "system of social practices" (Ridgeway 2011: 16) that is (re)produced in interaction (see West and Zimmerman 1987; Lorber 1994; Risman 1998; Acker 1990). Gender is an embodied process of relating with a system of social practices that associates certain social characteristics with membership in a particular social category based on corporeal characteristics that in part have to do with reproductive organs. Because of my narrowed focus on gender as a social system, I am unable to analytically contend with biological explanations regarding sex categories.

THE DISEASE FRAME

Gendered Concussion Culture

In the last decade we have seen the substantial expansion of public awareness and institutional attention to concussion/mTBI, including research funds, the media (see Provvidenza et al. 2013), medical training programs, educational and policy interventions (e.g., concussion laws or "return to play" protocols), concussion-focused outreach efforts, and position statements and guidelines for concussion in sport. The widespread concern about concussion in society today is highlighted by the fact that all 50 states and the District of Columbia now have sports concussion laws, or "return to play" protocols. A significant issue in concussion culture is the underreporting of symptoms, which has been found to be common among athlete populations (Sarmiento, Donnell, and Hoffman 2017). Some studies have suggested that underreporting is due to the stigma associated with reporting symptoms of being “weak” in a subculture that is dominated by ideals of strength and determination, as well as the perceived risks of losing future opportunities by being absent from play. As I will show in this section, public discourse on concussion is strongly gendered, presenting concussion as primarily a health issue for men.

Due to media coverage and increased public anxiety around concussions and CTE, the term “concussion” has become somewhat of a buzzword that has had the unfortunate consequence of diminishing the perceived severity of the condition (Sharp and Jenkins 2015). Instead, it may be referred to as “traumatic brain injury” or specifically “mild traumatic brain injury.” There is also rampant misuse of inaccurate terms in media coverage that qualifies the severity of the concussion used in the media, such as “mild concussion,” “minor concussion,” and “slight concussion,” when the medical community does not grade within the mTBI category (Ahmed and Hall 2017). The proliferating misunderstandings of mTBI across social arenas is further demonstrated by studies finding that there are inconsistent levels of knowledge about concussion across organizational positions, including players, parents, coaches, and medical professionals vis-à-vis an “information cascade” (see Block, West, and Goldin 2016). The media’s dissemination of concussion information is fragmented and incohesive (Ahmed et al. 2014). One problematic component of this is its contribution to sustaining the minimization of concussion as just “getting your bell rung.” Mainstream media reifies discourse concerning concussion by using softer language to describe concussion (e.g., blow to the head, head knock, bell rung) to frame concussion discourse in a way that minimizes the severity of the injury as having trivial symptoms, like headaches and dizziness (McLellan and McKinlay 2011). Such strategies of disease politics and institutional interests may be argued to diminish the condition and, consequently, the patient population too.

Medicalization and gender operate interactively to manifest head injury as a “men’s” condition. In so doing, these two social processes withhold women’s legitimate claims to the concussion diagnosis (i.e., the legitimacy deficit). The masculinization of concussion precipitates the legitimacy deficit that women with concussion face, which influences the diagnosing of and prognosis of women’s concussions. Because we get a lot of our concussion coverage from the world of sports, concussion is socially constructed as masculine. Watching the sports coverage on television, reading about it online or in the newspaper, or following the teams on social media, one may think that concussions are most prominent among male athletes because the media coverage of sports concussion in popular athletics is dominated by male athletes’ concussion cases – not to mention that the media favors male athletics generally in their coverage of popular sports. However, studies show that this is not the case, and in fact it is quite the opposite; female athletes are more likely to sustain a concussion (Powell and Barber-Foss 1999; Covassin, Swanik and Sachs 2003; Gessel et al. 2007; Hootman, Dick, and Agel, 2007; Lincoln et al. 2011; Davis-Hayes et al. 2017). We can further observe evidence of the masculinization of concussion in the case of society’s response to the National Football League’s (NFL) implementation of new policies for concussion protocol and prevention in the 2016 offseason. When the NFL implemented new penalties in the form of fines and suspension for players who deliver “devastating hits” or “head shots,” fans became outraged at what was, effectively, perceived as the feminization of football. This public outcry against the “pussyification of the NFL,” as one fan posted on an online discussion forum, is indicative of the entwinement of masculinity and concussion. This was not an isolated comment, either. Other posts read: “The NFL is turning into a touch football “Nancy Boy” League”; “Every single goddamn year the rules get more and more VAGINIZED”; “This is not good. Freaking women organs running this league." Such comments express the ideological connection of concussion etiology and masculinity. The very foundation upon which the entire sport is predicated – violence – is not compatible with concussion prevention (softness), in the very same way that concussion – because it is perceived to be caused by violent force – is not compatible with femininity (softness).

Dominant stereotypes about gender get woven into sports and medicine, constructing a cultural narrative that gets "under the skin" (see Lever 1976; Kessler 1990). That is, our culture comes to have physical manifestations in the body and through health. In the case of head injury, this manifests as gendered patterns in seeking treatment, symptoms, and prognosis with girls and women being left behind; they take longer to seek concussion treatment, experience more symptoms and more severe symptoms, and have longer recovery times (Banks 2007; Dick 2009; Coloantonio et al. 2010; Alston, Jones, and Curtin 2012; Chase et al. 2012; Harris et al. 2012; Munivenkatappa et al. 2016; Mollayeva, El-Khechen-Richandi, and Colantonio 2018). Given women's increased risk of and more severe experiences of concussion, why are they not the face of concussion? I argue this gender gap is due to the dual processes of medicalization and gender that concomitantly and iteratively produce head injury as a "men's" condition. As such, legitimate claims to the diagnosis of concussion are withheld from women by others. In turn, this prevents women from identifying themselves as potential patients and, consequently, they fail to seek timely treatment. The sequelae of such cannot be understated; from delays in treatment to preventing women from gaining the social support and resources needed for expedient and complete recoveries. We lack the necessary data on women's lived experiences of mTBI and how the legitimacy deficit is experienced, managed, and possibly overcome to produce favorable outcomes that could support intervention efforts. Relatedly, there is not yet an intersectional framework for mTBI resilience. It is also unknown how the legitimacy deficit operates across social institutions, such as medicine, family, education, employment and law, which may offer critical insights into the enduring processes of sexism and ableism.

A GENDERED DISEASE FRAMEWORK

This section outlines the extant scholarship that argues that diseases are socially constructed in ways that serve preexisting social structures and political agendas. Diseases and their diagnoses are not absent of politics as “pure” products of medicine, like is commonly believed. Diseases are classed, raced, and gendered. Understanding the emergence of a disease through a sociology of diagnosis makes visible the social systems implicated in producing and maintaining health inequalities.

The Sociology of Diagnosis

Diagnosis is the taxonomy of medicine; it is a way of categorizing disease based on symptomology. It organizes medicine, and in so doing, it organizes society. Diagnosis shapes our knowledge and practices, making a sociological investigation of diagnosis integral to understanding health and illness (Brown 1995). Diagnosis, as a process and as disease categories, is inherently social. Being social does not make diagnosis any less “real.” From a social constructivist perspective, what is considered “real” seems objective only because it is contrived through the repeated agreement of *many* individuals, making it appear independent of any one individual (Berger and Luckmann 1966). Ideas about what is “real” are processual and fluid as they are “constructed, negotiated, reformed, fashioned and organized” across cultures and time through interaction and influence future action (Sarbin and Kitsuse 1994:3). In the case of diagnosis, its tangible basis of the body is entwined with social conceptualizations vis-à-vis broader social forces, and interactive decision-making in categories and classifications in medicine. Diagnoses are fluid and situated; what gets labelled as "dysfunctional," how we interpret the causes, and how we respond to the bodily state is socially constructed. Thus, studying diagnosis provides insight into "how we comprehend disease, health, illness, and the forces that shape our knowledge practices" (Jutel 2011a: 5).

Disease categories are statements of disorder; they develop through societal beliefs about what is considered "normal" and, therefore, create and reinforce what is deviant. Medicalization is the process of bringing conditions of the human experience under the authority of medicine through evaluation and institutional recognition in culture and society (Zola 1972). Said differently, it marks a social problem as a medical one, henceforth legitimizing sickness and labelling it as "illness." The power to place bounds on behaviors and conditions stipulates medicine's authority vis-à-vis a diagnostic process that involves dynamic relationships between institutions and individuals, including the doctor-patient relationship. Diagnosis is a means for medicine to legitimize social concerns (Zola 1983). It founds and reinforces the social authority of medicine as an institution and the doctors who serve as agents of it. In this way, diagnosis is the vehicle for medicalization. The agents of medicalization are the doctors who have the power to certify a patient's complaint as medical in nature (i.e., to diagnose), to offer treatment plans, and to allocate resources (Conrad 2007; Davis 2010).

Nosology is the discipline concerned with classifying diseases using traits or characteristics that are commonly found together when a particular disease is expressed; it is used to identify or distinguish between diseases. These common traits that nosologists look for are called symptom clusters or symptom constellations. The identification and agreement of what makes a symptom cluster is a social process. Nosologists incorporate social context in the definitions of illness and health by referencing a culturally prescribed normative or "healthy" state to identify "others" or deviants – those who are experiencing symptoms that do not align with these criteria of experiences deemed normative or healthy (Zola 1972; Conrad and Schneider 1992; Brown 1995).

What does diagnosis do? Diagnosis makes sense of things, provides order, conditions social responsibilities, informs treatment protocols, and allocates resources to reintegrate individuals into society. Diagnosis is both an instrument for making sense of things and a form of meaning-making. In its rawest form, it is a classification system, but as an inherently social singularity, it is also a site of contest and compromise. Diagnosis is by no means absent of politics and is strongly linked to authority[4] (Weber 1919). It is a site for different fields and specialties to use diagnosis to validate their authority in credibility campaigns; for lay persons to campaign for a collective illness identity; and for policy and resource allocation campaigns.

Conflict perspectives illuminate how people in positions of power develop diagnoses within the frame of the constraints imposed by preexisting social structures. Diagnoses get developed, removed, and revised, further pointing to their socially constructed nature. The Diagnostic and Statistical Manual II (DSM-II) (1968) —a compendium of mental health disorders that outlines not only the disorder labels but also the symptom clusters that travel with them—once identified homosexuality as a mental disorder and listed it as a mental health pathology. In 1974, the DSM-II was revised to no longer list homosexuality as a mental disorder

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[4] The classical sociological definition of authority is that it signifies the possession of status, quality, or claim that compels trust and obedience from others. One important component of this is that authority signifies the potential to use force or persuasion to achieve compliance. To gain compliance of subordinate actors, authority incorporates two sources of effective control: these are 1) legitimacy and 2) dependence. Legitimacy refers to an actor's agreement with the claim that they should obey the authoritative figure; that these are legitimate authoritative figures; and that compliance with them is a good idea. The second is dependence, and this refers to an actor's estimation of foul consequences or possible repercussions that might follow their disobedience. This effectively subordinates actors to authoritative entities because they surrender private judgment.

after a mass social movement. The process of diagnosis starts with the rise of conditions in medical discourse that are then incorporated as disease concepts: a heuristic of how the social shapes our understandings of illness, medicine, and diagnosis. Diagnosis can be viewed either as validation of a particular reality just being discovered (Goode 1969) or as a reality that is taken for granted (Scott 1990). Diagnosis is, in effect, a symptom of society's preoccupation with classifying people that is manifested in medicine itself – and doing so in the belief that this will bring increased objective truth if earnestly pursued (Hacking 2001). This preoccupation with classifying people in terms of illness or disease is a process referred to as medicalization (Conrad 1992, 2007; Conrad and Schneider 1992; Horwitz and Wakefield 2007). To describe the process through which we classify people using medical criteria, Brown (1995) identified four stages in the disease discovery process: lay discovery, social movement, professional and organizational factors. Not all diseases go through each of these stages or follow these stages in a linear fashion.

While the diagnostic moment is often celebrated by sufferers as providing "a road map in the middle of a forest" (Jutel 2011a: 1), it is not value-neutral and can come with social detriments and iatrogenic consequences too (Scott 2006). Recognition of a symptom cluster as a disease can also be detrimental. For example, there has been much recent debate in Canada about whether the diagnosis of gender dysphoria is helpful or hurtful. Some argue that the diagnosis of gender dysphoria can provide patients access to certain resources, like insurance coverage for mental health services. Others argue that the stigma associated with gender dysphoria can only be perpetuated if the diagnosis exists, or, said differently: so long as we call this cluster of characteristics by a certain name or label, we indicate that there is something pathologically wrong with the individual bearing that label. Diagnoses like this can perpetuate stigma and prevent acceptance among individuals who carry this label. In this way, diagnosis is a double-edged sword. On the one hand, diagnosis can identify pathologies to treat and improve health through access to services and insurance coverage; it can also provide sufferers with a medical identity and a legitimate claim to the sick role. Yet at the same time, it can also create and perpetuate stigma that instead deteriorates health, rather than improving it.

By providing medical professionals with the means to identify and develop treatments, diagnosis gives order to symptoms. Therefore, diagnosis is typically welcomed by sufferers; it is a sign of hope for reprieve from their suffering. Diagnosis not only organizes and provides sufferers with access to resources and services, but it also provides the person who is sick with a well-defined social role: the sick role (Parsons 1951). The sick role emerged as a functional response to illness. In his research, Parsons noted that when a patient takes on the sick role, they become exempt from normal responsibilities that might interfere with recovery, and they are also released from responsibility for their illness. These exemptions, however, come with contingencies: the sick person must identify their condition as an undesirable one they wish to recover from, and they must actively pursue recovery with medical cooperation. The sick role, however, is not open to all; it is conferred upon select individuals through social judgement. Others judge legitimacy of a patient's claim to the sick role, in part, through diagnosis.

Thus, diagnosis serves to excuse irrational behavior and social role fulfillment and can lift moral condemnation of sick people (Parsons 1951; Zola 1973). Rather than holding the individual accountable, we displace responsibility for the actions on to the disease or the illness. However, Zola (1973) argues that this is not universal to all diagnoses. Only under certain circumstances can a diagnosis provide a claim for exemption from normal social activities or behaviors. Williams (2005) similarly identifies the inapplicability of the sick role to chronic illness and disability. While the sick role can offer protection, the pendulum can also swing from the sick role to patient-blaming, where others believe that the sick person is responsible for their condition and, therefore, undeserving of the benefits that should accrue to one who legitimately performs the sick role. The occurrence of such instances points to a legitimacy deficit: the social denial of the validity of a particular person's claim to a particular status, identity, or role.

The Legitimacy Deficit

The relationship between diagnosis and legitimacy is well-documented. Legitimacy refers to authority garnered through institutions as being valid. In the case of diagnosis, the determination of legitimacy is epistemological, moral, and institutional (Kempner 2014: 13). Legitimacy and resources have a multidimensional conditional relationship where the allocation of resources can substantiate the legitimation of a disease or vice versa where the legitimation can generate resources. It is through the conference of the sick role that the allocation of resources for the disease and its patient population follows; the deemed worthiness of a patient population determines the extent of resources afforded to them. Here, I address resources broadly, referring to anything that compensates for or supports one's functioning under adverse conditions (e.g., social services, federal research funding, media coverage, etc.). For these reasons, it is critical to understand the political economy of mTBI; how disease politics shape culture, and how discourse affect the disease frame or how we understand illness.

The potency of a diagnosis' cultural content affects the authority of a disease more so under conditions lacking physical observability (Jutel 2011a). Social framing in medicine is helpful for understanding how some diseases go undisputed, but nonetheless are socially negotiated categories. Aronowitz's (2008) concept of "social framing" refers to the way disease states are discovered, and their etiologies explained in societies. Social framing also comes to shape the perspectives toward and experiences of patient populations. The process of legitimating a diagnosis is conditioned upon the construction of a patient population being viewed as deserving the resources that accompany the diagnosis; a biomedical model and a specific disease mechanism are not guarantors. The question becomes, “Do these people deserve our help and resource?” Patients constructed as malingering receive fewer resources, if any at all, whereas more favorable patients who are regarded sympathetically have improved chances of winning precious resources. An important and interesting note in understanding this multidimensional relationship between diagnosis, resources, and patients is that in some cases the distribution of resources can be sufficient to assuage the legitimacy deficit, even in cases that lack biomedical evidence.

Barker (2005) addresses illnesses as a “continuum of verifiability” where conditions that can be plainly identified by objective markers (e.g., observable measures whether simply through visual inspection or through biomedical measures) are on one end of the spectrum of legitimacy and conditions that are only identifiable through subjective evidence (e.g., self-report pain scales) are on the other. The further a condition lies on the subjective end of the spectrum, the more likely it is to be questioned and the more likely sufferers are to experience a legitimacy deficit. The sequelae of experiencing a legitimacy deficit in the context of health are quite extensive. Whereas patients with plainly identifiable conditions benefit from sympathy, community assistance, insurance eligibility, and plentiful treatment options provided by medical and pharmaceutical companies, those who suffer from undiagnosable conditions are likely to be labeled negatively—often on moral grounds that reduce their condition to laziness or mental instability; after all, the symptoms are “all in their head.”

Labelling a condition psychiatric has been unreservedly used in medical history as a broad catch-all for really anything outside the norms that offered no other readily available explanations. Psychiatric diagnoses are often contested for this reason, but even diagnoses with observable indicators can be dependent on social judgements and beliefs. Mental health and invisible illnesses have a history of being feminized. Foucault (1973) famously noted the "hysterization of women's bodies" in phrenology from the 1800 and 1900s. The legacy of the image of the hysteric woman plays a significant role in the legitimacy deficit women with mTBIs encounter. The idea that it is "all in her head" persists in cultural narratives today, as does the idea that women tend to exaggerate their symptoms as the "fairer sex" with lower pain thresholds. Under such assumptions, women's symptoms are believed to be less severe than men's, making women less deserving of the sick role. This reflects the mind-body dualism – the distinction between what is psychiatric (a matter of the *mind*) and what is neurobiological (a dysfunction of *brain*). This has been well documented in the case of pain disorders. Kempner (2017) argues that "because pain is interpreted through a gendered lens, women are also much more likely than men to have their symptoms attributed to neuroticism, hypochondria, or emotional distress (Barker 2005; Kempner 2014; Werner and Malterud 2003; Hoffman and Tarzian 2001)" (p.1). As a junction of power and knowledge, discourse can concurrently be both an instrument of authority and a space for resistance.

A helpful theory in conceptualizing the relationship between medical authority, patient legitimacy, and illness experiences is Fricker's (2007) concept of "epistemic injustice": the systematic discrediting of marginalized groups' knowledge claims about their own experiences (see Liegghio 2013; Carel and Kidd 2014; Kidd and Carel 2016; Wardrope 2015; Crichton, Carel, and Kidd 2017). Uncertainty about the condition translates into skepticism of its sufferers. Said differently, when conditions are not completely understood and/or without diagnostic tests available to provide objective evidence of physical dysfunction in combination with the increasing demands on providers that limit their time, patients with negative results are more likely to be dismissed, to be psychologized, and to be labelled as illness seeking (Barker 2008). The psychologization by healthcare providers is a form of psychological “gap-filling” to make sense of the patient’s condition when other explanations are unavailable. Neurology is a complex field of medicine that, relative to the history of medicine generally, is in its infancy stage as we are developing new technologies to explore the brain more completely. Even today we do not have a diagnostic test for CTE in living patients; that is, it is a condition that can only be diagnostically proven after death. mTBI is a complex condition that has no reliable diagnostic measure and comorbidities that make it difficult to assert that symptoms are due entirely to mTBI and not due to another condition like PTSD – a common comorbidity due to the nature of the injury being an external bodily trauma. This makes it likely that mTBI patients are at greater risk for epistemic injustice.

Stigmatized labelling even occurs in the medical community. In their everyday practice, health providers usually label patients either positively or negatively based on the patients’ presentations of self (e.g., Hillman 2015). This is the distinction healthcare providers make between a “credible” and a “troubled” patient (Werner and Malterud 2003; Li and Arber 2006). When a patient is labeled negatively, they are marked as deviant and, therefore, take on a legitimacy deficit that, in turn, creates barriers to health resources and services, and negatively impacts their self-image. It is essential for patients to provide persuasive accounts of blamelessness, validity, and worthiness to pass with legitimacy and, consequently, gain access to the myriad of benefits accompanying patient status or “the sick role” (Parsons 1951). Thus, conditions approaching the undiagnosable end of the spectrum can negatively affect physical health and social wellbeing. The condition may also be affected by social determinants creating a feedback loop. Thus, these effects are not additive; they interact to magnify the sufferer's state of wellness.

Gendered Legitimacy Deficits

One social axis upon which legitimacy is determined is gender. Instances where others judge someone's claim to a status that is contingent upon their gender may result in a gendered legitimacy deficit. Gendered legitimacy deficits have been documented across varied contexts. We see one such example among women surgeons whose career choice was viewed as incompatible with their gender identity. Regarding the interaction of doctors and patients in the diagnostic process, Pescosolido, McLeod, and Alegria (2000) have identified "grey areas" – those that have unclear clinical presentations – as contexts where diagnoses are most likely to undergo social construction. Because the physician lacks a dominant medical template to apply to the patient's case, they instead rely on more commonly used social templates or stereotypes about characteristics of the patient, such as gender. This is an explicit demonstration of how a given social characteristic can affect a person's opportunity to receive a diagnosis and to be treated as a credible patient. In this instance, the patient is the object of medicalization, but a patient can also initiate medicalization.

Patients sometimes fight for diagnoses because they face a legitimacy deficit; important consequences can follow when a patient is denied the sick role because they do not have a diagnosis. Some consequences are instrumental; for example, the patient might be denied insurance benefits for services and treatment. Other consequences are social; for example, the patient might still have to meet social expectations, fulfill roles or perform behaviors that would never be expected of someone who was identified as authentically suffering. Thus, many patients fight hard to receive diagnoses. Diagnoses confer benefits, and the consequences of not having a diagnosis can be quite profound.

We see this most commonly in cases of contested illnesses: those without an available classification for their symptom cluster. Medically unexplained or poorly understood conditions, what sociologists call “contested illnesses,” are far more common among women than men (see Malterud 2000; Dusenbury 2017). Well-studied contested illnesses include fibromyalgia, irritable bowel syndrome, and chronic fatigue syndrome. Each of these conditions can be used to highlight how diagnostic labels provide legitimacy for symptoms and illness identities. For example, Barker (2008) demonstrates the role patient agency plays in defining a new disease. Her research examines how fibromyalgia patients use online forums as a platform to mobilize around their shared experience of illness in pursuit of medicalizing their conditions. Kempner (2014) provides a different example by demonstrating how ideologies about gendered morality influence the legitimacy of migraines as a diagnosis within both the medical community and society at large. Despite this important research, there remains a need for research that examines how diagnoses are legitimized in contexts where the diagnosis is medically recognized but are considered legitimate only when applied to a particular subgroup of patients due to the interweaving of beliefs about the sick role and gender roles. Kahn Best argues that diseases are highly politicized, stating that “conceptions of worthiness shape advocacy and policy,” meaning that benefits are distributed to “groups perceived as deserving and blameless and to punish or ignore stigmatized groups” (2019: 12). The present study counters the argument that it is the disease, not the patient, that justifies treatment (Rosenberg 2002) to suggest that in some cases of disease, disease in fact is *not* enough to justify treatment.

A strong vein of research focuses on how some health conditions are minimized because they predominantly affect women (Swoboda 2006), such as multiple chemical sensitivity (MCS), chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME), fibromyalgia (FMS), and headaches. Scholarship on the sociology of diagnosis has largely grown out of contested illness cases (Jutel 2011b). Other illness and disability scholarship focuses on men who grapple with a femininized diagnosis (i.e., a condition usually associated with women). In contrast to these three well-researched areas, this dissertation examines how patients interact with the medical paradigm of illness and inversely how disease frames shape the illness experience. Through this research, I consider mTBI as an example of a disease entity that is strongly framed by beliefs about gender roles and morality to show that such selective contestation and authorization extends beyond the diagnosis at the institutional level to interact with patient characteristics at the individual level. My study offers a heuristic for the principle of social framing through the concept of legitimacy deficits. It is the first to trace how the legitimacy deficit is experienced by patients across social domains and throughout the disease process. In doing so, this study problematizes the presently accepted and dominant frameworks for credentialing disability that recognize readily apparent and visibly discernible disabilities as serious conditions warranting support, as well as secondary frameworks that rely on social characteristics to make determinations about invisible disabilities. While women's life experiences have historically been medicalized more than men's, the present study offers a case of how women are affected by this century's increased medicalization of men.

CHAPTERS SUMMARY

In this introduction I provided a brief overview of the extant literature that I used to frame my study, including some basics of brain injury epidemiology and a review of a gendered disease framework. In the chapter that follows, I introduce my study's research methods and data analysis, as well as a discussion of my positionality. Following are my four analytic chapters where I detail the major themes in the findings of this research. I first present my findings on women's experiences, starting at the beginning of the disease process in Chapter 3 to examine how women get injured, get diagnosed, and make sense of their "new lives." In Chapter 4, I attend to the next stage of the disease process: treatment. In the treatment stage, I examine barriers and facilitators of treatment access and adherence, as well as the process of adapting to their condition in the illness experience. In the case of mTBI, there is often not a "recovered" stage as it is a condition that can be improved, but never fully ameliorated, so in Chapter 5 I examine what can be considered the final stage of the disease process for mTBI that is adapting to chronic illness. Here I examine what women patients self-reported as their new "normal" or the plateau of the recovery process, focusing on the social determinants of women's return to their typical activities pre-injury or adoption of a disabled status. In Chapter 6, I examine the lives of men with mTBI and to contrast their average disease process trajectory with that of the women's presented in the preceding analytic chapters (3-5). In my concluding chapter, I briefly review the findings from the study, discussing their contributions to the areas of gender, medicine, and health/illness, and identify possible future directions for advancing research on patient legitimacy deficits to improve quality of life and health outcomes.

CHAPTER 2

RESEARCH METHODS

While quantitative research has yielded useful knowledge about the mild traumatic brain injury (mTBI) patient population, this type of method is less compatible with identifying *how* and *why* disparities in incidence and prognosis occur. To understand what it means to be a man or a woman with mTBI, to learn how they navigated their recovery process, and to study how they perceive and manage legitimacy deficits, a qualitative approach was necessary. Because reality is a social construct (Guba and Lincoln 1994), the most incisive and complete understandings of our experiences and the social systems that shape them are gained by understanding the perspectives of those who directly experience them (Emerson 1988). The intensive interview is especially well-suited to tap into the meanings and processes that shape these subjective social realities because it allows participants to describe things I could not experience (Charmaz 2003, 2006). In short, I had to talk to the sufferers themselves to fully understand their experiences. To achieve this understanding, I interviewed 52 mTBI patients between May 2020 and June 2021. Of these 52 participants, 38 were women and 14 were men. The median age at the time of the interview was 44 years with a median of four years since their last injury. The most common cause of injury was vehicle-related collisions (23), followed by falls (16), sports injuries (5), violence (5), and then combat injuries (3). Twenty were single and 32 were married. Twenty-two had dependent children. Two identified as Native American, one identified as African American, three identified as Hispanic, and 46 identified as non-Hispanic White. Two identified their socioeconomic as upper class, 7 as middle-upper class, 30 as middle class, two as lower-middle class, three as working class, and eight as poor. Fifteen participants had graduate or professional degrees, 17 had bachelor's degrees, 19 had high school degrees, and one had a less than high school education. Thirty participants lived in the U.S. West, six in the Midwest, four in the Northeast, nine in the South, and three lived in Canada. For participant-level information, please see Appendix B.

DATA COLLECTION

Recruitment and Sampling

I used a fairly broad sample criteria, consisting of individuals who experienced one or more traumas that resulted in a concussion/ mTBI/ PCS [5] diagnosis[6] in adulthood because of the constructivist grounded theory approach I used in this study (Charmaz 2006). I first began my recruitment efforts by inviting friends on social media, including Facebook and Twitter, to participate in an interview for my dissertation. I also invited members of support groups I was a part of to participate in my research through announcements in our groups' newsletters and at meetings. From here, I gained participants through snowball sampling, where participants shared my study's information with other potential participants who contacted me to participate (Lofland and Lofland 1995). I then moved to expand my recruitment efforts by advertising my study on the websites of a handful of local Brain Injury Association of America (BIAA) branches that offered such a space for research participation opportunities. I also recruited participants through paid Facebook advertisements and in Facebook groups related to concussion

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[5] Mild traumatic brain injury signs and symptoms that persist one to three months post-injury are cases of PCS, while cases of symptoms extending beyond three months are places in the persistent PCS category of diagnosis. About half of diagnosed mTBI cases are classified as PCS, and 10-15% as persistent PCS.

[6] My sampling is restricted to those formally diagnosed with concussion, which may not capture all experiences due to the nature of diagnosis – i.e. that only those diagnosed with concussion are included in the population, and my very argument is that the social construction of concussion prevents many from claiming the diagnosis and therefore I am only representing those with diagnosis, not the experience itself.

or TBI with prior permission from the group moderator(s). Finally, I advertised the study in online forums, including Reddit threads related to concussion or TBI and Craigslist. Expanding recruitment efforts outside of my own social network diversified the sample geographically, racially, and economically, as discussed in the successive section that addresses the sample.

As grounded theory is an iterative process that simultaneously combines sampling, data collection, and data analysis, I used theoretical saturation to determine my sample size (Glaser and Strauss 1967; Small 2009). That is, I stopped collecting interview data when I was not finding new data that would help me develop my analytic categories. I was consistently hearing the same narrative from participant to participant, making me confident that my data was saturated. When I felt I was reaching saturation, I sought out a few additional participants who I thought would be likely to provide new data based on their demographic diversity: a man who was a medical doctor, a woman who was incarcerated, and an unemployed single mother who was living in a shelter with her two young children after recently fleeing domestic violence. Despite my efforts to expand the diversity of data to its farthest edges, the substance of my analytic categories remained unaffected, indicating that further sampling was not necessary.

Participants

I recruited 52 participants, with my sampling primarily separated into two gender groups[7]: men and women. Thirty-eight women and 14 men diagnosed with one or more concussions or mTBIs in adulthood participated in interviews for this research. While I had originally aimed to recruit a relatively equal number of men and women, as is common with grounded theory approaches, my sampling strategy changed with the development of my analytic categories. At the start of this study, it proved difficult to recruit men despite concerted efforts.

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[7] There is significant literature warranting the centering of gender and gender as a primary frame (see for example, Ridgeway 2010).

This initially surprised me due to the gender politics of concussion and TBI, but it is certainly characteristic of health research. However, this does not weaken the present study. Rather, by principally interrogating women's experiences, I give equal voice to a marginalized group and better develop theory (Glaser and Strauss 1967; Corbin and Strauss 2008; Timmermans and Tavory 2012).

The multipronged recruitment strategy yielded a sample that was clinically, geographically, and socially diverse. Diversity across these dimensions is particularly important in this study given the limitations of clinic-based research that tends to be skewed with more severely ill patients than the community population and often differs significantly in key social measures, like socioeconomic status, race/ethnicity, and educational attainment. Geographically diverse participants were sampled primarily in the U.S., as well as Canada. I had few racial minority participants (12%), despite efforts to target them in recruitment. To help address this, I was careful in my findings to address their unique experiences and highlight them, but this is an important limitation of this study, which I discuss in the Conclusion chapter in the section dedicated to study limitations.

Interviewing

I conducted interviews via video conferencing, phone, and email between May 2020 and June 2021. The intensive interview was the best fit for addressing the processual nature of my research question. The complexity of process-based inquiry requires a level of detail and depth that is accessible only in the intensive interview where the researcher can understand experiences, behaviors, motives, and opinions from the participants' perspectives (Rubin and Rubin 2011). While scholars have argued that intensive interviewing yields the best data when done in-person, virtual formats – like the ones I used – are becoming increasingly common in the modern research era and demonstrate positive outcomes (Egan, Chenoweth, and McAuliffe 2006; Hamilton and Bowers 2006; James and Busher 2006; Meho 2006; Creswell 2007; Kazmer and Xie 2008; Elmir et al. 2011; Wertz et al. 2011; Fritz and Vandermause 2018). Some interviews were also conducted virtually out of necessity during the COVID-19 pandemic that prevented meeting participants in-person safely.

Incorporating these different approaches into the intensive interview was practically and epistemologically beneficial to my study because my population had special needs. mTBI can affect vision, fine motor control, and cognition, making it difficult to write, type, or read, so it was important to incorporate both synchronous and asynchronous options with audio and text communication for inclusivity and representation. Not only were virtual interviews more inclusive, but they also produced richer data that was deeply reflective, as evidenced in my communications with participants who might have stopped an in-person interview or responded very briefly due to symptoms. Another benefit of employing virtual interview methods was that I had access to a more geographically diverse sample than I would have otherwise.

The methodological control, such as flexibility, available with interviewing increases analytic power. Using a grounded theory approach with a semi-structured interview guide ensured access to a variety of participants' experiences, rather than risking my understanding of their illness experiences being constrained by my own preconceptions (Rubin and Rubin 2011). This was critical given my shared patient status and because there is no singular mTBI experience given its extensive symptom cluster. I pursued interpretive inquiry by exploring distinctive considerations, ascertaining context, and gaining clarity with a semi-structured interview guide (Lofland and Lofland 1995; Strauss 1987; Charmaz 2008; Brinkman 2014).

I designed the interview guide as an outline of general topics with specific questions. I began each interview with demographic questions followed by ones about their TBI medical history. With a foundational understanding of their injury, diagnosis, and treatment plan, I prompted participants to walk me through their experience from the point of injury to where they were now. Along the way, I would ask who diagnosed them, what resources they received, and any resultant changes in their work and/or home lives. I also asked interviewees explicitly if they thought their gender identity shaped their experiences in any way. The interview guide served as a flexible template for me in terms of tailoring the order and delivery of each interview's unique flow. I would pose follow-up questions to gain clarity, to pursue potential directions for discovery, or to test concepts (Lofland et al. 2006). This inductive approach allowed me to refine the study guide and adjust the focus of subsequent interviews upon the discovery of emerging themes as the study evolved to be more focused in pursuit of specific data that targeted emerging analytic categories. For example, after conducting my initial 10 interviews, I identified an emerging theme of patient legitimacy and added an additional question to my interview guide that targeted this newly discovered analytic concept. Being able to do so generated richer data that ultimately promoted theory development by referencing preexisting theoretical frameworks and testing these concepts in later interviews (Burawoy 1998). In this way, I was able to advance our understanding of gender, health, and medicine by situating participant accounts within existing frameworks to further develop present theories and concepts, such as legitimacy deficits and contested illness. Interviews with audio typically ranged in duration from 45 minutes to 2 ½ hours. Completed textual email interviews were comparable in terms of length upon threading them into a transcript document.

DATA ANALYSIS

All interviews were digitally recorded with the participants' permission. I took notes during the interviews and wrote brief memos following each (Lofland et al. 2006). I later transcribed the recordings using pseudonyms and obscuring any potentially identifying information to ensure confidentiality. I began analyzing the data using the principles of grounded theory to organically identify meaningful and distinct emergent themes related to gender, health, and medicine through the coding process while remaining mindful of my role in the knowledge production process (Charmaz 1995; Lofland et al. 2006). I first coded by stages in the disease process and then by gender, coding both within and comparatively across genders to look for similarities and differences that explain systemic forces shaping men's and women's post-traumatic brain injury experiences. I then moved to focused coding, where I identified sub-themes through an iterative process where I returned to the data numerous times and refined the codes with each pass (Lofland et al. 2006). My constructivist grounded theory approach allowed me to pursue novel analytic categories during my sampling. This ultimately directed my study's focus to examine how gender acts as an organizing principle in the illness experience, which is particularly salient among mild cases of traumatic brain injury due to the combination of invisibility, fluctuating symptoms, and the capricious contours of the sick role that result in the application of a familiar framework for remediation.

Intersectionality is an important theoretical framework for studying gender and health (Springer, Hankivsky, and Bates 2012). Critical discussion on population health research has, since the 1990s, called for increasing integration of intersectional approaches to focus on the power dynamics contributing to health inequalities, particularly the relationship between social categories and power through process and structure (Bauer 2014; Mulinari et al. 2018). Intersectionality has significant methodological and analytical benefits to offer health research:

increasing precision, promoting transferability in terms of policy and intervention, and ensuring applicability across subgroups (Bauer 2014; Green et al. 2017). My analysis was system-centered, focusing on gender and medicine as "processes that are fully interactive, historically co-determining, and complex" (Choo and Ferree 2010: 129) in their shaping of mTBI patients' experiences.

I used various strategies to maximize the trustworthiness and minimize the limitations of my findings. Using constant comparative analysis and theoretical sampling afforded assurances for the validity of my study (Glaser and Strauss 1967; Corbin and Strauss 2008; Denzin and Lincoln 2005). Including participant involvement throughout my study's life supported internal validity (Creswell 2007). Regarding external validity, my development of grounded theory and use of theoretical saturation offers generalizability (Bickman and Rog 2008). I took precautions in my study design to ensure the accuracy of these findings by anticipating and addressing my own potential biases and personal perspectives (Creswell 2007). To minimize the effects of research bias, I maintained a continuous reflection, examination, and exploration of my own relationship to the data throughout the duration of this study (Conrad et al. 1993; Bickman and Rog 2008). In the section that follows, I offer a detailed discussion of my position in relation to my participants and the context of this study.

POSITIONALITY

While I was able to recruit some participants from non-white and/or working-class socioeconomic backgrounds, most participants shared my background as a white, middle class, educated person living in or near an urban or suburban area. Due to this study's focus on gender and health, I center my discussion here on the same as the most salient characteristics in this analysis. Being a woman affected the researcher-interviewee interactions with men and women differently, creating both bridges and barriers to data generation. In managing gender (in)congruence, lessons from Charmaz (2006), Riessman (1987), and Arendell (1997) improved the interview guide, the data collection process, and analysis.

There was one common experience I shared with each participant: being an mTBI patient. My own experiences with an mTBI and the conversations I had with professionals and fellow patients/survivors over the last couple years inspired my research topic. A benefit of having a shared diagnosis was that I had the capacity to share partial understandings of an experience that is ineffable. I also had a heightened awareness of the diverse and distinctive special considerations of the population that might otherwise have created practical barriers to participation and data collection[8]. It also helped reduce power differentials and assisted in promoting a "friendly conversation" that generated rich data (Spradley 1979). The tone of the interview seemed to change nearly instantaneously when I disclosed my patient status. My own experiences could very well have inadvertently narrowed the research, but instead, I was able to avoid this by diligently employing the methodological principles of grounded theory to discover new knowledges I had never considered, such as a legitimacy deficit. I was careful to attend to the power differences and differences in meaning-making between myself and participants. One strategy I employed to prevent misunderstandings or inaccurate assumptions/imposed meanings was to ensure participants were defining their experiences in their own terms. Within the interview itself I remained attentive to any presumptions I was making throughout the participants' narratives and would ask for confirmation of my understanding or for clarification.

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[8] e.g., background noises like a fan; people walking by outside the window; lighting obstructing lip-reading; transportation; mobility issues; looking at screens; reading; attention; social fatigue; light; etc.

METHODOLOGICAL LIMITATIONS

Despite significant efforts to recruit a demographically diverse sample, this research is unable to offer a fully intersectional analysis given its generally homogenous and relatively small sample. While I had aimed to recruit a relatively equal number of men and women, not uncharacteristic to health research where males comprise only about 20% of samples, men were much more difficult to recruit despite concerted efforts to purposively sample them (Ryan et al. 2019).

Similarly, my sample lacks racial and ethnic diversity, which I attribute to two primary factors: underrepresentation in the population and the recruitment methods. Regarding the former, non-Hispanic whites make up more than half of concussion diagnoses. Studies show that ethnic minorities are less likely to seek medical care for head traumas, and even when they do, are less likely to receive a diagnosis of concussion (Mannix, Meehan, and Pascual-Leone 2016; Lyons et al. 2019; Wagner et al. 2020). In many ways, concussion is a diagnosis of privilege as studies show that knowledge and access to medical treatment is stratified by socioeconomic status, vis-à-vis private health insurance as the primary mechanism through which patients are more likely to receive care from a specialist who may advocate for novel testing and for relative rest on their behalf (Zuckerman et al. 2017). Secondly, due to the COVID-19 pandemic emerging during my recruitment process, my recruitment strategies were significantly limited to online formats. This limits access to more economically diverse populations, which is strongly correlated with race and ethnicity.

A final potential methodological limitation is gender congruity. As a woman interviewer, I may have failed to identify importance or interpret meaning among men and women with different intersecting identities (Riessman 1987). Gender may aid in the process of generating rich data and accurately interpreting meaning, but it is not independently sufficient as the form and translation of meaning may be missed in the case of gender congruity but where there is ethnic incongruity.

Despite these methodological limitations, this research illuminates the gendered processes that shape the mTBI disease process and contribute to the gender gap. By interviewing patients, I am able to explicate the meaning making processes patients engage in when interpreting their experiences and navigating the intersecting systems that contour their recoveries. In the process, I unveil the gendered disease frame of the concussion diagnosis and how gender as a social system exacerbates health disparities.

CHAPTER 3

GETTING DIAGNOSED

> *"Feeling unwell is the usual prompt for seeking medical attention. And it involves a premedical assessment in which the individual attributes his or her unwellness to what he or she thinks is likely to be a disease rather than an external or nonmedical factor. But it is the inability of the lay person to fully interpret the situation, despite assigning it to the realm of the medical, that leads to the clinical encounter (Leder 1990). He or she seeks the explanatory power of the diagnosis, which the doctor is authorized to deliver." (Jutel 2011a: 63)*

While diagnosis is dominantly defined relative to its biomedical utility for identifying diseases, scholars in the social sciences argue that it is socially constructed as it is influenced by "social, political, technological, cultural and economic forces" (Jutel and Nettleton 2011: 793). Thus, diagnosis is also political as a social process that shapes and is shaped by social systems (Blaxter 1978; Brown 1995; Jutel 2009). Diagnosis can be analyzed "as a category, a list of diseases, and diagnosis as a process, the thing the physician does: the conclusion reached, or the act of coming to that conclusion" (Blaxter 1978: 9). Having clinical, social, and psychological implications (Nettleton 2006) makes diagnosis a critical space for sociological inquiry; it is a cornerstone of both medicine (Mishler 1981) and the illness experience (Pierret 2003).

For medicine, diagnosis signals an explanation of dysfunction, and with it, the knowledge needed to manage the condition (Lyng 1990). Diagnosis is a crucial pivoting point where illness becomes disease (Jutel 2011a). It serves as the vehicle for increased authority and privileges. Jutel (2009) nicely summarizes the import of diagnosis in stating, "being diagnosed gives permission to be ill. What was previously a complaint is now a disease" (p. 278). Socially, diagnosis validates individuals' illness experiences and their claims to the sick role (Telles and Pollack 1981). Legitimacy refers to the authority garnered through institutions as being valid. In the case of diagnosis, the determination of legitimacy is epistemological, moral, and institutional (Kempner 2014: 13). By endowing patients with legitimacy, diagnosis enables individuals to gain important privileges, like access to resources[9] and excusal from certain social roles (Steward and Sullivan 1982; Zavestoski, McCormick, and Brown 2004). In this way, physicians serve as gatekeepers, deciding who receives coveted diagnoses to attain patient status, along with the sick role's associated privileges (Mik-Meyer and Obling 2012). Because of these social implications, being diagnosed is also a matter of politics (Michailakis and Schirmer 2010). The third dimension of diagnosis is psychological. Diagnosis offers validation to the individual's own self by offering diagnostic evidence of their disease, supporting the "realness" of their symptoms (Broom and Woodward 1996). Effectively, diagnosis tells patients they are indeed not crazy, and their symptoms are not "all in their head" (see Kempner 2017; Barker 2005). This triad, in turn, affects patient prognosis and resiliency (Draucker 1991; O'Flynn and Britten 2000). In these ways, diagnosis is simultaneously a category and a process with diagnostic consequences.

In the sections that follow, I use Gerhardt's (1989) model of the diagnostic search[10] to outline how the gendered disease frame shapes illness experiences throughout the diagnostic encounter in the case of mild traumatic brain injuries (mTBI) or post-concussion syndrome/persistent concussive symptoms (PCS). The mTBI label serves as an umbrella category for concussions (conditions where symptoms resolve within three months following the injury) and PCS (conditions that persist four or more months after the injury). Interestingly, women are more likely to be diagnosed with PCS. While some have suggested this may be due

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[9] I address resources broadly, referring to anything that compensates for or supports one's functioning under adverse conditions (e.g., social services, federal research funding, media coverage, etc.).

[10] In Gerhardt's (1989) framework for the diagnostic search, both medical and lay persons engage in various forms of bargaining until an agreement of sorts is reached (aka a diagnosis); the patient is viewed as an active agent that has the power to reject and direct physicians' diagnoses and treatment plans.

to women's increased reporting of symptoms, the findings I present here suggest that the increased rate of women's PCS diagnoses may be in part due to the feminization of psychiatry that shades physicians' diagnostic assessments. In the sections that follow, I show how the contestation of the PCS diagnosis and the gendered disease frame come together to create legitimacy deficits for women patients in the diagnostic search. At each stage, there are various social systems that affect the trajectory of this process, including information accessibility, economic status, resource availability, and doctor-patient relationships. Studying diagnosis provides insight into "how we comprehend disease, health, illness, and the forces that shape our knowledge practices" (Jutel 2011a: 5).

I argue that women face obstacles at each stage in the diagnostic search due to the gendered disease frame of concussion. Women patients encounter difficulties interpreting their symptoms and identifying it as a serious medical condition in the pre-diagnosis stage. This is followed by the initial clinical encounter, signs and symptoms, and the diagnostic moment. The diagnostic process is contoured by the gendered disease frame of mTBI that manifests legitimacy deficits for women patients. I argue that legitimacy deficits arise for patients whose identities are incompatible with the dominant disease frame, and where the disease is characterized by non-specific symptoms and lacks available diagnostics[11], because mainstream[12] physicians rely on social frames, such as gender, to inform their medical assessments (Mik-Meyer and Obling 2012). It is important to note that this study is limited to those who received formal diagnoses of a mTBI, so I cannot capture the experiences of individuals who never progress past the pre-diagnosis phase of the disease process, wherein eight in every nine concussions are estimated by

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[11] Biomedicine or evidence-based medicine (EBM) differentiates symptoms from clinical signs, with the former being subjective and the latter being objective.

[12] Referring to physicians without specialized training in the diagnosing and treating of concussions or brain injury.

the Centers for Disease Control and Prevention (CDC) to be lost. By identifying challenges among those who ultimately persist and receive a diagnosis, this study suggests moments in the diagnostic search process where others may fall out of the diagnostic search process, thereby explaining some of the undetected cases.

IDENTIFICATION OF ILLNESS

In the pre-diagnosis stage, individuals experience uncertainty surrounding their illness experience and many potential patients fall out of the diagnostic search process because they fail to recognize their condition as medical, lack resources to seek care, or choose not to seek medical care for any other myriad of reasons (e.g., iatrophobia). The pre-diagnosis phase is a critical point in the diagnostic search, as well as the disease process more generally, because if one does not identify their condition as warranting medical attention, the individual never seeks medical care and does not go through the rest of the phases in the diagnostic search. Without a diagnosis to open pathways to treatment, one's prognosis is greatly encumbered. Recent work has examined patient experiences that lead up to the diagnostic moment, focusing on how patients first become aware of their symptoms (see Poole and Lyne 2000; Locock et al. 2016). Given that traumatic brain injury (TBI) requires a trauma to occur, all respondents in this study could definitively identify symptom onset from an acute injury. However, the timing of when they identified their condition as warranting medical attention varied. This is what Sheryl, a 51-year-old single mother, referred to as the "Oh shit, this is bad" moment.

Applying the Disease Frame

The concept of social framing in medicine is helpful for understanding how some diseases go undisputed but, nonetheless, are socially negotiated categories. Aronowitz's (2008) concept of the "social framing" of diseases, or disease frames, refers to the way disease states are discovered, and how their etiologies are explained in societies. Social framing also comes to shape the perspectives toward and experiences of patient populations. This is evident in this study as early as the pre-diagnosis phase. For some women, they only accepted the seriousness of their symptoms when they were still unable to do normal activities – like go to work, take care of their children, or watch television – days or even weeks later when they eventually sought medical care. Women's delay in seeking medical care for their mTBIs is not surprising given extant research and available statistics (see Desai et al. 2019). Misinformation about concussion's etiology and the image of the ideal type for concussion patients played a significant role in the women's identification of their conditions as potential concussions. The popular understanding of brain injuries is that they require a forceful impact directly to the head and/or an open head trauma, even with falls and whiplash being common causes of concussion. Despite the statistical prevalence of brain injuries from everyday activities, the women in this study cited "minor" accidents, absence of impact, and closed-head traumas as reasons they failed to initially identify their conditions as concussions. Margo, a 58-year-old married mother, said:

> It didn't even cross my mind that I could have a concussion or brain injury. You hear about that with football players and kids playing sports and stuff, but you never hear about concussions from people just doing everyday things, so it just never occurred to me that *I* could have gotten one just from a silly thing like my dog running into me. I'm not a linebacker for the Patriots.

Other gendered disease frames also influenced women's pre-diagnosis experiences. Emma, a 38-year-old mother of young children, thought she "must just be having a really bad headache" for the week following her motor vehicle accident. The disease frame for headaches fit better for her than a concussion did because women "just get headaches, you know, especially as moms, it just kind of comes with the territory." Lack of representation in terms of etiology and patient identity prevented women from identifying as potential concussion patients; that is, gendered disease frames shaped which diseases seemed appropriate for them as women (see Cutter 2003; Kempner 2014).

Identifying Clues and Cues

Similar to Locock et al.'s (2016) study of women with ovarian cancer, the diagnostic assemblage – including "clues" (unintentional) and "cues" (subtle but intentional) from their clinical encounter – shaped the pre-diagnosis experiences of the women in this study. Layla, a 27-year-old single woman, was in "a fender bender." She recalled "feeling kind of off" right after but attributed it to the adrenaline from the crash and assumed it would abate quickly:

> It wasn't until the next afternoon when I tried to drive to go run some errands – and I had spent the rest of the day prior and that night throwing up – that I realized I might not be okay and called my doctor to get checked out. But they transferred me to a nurse practitioner who told me to stop driving and go to the ER or urgent care right away. That was the moment – when this nurse sounded so concerned and was telling me that I needed to go to the ER – that I realized it was a bigger deal than just a bruise on my hip [from the seatbelt].

In Layla's case, it was the seemingly mundane breach of the expected routine of scheduling a doctor's appointment that cued Layla in to anticipate a more serious diagnosis than she had expected. Women's pre-diagnosis experiences were also shaped by those in their personal encounters as the women took cues from others about their condition. Maya, a 32-year-old single woman, also did not realize her symptoms were serious right away until her friends pointed it out to her:

> I was walking my dog and was coming home from a hike, and there was black ice on the sidewalk, and both feet just came out from under me, and I fell on my head – basically on pavement. And so, I didn't know that I had a concussion or that anything had happened because I blacked out, and I woke up, which should have been a clue, but I was just really fuzzy from the fall, and my back and leg really hurt, so I was more concerned with those. But then, the next day, my friends had planned a surprise [birthday] party for me. And so, they came to pick me up, and I wasn't feeling great, you know, but we were just supposed to go to dinner. Well, we got to the restaurant and I puked in the bush outside

> this restaurant. And they were like, "You don't seem okay. We're going to take you to the emergency room." So, I went in [to the emergency room]. And so, it was the next day that I found out I had a concussion and things just pretty much got worse from there.

In Maya's case, it was her friends who identified her symptoms and recommended she seek medical attention, but women also reported their families or colleagues doing the same. Consequently, this affected how quickly they were diagnosed and how soon they were treated. Expedient diagnosis is paramount to prognosis, as it may partially explain women's poorer outcomes. Thus, intervening in the cultural narrative of mTBI could help to address the gender gap in mTBI outcomes by increasing the public's knowledge of proper concussion protocol.

Getting Medical Care

A handful of women were able to identify their injuries as likely concussions from past experiences right away but faced other barriers to accessing care and getting diagnosed. In Alice's case, her workplace did not respond promptly to her injury. Alice was at school on the playground with her students as a paraeducator when one student "stood up and he took his head, and he threw it into the side of [her] head really hard." She said:

> I saw stars, and I was out of it and got nauseous and was holding my head. I've sustained other head injuries in the past, so this was my fifth diagnosed concussion incident, and so I knew exactly what had happened because I had head injuries before. The aid that was near me finally saw me holding my head and on the ground, and she came over to see what was going on and was like, "What's the matter? Do you have a migraine or what's going on?" And I said, "No, Joe hit me with his head." And she checked on Joe, and he was fine. And then this other teacher came over, and the aid told her what happened, and she rolled her eyes and walked away. So, they pretty much just left me there.

Alice further explained that once she managed to get her students back to the classroom and tried calling her supervisors for help, she was met with apathy and negligence.

While some women realized immediately after the incident that they needed medical attention, it was not always for their head injury, as they often had co-occurring injuries, like broken bones or lacerations. Sheryl, an emergency medical technician (EMT), was in route responding to a call when another driver collided with the ambulance at the passenger side door where she was sitting. Another EMT team responded to her motor vehicle collision, and they transported her to the emergency department, per work protocol. She reported anticipating just needing a few stitches but later realized her condition was more extensive than the laceration alone:

> I told her [the nurse] I got to pee. And she says, "I'll go get you a bedpan." I was like, "Okay, whatever," you know, and I remember trying to just sit up in the bed, and I couldn't sit up – I could *not* sit up. And I remember feeling sick and dizzy and scared at that point because I could not even sit myself up in bed. I couldn't get up just to go pee. And I was like, "Oh shit, this is bad…" It literally didn't occur to me until that moment.

While Sheryl received expedient medical care, it was initially for lacerations and bone injuries. It also was not of her own volition but rather a result of workplace protocols.

Other women who did not receive timely medical attention cited various reasons, such as delayed identification of their conditions, including being too concerned with others' conditions to attend to their own in cases with multiple injuries, attributing their symptoms to other injuries or pre-existing conditions, or believing the symptoms would resolve quickly and therefore did not warrant medical attention.

THE INITIAL CLINICAL ENCOUNTER

Having identified their condition as serious and medical in nature, patients move into the next phase of the diagnostic search: the initial clinical encounter. Throughout the disease process, most patients will have multiple clinical encounters for diagnostic and treatment purposes. However, the initial clinical encounter is where most patients anticipate the diagnostic moment, and doctors and patients form foundational relationships that shape subsequent interactions, making it an important event for analysis. While some conditions are easily diagnosed in the first clinical encounter, like a broken bone, other conditions require multiple clinical encounters to reach a diagnosis. Most of the women in this study expressed significant challenges obtaining a diagnosis.

Biomedicine values signs (i.e., objective, clinical evidence of pathology) over symptoms (i.e., patients' subjective, self-reported experiences of illness) (Foucault 1973). The importance of diagnostics, especially imaging, is so extensive that it is evident outside of the clinical setting. Even in the media, we see books, news shows, and newspapers presenting colorful brain scans that commonly accompany discourses of health and illness that we often assume the import of (Dumit 2004). Thus, images accomplish rhetorical work as vehicles for systems of authority. However, there are not currently any widely available and reliable diagnostic tests for mTBI. Sometimes a CT or MRI will show an mTBI if it is serious enough, verging on a more severe classification, but most often these images come back negative. This does not necessarily mean the patient does not have an mTBI, but rather that we lack technology sensitive enough to reliably capture these types of neurological dysfunctions[13]. In some cases, physicians will refer patients out to have further testing, such as neuropsychological testing that offers an assessment of cognitive functioning, and this can inform treatment, but such evaluations are not diagnostic in the same way that a blood marker would be viewed. In these ways, the mTBI diagnosis hinges in large part on patients' self-reporting of symptoms. Barker's (2005) model of illnesses as a "continuum of verifiability" offers a useful way for considering mTBI's legitimacy. In this model, conditions that can be plainly identified by objective markers (e.g., observable measures whether simply through visual inspection or through biomedical measures) are at on one end of

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[13] In the last few years, there have been some promising diagnostic discoveries with imaging and blood markers, however, these are not widely available to the public yet.

the spectrum as having complete legitimacy, and conditions that are only identifiable through subjective evidence (e.g., self-report pain scales) are on the other end. The further a condition lies on the subjective end of the spectrum, the more likely it is to be questioned and the more likely sufferers are to experience a legitimacy deficit. While in this chapter I exclusively address patients' experiences in the clinical setting, it is important to note that biomedicine's frame dominates not only the clinical setting, but also popular discourse (Good 1993, 1994). As a junction of power and knowledge, discourse can concurrently be an instrument of authority and a space for resistance.

Needing Signs

The absence of abnormal pathology poses challenges in diagnosis. In the case of concussion, this often results in the initial diagnosis being informal with physicians verbally communicating a (possible) concussion to the patient but not formally including the diagnosis in the patient's medical records. Phoebe, for instance, was riding her bicycle when a motorist turned in front of her. She saw the car, but it was too late to avoid a collision. Traveling at approximately 35 miles per hour, she crashed through the passenger side window of the vehicle and was taken to the hospital. She was diagnosed with several minor injuries, explaining, "They did do a CT of my brain and a couple more X-Rays. They told me there was no brain bleed, and I *probably* just had a concussion." Without an official diagnosis, Phoebe tried to return to normal life. However, she found herself forgetting simple things and being more sensitive to light and sound than she had been in the past. For a year and a half, she tried to push past these symptoms before seeking further medical attention from her general practitioner when she was finally diagnosed with PCS and referred to a neurologist.

The women also encountered physicians with inaccurate etiological knowledge of concussions and brain injury that ultimately delayed their diagnoses and consequent treatment. Audrey, a 41-year-old single woman, recounted her experience of seeking a diagnosis after being hit by an SUV as a pedestrian while walking her dog around her neighborhood:

> I went to the ER, and I kept telling them like, my head doesn't feel good. My head doesn't feel right. There's something not right. I said, "I think I need a head scan." "But you didn't hit your head." I mean it was just like back and forth with them. They just kept saying, "You didn't hit your head." And I was like, "But I got hit by a *car*. Like, I'm telling you something's not right. Like, something doesn't feel right." I mean the emergency vet that I take my dogs to is way better than that hospital. I don't even know if they gave me any instructions going home. And then, when I got home, and a couple days later, I still couldn't pick the glass up with my right hand, I was like, okay, something's seriously wrong, and I need to go to the ER. So, we went back to the ER. And they were like, "Oh, it's just muscle spasms, you know, don't worry about that." And then I was telling them the other stuff, like some vision stuff, and they were like, "Oh, yeah, then you probably have a concussion. But it's just a concussion so you'll be fine in like seven days." So that's when I got diagnosed with the concussion, like a week later after going back to the ER several times. And I wonder if I had just said I lost consciousness, or if I had done it [gotten the concussion] in a different way, you know, I wonder if that would have changed the whole trajectory of all this.

Women faced further skepticism because of *how* they got her injuries. For instance, Lisa, Alice, and Abigail were all working with children as paraeducators when they incurred their injuries. Felicity, Hannah, Margo, Eliza, Iris, Stella, Clara, Ivy, and Gianna all had falls or impacts to the head during daily activities, like walking the dog, diving into a pool, or doing the dishes. Alice explains how her credibility as a patient was affected by the social framing of concussion etiology.

> The sports guys or war veterans, those are the two that we give a lot of attention to – a lot of resources and validation. So, if you say, oh, you know, "I have post-concussion and have PTSD because I was in the war or in some battle and sustained this," then it's like, "Oh, that's legit," you know, like you *need* all these treatments, and we believe you. Same thing if you're a football player, and you've been hit in the head a billion times. Of course, we believe you. But you're a 53-year-old woman who teaches preschoolers? That makes no sense.

Lisa, a 47-year-old woman, similarly felt strongly that her experience was being invalidated because of the nature of her injury being from a child throwing a ball at her head while working as a paraeducator. She attributed this to the fact that "a lot of the focus on concussions has been on athletes and veterans, not schoolteachers." Because of the disease frame that constructs TBIs as almost exclusively sports- and military-related – both social arenas that remain masculinized despite women's entry into the fields – the ideal type for a TBI patient excludes women. Felicity, a 35-year-old mother of young children, echoed the importance of the cause or context of the injury for gaining credibility as a woman concussion patient explaining that her delayed diagnosis was due in "large portion to a lack of listening to the symptoms that I was expressing that I was having." When I asked her to tell me more about the poor communication she experienced with her physicians, she said:

> Probably because they just don't see me as one [a concussion patient] because of the stupid way I did it [diving into a pool]. It was just different I think as a woman because even though I'm saying like, "These headaches are unbearable. I don't know why I'm getting them," they were just looking for what fell into this general box of what they believed to be a concussion patient. They just weren't listening. I think I probably saw nine doctors before [I got a diagnosis]. I just think that they expected that I fit in this box, and they weren't listening. So, it was frustrating.

In Felicity's account, we see how the context of the injury is used to fill in for unavailable diagnostics and when contexts do not fit the dominant disease frame, they prevent diagnosis.

Communicating Symptoms

Being unable to present proof of their suffering, physicians were dismissive of the women's symptoms. While the women reported different symptom clusters of varied severities, a common feature of their clinical encounters was the skepticism they faced from physicians about the nature of their symptoms. Contestation was not about the diagnosis of an initial concussion, but rather the associated diagnosis of PCS because it was limited to somatic, cognitive, and affective symptoms (Auxéméry 2012). Lacking symptom specificity and no identifiable pathology, the presence of concussion symptoms still months after the injury lead to patients encountering skepticism from physicians. Lisa captured the overall sentiment of these women saying, “I wish that what I was expressing was actually checked out; that what I was saying was happening wasn’t just shut down.” Without a readily available diagnostic framework, physicians doubted their patients’ credibility, which impeded productive communication between patients and physicians (Jutel 2010). Such findings support Jutel’s (2011a) assertion that the potency of a diagnosis’ cultural content affects the authority of a disease more so under conditions lacking physical observability. Compared with other specialties, neurology has higher rates of outpatients with MUS than most (Carson et al. 2000), further suggesting that neurological conditions are more likely to lack medical authority. While most women never experienced observable symptoms, most commonly seizures, the handful of women who did, like Gabriella, reported an “instantaneous change in how seriously my doctor took me because now they had to pay attention, and so they were finding out more stuff because they were actually paying attention to what I’d been saying this whole time.” This provides further evidence that the invisible nature of most mTBI symptoms negatively affects the perceived credibility of the patients and is detrimental to the quality of care they receive as a result.

In Spandler and Allen’s (2018) study of ME/CFS, they similarly found that “without a diagnostic test to provide ‘hard evidence’ of illness, the subjective experiences of patients can be more easily discredited, and professionals engage in psychological ‘gap-filling’ in order to theorise about the nature of the condition” (p. 132). The relevance of social roles in diagnosis is further evident in this study through the accounts from mothering women who reported doctors dismissing symptoms and attributing them to their roles as mothers. Felicity recalled her primary doctor suggesting that her extreme fatigue was because she had kids, and she thought this was "total bullshit." She explained:

> They were attributing [it to] things that didn't matter because I have a husband that was supportive, and I had family here helping with my children, and my children are well-behaved. They weren't a huge chore. They didn't wake up in the middle of the night anymore. They weren't the reason I was tired. There was always this "play-down" to what I was saying.

Similar to Werner and Malterud's (2003) study of women with chronic pain, women in this study experienced that their status as mothers overshadowed their status as brain injury patients. This diminished their credibility as patients and led doctors to be dismissive of their symptoms. When conditions are not completely understood and/or without a diagnostic test available to provide objective evidence of physical dysfunction in combination with the increasing demands on providers that limit their time, patients with negative results are more likely to be dismissed, to be psychologized, and to be labelled as "illness seeking" (see Barker 2008).

Physicians also attributed symptoms to female physiology. This was true across ages, with varied explanations cited by age. For younger women, physicians identified menstrual cycles as the cause, while older women's symptoms were explained away by menopause. This was particularly troubling for Scarlett, a 58-year-old married woman, who said:

> I have heard more than once that anxiety and overwhelm are typical with menopause, and I should try medications – even though I was already five years into menopause at the time of my accident and did not have any of the symptoms I ended up with after the accident.

Studies have identified menopause, or even a perceived menopausal status through perceptions of age and gender, as being used to prematurely dismiss women's symptoms across a range of other conditions (see Lock 1985). Menopause also has a torrid history of psychiatrization (Wentz 1976; Posner 1979; Bell 1987).

The severity of symptoms and resultant disablement also influenced how much attention the women received from their physicians. Gabriella, a 39-year-old married mother of young children, explained how having a condition that significantly impacted her quality of life but was not severe enough to be medically life-threatening affected the quality of care she received from her neurologists:

> It was just a very weird situation with neurology I think because I wasn't so severe, like to the extent they maybe had seen with some people, but I also wasn't really – like it wasn't nothing either. I was right in between. It was just like – I fell into this weird space where it felt like some people didn't care enough to look into it because I wasn't so, so bad. It was like, "You're not listening to me."

The qualifying of suffering was commonplace in the women's narratives, as is the case in both lay and scholarly discourses, as well. Health is most commonly addressed in terms of mortality rather than morbidity, consequently minimizing the importance of other measures of health, like quality of life (QoL) or disability adjusted life years (DALYs).

While severe TBIs, including the progressive brain disease of chronic traumatic encephalopathy (CTE) that results from accumulated mTBIs, have received more authority as of late, conditions with persisting symptoms resulting from individual mTBIs are less well known and accepted. The two ends of the spectrum of TBI are the most recognized: concussions (symptoms resolve within three months) and CTE (permanent dysfunction and is fatal). This "in-between" area of PCS is less recognized and poorly understood. The first entry of a Google search for "PCS" reads, "PCS is real and can be diagnosed by a healthcare professional." This shows that some illnesses can be formally recognized as diagnoses yet remain contested. Other diagnoses that are less contested or that have more authority, say osteosarcoma, do not include language that asserts its "realness."

In many ways, the experiences reported by respondents in this study mirror that of patients with medically unexplained symptoms (MUS) (see Malterud 2000). MUS is a label used to categorize conditions that lack evidence of an organic basis and that cannot be categorized in any existing "named" syndromes. Literatures on other named syndromes, like ME/CFS (see Cooper 1997; Hyden and Sachs 1998; Clarke 2000; Horton-Salway 2001), have well documented the importance of a disease label. Being called a "syndrome" means the condition is believed to have no pathological basis, otherwise it would be a disease. PCS previously stood for "post-concussion syndrome" but has recently changed to "persistent concussive symptoms" as a result of advocacy groups identifying the problematic use of the term "syndrome." While the name has formally changed, the old terminology remains common and the sociolinguistic effects on social stigma are delayed. Furthermore, the diagnostic frame has many overlaps with other psychiatric diagnoses, like post-traumatic stress disorder (PTSD). The non-specific symptom assemblage used to diagnose PCS is much like that of other well-studied contested illnesses, such as FMS. The process of legitimating a diagnosis is also conditioned upon the construction of the patient population being deserving of the resources that accompany the diagnosis; a biomedical model and a specific disease mechanism are not guarantors (Aronowitz 2008).

The women in this study identified the responsibility they had as patients to support their illness claims. They often reported a heavy psychological toll that came with bearing the burden proof as patients, much like the women in Barker's (2005) study of FMS. Gabriella explained:

> With all my symptoms, I kept saying, "Something's wrong, something's wrong." And feeling like for so long that they didn't even believe me. Like that's what I felt – is that they weren't listening, or they didn't believe me. Like, I just didn't understand how I could be going through *that* much pain and have virtually no [medical] care. Like, how do I show that I'm in so much pain? You know, like, how do I *prove* to them I'm in so much pain. And it was like, you know, there's no way to prove it.

Fricker’s (2007) concept of “epistemic injustice” offers a helpful framework for conceptualizing the relationship between medical authority, patient legitimacy, and illness experiences. Epistemic injustice is the systemic discrediting of a marginalized group’s experiences through testimonial and hermeneutical injustices (see Wardrope 2015; Crichton, Kidd, and Carel 2017).

To counter such epistemic injustice and instead present as a credible patient, women emphasized the need to “dress the part,” as Alice, a 53-year-old married woman, said. Alice explained how she noticed that her doctor spent less time with her and offered fewer recommendations when she “looked pretty good” at appointments, so she started making a point of not showering and wearing sweatpants on days she had doctors’ appointments to “help them [the doctors] believe me when I tell them about how bad my symptoms are. Just because I’m having a good brain day doesn’t erase all the other really, really bad days.” Approaches like Alice’s are not unfounded as extant research has well-documented physicians’ use of visual markers in the clinical encounter (see Stafford, Puma, and Schiedermayer 1989; Monaghan 2001; Croskerry 2002; Jutel and Buetow 2007). Croskerry (2002) finds that visual assessments of patients frame the clinical encounter in ways that are simultaneously beneficial and detrimental to patients’ care. On the one hand, visual markers can help cue physicians into important diagnostic markers that influence treatment. On the hand though, it leaves the potential for anchoring bias and hastily defined diagnostic decisions. Margo similarly explained how presenting as a credible patient also required presenting as a certain type of person; for her, an athlete rather than a housewife. She went to a sports concussion doctor to be seen at the recommendation of her general physician since her concussion happened during a softball game. She felt that she was quickly dismissed by this physician because she “looked like a housewife in that dress, not a softball player.” She said, “My husband, who had went with me, even said like, 'He sized you up in two seconds.'" Such accounts demonstrate how the ideal type of patient manifested by the gendered disease frame contributes to the legitimacy deficit women face.

The ideal type shapes beliefs about credible patients and guides physician assessments in the absence of valid and reliable diagnostics for mTBI. The social construction of gendered disease frames and its consequent power in physicians' diagnostic decision making is well documented in other conditions as well, including coronary heart disease (Welch et al. 2012), cancer (Comeau 2007), FMS (Barker 2005), headaches (Kempner 2014), and Lyme disease (Dumes 2020). In their everyday practice, health providers usually label patients either positively or negatively, based on the patients' presentations of self (e.g., Hillman 2015). This is the distinction healthcare providers make between a "credible" and a "troubled" patient (Werner and Malterud 2003; Li and Arber 2006). When a patient is labeled negatively, they are marked as deviant and, therefore, take on a legitimacy deficit that, in turn, creates barriers to health resources and services, and negatively impacts their self-image. Thus, it is essential for patients to provide persuasive accounts of blamelessness, validity, and worthiness to pass with legitimacy and, consequently, gain access to the myriad of benefits accompanying patient status or "the sick role" (Parsons 1951). These findings support extant research that suggests that MUS patients are seen as problematic and that the doctor-patient relationship is characterized by conflict (see Page and Wessely 2003).

Psychiatrizing the Illness Experience

The combination of a nonspecific symptom cluster and the absence of signs contributed to women's conditions being psychiatrized. The gendered phenomenon of psychiatrization has been well documented in the case of pain disorders. Kempner (2017) argues that "because pain is interpreted through a gendered lens, women are also much more likely than men to have their symptoms attributed to neuroticism, hypochondria, or emotional distress (Barker 2005; Kempner 2014; Werner and Malterud 2003; Hoffman and Tarzian 2001)" (p. 1). Using the case of headaches and migraines, she argues that diseases themselves reflect the gendering of the mind-body dualism and the distinction between them being based on patient populations and gender ideologies. Headaches are associated with women, often trivialized, and often treated as psychiatric (a matter of the *mind*), while migraines are associated with men, often treated more seriously, and treated as having an organic basis (a dysfunction of the *brain*). This is consistent with Ware's (1992) classic study of patients with chronic fatigue syndrome where she finds that what she refers to as "delegitimation" occurs in two primary forms: 1) patients' symptoms are seen as insignificant and thus trivialized, and 2) their conditions are labelled as psychosomatic or being "all in their heads" (p. 350). Labelling a condition as psychiatric has served as a broad catch-all throughout much of medicine's history for really anything outside the norms that has no other readily available explanation. Women are more likely than men to receive psychiatric diagnoses (Rogers and Pilgrim 2014). Psychiatric diagnoses are often contested because they often lack pathology and are diagnoses of exclusion, but even diagnoses with observable indicators can be dependent on social judgements and beliefs. Mental health and invisible illnesses have a history of being feminized. Foucault (1976) famously addressed the "hysterization of women's bodies" in phrenology from the 1800 and 1900s. The legacy of the image of the hysteric woman plays a significant role in the legitimacy deficit women with mTBIs encounter. The idea that it is "all in her head" persists in cultural narratives today, as does the idea that women tend to exaggerate their symptoms as the "fairer sex" with lower pain thresholds. Under such assumptions, women's symptoms are believed to be less severe than men's, making women less deserving of the sick role.

In this study, the legacy of the hysterization of women's bodies influenced practitioners' interpretations of women patients' symptoms with women reporting providers discrediting their symptoms as psychogenic, some even explicitly referring to their condition as hysteria. Here again we see similarities to the literature on MUS, with terms like "functional symptoms," "non-organic illness," and "conversion disorders" being quite common with patients labeled as "somatizers" (Kipen and Fiedler 2002). The experiences of women in this study suggest that women with mTBI are more likely to have their conditions psychiatrized, trivialized, and stigmatized. Lisa recounted two separate instances with different providers where she felt that her identity as a woman shaped her care:

> As a female, I feel like it's been different. For me, there are two particular [instances]. The first one was when I went to the doctor, and he was like, "You're just overdoing this and you're trying to blame your injury for everything." And the second one – I did neuropsych testing. I did really poorly in some cognitive tests, and I wanted to talk about that. But he [the neuropsychologist] didn't. He wanted to focus just on the mental health scores. He started talking about convergence – not in the visual way but in the mental way. What he said was, "Well, it's what Freud called hysteria." Having him say that in particular – that word "hysteria…" It was like him telling me that this is all mental.

Lisa certainly was not alone, albeit hers was the most explicit reference to hysteria. In other accounts, it became clear that it was the confluence of the contestation of PCS due to its nonspecific symptomology, poorly understood pathology, and lack of available diagnostics in addition to the legacy of the hysterization of women that produced physicians' disbelief. Phoebe, a 51-year-old single woman, completed neuropsychological testing to determine the root of her persistent symptoms in hopes of better managing them but left her physician's office feeling only more despaired:

> Phoebe: He [the neurologist] said, "Yes, she's [Phoebe] definitely lacking in these areas, which is very indicative of concussion or post-concussion syndrome." And then in another paragraph, it's evident that he [the neurologist] really doesn't believe in post-concussion syndrome or that it's something that could last that long. So, then it became just a real frustration.

> Interviewer: What was the impact of that on you?
>
> Phoebe: Kind of devastating. He was like, "I don't think you have this. I don't think that people suffer from that." I mean he literally said that. And said, "I think that you need to go see a psychiatrist because I think this is more emotional than anything." Which, I mean, it upset me. It still does to this day. So, it was pretty devastating because I knew what I was feeling in my everyday work, and just the frustration and the lack of being able to be organized and to do the things I needed to do and used to be able to do. And then he's basically saying this is all in your mind, or it's a psychological issue and maybe you need to get on some medication.

Phoebe's case illustrates women's common experiences with various medical professionals – including primary care providers, neurologists, and psychologists – telling them that the condition other medical professionals had diagnosed them with was not "real": that is, there was no physiological dysfunction. Rather, that their issues were psychiatric; that is, it was "all in their head." Similar to Phoebe's account, Piper, a 44-year-old married woman who was hit by a vehicle while on a bicycle, was assessed by a neuropsychologist after scoring in the lowest 12 percent across various cognitive functioning tests. The neuropsychologist "said that mine was a psychological condition, not a physical condition. What he said was that my brain injury is in my head, and I needed to think about my injury differently." This illustrates how the ambiguity of a diagnosis gets translated into suspicion of the patient (Blease, Carel, and Geraghty 2016). The psychiatrization of a condition has important ramifications beyond stigmatization socially, having important clinical and legal implications that stem from the epistemic injustice of discrediting patients (Liegghio 2013; Spandler and Allen 2018).

THE DIAGNOSTIC PROCESS

Following is the initial clinical encounter is the diagnostic process. The diagnostic process engenders power competitions of knowledges amongst physicians and between physicians and patients. Diagnosis is a process wherein physicians from different specialties vie for medical authority over other specialties and generalists (Dumes 2020). Patients and physicians negotiate the outcome of the diagnostic process by deploying various knowledges and, in the process, compete for the authority of their own knowledges. Such epistemological competitions have important consequences for physician referrals and the diagnostic moment.

Negotiating Medical Authority

The women reported physicians being unequipped to properly diagnose and treat their conditions as they seemed to have a basic knowledge of concussion. Physicians lacked the necessary knowledge to identify the women's symptoms as serious in terms of severity and potential duration. For instance, Felicity's doctor said to her, "I didn't know that just a concussion could cause all this." The minimization of concussion was evident in both initial and follow-up visits. Audrey described how the minimization continued even with persisting symptoms with physicians expressing sentiments like, "'It's just a concussion. You'll be better in a week," or "Oh, you'll survive. Give it another week." Outdated and inaccurate medical knowledge of concussion among physicians may also contribute to the lack of information given to patients by providers at the time of diagnosis, which nearly all the women in this study reported. For example, Eliza said, "I had no idea what that [PCS] meant but didn't ask him [the neuropsychologist] …and just came home and looked it up." This may also suggest that physicians assume a lay knowledge around concussion, much like the common cold, and/or that they do not perceive it as serious enough to warrant such extensive information and resources.

Such sentiments were especially common amongst physicians who were men, once again demonstrating the heightened importance of doctor-patient gender congruency in cases of gendered disease frames. For example, Evelyn recounted her experience with an emergency medicine physician who was a man:

> I would rate my diagnosis experience as a zero. The diagnosis was missed…and I was dismissed by the male physician who did not believe me – that I had fallen – and denied that it was a serious fall. I fell off a *roof*. He belittled me, dismissed my backpain as related to being "out of shape," despite me being a triathlete at the time. To be clear, my health had done a complete 180. I had no problems before this. He did a 1-minute exam…The ER doctor refused to do any x-rays or lab tests and sent me home with no follow up. He was an older white man, likely in his 60s or 70s. He did not have any issue with me being in pain, nor did he have advice or ideas on what to do for my concerns about the fall…He did offer pain medication, which I declined because…I feared it would simply make me look even worse in his eyes. He had already been completely dismissive of every one of my concerns and I did not want to be further labeled in some pejorative way when I was clearly being dismissed already. Especially since I wasn't given a diagnosis – and effectively, was denied care due to being dismissed and not believed – I was forced to try and figure it out on my own.

Negative doctor-patient relationships were also more commonly described by the women in interactions with physicians who were men. In fact, many of the women themselves noted this and reported seeking out women doctors specifically after having negative experiences with doctors who were men. Eliza, a 53-year-old married woman, said:

> My experience with male doctors was very different than female doctors. It was the two male doctors I saw that seemed to have the most disbelief around what was going on with me. Even the one who I've known for 20 years – he was the most dismissive. He was dismissive outright. And the other was – I guess you'd say – disbelieving. That was the one where he said "Wow, she's supposed to be good," when I told him that she [the neuropsychologist] had diagnosed me with post-concussion syndrome. I was like, she *is* good – that's why I waited four months *and* paid out of pocket to see her.

Here, we see the broader institutionalization of gender bias in medicine. Doctor-patient gender congruency played a significant role in the legitimating process of women's mTBI diagnosis, consequently impeding their access to treatment and resources. The import of doctor-patient gender congruence has been documented across many dimensions, such as patient comfort and clinical decision making (see Weisman and Teitelbaum 1985; Lin and Zabar 1991; Franks and

Clancy 1993; Lunn et al. 1998; Jahng et al. 2005), with evidence indicating the potential to negatively impact women's prognoses.

While some women's accounts suggested a general lack of knowledge about concussion, others experienced battles over medical authority amongst their providers. Avery was diagnosed with a concussion by her general practitioner and then with PCS by a neuropsychologist. However, this diagnosis was later delegitimized by another provider – one who was even recommended in the brain injury community. In recounting her experience, Avery explained that while she had participated in multiple treatment modalities at the beginning, she stopped treatment in part due to a negative doctor-patient interaction. She expressed that she felt brain injuries "aren't taken seriously" or are "pooh-poohed, like 'You don't really have a brain injury.'" Initially, I thought she was referring to the public, but she clarified saying:

> No, I was told that by a professional. There was one who was highly recommended by other brain injury professionals, so I went to him. And he said that I didn't really have an injury – that I just had a bump on my head. And to be honest, that's probably what turned me off for a long time on either expressing my thoughts about my brain injury or pursuing care because that's always stayed with me – that all I had was a bump on the head.

Such accounts highlight diagnosis-as-process. Diagnosis is not a finish line; it can be challenged, negotiated, or revoked during any stage of the disease process, further demonstrating the fluidity of authority amongst physicians and across specialties. This finding offers partial support for Gerhardt's (1989) negotiated order framework in that patients indeed are not passive recipients in the diagnostic process; rather, they are active agents with the power to negotiate their diagnosis with clinicians. However, this finding also suggests that diagnosis cannot be bound to a phase as it is a process that is in motion throughout the entirety of the disease process.

Referring to Specialists

As a result of the contestation of mTBI and its gendered disease frame, many of the women described adversarial diagnostic encounters where they had to “fight” for their diagnosis in the exam rooms. One often blocked pathway to diagnosis was physician referrals to specialists. For example, Evelyn, a 34-year-old woman who incurred her injury as active military, was only diagnosed after “finally being sent to a specialist over a year later [after the fall].” Expedient diagnosis is important for quality of life and prognosis. The consequences of delayed diagnosis on prognosis can be insurmountable in some cases, as was the case for Evelyn. Her “deficits were considered permanent with little hope of change…since it was caught over a year after [her] injury.” A changed prognosis also means a change in treatment and referrals. Rather than trying to improve her condition, her care centered “mostly [on] instructions on how to adapt to a brain injury, since at this point, there wasn’t hope that it would improve.” Evelyn’s account demonstrates how the diagnostic search affects subsequent stages in the disease process, making it an important stage for intervention.

Mainstream physicians referred patients to specialists in cases where they believed the patients’ condition extended beyond their training or where the specialist may further aid in the recovery process through novel treatments. For some women in this study, their diagnoses were delayed due to being undiagnosed or misdiagnosed by their primary care provider until receiving a second opinion by a specialist. Evelyn, who was active military at the time, explained that her diagnosis was happenstance, resulting from workplace protocols. She said:

> Towards the end of being separated from work [the military], I finally was being out-processed by the VA and VA medical examiners. Here, they pointed out I had all the red flags for a brain injury and were shocked it had not been diagnosed or caught yet. They strongly recommended I see a specialist. I took this information back to primary care where I was finally referred to a TBI evaluation specialist…They were shocked this

hadn't been caught sooner.

For others, like Eliza, receiving the proper diagnosis required seeing multiple different specialists, after extensive self-advocacy of course. As she said, "It was very convoluted – [it took] from November of 2018 to April of 2020 to get diagnosed." In these 18 months she saw four different specialists: an audiologist, a speech language pathologist, a visual behavioral optometrist, and a neurologist. The neurologist, who eventually diagnosed Eliza with an mTBI, "was the first person that'd ever-mentioned concussion [to her]."

Some women who were unable to obtain referrals from their doctors sought out specialists independently. Harper, a 23-year-old single woman, recalled that it was her mom who noticed that she would "zone out more" and "become more exhausted or overwhelmed." She began to suspect that Harper did have a concussion despite not being diagnosed at the emergency department weeks prior. She found a doctor who specialized in concussion and took Harper there, where Harper was diagnosed with a concussion and later PCS. Harper noted that luckily her insurance did not require a physician referral to receive coverage; however, this was not the case for many women who, without a physician referral to significantly reduce the patient cost, could not afford the out-of-pocket costs associated with specialist services.

Experiencing the Diagnostic Moment

Mounting research provides evidence that the diagnostic moment is not always welcomed or celebrated (see Jutel 2011a). Diagnoses can offer pathways forward through treatment, but they also serve as labels of dysfunction and can force limitations on daily life. For many of the women, the diagnostic moment was disappointing. What they had anticipated to offer relief, validation, and hope was instead met with frustration, invalidation, and despair. Iris said, "The diagnosis wasn't taken seriously enough, and I didn't get referred or recommended anything to help in the early days." The common absence of information being communicated at the time of the diagnosis also contributed to the women either minimizing or catastrophizing their conditions. Some women described the diagnostic moment as devastating, and others compared the diagnosis to a loss. Eliza invoked the stages of grief in describing her reaction to the diagnosis saying, "I didn't believe it at first. Like how can that be? I've just been in a regular car accident. And so, there's this period of denial." She cited the preexisting relationships she had with her physicians as validating the diagnosis for her, saying "I started to think, "Oh my god, I have three people in the medical field – doctors – that I have a relationship with and that I respect telling me this," which helped her move into what she called "the acceptance phase" in processing the diagnosis. Lydia, a 47-year-old married woman, explained that it took time for her to process and accept her diagnosis:

> I've been playing sports and getting banged up my whole life. I just didn't – I honestly didn't think it was a big thing. And it took like a year for me to actually admit to myself, like I am injured, and that was an injury. Honestly, it's ridiculous – I don't know why – I mean, it's almost like a dream – like it almost feels like it's fake or pretend. Like, I felt like I was making it up at the time.

Lydia's narrative shows how deeply ingrained the ideal type is in the disease frame that women use to interpret their symptoms and experiences. Even when women have the medical authority and legitimation that comes along with a diagnosis, they struggle to see themselves as patients. Lydia's account foreshadows what I address in greater detail in my next chapter on the illness experience. Here, I discuss how the legitimacy deficit is experienced socially during the post-injury recovery phase to understand the social determinants of mTBI prognosis.

In contrast to these negative diagnostic experiences, it is important to note that a few women in this study did not experience significant barriers to diagnosis. Although their accounts lend further evidence of the commonplaceness of delayed concussion diagnoses as they were keenly aware of their privileged diagnostic experience – describing themselves as “lucky” or “blessed” to have had such a “rare” diagnostic experience. These women shared three commonalities: their incidents had witnesses, they were in motor vehicle collisions, and they were middle to upper class. They had someone who accompanied them to their medical appointments who could corroborate their stories and offer additional information that the patients could not recount in cases where they lost consciousness or could not remember. They were also all in motor vehicle collisions where police responded and documented the incidents. In most of these cases, they were also transported by ambulance to the hospital for further evaluation. Finally, all of these women were middle to upper class. Health outcomes are affected by a variety of post-natal social factors, including race, gender, and socioeconomic status. The health inequalities associated with socioeconomic status are quite large, robust, and well-documented – indeed, the saying, “In wealth and in health,” is true and has been since at least the early nineteenth century (Antonovsky 1967). Despite dramatic changes in health mechanisms, such as our technology, medicine, and sanitation, these disparities persist, leading Link and Phelan (1995) to identify socioeconomic status as a fundamental cause of health inequality. They explain that flexible resources, such as knowledge, money, and social networks that can be employed to prevent and to mitigate poor health, are unevenly distributed across society (i.e., resource inequalities), making some folks more or less able to protect their health. Findings from the present study add to the mounting evidence that supports the theory of fundamental causes as it was the wealthier women who reported more expedient diagnoses through access (e.g., information and available finances) to physicians with specialist knowledge. Here, wealth served as a flexible resource that helped to moderate the negative effects of being a woman with an mTBI.

DISCUSSION

While extant research has examined contested illness, disease frames, and legitimacy deficits, this study offers an integrated and intersectional framework for understanding how diagnosis-as-process is contoured by disease frames and patient identities in the diagnostic encounter. Recently, scholars have addressed how disease frames are gendered due to the patient population's gender composition and how that affects women. Barker (2005) examines the relationship between biomedicine and patient populations in her study of women with fibromyalgia patients, a disease that dominantly affects women. In Kempner's (2014) study of headaches, she shows how gendered morality influences the legitimacy of migraines as a diagnosis within both the medical community and society at large. In her study of Lyme disease, Dumes (2020) argues that the quality of the doctor-patient relationship is negatively affected by the disease frame; that is, the belief that Lyme disease primarily affects wealthy women. While Kempner (2014) addresses gender incongruence between disease frames and patients by including a chapter on men's experiences with the feminized diagnosis of headaches and migraines, this study considers the inverse relationship, addressing women's experiences with a masculinized disease. Given the imbalance of power in the current gender system, understanding how women fare with a women's disease is going to be different than how women fare with a men's disease; in the latter, the subordinate enters the realm of the privileged group. I argue that legitimacy deficits arise for patients whose identities are incompatible with the dominant disease frame in cases where the disease is characterized by non-specific symptoms and lacks available diagnostics[14] because mainstream[15] physicians rely on other social frames, such as gender, to

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[14] Biomedicine or evidence-based medicine (EBM) differentiates symptoms from clinical signs, with the former being subjective and the latter being objective.

[15] Referring to physicians without specialized training in the diagnosing and treating of concussions or brain injury.

inform their medical assessments. In doing so, I speak to the debate over the nature of suffering, particularly its gendered dimensions, and shed light on the entanglement of patient populations, disease frames, illness experiences, the doctor-patient relationship, and medical authority. This study demonstrates the utility of a sociology of diagnosis as a novel vantage from which to examine gendered health disparities.

In this chapter, I showed diagnosis-as-process, highlighting that it is indeterminate and contestable. At the end of my findings, I showed how diagnosis reoccurs throughout the disease process, suggesting that diagnosis cannot always be seen as a bounded phase in the disease process; it can be revoked, altered, or replaced. In doing so, I foreshadowed the importance of diagnosis for accessing adequate care post-diagnosis. In the next chapter, I examine how the gendered disease frame shapes women patients' illness experiences post-diagnosis, including how they live with mTBI and manage a legitimacy deficit, and how that affects their recoveries through access to treatment and resources.

CHAPTER 4

BEING BRAIN INJURED

"…illness is a state of disturbance in the "normal" functioning of the total human individual, including both the state of the organism as a biological system and of his personal and social adjustments. It is thus partly biologically and partly socially defined. Participation in the social system is always potentially relevant to the state of illness, to its etiology and to the conditions of successful therapy, as well as to other things." (Parsons 1951: 431)

In the last chapter I examined how individuals get diagnosed. In this chapter I look at the next stage of the disease process: recovery. Here I conceptualize the recovery process holistically to include experiences in and out of the clinic to better understand the relationship between the illness *experience* and disease *knowledge*; how patients "do" and "know" disease (Mol 2002:12). In doing so, I challenge the common conceptualization of illness as being independent of the illness context (see Stephens 2011). The gender system is a powerful social structure that contours men's and women's experiences differently, including the illness experience (Bird and Rieker 2008; Ridgeway 2011). Through an intersectional analysis of patient resilience that attends to parental status, partnership status, and socioeconomic status, I argue that the negative consequences of being a woman with mild traumatic brain injury (mTBI) can be lessened by social capital. In my analysis of the women's illness narratives, four interesting patterns emerged: 1) living with persistent symptoms, 2) experiencing a legitimacy deficit, 3) managing role conflicts, and 4) finding flexible resources. In examining the illness narratives, I show how a complete understanding of social health inequalities requires an examination of the illness experience. I argue that women with mTBI experience poorer health outcomes due to the legitimacy deficit that limits their social support and access to resources. I also find that discrimination and role conflicts add stress, reduce their quality of life, and increase their suffering, thereby being of further detriment to their mental health. Thus, addressing gender as a social determinant of health provides a significant opportunity for intervention to improve women's mTBI resilience.

BEING CONCUSSED

Unlike the men I interviewed, the women in this study emphasized the effects of their symptoms on their social lives in terms of their ability to fulfill their social roles and to maintain their social connectedness. This may be partly explained by the well-established gender differences in symptom reporting generally, but my analysis suggests that other gender processes undergird gender differences in the social impacts of symptoms. As I show in my later chapter on men with mTBI, men largely avoided the negative social consequences related to their symptoms because they were perceived as credible patients and were awarded the sick role. As such, they received exemptions from their social roles and avoided the stigma that would otherwise have been detrimental to their social connectedness. Thus, at the crux of the women's experiences of being concussed lays the gendered legitimacy deficit. That is, the physiological symptoms were more salient in the women's illness narratives because they were still trying to fulfill social expectations, and they faced stigma that deteriorated important social ties and exacerbated their symptoms, which resulted in gendered social suffering.

Symptoms and Stigma

In the women's illness narratives, the symptoms were more salient relative to men's illness narratives because the women were attempting to maintain normal social roles without excusal or accommodation. Because of the imbalance between impairment and social expectations, the two words that typified the women's experience of living with mTBI were "exhausting" and "overwhelming." Living with mTBI can include sensitivity to light (photophobia) and sound (hyperacusis), ringing in the ears (tinnitus), dizziness and balance issues (vestibular dysfunction), fatigue, headaches, cognitive deficits (e.g., attention/ concentration, memory, organization, brain "fog"), emotional dysregulation (e.g., feeling irritable, anxious, sad), vision issues (e.g., oculomotor dysfunction), disordered sleeping (e.g., insomnia, napping), and nausea. Patients often have multiple symptoms, and these can be unpredictable – fluctuating in duration and severity. This can make even the most seemingly mundane tasks – cooking meals, driving, or going grocery shopping – challenging as women must manage their unpredictable symptoms under conditions of unknown stimuli while trying to accomplish a given task. Eliza, a 64-year-old, explained:

> You know, going to a coffee shop is not, "just going to a coffee shop." Going to a coffee shop is, "Oh my god, I need to be as far away from the espresso maker as I can…" There are days I can't go in a grocery store, or days when I can't go three aisles near the laundry detergent aisle because the smells are just so nauseating. Or, if I've forgotten my hat that saves me from the lights, then I can't go into the store. And it's – you know, all of this is *exhausting*.

The women with mTBI either avoided new and uncontrollable environments or engaged in extensive management strategies – using earplugs, tinted eyewear, notes, phone applications, or relying on other people for assistance. There are many activities they could no longer participate in due to safety concerns, such as drive or even cook (due to the potential fire hazard). Aurora, a 46-year-old, explained how much her life had changed due to mTBI:

> I used to work full time, do my own house repairs, see friends often, cook dinners, play music weekly in an orchestra, run a busy charity, coach two sports teams each year, and tutor my children whenever they needed assistance with homework. None of these are possible in my life anymore. All of the therapies have improved my quality of life; however, I have not returned to anything normal from my previous life. I still have daily painful migraines and extreme fatigue that impairs my ability to participate in life in a normal way. I have worked very hard with multiple rehab specialists to gain minimal

> function and tolerance of day-to-day life and it is frustrating to look back at my old life, so I try not to do it that often. I have learned to cope with my new normal and I am lucky to have a supportive family as well as a working partner as I am not able to be gainfully employed. I know that many people with concussion injuries as severe as mine are not always as lucky to have both the support of family and also a thorough recovery plan accessible to them.

Aurora's account illustrates the impact of mTBI on daily lives and signals the importance of social determinants in prognosis, which I will discuss in later sections. For the women in my study, dealing with multiple unpredictable symptoms while still trying to maintain some degree of normalcy resulted in suffering. Evelyn, a 34-year-old, explained:

> I get tremendous judgement publicly when I'm unable to perform some basic interactions. [For example, when I was] meeting a neighbor, I was unable to hold a conversation because he was talking too fast, and I couldn't process it. I didn't come up with a witty reply in time. He just stared at me, then left. He hasn't tried engaging again. I have from time to time but it's hard to overcome an initial impression where you're unable to immediately perform to expected social standards…It makes it hard to connect or be present with people…I'm not able to join in long conversations anymore or long talkative gatherings…I do okay if it's not for very long—it's not for more than 10 minutes at a time – and there aren't lots of expectations that I respond with speech, [and it] can't be a fast talker [due to deficits with processing speech].

Thus, symptoms often led to social suffering beyond the physical suffering of pain. Public perception of what it means to "be concussed" contributed to further suffering; that is, issues of being believed shaped illness experiences in significant ways that only made the illness experience worse for women (Dumes 2020). As we saw in Eliza's case, the social consequences of physical symptoms came full circle to negatively affect the women's health further through isolation and mental health.

Symptoms were constantly in flux in terms of both type and severity; one may resolve while another develops, or one may abate while another intensifies. A singular symptom or the whole set of symptoms may be mild one day and debilitating the next. As Alice, a 53-year-old, said, "The only constant is change, and the only certainty is uncertainty." This was anxietyprovoking for the women as they faced constant uncertainty about their future abilities, which limited their ability to plan and diminished their hopes for recovery. Because of this, women were hesitant to commit to anything social (i.e., not medical) for fear of having to endure the event with severe symptoms and suffer or having to break social conventions to cancel last minute. For example, Hannah, a 53-year-old, said of her adult daughter:

> If I would cancel – and I had to cancel a lot of plans in that period of acuteness – she just didn't understand that. And it would come off to me as being abrasive or kind of pissed-off. And that's not what I needed *at all*.

So, Hannah stopped making plans altogether to avoid the potential fallout of cancelling. Other women stopped seeking out social activities because of others' attitudes towards them. For many, like Alice, it was that:

> Friends didn't quite get it, so it would just end up not being a very enjoyable time for me. They weren't mean, I just didn't have anything worth contributing so they'd just talk about themselves the whole time and not really ask how I was doing.

A common sentiment amongst the women was that having a brain injury teaches you who your "real friends" are since many people "ghosted" the women, as Harper (23-years old) said, referring to what Emma (38-years old) described as her friends "suddenly disappearing." Serena said that "people started to realize that [I needed a lot of help] and they just stopped asking." Emma described a moment where a friend contacted her to ask:

> Where I've been and what I've been up to. I was honestly just so stunned. Like, "What do you mean? I've been right here, in my house, pretty much alone for the last two years. Where were *you*?" I told her after the accident – I thought we were pretty good friends, but after she came over one day to see how I was doing, and she just never checked in again. I don't think she could handle how shut down I was and just all my issues even during that first short visit. Anyways, we're not really friends anymore.

While the women often reported choosing to decline invitations or not to initiate plans, they also commonly noted the negative consequences of cancelling or needing special considerations when socializing. This may be explainable in part by the gendered social expectations of women, particularly their increased burden of care work. When the women did engage in their social lives, they often experienced overwhelm. Symptoms made acute experiences feel like sensory overload, while social conditions, such as financial stress, overwhelmed them emotionally. In this way, the women not only experienced physical suffering, but they also experienced social suffering (Dumes 2020).

The women commonly reported delayed processing, which led to delayed responses and others' interpreting this as them being rude or stupid. "Concussion" is so common in lay discourse today that it has come to replace other sayings that reference cognitive capacity in a stigmatizing way: "Are you concussed or…?" is the new, "Are you stupid or…?" or the even older adage, "Are you retarded or…?" Even famous comedian Aziz Ansari recently did a set about it on his television series *Aziz Ansari: Nightclub Comedian*:

> Who's that guy? The football player…Aaron Rodgers. What do you think about that guy? People hate that guy. They're like he's a fucking idiot…It's like okay, calm down, he's a football player…This poor guy. It's like we're all in high school and we're making fun of the quarterback for doing bad on the science test. "You're a dummy Aaron, you're a dummy. You don't know anything do you? You're a dumb-dumb." This guy *makes a living* getting hit in the head. Can we cut him a break?

For this joke to be effective, the audience at large must have a common understanding that getting hit in the head repeatedly makes you "dumb." The effectiveness of this joke demonstrates that the inexplicit stigma that marginalizes mTBI sufferers and silences their experiences is widespread and well-accepted.

Identity and Mental Health

Even when women were able to "pass" in daily life, they had internalized the stigma of mTBI and applied it to themselves. Of her cognitive symptoms, Maya, a 32-year-old, said: "It makes me feel really stupid." For her, it was not that others were treating her poorly, but rather that she had internalized this generalized meaning of concussion so that her experience of symptoms affected her self-concept. She said:

> I moved to a new place and didn't know anybody. And so, everybody I've met here only knows me since I had a brain injury, so they don't notice…but I feel like I talk way more slowly. I need more time to process. I forget things. I have to write everything down. *I can feel it.* So, I think it's self-imposed.

The sequelae on one's identity and mental health cannot be understated. The internalization of stigmatizing stereotypes impacts one's identity and the uncertainty contributed to the women experiencing poorer self-image, heightened anxiety, depression, and suicidality. Maya said:

> Although it's not exactly a symptom, I would say just the overwhelm of this happening and feeling like my career was over. I was going to have to live with my parents for the rest [of my life]. Because it went on for about a month of that. And so, I was just thinking, "Well, this is it, I guess. My brain is gone." So, although it's not a direct symptom, like the mental health and wellbeing implications of it were a big deal too…I think there's been a lot of my identity stuff that I've had to think about over the years, but for better or worse, a lot of my identity was tied to being intelligent. So, I think I had to unravel that quite a bit and, still, I'm unraveling that. And so, I think that also got at my identity…I think it's definitely affected my self-esteem…So, I think there's some anxiety and some self-esteem that's gone. And yeah, as I said, I think that I'm probably still working through it, but my identity has definitely been impacted.

Anxiety, depression, post-traumatic stress disorder (PTSD), and suicidality are, unfortunately, common comorbidities among TBI patients (see Carroll et al. 2014 for review; Hammond et al. 2019). Referring to the "the full-blown horrors of brain injury," Camila, a 62-year-old, said, "If someone told me the straight-out facts about TBI at the onset of this…then I think I would, as others, contemplate suicide." For Camila, ignorance was bliss. Piper explained that:

> I really thought, if this doesn't improve, I don't know that I want to live like this – just feeling so terrible on a daily basis and not being able to do anything that brought me any joy. I just couldn't imagine that continuing.

While more research is needed to better understand the social processes that shape the social determinants of suicide risk, the statistical data is clear: there is a significant increased risk for suicide post-TBI. Just over 10 percent of individuals who commit suicide have sought treatment for a brain injury[16] (Madsen et al. 2018), and that risk of suicide is only heightened among women (McIntire et al. 2021). "There is increasing evidence that their [women's] depression symptoms and suicide risk factors may be different than those of men with TBI due to their gender-related experiences" (McIntire et al. 2021: 161). In the sections that follow, I outline some of the ways that gender shaped women's experience and contributed to their suffering, including experiencing a legitimacy deficit, role conflict, and limited resources.

THE LEGITIMACY DEFICIT

Having others, both in personal and clinical relationships, doubt their condition was a central feature of the women's narratives. I showed how the legitimacy deficit played out in the diagnostic encounter in the previous chapter. In this chapter, I discuss how the legitimacy deficit continues to shape women's access to care, experiences in treatment, and their social lives – the key elements of the illness experience. I first offer a thick description of how women experienced the legitimacy deficit, followed by how women managed it by employing technologies of the self (Foucault 1986, 1997), and finally, the effects of their illness' (in)validation. Common ways the women managed the legitimacy deficit included nondisclosure, absenteeism and silence, disease comparison, and addressing individual symptoms. Recovery also served as proof to others of the realness of their conditions, conferring legitimacy and its associated privileges to the women.

The concept of a legitimacy deficit is not new in literature on the illness experience. In fact, it is quite common among research on chronic pain conditions and contested illnesses (see Kleinman 1988; Kleinman, Das, and Lock 1997; Ware 1992; Kroll-Smith and Floyd 1997;

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[16] This included all three brain injury severity classification categories: mild, moderate, and severe.

Barker 2005; Kempner 2014; Dumes 2020). Kleinman (1988) refers to the skepticism patients face as “social suffering,” while Ware (1992) refers to it as “delegitimization,” and still Kempner (2014) refers to it as a “legitimacy deficit.” Despite inconsistent terminology, the content of the experiences they refer to is alike in that patients contend with the seemingly substantial task of persuading others to accept their condition as legitimate and their suffering as authentic (Kleinman, Das, and Lock 1997: 65). In Ware’s (1992) study of chronic fatigue syndrome (CFS), she attributes this to the trivialization and psychiatrization of their symptoms that leads others to view patients as undeserving of the sick role. While other studies have examined how patients deal with being the “stereotype” as a woman with a contested illness (see Barker 2005; Kempner 2014; Dumes 2020), this study examines how women deal with *not* fitting the patient stereotype. In Dale Stone’s (2009) study of long-term survivors of hemorrhagic stroke who are young women, age was the salient social frame that discredited the women’s illness. In this analysis, I argue that gender is the salient social frame that discredits women’s illness due to gender incongruence between the disease frame and patient identity that results in a legitimacy deficit for women with mTBI.

Experiencing Legitimacy Deficits

The women in this study could all report having the legitimacy of their concussion diagnoses questioned at least once, whether that was medically or socially; however, women who incurred their injuries in more feminized contexts experienced the legitimacy deficit more than others. Lisa, a 47-year-old, captured the overall sentiment of the women participants saying, “I wish that…people would believe me. It’s hard when you feel like people don’t believe you.” Effectively, the legitimacy deficit accused women of “faking it.” When asked to discuss their experiences with people not believing that they had brain injuries (BIs), the women’s narratives revealed three key patterns of experience: the invisible nature of the condition, the power of experiential knowledge to resist delegitimization, and the prevalence of a social framing that stigmatizes people with invisible disabilities.

Visible markers of illness. The invisibility of both the injury and the symptoms was overwhelmingly discussed in the women's narrative constructions of the legitimacy deficit. In brief encounters, others lack clues that indicate the mTBI sufferer's status. The commonplace idea is that to be injured or disabled is to be physically and visibly injured or disabled – even if it is not the condition itself but instead props like a wheelchair, a hearing aid, or a guide dog. To this end, Lisa suggested she should "[m]aybe wear a t-shirt that says: '*I have a brain injury; give me a break*.'" Other women made references to signs, but the message was the same: they needed a way to effectively communicate their status. Avery, a 56-year-old, called it a "a double-edged sword," referring to the benefits that come with not having physical disabilities or any corporeal markers and problematic consequences of invisibility because people would say, "'Oh, she's just a normal...' And so, they didn't take our concerns seriously."

Furthermore, because symptoms largely did not affect the women's ability to do basic daily personal care activities (e.g., personal hygiene or prepare, consume nutrition, etc.), their suffering was not taken as seriously; they often did not meet the legal parameters to qualify as disabled and many times were able to aesthetically present themselves as "put together," at least on "good head days." The women often described how appearance was used as a proxy for health, reporting increased disbelief when they "looked good," with people saying to them things like, "Oh there's nothing wrong with you, you look great" (Piper), or "You look fine, you should be fine" (Sadie, 38-years old). Felicity, a 35-year-old, said, "Everything was so awful, and nothing was normal in my head, but everything looked normal. So, I think it's hard. Even people that love and want to support you – 'You seem fine. What do you mean?'" Here, we see the commonplaceness of the conflation of "good" appearance with "good" health in social discourse (Jutel and Buetow 2007). Iris, a 20-year-old, addressed how it was not just corporeal appearances, but also surface-level indicators of functioning:

> I would like friends, family, and the general public to know also that although we look "fine" on the outside, so much more is going on inside. It's a constant struggle each day fighting through pain and symptoms that make even the smallest activity difficult. Our lives have changed so much, and we have suffered lots of loss…We are trying our hardest but please don't think that, although we may make it look easy, it is – it's not at all. It is simply just our new reality. Our pain is real, and people like me deal with it on a daily basis. We never get a break. We may seem "fine," but we are really trying so hard to just get through the day…Let us know you believe our pain is real.

Skepticism was so significant that even secondary contacts would challenge the women's conditions, from partners' colleagues to children's friends. Eliza said that "[y]ou can be judged at any time, even by people you barely know." She elaborated explaining that because mTBI affects one's whole life, there are no social spaces where one's patient status does not become relevant. She recounted how colleagues of her husband commented to him, "There's nothing wrong with your wife" while they were attending a work function. She said, "It's really a terrible feeling to feel judged that way." In Eliza's account we see how others police the sick role, even in contexts where the condition is not relevant and others are distantly connected in their social networks or their loved ones' social networks. Eliza culminated her story by saying, "And you know, I cannot even imagine any situation where this would be flipped, where one of my coworkers would come up to me and say, 'You know, there's nothing [wrong] with your *husband*.' They wouldn't do that, no one would ever say that." Here again we see the gendered social framing that contours beliefs about illness.

Even comments intended to compliment the women were experienced as discrediting. The women were not, as Layla, a 27-year-old, said, "being fully seen for all of who we are and all we're going through. No one recognizes the struggles or the strength, and so it's kind of like there's no space for a part of you in the world." The women encountered other more subtle ways that their experiences of mTBI were invalidated because of mTBI being poorly understood. After not being able to go to church for several years due to her symptoms, Serena, a 60-year-old, tried going with her husband one day when she was feeling well enough:

> My pastor said "You're doing so great. I can't even tell." I know his heart, I know he's trying to be encouraging but for me it's maddening because I'm like, you have no idea how hard it was for me to take a shower and sit through the sermon and all the sensory and now I have a migraine and I'm going to have to lay down for three days.

When I asked her if she had ever offered such explanations to people, she said, "I don't have that type of energy to try to inform people." In subsequent sections, I show how women commonly defaulted to passing or absenteeism due to confirming experiences of futility and the lack of energy that Serena speaks of here.

The power of experiential knowledge. A common response to what is unknown and what is poorly understood is disbelief. As shown in the previous chapter, this manifested in the clinical setting as psychiatrization. This rhetoric was commonplace in lay discourse, as well, with women reporting friends and family saying their condition was a product of their imagination and suggesting they were hypochondriacs. For example, Piper, a 44-year-old, recalled how her mother, who happened to also be a primary care doctor, challenged the legitimacy of her concussion diagnosis:

> She would really question me, like, "So, when are you going to go back to work?" Or one time I remember I was with her, and I started having some aphasia with the really stilted speech – you know, like one word at a time – and she was like "You were just fine a few minutes ago." And I was like, yeah, I was *a few minutes ago*, but then I reach my breaking point and the light switch goes off. I think she never really, fully grasped it…She was so dismissive…it was really hard. I felt so belittled, and people just thought I was faking it and it was really hurtful.

Even with formal medical training, Piper's mother had difficulty believing her daughter's condition. Yet, an important element of the women's narratives surrounding the understanding of mTBI was an emphasis on experiential knowledge; that is, a sense that knowledge is gained from bodily experience. Hannah said, "With a TBI, you would have had to have one to really get it and understand what a person needs…Somebody who hasn't gone through it, they just don't have the experience." Experiential knowledge was the only way to understand mTBI, as explanations were insufficient because, like Avery said, "[T]he experience is incommunicable. We don't have the words to express these experiences or the pain." To this end, women often tried using comparisons to other illnesses, like headaches, in their campaigns for legitimacy, but even that fell flat. As Sadie noted:

> It's something that you can't really explain. Even something like headaches, people don't really understand what a headache is, and how debilitating it is if they've never had a headache. So, it's hard to get, to a degree. It's hard to explain these things and to get people to kind of buy into it. At the end of the day, there's things you won't understand if you haven't experienced it.

The language of pain lacks the texture of *feeling* pain or living with pain. Pain is a complex biopsychosocial phenomenon requiring interpretations of sensations and embodiment (Kelly and Field 1996; Barker 2005; Kempner 2014). Such interpretations are personal in that they are affected by individuals' unique social positions and cultural backgrounds. Thus, others may understand or value pain differently due to their own social contexts.

Further, biomedical and lay discourses on pain reflect dominant gender ideologies, and these gender ideologies also shape how patients with pain are seen by others. For example, Kempner (2014) illustrates how medicine adopts and maintains gender ideologies by using the case of cluster headaches to show how disease knowledge adopts the gendered characteristics of its dominant patient population. She shows how cluster headaches went from a condition common among men to a disorder of hyper-masculinity. Biomedicine's gendered disease language and its institutionalization of gendered ideologies of pain (e.g., Johansson et al. 1999; Bendelow 2000) lend credibility to men's pain and suffering. The effect of this is that men's pain is valued more than women's pain. This has been explained by gender ideologies that imply that because illness and weakness challenge hegemonic masculinity, a man would only risk this threat under severe distress. Thus, men's reports of pain are seen as more credible while women who report pain are seen as "whiners and complainers" (Werner, Widding Isaksen, and Malterud 2004). Thus, gender ideologies have profound impacts on men's and women's embodied experiences of pain.

Social framing. The women frequently identified instances where the invisibility of their condition limited the assistance and support that they received from others because their disability was not visibly identifiable, making the social identity of mTBI patients different from other forms of disablement that have observable markers. In Lisa's account, she described how not only do mTBI patients not receive assistance from others, but they also experience stigma if they request assistance. She said:

> If I went into the grocery store with the cast on, someone would ask if I needed help. But, if I go into a grocery store with a brain injury and can't remember even what the aisle was that I was in before and ask someone for help, it's almost like "Are you special needs? Is there something wrong with you?" It's not, "Oh, you've got an injury." It's not that you're hurt, or that you're recovering…No, it's like there's something really just *wrong* with you. It's harder for people to believe a brain injury 'cause you can't see it. And I think especially when it's something brain-related because a lot of mental health things are seen differently than a physical injury. There's social stigma to mental illness, and I think TBI falls under that and gets looped into the mental health stigma because of that – that there's something *wrong* with you.

Lisa's account illustrates how a lack of readily apparent physical disability gets interpreted by others as a psychological or psychiatric condition. Lisa identified invisibility as the mechanism through which the stigma she experienced as a brain injury patient was similar to the stigma attached to mental health conditions. Often the brain is conflated with the mind. The importance of the brain as the body's command center for surviving and thriving is often forgotten or not realized. The brain is responsible for physiological functioning (e.g., telling the body to breathe, regulating body temperature, controlling hormone levels, etc.) and social functioning (e.g., regulating emotions, interpreting social cues, communicating, etc.). Phoebe, a 51-year-old, said that one thing she wished people knew was "That they're very serious. That we're not just faking it. That truly, you lose some skills." When women did make attempts to communicate their illness experiences, they were often in vain as others still diminished their condition. Hannah said, "When I tell people about it sometimes it's like, that's whatever, you know." The lack of understanding resulted in others responding to the women in negative ways, such as anger, ridicule, and blame. The belief that visible indiscernibility alleviates the effects of disability by allowing individuals to avoid stigma (Kelman and Lester 1997) is thus unfounded. Davis (2005) argues that "[t]here is no reason to believe that the invisibility of a disability itself necessarily lessens its impact or makes the disability less serious" (p. 154). While the contents of the challenges vary, it is no less difficult to engage and be successful in an ableist society with an invisible disability.

The women's conditions were also moralized by others. They recalled people making claims about their character, such as being lazy or a liar/cheater – suggesting that the women were taking advantage of social benefits (e.g., trying to "cheat the system"), especially in cases where there were financial benefits (e.g., workers compensation or social security disability), which I will address more in the following chapter. For example, Harper said of her experience trying to get accommodations when returning to college, "I think they thought since they couldn't visibly see anything wrong with me, that I didn't really need these accommodations and was trying to get an unfair advantage." Emma similarly noted encounters where her extended family and some friends suggested she "was basically being lazy – like, just didn't want to work or deal with the kids." She explained that nothing could be further from the truth: "I *love* my kids. They're so much fun. I loved my job too, you know, it was my dream job. I would love nothing more than to be able to do everything like I used to." The use of moral narratives in discrediting patients is well-documented in literatures on the illness experience and the sick role (see Werner and Malterud 2003). A component of the sick role is that patients are not held responsible for their conditions; thus, claims that a sufferer's condition is due to moral failings discredits their condition as being outside of the individual's control, thereby precluding them from the sick role.

Finally, the women connected their illness experiences to current gender bias as well as enduring historical ones, such as the legacy of hysteria (see Johannisson 2001). Extant literature provides similar evidence of the legacy of hysteria in conditions such as fibromyalgia and other functional disorders (e.g., Shorter 1992; Ford 1997; Showalter 1998; Scheurich 2000; Werner, Widding Isaksen and Malterud 2004). Overwhelmingly, the women in this study felt their experiences were interpreted by others through a gendered lens – one that viewed them negatively and endorsed discrimination. Others drew on the social frame of gender; specifically, gender stereotypes that construct women as being more sensitive or having a lower tolerance for pain and contribute to the popular societal belief that women are likely to exaggerate their symptoms. Piper told me that she felt like she would have had a different experience with her mTBI if she was a man. When I asked her why she thought that would be the case, she said:

> I'd say I feel there's a lot of gender stereotypes and…as a man, you're more believed. And as a woman – are you just being whiny and needy? I have a friend who has had very similar symptoms – I'd say same level of disability – and he got his disability [the same way] – he rides bikes, too. So, it's just like…what was the defining thing there?

Piper's account shows how women's symptoms were minimized, often drawing on the narrative of hysteria, while men's symptoms were seen as legitimate.

Managing the Legitimacy Deficit

Parsons (1951) theorized the "sick role" as a temporary social position one occupies during sickness when they are exempt from their normal responsibilities in order to recover. To be seen as legitimately sick in society, the sick person must identify their condition as an undesirable one that they wish to recover from, and they must actively pursue recovery with full medical cooperation. However, the sick role, as Parsons theorized it, does not account for untreatable/chronic or invisible conditions, like mTBI can be. In this conceptualization of the sick role, an individual is viewed as either legitimately (acutely) sick or deviant. The women employed four primary strategies in response to the delegitimization of their conditions: 1) showing their disablement, 2) disease language and individualizing symptoms, 3) non-disclosure and passing, and 4) absenteeism and avoidance.

Seeing is believing. Illness experiences are co-constructed within partnerships and may be more or less concordant (Klein Woolthuis et al. 2013). Many of the women in this study said that their relationships with their partners were strained due to discordant ideas between them and their partners about the meaning of their conditions and how to best manage it. Studies have found that the gender of the patient in relation to the gender of their partner influences the relationship as well as the illness experience of the patient. The women in this study felt that they had to "fight" for validation of their condition with their partners, providing further evidence of the tendency for heterosexual men to dismiss and minimize their wives' illnesses (García-Calvente et al. 2012; Umberson et al. 2016). Building on this work, the findings of this study suggest that gendered legitimacy plays a crucial role in co-constructions of illness amongst partners. For example, Eliza noted that what helped to improve her relationship with her husband was addressing her husband's skepticism. When I asked her what helped to repair their relationship, she told me:

> It wasn't until COVID and my husband being home every day working from home that he saw how I struggled with things… And so, it's him observing me on a daily basis that has really made it sink in for him – that I have a disability.

This "seeing is believing" narrative was common amongst the women who reported that they faced the most doubt from those they interacted with the least, suggesting that observable indicators, even if not corporeal but behavioral, can also serve as evidence to support individuals' claims to the diagnosis and the sick role. Albeit not absolute, it did improve women's legitimacy. Some of these behavioral markers included forgetfulness, fatigue, sensory sensitivities, vestibular issues, and speech. For instance, leaving an external door to the house open at night repeatedly, having no recollection of cooking food in the oven, staying in bed with the lights off all day, or losing words (aphasia) and stilted speech. Observing persistent and consistent symptoms among the women seemed to lend credibility to the reality of the women's conditions to those around them; they were not making it up after all. Eliza pointed out that while she was able to make strides in convincing her husband and her adult children that her condition was real and significant, she still had to contend with the skepticism from those less socially proximal because those were relationships that could not be addressed with this "showing" strategy due to lack of time with them and others' knowledge of the women's prior "normal."

Individualizing symptoms and disease language. The women learned how to talk about their injuries in particular ways that bolstered their credibility through narrative construction (Werner, Widding Isaksen, and Malterud 2004). In fact, there was a common structure to the ways they told their stories. This suggests that patients who experience the legitimacy deficit are informally taught narrative construction strategies through personal trial and error and cautionary tales from others to tell particular "illness stories" (Frank 1997). There were four apparent primary guidelines:

1. *Avoid the terms "concussion," "mild," and "syndrome":* Terms like these minimize the condition due to social framing. Generalize the condition to "(traumatic) brain injury" to bolster its credibility and severity.
2. *Generalize the context:* Include select details from the accident. For example, rather than saying that your dog "bonked" into your head, say that you experienced an impact to the head. Leave it up to the interpreter to imagine the severity; they will probably assume the worst, which only helps to reduce skepticism.
3. *Emphasize the gravity of your condition:* While in most interactions it is best to be positive and minimize one's hardships, in this case it serves you better to focus on the worst. It can also help to simplify symptoms, either by identifying each symptom independently or through comparisons that make it relatable to others.
4. *Outline attempts to improve your situation:* Make it clear to others that you are not trying to gain unfair social benefits by identifying all the ways you have tried to persist through your condition and to improve your condition.

These strategies seemed to have arisen in response to cultural narratives of mTBI that minimized and discredited the women's impairments, as well as through cautionary tales spread within the patient community. With these strategies, the women aimed to establish the severity of impairment and prove their credibility as patients.

A second way the women used disease language was through disease comparison, often autism and ADHD. They linked their mTBI to these diseases through similar symptom clusters and shared belonging to the broader categories of neurodiversity and invisible disability. A third way women employed disease language was by individualizing their symptoms. This made their condition both relatable and specific, which bolstered their claims because "brain injury" is a broad and diffuse term and the sheer number of symptoms was suspicious. Focusing on one or two symptoms most relevant to that particular situation or relatable to that specific individual, say headache or vertigo, helped women more effectively communicate their disablement.

Passing and non-disclosure. Another strategy the women employed to mitigate the stigma they experienced was through non-disclosure to "pass": "the management of undisclosed discrediting information about self" (Goffman 1963: 42). The women who were most socially active had someone helping them in social situations. In practice, this included others covering for them, disclosing their status to others, or making accommodations. For instance, Piper recalled the help her husband provided by easing conversations while attending her husband's company holiday party:

> I just couldn't follow conversations and people would try to talk to me and, as my husband wasn't right there with me, I had trouble following the conversation and I would start talking and then forget what I was saying. It was just so overwhelming unless my husband was there – he would occasionally just jump in and banter back and forth with me a little bit and make it easier.

Thus, social support impacted the women's strategies. Women who had someone that believed them and supported them were more likely to engage in social activities as it reduced their social anxiety by minimizing disruptions in social conventions and allowing them to pass.

The women were also concerned with managing their social relationships and how others saw them. To this, Hannah said:

> I think that sometimes we filter ourselves when we talk to friends because you don't want to – you want to help them understand and connect with them, but you also don't want to be that person who's a Debbie Downer and constantly complaining.

The common concern among the women about sharing their illness experience and being perceived negatively as complaining and attention seeking was also accompanied by the concern for protecting others from the burden of empathy. For example, Iris noticed that her condition was negatively affecting her mothers' happiness and stress, so "to avoid any more burden on her," she tried to hide her symptoms from her mother. Women's concerns for others and their social relationships contributed to their decisions to pass. Because traditional gender roles construct women as "nurturers," individual women feel compelled to prioritize caring for others over receiving care themselves, even when experiencing illness, and thusly reject the sick role in favor of being caregivers for others (Thomeer, Reczek, and Umberson 2015). This sheds light on why the illness experience of mTBI was, overall, more stressful for the women than the men in this study.

The women also feared social stigma. Gianna, a 37-year-old, said, "I try not to tell people about cause I'm always in fear of being treated as less than." Most of the women said that they did not tell people about their mTBI unless it was necessary or if they became "discredited" (Goffman 1963); that is, their symptoms became apparent to others, and they faced stigma as a result. In such cases, offering a medical explanation minimized stigma and allowed them to "save face" (Goffman 1963). While "passing" was at times an empowering experiencing as a means to maintain some normalcy, at others it was compulsory as a way to survive. Regarding the latter, Eliza said:

> Of course, not being believed, you can't just speak your truth. You can't be authentic. You can't be who you are because people don't believe you. And you don't have the energy to deal with that, so it's constantly "How are you doing?" "I'm fine." I always say that if you want to find an actor or an actress, find somebody who's had migraines and worked through them or has been depressed. We sail through life pretending to be something that we're not just trying to fit in in the world of normal.

Women are taught to be emotional laborers and prioritize others. Women bear a greater burden than men to perform emotion work: the emotional regulation one does in the private sphere to render feelings in a given situation as appropriate according to the social situation (Hochschild 1979, 1983; Devault 1999; Illouz 2007; Kang 2010). Women often fear burdening family and friends with their own troubles, including illnesses (Kagawa-Singer and Wellisch 1997; Ashing-Giwa 1999; Tam et al. 2003). Research among breast cancer patients found that the fear of burdening one's family emotionally with their illness was second to none. By avoiding burdening others, the women in this study faced the unfortunate consequence of having one's own needs for emotional support go unmet (see Ashing-Giwa 1999). In this way, passing and non-disclosure resulted in a disconnect for the women that contributed to their choices to engage in the next strategy: avoiding and absenteeism.

Avoiding and absenteeism. As an alternative to passing, whether due to physical symptoms or the emotional stress of concealing one's illness, some women instead avoided interaction all together. The stigma and rejection these women faced caused significant strain, leading them to distance themselves from others to avoid such negative appraisals. Women stopped doing most things for at least some period of time right after their injuries, including paid work, visiting with friends, going to stores, or attending other social gatherings. Eliza said:

> You're isolated…I can only handle one conversation at a time, so if there's more than like three people talking, you get this "deer in the headlight" thing – you don't answer anybody, and people assume that you're stupid. They assume that you're stuck up because I don't hear them. People assume I'm stupid because I can't answer quickly enough for them. Or I'm having a bad day and I just can't track information anymore; I can't take it in. And so, it's very, very isolating, you know, because you don't really want to go do those things and then people stop wanting to invite you too.

It was not just the sensory overload and severity of symptoms that prevented women from going to public places and social events. As discussed in previous sections, the women were unable to gain the understanding and support from others that they needed to navigate social environments, whether that was from store clerks, family, or friends. Sometimes they were not recognized as patients due the invisibility of their injuries, sometimes they could not advocate for themselves, and, still other times, their claims were denied and requests for support rejected.

Finding Validation

Among the women in this study, validation supported self-advocacy by creating pathways to treatment and improved mental health. The women experienced validation through the corroboration of their experiences by other patients and confirmation of their symptoms from specialists. Perhaps the most significant way women found validation was through online resources. The internet significantly shapes illness experiences today; nearly 150 million Americans regularly look on the internet for health information (Conrad and Stults 2010). This was true among the women in this study, as well, who found support online through discussion forums, like Facebook Groups or Reddit. Sadie, for instance, discussed the validating effects of being able to read about others' experiences: "If you're going through the same thing, you could say, 'Gosh, there's somebody else with the same symptoms. I'm not alone. I'm not crazy." This was a significant moment in the women's illness narratives, with the phrase "I'm not crazy" being quite common. For many women, resources online were not about finding medical care or seeking medical advice, but about finding social support. Facing doubt in so many other areas of their lives, this was one of the few spaces where the women's embodied epistemologies were not only permitted but empowered.

Others found support through formal support groups. Eliza highlighted the beneficial impact support groups had on her recovery through the information she acquired there. Contrasting the effects of medical interventions with that of validation through support groups she said, "Some resources like that [practitioners who specialized in TBI] helped, but it's the support group type environment…that has done the most to help me accept who I am now and where I am." Later in her interview, she noted that there is an issue with access to support groups, however, in terms of finding them and accessing them. She reported having a difficult time finding the one she did, saying, "I was very surprised to find a lack of support groups for brain injury…It took me like six months." Eliza, as well as other participants, further noted that there are other practical barriers TBI patients face even once locating a support group. Eliza said, "You've got this community that is brain injured and has trouble cognitively…yet it's really hard to find support groups." Before COVID when support groups met in-person, transportation was an issue as many of the women could not drive themselves to the support groups or the distance to the nearest one was not practical. Then, there was a different barrier with support groups moving online: access to internet, cognitively navigating the websites or programs, as well as screen sensitivities.

Support groups offered validation of women's experiences while simultaneously serving as a space for consuming and producing lay knowledge. These spaces often provided a catalyst from which the women felt empowered to assert themselves in clinical encounters, making it a vehicle through which patient groups organized and resisted dominant medical views. In doing so, it also led many women to find new medical care that was TBI-literate. Alice's case highlights this process of experiencing the legitimacy deficit in clinical encounters, in her case, her symptoms were explained by aging and anxiety. She disagreed with this particular medical assessment saying:

> I went to the ophthalmology department, then optometry department where both of those said, "You're fine. Just normal aging your eyes. You could see the letters so you're good." And I kept telling them it's not about seeing the letters—I'm seeing *two* of the letters. I'm not seeing things on the side. I'm having much more blurriness than I had before. And it comes and goes, but they wouldn't believe me because of the anxiety aspect of this, you know, like, "It's just your anxiety." So, I kept saying I was seeing some flashes…and I get these black spots. Then they said "We don't see anything. Maybe there's some degeneration, but that could just be with age." Then, I finally insisted on seeing if they had a neuro-optometrist because I've done a Facebook Group that's a support group and everybody's saying to get that. So, I asked, and they said, "Well, you have to go to a neuro-ophthalmologist first." So, I went…and she confirmed everything I was saying because she deals with the brain. She's like, "Yeah, no, you can see things, but you don't. You need to see a neuro-optometrist so we can get you the right glasses and we can get you therapy." So, I saw that person, and she's like, "You're absolutely right. You're having conversion issues. You're one eye is deviating from the other issues." She used all the terms that everybody was saying in my Facebook support group that they were gonna find and she said it! She said I needed prism glasses and like tinted glasses – all of it, you know? Like, finally, *thank you*.

Here we see how epistemology wars extend outside of the doctor-patient relationship where patients use other patients as a resource for experiential validation and knowledge transference (Hardey 1999). As Barker (2008) said, "The process of understanding one's embodied distress has been transformed from an essentially private affair between doctors and patients to an increasingly public accomplishment among sufferers in cyberspace" (p. 21).

However, support groups came with an important caveat. While they could be a space for peer support, they could also become an arena for competition about the relative severity of disablement. Avery reported that she found the most support from "talking to other survivors," but noted that this was also "very thorny," saying:

> I got into a bad situation in a support group, more than once, because it was just a bunch of complaining and I just had no tolerance for it. And I think again, there's almost a competitive nature that comes out in people where it's like, "Well you think you have it bad? Listen to this." Like competing over who's lost more money, or who had a more traumatic incident, or whose family is more supportive or less supportive. But I do think there are some other survivors who I have found and you kind of learn to support one another.

Other women chose to avoid support groups for this reason, anticipating either negative reactions from others, worrying about their capacity to be empathetic to others, or fearing others' negative experiences could further diminish their optimism for recovery. Extant literature has established that health-related support groups are largely gendered regarding both the gender composition of participation as well as the format or content of them; women are more likely to participate in support groups and support groups are feminized due to gendered norms about expressing vulnerability (e.g., Lieberman 2008).

ROLE CONFLICT

Parsons' concept of the sick role is based on traditional masculine roles that assume work occurs outside the home. It also assumes a breadwinner-housewife relationship where a man's sole responsibility is to his paid employment, and thus, when too sick to work, can worry only about getting better. Parsons' theorizing of the sick role has been criticized for its restrictive modeling that is exclusionary of forms of difference, such as gender. In contrast to Nathanson's (1975) assertion that women's roles are more compatible with the sick role, I argue that women's traditional gender roles are *less* accommodating of the sick role, thereby creating *more* role conflict and increased stress that only further exacerbates their illness and impedes recovery. Role conflict occurs when the expectations of two or more social statuses are incompatible or competing. Since women are likely to be responsible for most of the childcare and housework, women may not be able to focus exclusively on getting better due to other gendered responsibilities that they cannot so easily be excused from, like child rearing. The women in this study experienced role conflict as patients and workers, partners, and mothers – virtually every role they occupied. Because of this conflict, the women reported significant changes in their lives, saying things like, "My whole life changed" (Gabriella), "Literally everything [changed]" (Serena), "There's nothing that didn't get turned upside down by this in life" (Layla). Serena explained:

> With the brain injury, literally everything [changed] from being able to work, drive, go into a grocery store, use a computer…I can't do endurance sports or anything upright like walking…[or] socialization, like understanding what people are saying, and I always have to tell them to slow down. Like if two things are going on at once – oh my gracious. I have PTSD now, so driving in the car, I always freak out. Or, if there's a loud noise, I always freak out. Never used to have anxiety and I have that now. That would be a lot of what's changed.

Such changes resulted in negative outcomes both socially and clinically, negatively affecting personal relationships, preventing them from working, limiting how much treatment they pursued, and negatively affecting their mental health.

Being a Worker

All but two of the women who were working for pay outside of the home at the time of their injuries stopped working; for a handful, it was only for a month or two, but about half of the women still had not returned to paid employment at the time of the interview. When I asked the women who reported being employed at the time of their injury if they continued working post-TBI, they commonly responded in a way that suggested that it should be *obvious* that they, of course, did not. The nonspecific symptom cluster of mTBI can inversely be interpreted as extensive. The women commonly reported noise sensitivity, light sensitivity, cognitive deficits, vision dysfunction, and vestibular issues. With symptoms that reduce basic functioning, being able to perform at a high level in a work context was incomprehensible. Some of the women did try returning to work but, like Piper reported, "it did not go well at all." Lydia explained how her lack of working was not due to a lack of trying, citing three attempts at retuning to work:

> I tried to go back to work, like I *tried*… I actually did a project in August through my old employer, and I was working like two hours a day, but it was like every hour I worked, I was sick for like one to two hours. So, I just – it just was too much. I had to just like come home and lie down and just like ignore the world. I talked to my doctor, and he's like, "Okay, you're not ready." Then I tried again – that was a different project. So, I tried again on this one project – I only tried to do it for a week – and I had to quit. I couldn't do it. Because it was just way too much, and it was just not going well. Then I tried again in January. But like, I had tried to go back to work like *three* different times.

In Lydia's account we see how women wanted to work but that symptoms prevented them from being able to complete their work.

In addition to symptoms preventing women from being able to work, time was also a factor as they faced competing priorities of being a good worker and being a good patient. Blair-

Loy (2001) provides a helpful framework for conceptualizing how the gender structure shapes individual agency through schemas of devotion: cultural models that guide how we use our time and where we devote our energy (p. 689). While Blair-Loy addresses schemas of devotion to work and to family, the concept may be extended to a schema of devotion to health to describe how culture influences patients' constrained choices. As a worker, they were expected to prioritize their work and be dedicated completely to the job. But, as a patient, they were expected to be "100% dedicated to recovering," as Gabriella said. Already dealing with symptoms that prolonged their work plus extended recovery times that further delayed their progress, the women had limited time with which they could seek treatment to recover. Working, even without a brain injury, limits scheduling medical appointments because working shifts often overlap with the times that physicians see patients. Thus, women had to manage competing devotions and negotiate role conflict. Most of the women resolved conflicts by prioritizing their patient role, in part because the benefits of working did not outweigh the struggles they faced at work.

There were several factors that contributed to the women's decisions to leave the workplace. The lack of flexibility by their workplaces to accommodate them pushed the women out. Because women faced a gendered legitimacy deficit and their conditions were not believed, their workplaces did not offer sufficient accommodations. As I discuss in the next chapter on women's (re)entry into education and employment, their legitimacy deficits created hostile work environments that prevented them from accessing accommodations and from employers offering flexibility for them to be both workers and patients. Some women were not the sole or majority income in their household and had partners whose incomes could, at least temporarily, support their families. The women were also dealing with the "second shift" (Hochschild 1989) that pulled them back into the home. Some women addressed constrained choices in that they only had so much energy and they could either "mom or work, but not both." Felicity elaborated by saying, "I couldn't manage working and the kids at the same time. [Whereas my husband] could go to work and come home and there wasn't a lot sitting for him to do." Felicity keenly picked up on the ways in which gender roles differently determine men's and women's abilities to manage sickness. As I show later in my final analytic chapter, men with mTBI did not have the same expectations to come home and keep working as a parent, so they could afford to max out their energy at work because they knew they would be able to come home to rest and even be taken of care of afterwards to recover for the next paid workday.

For the handful of women who did return to paid employment, they cited financial reasons, noting that they would not have returned as soon as they did, or ever at all, if finances had not been an issue. Lorelei, a 41-year-old, highlights the importance of finances and flexible resources in return-to-work decisions, saying:

> You need money to pay bills and I didn't have anybody to ask for help – I was the only one supporting myself…If I had had sick pay, I would have stayed home. That would have been huge for me to be able to stay home and actually recover.

Like Lorelei, all of the women in this study who relatively quickly returned to work emphasized that it was not by *choice*, and further suggested that doing so was detrimental to their recoveries; that they would have seen greater or more expedient improvements otherwise. In the next chapter, I expand on the women's experiences of returning to work to address how prognosis and workplace practices prevent them from reintegrating back into the workforce post-TBI.

Being a Partner

Among survivors, TBI is colloquially known as the "relationship ruin-er." Madison said, "I was a member of a support group at [a hospital] and I remember how high the statistics were for people that were married – that most end in divorce after TBI and I thought the odds were against us and we weren't even married yet." This is a common finding within illness research, as treatment can cause time-, emotional-, and financial-strain. Karraker and Latham (2015) find that, among heterosexual couples, divorce is more common when a wife is seriously ill than when a husband is. This is suggested to be due to the uneven burden of caregiving, where wives take on more spousal care during spousal illness that is not true of men when their wives are sick (Pinquart and Sorenson 2006; Freedman, Cornman, and Carr 2014; Penning and Wu 2015). Many partnered women identified the need for "some kind of support group for supporters of those brain injuries [because]…they need support figuring out how adjust to this change in their lives too" (Felicity), highlighting the impact of TBI on relationships and the strain that TBI causes due to shifting roles within a relationship. Felicity discussed how no longer being able to be the primary homemaker and caretaker of the kids caused "strain" in her marriage.

> I couldn't manage working and the kids at the same time, so I had to stop [working]. And even then, I definitely would say my husband's had to pick up a lot more. [Before the TBI] I was pretty independent, you know, I could handle most mom, household, bill – every household responsibility – and he could go to work and come home and there wasn't a lot waiting for him to do, and now it's more like I need help figuring out dinner – I just can't do that on my own anymore. I just need more help. So, he's had to add a lot more like house- and kid-related stuff to his plate. He was great about it – he's wonderful. But it definitely caused some – I would say strain might be a good word – strain in our relationship. Kind of like when you do a remodel on a house, just because there's so much adjustment. But he's worked really hard to help and to work through it, so I just got lucky that it *was* in sickness and health. But it definitely caused strain.

The women reported that while tasks and finances were part of their relationship challenges, there was also an emotional component to it, too. As Layla put it, "I wasn't emotionally available for him." Regarding her former long-term relationship, she further explained that:

> I was in this shithole just completely overwhelmed by literally everything and spending so much of what little energy I had just on figuring out how I was going to survive. I had no energy, no capacity for empathy because I was focused on my own pain and my own suffering that I had nothing left to give to anyone else. And, you know, that's not a healthy relationship. That wasn't fair to him. That's extremely one-sided and he wasn't getting his needs met. And if I'm being totally honest, it wasn't anything even resembling a relationship. We didn't do anything – I couldn't really do much. I couldn't go out to dinner – that was too loud and too many lights. I didn't even want to talk with him – not

> that it was him, it was just that talking took so much focus and energy. So, I get it. I get why it took its toll on our relationship.

In addition to socioemotional changes in the dynamics of romantic relationships, romantic relationships can be challenging for women with illness and disabilities because of the stigma that results from traditionally valued traits related to femininity like beauty, sexuality, and caregiving (Berger 2013). For example, Gabriella said, “It definitely put a strain on my relationship with my husband. Um, obviously like affection, sex, things like that.” Because of new stressors like the ones Gabriella and Layla outlined, some of the women and their partners sought out marriage counselors. Piper, for example, said:

> At first, it really was a huge strain on our marriage and things got really bad there for a while. We were maybe three months in, and we went to marriage counseling. It was hard. He was having to do everything. He was having to take care of me. He was having to work. He was having to take me to all sorts of therapy appointments. He had to do the grocery shopping and the cooking and the cleaning and – he had to do *everything*. And I was angry and bitter and didn’t want his help with everything. I didn’t want him telling me I should go take a nap… And then after we started going through marriage counseling and I realized that everything that I was mad about was just him trying to help me, and he was mad that I was pushing him away and didn’t want his help. I think when we finally realized that we needed to approach this like a team, we started talking about *us* going through this concussion – going through this injury – and when we started approaching it as a team, and what did *we* need to do, it really changed things…I think it really changed our marriage fundamentally. I didn’t like being so codependent, but we learned over time to adapt to that and that became our new normal.

In Piper’s account we see how mTBI creates role conflict between being a partner, where the expectation is equally support one another, and being a patient, where the expectation is to be taken care of and focus on taking care of oneself. This role conflict was exacerbated in cases where the women were also caretakers for their partners. Evelyn’s case highlights how becoming a patient creates strain in relationships through competing care expectations.

> I filed for divorce from my first marriage after the injury. I was already in a care taking role for my first wife… After I was injured, I was unable to support her, and our roles reversed… I could not help her anymore. My needs dramatically changed after the injury. Now, for the first time in my entire life, I needed help with things… I no longer just

> needed a companion, I needed someone who could actually meet my needs, including logistical medical support and the emotional needs that occur after a huge injury, losing your career, losing your income, losing all your hobbies, losing your bridges to new friendships and new jobs, etcetera. So, I asked for a separation. I asked for marriage counseling to ensure the relationship was irreparable, and it was.

Due to competing needs, couples, like Evelyn and her wife, were unable to adapt and divorced or separated. Evelyn later explained in the interview how the relationship had become "toxic." Hannah similarly explained how her once relatively happy cohabiting relationship became an unhealthy one after her accident:

> I really couldn't heal living with him – I couldn't. And it was so difficult because I didn't have any capacity to do anything about that. I mean, it was just like – I'm just here. I couldn't stick up for myself. It was just like, "All right. If that's what you think, then okay." You know? And I've never been like that. I used to be pretty assertive. I felt like I was kept kind of down. I don't know, oppressed almost.

Hannah and her partner separated, which she thought aided in her recovery because she was no longer expending energy worrying about her partner's responses and felt better about herself, which supported her mental health. Hannah's story also highlights how mTBI increases women's vulnerability to abuse. While I lack the data to fully explore this issue at the length it deserves, it is an important point to draw attention to as a handful of women in my sample discussed their vulnerability with a double jeopardy as a woman and with diminished capacities. Abuse is twice as common amongst individuals with disabilities, with people with mental and intellectual disabilities having the highest risk (Bureau of Justice Statistics 2009 – 2015). Being a woman with a disability further increases the likelihood of being a victim of sexual assault with 25.6% of women with disabilities reporting lifetime victimization compared to 14.7% of women without disabilities, 8.8% of men with disabilities, and 6% of men without disabilities (Mitra et al. 2016).

Being a Mother

While disability and gender stereotypes about women may reinforce each other in many ways, in other cases disability serves to exclude women from traditionally feminine roles, such as child rearing (Walsh-Gallagher, Sinclair, and McConkey 2012; Frederick 2017). Rather than being seen as caretakers, they are often seen as needing care. The issues that come with simultaneously being a patient and a mother are well-documented across disciplinary bodies of scholarship. Women with illness and disability face discrimination in childbearing and parenting (Lewiecki-Wilson and Cellio 2011; Fritsch 2019; Blum 2020). Parents with disabilities face many challenges including inaccessible housing, poverty, and lack of transportation, the presumption that people with disabilities are unfit parents, the lack of services and supports to assist with parenting, and the lack of reproductive health care (O'Toole 2015).

All the mothers in this study who were actively parenting dependent children described the role conflict of being a patient and a mother. As Felicity said, "It definitely caused strain because as a mom, your job is to hyper-focus on your kids, and once you get a brain injury, your job becomes hyper-focusing on yourself – those don't go together well." This was even true for some mothers of adult children, especially if their adult children still lived in the home or lived nearby and they interacted regularly. The expectations that come along with being a mother and those of being a patient are incompatible in a different way than fatherhood is due to the gendered expectations of parenting. The social expectations of being a "good mother" are predicated on the traditional male-breadwinner and female-homemaker gender roles that produce a dominant mothering ideology that assumes the privilege of married middle-class mothers who can practice "intensive mothering" (Hays 1996) and "concerted cultivation" (Lareau 2011). These ideologies expect that women not only put their children's best interests first but also spend all their available time investing in their children through nurturance and activities that will maximize their children's development (DiLapi 1989; Hays 1996; Johnston and Swanson 2006). Despite women's increasing entrance into the workforce and more dual-income households, traditional gender roles in childrearing persist, such that the expectation of fathers is to "help" with the children, leaving the primary responsibility of childrearing up to mothers (Lareau 2011).

The mothers in my study discussed three main concerns about mothering with an mTBI: emotional consequences for their children, being an active parent, and limiting their children's quality of life. Mothers worried not only about how they were feeling but about how their injuries made those in their families feel as well. They also mourned the loss of the mothers they "could have been" (Felicity) without an mTBI. Felicity expressed the complicated feelings mothers experienced surrounding how her injury was impacting her family. She said:

> It's hard because you want to advocate for yourself, and you also are worried about your family, and you don't want your kids being sad or your husband being sad, so yeah, it's really hard…It's hard to think about the effect it has had on my kids. I worry about my husband frequently, too. It's hard to think that they'll never know the person I was because they were too young to remember.

To minimize their injuries hurting their families, the mothers made attempts to conceal from or to compensate for their symptoms with their children. For example, Avery talked about how she wanted to avoid making her children feel badly, so her husband and her had agreed not to discuss her condition around the children: "Even now, talking to my oldest daughter, she will say, 'Well, I never knew that.' And I said, 'Well, I guess we did a good job then.'" Extant literature finds that mothers want to protect their children from the negative emotionality around their illness across various conditions (see Lewis et al. 1996; Davis Kirsch et al. 2003), and this was true of the mothers in this study as well. In this sense, it is common for women to conceal their conditions all together or to censor topics surrounding their illness with the with the goal of shielding their children from their suffering (Ambrósio and Santos 2015).

Mothers also worry about how their reduced involvement in their children's lives will impact their children's development (Forrest et al. 2009); they worry about being "good moms." Madison, a 39-year-old, talks about the dualisms of being "an effective mother and not a failure. Being a mom with a TBI is incredibly challenging…I used to cry about the things I couldn't do and the overstimulation and migraines and subsequent days I'd spend in bed recovering." Being unable to participate in their children's lives as much as they would like to results in mothers feeling guilty and experiencing increased stress (Tavares, Brandão, and Mena Matos 2018). For example, Gabriella said:

> I couldn't do mom duties. I couldn't help my kids with homework. I couldn't help my kids do anything. I couldn't drive them anywhere. You know, I couldn't even talk to my kids – even that was work. I couldn't do nothing. Just my whole entire life changed as a mom. That was pretty emotionally hard for me. It caused a lot of depression – not being able to have that with my children.

Bultmann et al. (2014) found that social support – having reliable and trustworthy caretakers for their children – reduced women's stress.

However, this was not always possible. For some women, they did not have anyone in their social network to help care for their kids, or the individuals were not geographically accessible or did not have availability in their own schedules. Financially, some women could not afford to either lose the income of their working partners or to hire someone on top of their medical bills. This was true for Avery who "didn't have any family in the area, so I didn't have any choice. I think I ran on adrenaline basically, and just kept going because I felt that we had to keep doing whatever we could do." What was also unique about Avery's case was that she was the only mother in this study that also had a child with a medical condition. Studies have found that mothers with health vulnerabilities experience poorer health outcomes when a child has a health problem (Elmberger, Bolund, and Lützén 2005; Öhlén and Holm 2006; Elmberger et al. 2008). This was true in Avery's case as well; she prioritized her daughter's care and, consequently, did not have the energy, time, or finances to pursue her own care. She said:

> I think because I was so focused on her. I don't have that luxury [to rest and take care of myself], and part of it is maybe my fault. I think managing her care was enough, where I just couldn't. I was so focused on Jane, and…I worried in the beginning, how is she going to be perceived by her peer? So, I just buried my own issues down and just tried to compensate for it, and I think I did that really well.

However, prioritizing their children over themselves was common even among mothers of healthy children. The burden is even greater for single mothers who are solely responsible for their children's care. Violet, a 31-year-old single mom to a toddler and infant, said:

> I love them so much but it's also very overwhelming being a mom after the TBI. If I had to do over again, it probably would have been smarter not to have kids just because it's so overwhelming. As a mom, and as a mom who's raising them as a single parent, it's very easy to get overstimulated. Because you know, kids are loud and they need your attention all the time, especially at this age, and the baby doesn't sleep very well through the night, and then insomnia makes it more difficult. I'm exhausted. And I know that's part of being a mom, but even when they're asleep, I can't sleep, and then it makes me like cranky the next morning when I still have to get up early to take care of them. And it's just hard because I don't want to yell at my kids…I love them so much.

Mothers with illnesses struggle to balance caring for their kids and caring for themselves or "allowing themselves to be ill" (Elmberger et al. 2008: 59). Felicity captured this sentiment by saying:

> Once you have kids, and especially when you're a stay-at-home mom, you live for them; you live for making sure that their meals are cooked, and their clothes are clean and in their drawers, and that they go to these camps, and they're socializing, and they're having the proper social interaction, and they're making the right choices. And especially at the age that mine were – they would have been four and six – kids just need something all the time; it's just how they work – all the time they need something. So, you're doing something for someone else from the moment you get up until the moment you go to bed.

When experiencing illness, mothers have new challenges in maintaining their children's participation in activities. The mothers in this study were concerned about how their conditions limited their abilities to be a "good mom" by actively parenting and being involved in their children's lives, but also being a "good mom" by trying to recover so they could be a "better mom," as Felicity said. In many ways, symptoms from an mTBI placed limitations on the demands of caring for children: physically (e.g., vestibular issues can mean a patient cannot bend down to pick up a child or lacking the energy due to fatigue), cognitively (e.g., being able to organize and plan children's schedules or execute activities on time), and emotionally (e.g., overwhelm can cause emotional outbursts that are not exactly recommended as good parenting practices). For example, Felicity said:

> Keeping up with schedules and not forgetting small things. My kids wear uniforms for school. Only one of my kids wears the different uniform on Wednesday, and one wears the different uniform on Friday – so, which kid needs which [uniform]. So that's super challenging; remembering which day of the week it is, which uniform to get out for them – it's stressful. I wouldn't even have thought about it before the brain injury, and now those things are challenging.

As a result, Felicity said, "I made my kids be more responsible for things, which isn't really fair to them either because they're just kids, you know, they deserve to just be kids." This was a common sentiment expressed by mothers with children of all ages. Sheryl, a 51-year-old, for example, was a single mother of two teenage children. She said she felt lucky because her children were old enough to be somewhat independent, so there was not as heavy of a burden to be as heavily involved in their daily lives. However, she said, "I feel like I wasn't capable of being there to support them in some ways…I was doing just really the most bare minimum…I wasn't available emotionally. They're teenagers, but they're still kids, you know. They still need their mom."

A third concern was how they limited their children's activities and their quality of life. Mothers felt obligated to maintain their children's activities to minimize the impact their condition had on their children. For example, Gabriella, said:

> My kids used to be in sports all year round and pretty active, and we'd always be pretty active in that, but after that, just nothing, you know – they didn't get to be in nothing. They didn't get to be a part of nothing at all for a significant amount of time.

Felicity explained how they could not "have it all" when it came to being mothering patients. That is, they could not be good patients who were completely dedicated to their treatments and recovery while also being good mothers who were completely dedicated to their children and their well-being. The competing expectations of being a mother and a patient were not able to be reconciled under time and financial constraints, and so women had to choose where to make sacrifices. As a mother and a brain injury patient, Felicity explained:

> Felicity: You don't have time to deal with these different things. So, you have to be making your therapy appointments, and if that means no soccer practice for the kids – that you have to pull them out of soccer – you have to pull them out of soccer. But your goal as a parent is just to do what you think is best for them. So, it's really hard to say, "Well, you're going to be a year behind on soccer so mommy can go to brain therapy to remember to take you to everything else." I mean, it's very unnatural to have to do that, you know – to ask your little kids to make these sacrifices for you and that they have no choice in either.
>
> Interviewer: So, you found that you needed to make trade-offs? You either needed to sacrifice your health for your kids, for their wellbeing, for them to be able to do these activities, or vice versa, you had to sacrifice what they were going to do for your wellbeing?
>
> Felicity: Yeah, 100%. There just isn't enough time in the day, you cannot hyper-focus on your recovery like you have to, or even sort of focus on recovery. You get thrown into it, you know, like you didn't plan for a brain recovery; you didn't say like, "My kids are in school right now, it will be a wonderful time [for a brain injury]. I'll recover fine." Like no one says that.

Earlier we saw this contrasted in the case of Avery, who like other women in this study, made a different choice and forewent their own treatment in favor of prioritizing their roles as mothers and focusing on their children's needs instead.

To illustrate the severity of the struggles of caring for others and performing basic tasks, Piper discussed how on some "bad head" days, she struggled to be a good "dog mom"; that is, to manage the care of her puppy by herself. She recounted how her husband would alleviate this stress by taking the puppy with him to work. She would tell her husband, "You need to take him to work with you because I can't deal with him today. I can't do it." And luckily, that was an option at that point, and that was really helpful." Piper said that she knew it sounded "silly," but that it was a significant challenge for her to have the energy to manage the puppy's behavior, remember to feed him, remember take him outside regularly, and tolerate the noise when he barked. Seemingly mundane things that most would not think about being a potential limitation or requiring significant effort posed important challenges. In this way, mTBI patients must navigate and try to communicate their needs for things that most people take for granted as part of daily life. Piper calling it "silly" reflects the minimization of the daily challenges women face due to the social framing of their symptoms. In the last two sections I outlined how women negotiated their roles as patients and their roles as partners and mothers, showing how, like Avery said, mTBI "has impacts, not just on the person that was injured, but on the entire family."

Similar to the previous chapter where women described their clinical encounters as comparable to being in a court room because they needed to *prove* their conditions, women also needed to prove their patient status in their personal lives with family, friends, and coworkers. The women in this study had to "walk a fine line," negotiating the sick role and other role expectations because being able to fulfill some social roles, even just some of the time, led to others disbelieving their pain. With mTBI symptoms being nonstable, this was particularly worrisome for the women. Like Johansson et al.'s (1999) study of women with chronic pain, the women in this study reported pressure to perform multiple roles (e.g., wife, mother); however, there was an important "Catch 22" because successfully meeting these other role expectations led to perceptions that their pain was not real. This legitimacy deficit has important implications for women's access to resources, as I show in the next section.

In this section I illustrated how the women experienced role conflict due to their social position as women, and how the legitimacy deficit exacerbated the stress they experienced as a result. I then showed how gender determined access to resources, both material and non-material in the form of social connections, through the gendered legitimacy deficit that exacerbated structural gender inequalities. In so doing, I demonstrated how the gendered legitimacy deficit resulted in lost ties in the women's social networks and reduced social support, which also posed further strain in their role conflicts without as many social connections to serve as a safety net and provide flexibility to successfully meet competing role expectations. Without "believers" to rely on for support, the women's abilities to access care were limited because they themselves were unable to drive, manage their own treatment, or lacked the finances. Failing to seek treatment – even if the women wanted to pursue care to but were unable to – made the women's already fragile credibility as patients that resulted from the social framing of the diagnosis appear even less believable to others. Thus, to others, women appeared to be in violation of two aspects of the "sick role" (Parsons 1951) – wanting to get better and getting care – effectively voiding their claims to the sick role and relegating them to the status of malingerers unworthy of receiving helpful resources.

RESOURCES

There are many barriers that mTBI patients commonly face when accessing treatment including knowledge, finances, physician referrals, and geographical availability. Relative privilege in these regards produced identifiable differences in the women's illness experiences across dimensions of mental health and quality of health care. This fact was well-known even by the handful of women in this study with relative privilege who had sufficient access to treatment as they described themselves to be "lucky." For instance, Aurora said:

> Because I have access to funds for medical care, I have been able to quickly access therapists who have private practices. If my concussion had occurred some other way than a car accident, my care would have been limited to a combination of the limits of my personal health insurance that usually limits private therapist visits to five per year (in my case, I don't have any health insurance), and what I could afford out of pocket (I don't have savings that would have covered these expenses). And, because I reside in a city that is a desirable location to live, many therapists and doctors live and practice here as well, so I have been lucky to have access to therapists without having to drive long distances each week to see them. I am lucky to have a supportive family as well as a working partner as I am not able to be gainfully employed. I know that many people with concussion injuries as severe as mine are not always as lucky to have both the support of family and also a thorough recovery plan accessible to them.

Substantial research has found that greater access to flexible resources can improve access to healthcare and thereby mitigate the detrimental effects of illness and increase the likelihood for survival. Inversely, systemic inequalities worsen health and increase mortality. Social processes at both the institutional and individual levels contribute to unequal access to high-quality health care (Lutfey and Freese 2005; Shim 2010), and the inequality is even greater for state-of-the-art treatments. In the case of TBI treatment, this included things like hyperbaric oxygen chambers.

Studies have established the importance of flexible resources: resources of "knowledge, money, power, prestige, and beneficial social connections…[that] can be used in different ways in different situations" (Phelan, Link, and Tehranifa 2010: S29). Differences in flexible resources are not random but rather a result of our social organization that makes some people have more or less access to flexible resources (Link and Phelan 1995). One social dimension through which differential access to flexible resources manifests is gender. Gender directly impacts health through gender norms that shape health behaviors but also indirectly through social connections and socioeconomic status that shape access to health-promoting and health-protective resources. In this section, I examine the ways that gender determines access to two critical forms of flexible resources in the case of mTBI: social support and financial resources.

As demonstrated in the previous section, not all diagnoses maintain the same medical authority, just as not all patient populations are seen as being equally deserving of resources. The case of mTBI demonstrates that the consequences of experiencing a legitimacy deficit in the context of health are quite extensive. In subsequent sections, I show that even as women's narratives constructed the clinical and social spheres as distinct, they are nonetheless related since the resources that are attained in one serve as vehicles for privileges in the other. This provides further evidence that resources are determined by whether patients' conditions are considered somatic or are attributed to their moral character. Patients constructed as malingering receive fewer resources, if any at all, whereas patients who are viewed more favorably – often with plainly identifiable conditions – have improved chances of winning coveted resources: sympathy, community assistance, insurance eligibility, and treatment options.

Social Support

The weight that social relationships carry in health cannot be understated. There are robust and extensive studies demonstrating that social relationships are protective of health (see Christakis and Fowler 2009). The concept of "social support" initially appeared in the mental health literature (Caplan 1974) but was then translated to epidemiological studies just a couple of years later (Cassel 1976; Cobb 1976). While the field of social support research is relatively new since the 1970s, the concept is not; in fact, it was the area of study for the first empirical study in sociology. In Durkheim's classic *Suicide* (1951), he finds that lower social integration is associated with increased risk of suicide. Successive research has examined other pathways through which social relationships and health are connected, leading to the emergence of research on "social support."

While much research has examined factors affecting health, less attention has been given to how health affects social relationships (House, Landis, and Umberson 1988). In this section, I show how the relationship between mTBI resilience and social support during post-injury is bidirectional. Social support initially frames access to care (medical and private), but gendered perceptions of disablement from mTBI changes social relationships, thereby further affecting social support such that the gendered legitimacy deficit women face leads to the erosion of even once strong ties ("lost ties") in their social networks. This offers a critical insight into social networks as less attention has been given to the processes underlying the erosion of ties as opposed to the building of new ties. Scholarship on tie loss has largely addressed it in the context of divorce.

Studies find that being married has positive effects on health (e.g., Kraus and Lilienfeld 1959; Carter and Glick 1970; Kitagawa and Hauser 2013). This was certainly the case among the women in this study who reported many positive ways that their marriages supported their recoveries and eased the illness experience. As discussed in the prior section, having a partner could aid in the women's recoveries by allowing them to rest and access treatment. At the same time, however, disablement also took its toll on many marriages and partnerships.

Marriage is just one kind of relationship through which social support can be received; others include extended family, as well as non-kin ties that can be confidants and practical helpers. The strength of weak ties lays in its bridging potential, which can serve as resource to promote health (Cornwell 2011). While women may have a relational advantage over men in health outcomes due to women being more likely to have larger and autonomous social networks, studies have yet to examine how the stigma of a health condition may contribute to lost ties, thereby impacting health outcomes.

Hatzenbuehler, Phelan, and Link (2013) argue that stigma is a significant social determinant of health. In my analysis, I argue that the gendered stigma of mTBI that produces a legitimacy deficit for women patients is a powerful mechanism driving tie loss among women that further contributes to their reduced resilience relative to that of men. The women in this study were more likely to report having experienced a legitimacy deficit. Those who doubted the women's conditions were less willing to provide support to them, such as transportation, financial assistance, childcare, organizing medical care, or simply an empathetic ear. Thus, women experienced tie loss that, in turn, affected their access to care due to time, financial, and cognitive limitations.

There were two primary pathways through which social support was impeded: the symptoms made it difficult for the patients to communicate their needs, and when they did seek support, they were met with aversion and hostility. Similar to the women being unable to manage their medical care due to the nature of the symptoms (e.g., cognition and fatigue), symptoms left women struggling to communicate their needs. When I asked Hannah if she felt she had sufficient support post-TBI, she responded:

> That's a hard question because for me, I had compassionate people around me, but because I didn't know what I needed – how can I express that to them? And that's why I think it becomes so isolating, too, because people want to help, but you can't accept it because there is no energy to even speak. And, for me – and I think for a lot of us – the not knowing how long this is going to last and feeling like it's never going to change. You know, if I stood up, I'd get nauseous. I get tired, I get nauseous. And there isn't

> anything anybody can do about that. Like, bring me soup? I probably am not going to eat it. So, that's a difficult one. And I think that's why the situation is what it is. Because no matter if people want to help, they don't know, and I can't tell them what I need in that moment. And then that compassion eventually – it doesn't go away necessarily, it's just like, "I don't know what to do," and so people just sort of stop doing anything.

Other women similarly noted issues of asking for help but cited gender stereotypes instead as one of the reasons they did not seek help. For example, Piper said that she worried about reifying gender stereotypes. She said:

> I also think that, for myself, I didn't want to be that "needy woman" that relied on her husband – that *needed* her husband. I didn't want to be *that*…I was going to do it myself and I didn't need anybody to take care of me. And that became an issue… because I did – I did need somebody.

Women worried about undoing feminist efforts to frame women as capable human beings. Inversely, women also worried about the effect of such gender stereotypes being used to minimize their needs and requests for help due to their gender. Like Emma said, "Because I'm a woman, I didn't want to ask for help only to be criticized because I'm a woman, you know, like that I'm being too sensitive or emotional or whatever." But, in times of illness, women do need help, and thus, gender stereotypes still inhibit women's recovery and contribute to worse health via women's inhibitions to make requests for support from others.

In a different way, social support as social recognition and validation further affected women's access to resources. When the women did not feel believed or anticipated their claims to be rejected, they did not seek out resources. In talking with Eliza, she explained that:

> The difference that I see now is I'm a lot less confident. My self-esteem, my self-identity, my confidence has tanked for the reasons I've mentioned throughout the interview. And so, when I walk into a doctor's office, I don't present with that same air of confidence and authority that I used to, and I noticed that difference. And I can't in the moment…I often can't come up with the logical arguments and push back enough to feel heard. I can think of it afterwards, or I can prepare beforehand, but I can't do it in real-time any longer. And that's a huge detriment…a detriment to getting resources. It's a detriment to – to my self-confidence just not being reinforced. And it's a detriment to being believed, right? Because now it's to the point where I expect someone not to believe me and that's

> bad. You know, when someone believes me it's such a breath of fresh air, and then when someone understands you it's like, "Oh, my God" – clouds parted, and the sun came out.

Women internalized the legitimacy deficit they faced from others, which, in turn, prevented them from accessing resources through a reduced sense of self-efficacy. The social reinforcement of having their condition invalidated affected their ability to advocate for themselves, thereby translating into the clinical encounter and diminishing the quality of care and number of recourses they received. Similarly, Olney and Brockelman's (2005) study found that being a woman was associated with less positive evaluations of self and feeling less supported by others.

Financial Resources

Financial resources significantly affected the women's prognoses through economic access to treatment. Financial resources included monetary funds to cover basic needs like food and housing, but also indirect financial benefits such as health insurance coverage, auto insurance coverage (e.g., un- or under-insured and legal claims against the at-fault party), workers compensation funds, or retirement funds. Furthermore, women who were poor to middle class emphasized the importance of flexible resources – for better or worse. Some had social connections that could offer them financial assistance post-injury to minimize the negative sequelae of disability. The secondary effects of which were significant, including benefits to them medically in terms of treatment access, as well as psychologically since they experienced less stress about the social implications of their disablement and were able to use the funds to gain resources to better adapt, including household cleaning services, food delivery services, and childcare. Others, however, had fewer social connections available to them from whom they could receive such financial support.

To demonstrate the impact of personal and flexible resources on the post-injury experience, we can compare three cases: Piper, a middle class, 44-year-old, married woman, Serena, a 60-year-old, middle class, married woman, and Violet, a 31-year-old, poor, single woman. Piper said that her husband's insurance coverage and his family's support both played "huge" parts in her recovery. When I asked her how these impacted her recovery, she responded:

> Because of family we were financially okay. We were super lucky to have family support…Because we were able to stay in our house. Otherwise, we would have had to, within a few months when it became clear that I wasn't getting better, we would have had to sell the house. We would have had to... I don't even know where we would have moved. I don't know what we could have afforded…And I was definitely the primary earner, and so, if we didn't have financial support, we would have had to sell a car and sell the house and I wouldn't have been able to get most of the treatment I got because so much is cash pay and so I wouldn't have been able to do a lot of the treatments that I did. I was able to keep my insurance because it was through my husband – through his work.

Even though Piper had financial support, she was able to imagine how different circumstances likely affect the mTBI illness experience saying, "It's a horrible situation for most people to lose all your income and then not be able to afford any treatments. And how are you supposed to get better? I don't know. It's a terrible situation for a lot of people." And indeed, she was correct. In talking with women who had fewer financial support options, it became evident that mTBI created significant financial hardship and that flexible resources through one's own social network were really the only options until, and if, one could qualify for disability – another sociolegal barrier I will discuss in my next chapter. A huge component of financial resources was, as Piper identified, insurance coverage due to its ability to make some providers and treatments financially more accessible. Physician cooperation in treatment plans was also important as some insurance companies required referrals to be eligible for coverage – what Camila referred to as "valuable referral resources."

Piper's experience is contrasted by Serena's experience, who similarly identified as middle class but lacked the flexible financial resources of Piper. After her injury, Serena and her husband found themselves in a difficult financial situation: "Suddenly, without me working, it was like, we need money just for groceries." They were homeowners at the time and were able to sell their house and downsize to increase their available finances, but that eventually ran out after months of bringing in only one income on top of the medical bills. Serena said, "So, we reached out to all our family asking for help – which is really, really hard to do – and zero help."

Having been unable to work since her injury, Violet's only source of income for herself and her two young children was the child support she received. She was temporarily living at a women's shelter since leaving her abusive boyfriend because, as she said, she had "nowhere else to go – nobody to help me. I wish my mom would help me." As a result of her injury limiting options for employment and lack of flexible resources, she did not receive treatment for her mTBI outside of her pharmaceutical treatment for the epilepsy caused by the injury. Given that women are at an increased risk of living in poverty (Berlan and Harwood 2018; McLanahan and Kelly 2006), being single parents (U.S. Census Bureau 2020), and experiencing domestic violence (Alhabib, Nur, and Jones 2010), cases like Violet's are likely quite common despite representing a small portion of my study due to selection. Additionally, TBI from domestic violence is estimated to be quite prevalent (Costello and Greenwald 2022).

These three cases demonstrate how flexible resources contribute to disparities both across and within gender. Flexible resources have the potential to mitigate the negative financial consequences of disablement, which, in turn, contribute to prognosis. A within-gender analysis revealed that the negative consequences of disablement on the less privileged positions women already occupied through systemic disadvantage could be cushioned through flexible resources. By analyzing across genders, I showed how women were, overall, at greater risk for fewer flexible resources due to stigma associated with the gendered legitimacy deficit of mTBI. mTBI offers a unique context to examine the power of flexible resources on resilience as it largely removes personal characteristics due to functional impairments that could arbitrate their effects.

Hanna and Rogovsky (1991) describe the "dual discrimination" that women with disability face. Grollman (2014) refined the "double disadvantage hypothesis" to argue that the increased discrimination that those with more than one disadvantaged or stigmatized status face partially mediates their poorer health relative to those with only one or no disadvantaged statuses. Maroto, Pettinicchio, and Patterson (2019) refer to the "hierarchies of disadvantage" that produce patterns of stratification wherein multiply marginalized groups experience lower incomes and higher rates of poverty. In my analysis I discussed the impact of social capital on access to healthcare and quality of life (Kawachi 2010). I showed how persisting gender inequities in illness experiences are best understood through the interactional dynamics wherein treatment occurs and illness is experienced. Understanding the interdependence of legitimacy, social roles, and material resources helps to explain why illness experiences are disparate both across and within genders and affects even those with the greatest access to high quality healthcare (Goldman and Lakdawalla 2005; Gengler 2014). These findings offer insight into how flexible resources "work more effectively in some groups and in some contexts than in other" (Masters, Link, and Phelan 2015: 26) by showing how stigma can constrain flexible resources (Hatzenbuehler, Phelan, and Link 2013) in the case of a gendered legitimacy deficit.

My analysis further shows how gender intersects with other social systems, such as socioeconomic status, to shape access to flexible resources. Feminist theorist Carol Pateman (1988) argues that not only is gender unique, but that it is primary being the fundamental social system of all inequality. This may be extended to address inequalities in health outcomes as well.

Thus, further investigation of gender as a fundamental cause (Link and Phelan 1995) would be a productive avenue for future research.

DISCUSSION

In this chapter I presented accounts of women's lived experiences with mTBI after diagnosis to add texture to the understanding of the condition. I explored how disablement is experienced with an invisible disability, what it means to be a woman with mTBI, how women's lives are disrupted by mTBI, and how women accessed resources to aid in their recoveries. Their narratives showed that, just like any other illness, mTBI is not just a diagnostic label with physiological meaning, but a social label with social meanings as well. mTBI is different from other contested illnesses because it is medically explainable with a known biological basis, albeit incompletely understood, yet it is still commonly treated otherwise in practice. As such, the women had to contend with competing epistemologies that left them socially unintelligible, ultimately, leading to further suffering. Thus, I showed that while women with mTBI may be surviving, they are not thriving. There are many areas for improving women's prognosis and quality of life through social interventions that improve access to important resources and reduce or remove detrimental effects on mental health that may contribute to the increased risk of suicide among brain injury patients generally (Madsen et al. 2018), and especially women (McIntire et al. 2021).

This study also highlights the need for addressing the upstream social determinants of mTBI recovery. While mTBIs are difficult to prevent given that they can affect anyone at any time even in mundane activities like going down a stairway, commuting to work, or playing on the playground, as this study shows, there is significant room for improving *recovery* outcomes through social, political, and economic means (McKinlay 1979). Understanding how gender matters for mTBI treatment and recovery as a social system structuring social determinants of resilience presents a significant opportunity to improve women's outcomes post-TBI. Effective intervention has the potential to increase quality of life, morbidity, and mortality rates post-TBI. While the next traditional stage in the disease process is recovery or returning to health, I instead address *resiliency* because most mTBI cases never fully recover. This was true for the women in this study who were all still experiencing symptoms, and most were still disabled or had not returned to normal life at the time of the interview. Therefore, in this next chapter, I discuss women's resilience and offer a gendered framework for understanding outcomes post-mTBI.

CHAPTER 5

NAVIGATING A NEW “NORMAL”

[T]hose who have sustained a mild traumatic brain injury (MTBI) may all appear “normal” to people with whom they have casual interactions. Yet they may still be disabled: the quality of their lives may be no less profoundly or adversely impacted by these conditions than is the quality of life of those whose disabilities are more obvious: something can “substantially limi[t] one or more of the major life activities” of an individual even if other people cannot easily identify the source of such limitations in casual interactions with that person (ADA, sec. 3, 2a). (Davis 2005: 153-154).

Mild traumatic brain injury (mTBI) is a unique diagnostic case for understanding how an injury becomes a chronic disability, and how individuals navigate this process. It presents a distinctive opportunity for understanding processes and experiences of “recovery” since prognosis is uncertain, and the pathways of disparities in outcomes are poorly understood. Typically, major concussion symptoms resolve within the first two weeks. Persistent impairment is less common, and most recover within three months to one year. This is what we would traditionally define as “recovered” patients. For about 15% of those who incur a mTBI, however, symptoms persist for years or never dissipate (Rutherford, Merrett, and McDonald 1979; McLean et al. 1983; Kay et al. 1992; Ruff, Camenzuli, and Mueller 1996; Ponsford, Willmott, and Rothewell 2002). These patients are diagnosed with persistent concussive symptoms or post-concussion syndrome (PCS), and they make up what is often referred to as the “miserable minority” (Zasler, Katz, and Zafonte 2013: 44).

It is difficult to apply the “recovered” stage of the disease process to those with PCS because there is not always a return to one’s pre-injury state of health; being “recovered” never comes. Rather, recovery has more or less plateaued and is conceptualized as “maximum improvement," which essentially defines a new "normal" state of health where individuals must learn how to live with the condition. Thus, mTBI comes to be experienced as chronic illness and disability. However, our existing conceptualizations of illness and disability fail to consider conditions like mTBI that have an uncertain prognosis and therefore *may* be disabling, consequently undermining the experiences of those who suffer the worst outcomes, like the "miserable minority."

The "miserable minority" is a subpopulation of patients with mTBI who experience the poorest outcomes, which are "poorly understood despite decades of research" (Zasler, Katz, and Zafonte 2013:234). This leads medical researchers to believe that they may still have the potential for improved recovery with more research that focuses on the psychosocial aspects of resiliency: maladaptive beliefs, coping behaviors, and environmental influences (Zasler, Katz, and Zafonte 2013: 488). In such cases where symptoms persist, litigation is known to be strongly correlated with prognosis, but there is only weak evidence supporting the reliability of other predictors (Carroll et al. 2014). This association is believed to be mediated through the treatment and resources that are made financially accessible through compensation in litigation. At the end of my previous chapter, I offered social determinants as predictors of prognosis, chiefly gender, socioeconomic status, and social capital (the combination of social networks and flexible resources). I dovetail this discussion into the present chapter, wherein I examine how the illness experience of the acute phase post-injury that I discussed in the previous chapter translates into the plateaued phase of "recovery" where women experience mTBI as a chronic illness and disability. This chapter outlines how women navigate their lives with the new premise of mTBI as a chronic condition and disability as opposed to an acute experience of illness. I identify the pathways and barriers to reintegration that women encountered to better understand the social determinants of mTBI-related disability. In the process, I show how women with mTBI continue to face barriers to accessing support in an ableist and patriarchal society when navigating formal institutions, including education, employment, and law, due to the gendered legitimacy deficit.

Most of the women I interviewed had not returned to the activities they regularly participated in prior to their mTBI. The symptoms and deficits alone posed significant challenges to the women's (re-)entry to school and work. Evelyn, a 34-year-old, aptly summed up the impact of mTBI on being a traditionally productive member of society saying, "This is catastrophic to someone trying to build a career [or] to learn." The women in this study often experienced stigma and discrimination that posed barriers to reintegration. Women with disabilities experience a greater emotional toll from their work, reporting decreased psychological satisfaction with work and increased depressive symptoms due to unequal working conditions (Brown and Moloney 2019). They earn less, experience more stress, and have less creative and autonomous jobs than any other group (i.e., women without disabilities, men with disabilities, and men without disabilities). In the sections that follow, I outline the various barriers that the women encountered when (re-)entering different institutions, such as higher education or employment, and in law when pursuing disability support in cases where their pathways to education or employment were blocked. I argue that formal social institutions rely on gender as the primary social frame to inform assessments of disability status and decisions about accommodations in the absence of visible evidence of disability. My analysis also illustrates how accommodation requests and disability claims serve as battlegrounds where different authorities vie for decisive power.

Evelyn was a veteran who had recently exited the military and was using her G.I. Bill to pursue graduate education. She explained how her experience entering graduate school with an mTBI was different than her undergraduate experience without the injury, saying:

> I applied to graduate school [because]…it would give me a buffer before having to find another job, if that was even possible, and to come to terms with my injuries. I had to get significant accommodations through the university's disability office, including permission to stand during all classes, access to a standing desk, additional time for assignments, permission to have copies of handouts or slides, etcetera. This is night and day different from my previous educational experience. Before this, in college, I took 20 credits while working full-time across three jobs, volunteering on the side, earning a scholarship, and getting straight A's…I never felt I was smart but looking back I definitely was, and now that is gone. I have a lot of trouble functioning as a student. I struggle to take in new information and processes it…I can study for hours and within one day not recall what I learned.

Because of these new challenges, Evelyn accessed accommodations at her college. However, as the experiences of other women interviewees also show, there were systemic barriers to accessing the educational accommodations that should have mitigated difficulties in the classroom. While most universities are required by law[17] to make their programs, services, activities, and facilities accessible to all persons regardless of ability, the practice of such laws remain flawed. Research has investigated how institutions continue to fail students with disabilities, but these studies have dominantly focused on physical access, failing to address the unique needs of students with invisible disabilities. The women in this study who (re-)entered higher education faced a legitimacy deficit when pursuing academic accommodations. To illustrate the experiences of women who (re-)entered higher education programs, I present Harper's experience below as a typical case.

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[17] Protections are ensured to individuals with disabilities in post-secondary educational settings under the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.

Harper, a 23-year-old, was entering her first term at a local college where she had completed the registration process for accommodations through the college's disability services department prior to the start of term. Part way into the term, she realized she had misunderstood one of her accommodations. She was originally granted extended time, and she assumed this included other work as well as tests, but came to find out that it only applied to testing. So, she returned to her disability service coordinator to request an adjustment to her accommodations plan, such that extended time on homework be included. Her accommodations coordinator told her that they did not offer that as an accommodation, so she left. She returned a second time to pursue the accommodation after learning that this information was, in fact, incorrect. She said:

> I went back to disability services, and I told them what I had, and I was fine disclosing that because I think I am very open about it now. And I told them I had traumatic brain injury, that it reduces focus, and it takes a longer time for me to complete assignments. So, I talked to her, and she said, "Well, we don't even give this accommodation to people that are way far on the autistic spectrum." And receiving that comment, I felt like that was extremely inappropriate for someone in that type of position.

For Harper, this comment minimized her condition, suggesting that her condition was not as severe as autism. She also felt that the accommodations coordinator should not have had the authority to make decisions about what was considered an appropriate accommodation for her because the accommodations coordinator lacked the necessary expertise about her condition to make such assessments. Despite such discrediting comments, Harper returned multiple times, each time with new evidence to "document and support [her] case." Eventually, she met with the Dean of Disability Services, then the Dean and her accommodations coordinator, and finally another meeting with the Dean.

> She [the Dean] reviewed everything I had, and she wanted to talk again. So, I came back and she's like, "We don't really feel like you need this accommodation. You have A's and B's in your classes, which is pretty good, so you seem to be doing okay." And this part is *crazy*. They were like, "Well you're really good at keeping eye contact and contributing to a conversation, so we feel like you don't need this." I didn't really know

> what to say…So, then we went to the Dean of the College, and we talked with her, and we explained the case again, and I felt pretty optimistic…She denied the accommodation. So, then we signed three grievances…It took so long and just the different comments I got from Disability Services…Then they also said, "Oh, wow, you have a lot of accommodations. Do you want to take some off?" I was just shocked by that.

Harper's case shows how women face a legitimacy deficit even with professionals who specialize in disability accommodations because of the invisibility of their symptoms. Mullins and Preyde (2013) found that university students with invisible disabilities encountered social and organizational barriers (Mullins and Preyde 2013). They identified how the nature of the disability was a divisive factor in these unique challenges. Having a disability that is invisible can be a double-edged sword; it can make it easier for students to pass and be treated normally in social interactions, but it also means that "the validity of the disability can be questioned and that others may not understand the full extent of their limitations" (p. 147).

Just as was the case in the women's illness experiences discussed in last chapter, the issue of invisibility was apparent when receiving, or rather not receiving, accommodations for mTBI. Harper explained:

> I think part of it is that if you see someone in a wheelchair or someone who physically maybe looks different than someone else, it's easier for someone to see that, "Oh, this person maybe has a disability or maybe has difficulty with certain things." With invisible [disabilities], you can't actually see that [the disability or difficulties], so it's hard for a lot of people to believe that I have a disability or to believe the things that I have gone through or experienced. And I think that's part of the challenge with invisible [disabilities] – that because you can't see it or it's not obvious to be able to tell.

Harper's account also illustrates how accommodations for invisible disabilities are highly politicized as threatening meritocratic integrity. Because people fear individuals wrongfully taking advantage of systems implemented to protect and support those with disabilities, individuals with invisible disabilities bear an exceptional burden of proof. Like Harper said, "There's also some of the disbelief because there are people who will say things to get excuses or exceptions. But it's hard when you *actually* need them." Further evident in her account is that accommodations in higher education are a space where authority remains highly contested. For example, who is expert enough to decide what is considered an appropriate accommodation? Is it the disability coordinator, the Dean, or the doctors – and if it is the doctors, which one(s)? Here, we begin to expose the scaffolding that underlies the social construction of disability. Harper's grades were used as evidence against her disability status; if you can perform at some defined acceptable level, then you are, in fact, not disabled and do not deserve accommodations. However, this fails to take into account the experience of disability; the undue mental and physical detriments that performing at this level without accommodations may cause. Harper explained how the disbelief translated into unequal access, saying:

> I face people who don't believe it and that's really frustrating because we want to try and get these accommodations to succeed in things and then you can't get those…because the people who are in charge of providing those [accommodations] don't believe you…It's really challenging. And then it takes you so much longer to be able to get there, or you need help.

Relatedly, the women commonly reported being able to pass, or do "normal" things, but would "pay for it later," as fatigue and the symptoms that the activity triggered set in. This then catapults disablement into other areas of social life, like taking care of one's family or participating in a hobby. For example, in the case of education, the student may be able to take a test without accommodations one day but, due to the cognitive fatigue, headache, vision dysfunction, nausea, and vertigo that doing so caused, be unable to leave their bed for a day or two afterward. Thus, disability with mTBI can be mutable through the delayed onset of symptoms. This highlights how the social construction of disablement is one that is "all or nothing," failing to capture some experiences of disability, like those with mTBI.

DISABILITY IN EMPLOYMENT: RETURN-TO-WORK

Many people with mTBI are unable to sustain employment post-injury, resulting in economic, social, familial, and psychological problems (Zasler, Katz, and Zafonte 2013). For those who are able to return to work, they face unique challenges that are common with invisible disabilities regarding (non)disclosure and the recognition of having a disability in the workplace. Disability disclosure has numerous consequences, including the more obvious effect on worker productivity but also individuals' health, social relationships, and outcomes for the employing organization (Santuzzi, Waltz, and Finkelstein 2014). Most of the women in this study who returned to work faced challenges re-entering the workplace. The women also struggled with whether, and how much, to disclose about their conditions at work, both with pre-existing and new employment opportunities. Lydia, a 47-year-old, had a positive experience with disclosing her condition and expressing her accommodation needs with her pre-existing employer, saying:

> I kind of struggled with how much I share versus not, just medical stuff is kind of weird, but I just decided to like, you know, be more open about it. And I think that served me well to say this was going on me and this is how I need to manage my symptoms and, you know, they were amazing. I was able to do it and they were really supportive.

Women who returned to work with employers they had worked for prior to injury reported more positive experiences than those who attempted to enter new positions and disclosed their status. Maya, a 32-year-old, contrasted the positive experience she had with her employer at the time of injury with subsequent experiences with new employers where she chose to disclose her status:

> I've just had bad experiences since then where people don't really believe you. So, I guess I'm trying to say that, in a very positive way, they [the employer at the time of the injury] were understanding and didn't push on [the issue of] "Oh, well you only have x-amount of days off and so get yourself together." They were just very accommodating.

This illustrates the notable difference in experiences that seemed related to whether the women returned to their same employers pre-injury or entered positions with new employers, such that those returning to their prior employers had more favorable reentry experiences. Maya further explained that her second employer post-injury challenged the accommodations she had approved by the company's ADA compliance department. Because of this experience, she made the decision not to disclose her status to her next employer, opting instead to forego accommodations and pass to avoid negative consequences in the workplace. She also did not identify herself as having a disability on her job applications either. The women experienced uncertainty in navigating the disclosure of one's TBI status in the initial job application process, explaining how they were not sure whether they were considered to have a disability and, if so, how that would affect their candidacy. Concerns about perceived employability are common amongst individuals with chronic illness and disability (Bishop and Allen 2001; Fesko 2001; Spirito-Dalgin and Gilbride 2003; Goldberg, Killeen, and O'Day 2005). Studies provide empirical support for the women's concerns, finding that employers identified those with psychiatric conditions as least employable, after candidates with physical disabilities and no disclosed disabilities (Stefan 2002a; Corrigan and Matthews 2003; Spirito Dalgin and Bellini 2008). Ultimately, the women unanimously took conservative approaches when applying for new job positions, opting for non-disclosure. They worried about the potential for their TBI status to negatively impact their candidacy because potential employers may think their condition would limit their ability to perform in the position or may want to avoid to troublesome accommodations that cost money and time on the employer's behalf to implement (Hazer and Bedell 2000). Despite laws against discriminatory hiring practices based on disability status, it commonly happens, and this was evidently well known among the women in my study.

Another important factor in the women's decisions to return to work was fear of failure and "burning bridges." That is, the women experienced anxiety around returning to work because of uncertainty about their ability to perform until they tried it. They also worried about the potential negative effects that failure to perform could have on their relationships with their employers, which could affect future employment either with that same employer or with potential new employers due to an unfavorable reference. The women also worried that additional failed attempts could be detrimental to their reputations and careers, making it even more difficult to find employment in the future. Lydia, for example, said:

> Then, when I was ready to try again, I was really trying to like work with a different company…because I didn't want to do that same thing again because I didn't know until I put myself out there whether I could do this or not, and I didn't want to let them down again – like I don't want to burn that same bridge a *second* time.

Fear of stigmatization due to poor performance before having the opportunity to learn how to best adapt to their conditions affected their return-to-work decisions. Because women were unsure of their abilities, or how to navigate getting accommodations, they delayed re-entry. The women commonly cited a lack of knowledge and resources as barriers to re-entry. Hannah, a 53-year-old, said, "I don't know what they could have done, like accommodation-wise. I didn't really know what options there were or who I would even go to about that." I asked Hannah if she could "dream big" and anything was possible – money was no issue, and her employer was fully supportive – what resources could have supported her in returning to work, like she desperately wanted. She replied, "I have no idea. I don't even know what's out there. As far as I know, there's nothing besides like just letting me work whenever I can, I suppose." She cited multiple reasons why she was unable to return to work, including being able to type, being in an open office environment, and working for a full 8-hour day. Accommodations do, however, exist for needs like these, including talk-to-text software, private office space, and flexible work schedules, including breaks or part-time employment. Ultimately, Hannah took an early retirement from her job as an office assistant. Her case highlights how a lack of awareness about accommodations generally, as well as TBI-specific ones, thwarted women's return to work.

The women often pointed out that, despite existing protections in place for those with disability, they still faced discrimination. For example, they noted that, in practice, *reasonable* accommodations are indeterminate and quite discretionary. As Gabriella, a 39-year-old, said, "Even as somebody who has a disability that's verified and has gone through all the right systems, getting accommodations has been really difficult for me, even though there are those laws." She explained that this was in large part due to the legitimacy deficit she faced in the workplace from colleagues and supervisors. Gabriella said:

> That was really hard when I was working, like, "Oh, you're this certain way. You're stupid." Some really derogatory comments. So, the way you get treated sometimes – like I've been treated hostile, like *really* hostile. Sometimes I'll be explaining and the fact that they can't quite understand me and certain things, they'll dismiss me. I always felt like I didn't look bad enough, so nobody cared because I didn't present a certain way. So, no, people didn't want to help me…I would get told things that would be really negative, like that I looked normal but that I wasn't functioning normal[ly]. So, either I'm not qualified or I'm not good enough, but if I don't qualify and I'm not able to get the accommodations then I can't do good enough in the job. So, I really get it from both sides.

Other women experienced less explicit barriers that pushed them out of their jobs. For example, Alice, a 53-year-old, explained how her accommodations went unmet by her employer. She had requested accommodations to support her in staying involved at her school until she was able to return to teach in the special education program, but she got pushed out of her work community:

> Even in the beginning when I tried to go back on modified I contacted the special ed department – the head of the department – [because] they were having a meeting that I thought I needed to be a part of for this new program that they were rolling out and I said, "I'm on this modified schedule, [and] I can't go to the meeting. Can you accommodate me? Is there a way that I could Skype in or do something from home?" "No, but I'll contact you and I'll let you know what it was about after." He never did that. And I followed up and he never contacted me. So, I got totally cut off. And that's the other thing, like because they don't understand it, they don't know what to do. They don't

> know what they can say and what they can't…They don't want to set you off, so then they don't contact you…So, there is that real isolating piece that you do lose a lot of friends and contacts because everyone at work just doesn't know what to say or what to do. It's just like, I'm not dead, like, I'm still me. I might not be able to talk long, or I might ramble [but] I still want to try to have these conversations.

Alice is now on maximum medical improvement (MMI) through workers' compensation and is trying to negotiate accommodations with her employer to be able to return to work in some capacity. The workplace can become hostile for individuals with invisible disabilities. Because of the widespread unfamiliarity with invisible disabilities, supervisors and co-workers often make moral and character attributions that lead to workplace sanctions or termination of employment (Neal-Barnett and Leon Mendelson 2003).

While women like Alice and Gabriella had trouble accessing the accommodations that could have supported them in their roles, another common barrier to maintaining employment was that, due to symptoms, the women practically could not perform the expected duties of the position even with *reasonable* accommodations. For example, Sadie, a 38-year-old who previously was an emergency medical technician (EMT), explained how her employer was not at-fault for her not working; rather, she just was not a good fit for her position anymore due to the nature of the job. That is, there were no such accommodations that would make it safe for her to serve as an EMT with her new condition even if her employer was willing to do so. Lydia similarly explained that her employer welcomed her back with each of her attempts to return to work but, because of the nature of the work she did in that position and the time-sensitive deadlines, there were no accommodations that her employer could have offered her that would still make her an economically profitable employee. She said:

> I was really nervous when I first tried to go back to work…as like a part-time employee. The first time I tried to go back to work, after a week I had to quit and I was like, "Look, you don't even have to pay me" – like I felt *terrible*. I really bit off more than I could chew, and I didn't think I was doing that. I was just trying to get back to work, and I

> really thought that I could…Like I told them you don't have to pay me for the work that I did because when you start a project like that, the first week or two is a lot of onboarding – getting up to speed – you're not really delivering value yet. But they paid me, and they were so gracious, and they were really kind. I was kind of blown away by that.

In an ideal world, individuals with disabilities could do any job they wanted through accommodations, but as it is presently, that is not the case – for technological and capitalist reasons alike. In contrast to successfully re-entering the workplace, others have considered alternative employment opportunities. For instance, Violet, a 31-year-old, recently decided to study to become a certified dietitian to be self-employed, which would offer a reduced environment and allow her to set an incremental and conservative schedule.

The importance of relativity, adjusting traditional goals, and finding a new "normal" way of working were other helpful strategies the women employed when returning to work. Setting different goals and expectations for themselves than what is "normal" in society or even for them pre-injury aided in women's re-entry into the workforce, whether that was by reducing how much they worked or changing the type of work they did. The most commonly successful way the women re-entered the workforce was by working part-time and incrementally adding more hours per day and per week over time. For example, Piper, a 44-year-old veterinarian, eventually went back to see clients part-time:

> I'm four and a half years out…I think it was two and a half years when I tried to go back to work, and it did not go well at all. I was so slow with processing, and I just couldn't do it. When I went back, they scheduled me for hour-long appointments, which normally they're 30-minute appointments but they gave me an hour for the appointments [to give me extra time]. Normally, within that 30 minutes you see the patient, come up with your treatment plan, you do whatever needs to be done, then you make phone calls to other clients, and you write up your records. But it was taking me *twice* as long just to do *half* as much of the work. So, that was really eye-opening.

Piper stopped working for about a year after this first attempt to return to her veterinary practice, but tried again:

> It wasn’t until last summer – that was three and a half [years out] – that I finally was able to go back, and then it was very different. At that point, I felt like I could actually do the job. It was hard, and I was so slow, but I felt like I could actually do the job. And so, I started just with 15 hours a week, and then after a few months I increased to 18 hours a week, and then in a few more months I increased to 21 hours a week.

Lydia similarly found success reintegrating into the workforce by employing an incremental return-to-work strategy, slowly increasing the amount of time she spent working each week. Despite her initial attempt being unsuccessful, Lydia tried again to return to work:

> I worked on that one really small part-time project…that was like a two-hour a day one…And then, 20 hours a week I could do. Then, the next project I did, I was like “Well, I’m going to try.” I think it was part time still but there was one week where I was like, “I’m gonna try 40 hours a week for a couple of weeks.” And, you know what? I could do it. It was kind of too much because – like if work was the *only* thing in my life, I could have done it, but being a mom and having a house and feeling responsibilities outside of work, it was too much. But, it was kind of nice to try it, you know. And so, then I scaled back to part time again, and that was good. And then my next project I was at 32 hours a week, and that was months later. So that’s when I was like “Wow, look at this,” you know, like, “Look at me.”

Thus, failed attempts at re-entering were a necessary process for learning how to best adapt as the women had few to no resources that offered blueprints for doing so, leaving them to either “swim or sink” through trial and error. For women who successfully re-entered the workforce, persistence was paramount.

These findings generally support extant literatures on employment and invisible disabilities, such as obsessive-compulsive disorder, dyslexia, epilepsy, and autism, that call for greater awareness of psychoneurological conditions to reduce fear of stigmatization and increase workplace support to maximize individuals’ productivity and success. Mainstream disability scholarship largely does not consider disclosure, which is specific to invisible disabilities. Prince’s (2017) study highlights how disclosure can be a double-edged sword, simultaneously serving as a vehicle for accommodations that can support employee success and a risk for disadvantage through stigma and discrimination, thus resulting in a “predicament of disclosure” for those with invisible disabilities in the workplace. Norstedt (2019) found that there are divides in employer and employee understandings and expectations surrounding disclosure that lead to challenges for employees with invisible disabilities. In suit with Norstedt's finding that there is a general lack of awareness and clear sense of best practices with invisible disabilities, emerging research suggests that, as with visible disabilities, the crux of many workplace accommodations for people with invisible disabilities must be increasing awareness and transparency through management of expectations, open communication, and inclusive practices (Prince 2017).

DISABILITY IN LAW: SEEKING LEGAL STATUS AND FINANCIAL COMPENSATION

While there is little evidence of reliable prognosis predictors amongst patients with PCS, the most robust predictor known to date is the positive effect of litigation on prognosis (see Carroll et al. 2014). This has largely been explained by financial compensation, which increases access to resources that aid in recovery that patients may otherwise have not been financially able to afford. While not all patients can or do pursue compensation, even those who do receive it face barriers, as the women in this study reported. There are few sociological studies of invisibility disabilities in law, but there is some scholarship in the field of disability law that suggests invisible disabilities are treated less positively and have less favorable outcomes (e.g., Emens 2020; Rabinovich 2020; Butcher 2021).

Workers' Compensation

In the case of accessing workers' compensation, there can be many barriers to accessing medical care and receiving financial support. As such, Alice, who incurred her injury while teaching at her elementary school, explained how important it was to have a lawyer:

> Someone told me to get a lawyer: "You need a lawyer for workers' comp. You're not going to know how to navigate this. They're going to take advantage of you." I've never

> had a lawyer for anything before, but I'm glad I got one because they were right. They start denying everything, you know, like, "You don't need this or that [treatment]."

Alice further elaborated that even with a lawyer there were still barriers to care, one of which was getting referrals approved. In the interest of her continuance of care she had "to get care outside of that [workers' compensation]." However, this posed yet another barrier: personal finances. To access care, she set up a personal fundraiser using an online fundraising platform, relying on her social network as a flexible resource. She described her experience as "workers' comp hell" and a "nightmare of a battle."

In addition to financial access, there were also some practitioner-based policies that posed barriers to treatment. Some physicians may elect to work with workers' compensation and some may choose not to – similar to practices of contracting with insurance companies where physicians may choose to contract with a select few or none at all. Alice explained that this was not only frustrating for her, but also impeded her quality of care and recovery process, saying:

> I built up a relationship with this therapist that was good and now I can't see them, so there's a lot of starting over with new people and having to waste appointments re-explaining your medical history to someone new and then trying to build up that relationship again.

Thus, it was not only the initial approval for workers' compensation that the women had to fight for, but they had to continuously prove their condition to be granted additional services. Alice explained how workers' compensation programs are "frustrating" because they exist under the pretense of supporting workers who are ill or injured, but that this not the case in practice because the programs are financially supported by and invested in corporate interests. She said:

> With workers' comp, they like to find ways to deny the treatment. So, it's all playing games. Like, you get something given to you, if it's not too expensive, they'll give it to you – like physical therapy or acupuncture or whatever – and then they'll approve a certain number of sessions, but those just get you started to see *some* improvement…not to *fully* improve.

The women explained how they did not feel that workers' compensation bureaucracies were dedicated to their recoveries because workers' compensation had financial interests in denying their conditions and limiting their treatments. Alice explained how workers' compensation offices contract with certain providers, so, to continue this patient stream for their practices, they also served the business interests of workers' compensation:

> A lot of the workers' comp doctors, they want to help the patient, but they also work for workers' comp, so they just churn people through the system. And so, you get that monthly or bimonthly appointment and it's like okay, they're not there to really get you better. It's just that you're a client that's keeping their business afloat.

In this way, having resources through workers' compensation can potentially be beneficial to patients by offering access to at least some form of treatment, especially for patients with few financial resources, but it can in other ways impede patients' potential for recovery and ultimate prognosis through restricted physician access and limited treatment plans.

Civil Lawsuits

A handful of other women pursued civil lawsuits, either against those believed to be directly responsible for the accident that caused their mTBI or against a third-party, such as auto insurance companies. For some women, lawsuits were not necessary to gain the benefits of auto insurance. For example, Aurora, a 46-year-old, reported:

> I sustained my injury in a car accident. Because of the way auto insurance works [here]…my own car insurance company will pay for medical care for a total of up to either four years after the accident or up to $50,000 in expenses; anything above this amount or later than four years of recovery time is the responsibility of the "at-fault" driver's car insurance. So, because I have access to funds for medical care, I have been able to quickly access therapists…If my concussion had occurred some other way then a car accident, my care would have been limited…[because] I don't have any health insurance and what I could afford out of pocket – I don't have savings that would have covered these expenses.

Other women did not have Medical Payments Coverage (MedPay) through their auto insurance to coverage medical costs, or their states had different laws for how and when payment is provided to the claimant (e.g., retribution is awarded in full upon the closing of the suit, not with bills paid directly or incrementally throughout the treatment process).

Layla's case typifies the general experience of the women who fell into this group. Layla, a 27-year-old, was in a motor vehicle collision. She explained that due to the at-fault party being underinsured, her lawyers took up a claim with her insurance company to cover the remaining difference. When deciding whether to accept to the insurance company's settlement offer or not, her lawyers recommended that she take it because her "injury claim was weak because it was only a mild injury and going to court would also be emotionally difficult" because it would, effectively, be a process of the insurance company's lawyers trying to delegitimize her and her condition. She said:

> My lawyer even said that, that the judge would look at me and see a perfectly fine young woman and wouldn't believe me. She said it would be risky and that it was very possible that I could lose even the small amount of money they were offering now [in the settlement offer]. And this was despite all of these tests I've had – that I've *personally* paid for already.

Layla reported that her legal team had worked with other brain injuries and strongly advised that, based on these prior experiences, she settle to avoid likely unfavorable and uncomfortable court proceedings. Other women reported similar experiences of their own legal teams being skeptical of legal success due to the nature of their injuries, reflecting the widespread contestation of mTBI in law and society at large. For some, it was the fear of not only being legally discredited but enduring the process of facing further skepticism: medically, they would have to go through independent medical examiners (IME) prior to court proceedings, and legally, their credibility as patients could be upturned by the court. Layla, like the rest of the women I spoke with, accepted the settlement offer to avoid court because they believed they were unlikely to receive a favorable outcome due to disbelief around the existence and/or severity of their conditions, which could financially jeopardize their continued recoveries and cause additional psychological distress.

Some of the women, like Gabriella, who lacked the flexible resources that other women had, took out loans or used credit cards to finance treatment due to the ordering of the compensation process. She further explained that she will still be in debt even if she receives full compensation because, legally, claims cannot cover any interest or legal fees. She said, “Like right now, I have $150,000 in medical debt. So, the fact that I may not have nothing to show for it, and still have to pay all that back and pay those liens, um, is very sickening to me.” The impact of constrained financial resources on the women’s recoveries is evident in their limited access to treatment and constrained choices for returning to work. Gabriella said:

> Not having financial [affluence], it could do so much for me. I didn’t get to choose what kind of treatment I wanted either. And not only did I not get to *choose* it, ‘cause my case would be lost ‘cause those providers are not valid providers – which I think is ridiculous – but then also if I wanted to get those, I had to pay for them out of my pocket. And when you’re not working and your doctors are saying you can’t work and you’re disabled, how are you able to pay for that? You’re stuck. So, you’re kind of stuck going with whatever Medicaid says, because that’s all you have available to you.

Piper elaborated on how this creates a double bind with access to treatment being affected by one’s employment and receiving treatment affecting one’s ability to be employed. She said:

> It’s a horrible situation for most people – to lose all your income and then not be able to afford any treatments. And how are you supposed to get better? You have to get better to go to work to make money to pay for treatments that will get you better, so I don’t know. It’s a Catch 22. It’s a terrible situation for a lot of people.

Being employed affects income and insurance coverage. Reduced or lost employment can result in lost insurance coverage, which financially limits access to health care and impedes recovery.

Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI)

For women who were unable to return to learn or to work, pursuing legal disability status was their final option. Pursuing legal disability status has important social meaning and prognostic implications. However, it is not easily achieved. In this study, the women reported many barriers to receiving formal, legal recognition of being disabled and receiving the associated benefits. One of these challenges was practical; being aware of and knowing how to navigate the system. For women who were unable to do so on their own or were unsuccessful in earlier attempts, another barrier was economic access to a lawyer who could pursue the claim on their behalf. Women faced barriers in the courtroom and in encounters with judges. Piper, who formerly had a successful full-time career as a veterinarian, was denied her disability claim despite all her medical professionals providing a unanimous diagnosis. A second woman, Lisa, who was 47-years old, was unable to make a disability claim because of a single medical professional's rejection of her brain injury diagnosis, even amongst a handful of other physicians' positive diagnoses. Finally, some women struggled financially, yet did not qualify for Social Security Disability Insurance (SSDI) due to the income thresholds of married individuals. Because of this, some women considered or did legally divorce their partners to access the benefits that come along with legal disability status. This points to a larger systemic issue of the institution of marriage: it poses barriers and grants privileges.

The women universally reported their claims for SSDI being denied on their first attempts, citing the judges doubting their conditions – calling them "liars" (Lydia) and rejecting "multiple doctors' expert assessments, who were some of the bests in their fields" (Lisa). Lydia explained that while her judge seemed empathetic in the hearing, "he just basically called [her] a liar in his written report." Through the women's accounts of their experiences with the SSDI claim process, we see how women are discredited in the courtroom; evidence of the ways in which the legitimacy deficit materializes even in law.

Within the context of law, we see the gendered legitimacy deficit of mTBI resurface yet again. The mechanisms that manifested in the women's clinical experiences and illness experiences re-emerged in their experiences with legal processes. Here again we see how appearance is used as a proxy for determining illness and disability, this time in the courtroom, with one judge having said to Emma, a 38-year-old, "You're here today, you're talking to me. You look and sound just fine to me." Piper similarly explained how common misunderstandings about the effects of brain injury guided the judge's decision in her hearing. In her case, the judge relied on her ability to exercise, specifically to run long distances, as an indicator of ability, and thus exclusionary of disability status. She said, "I actually was denied disability because of my running." Piper had returned to running after her accident as a means of recovery, noting that it had been recommended by her vestibular therapist as a mode of physical therapy. Without having much else she could do post-TBI, she started training, even running 100 miles as an awareness campaign for TBI. In the courtroom, however, her physical endurance translated into the assumption of comparable cognitive stamina. She explained:

> I had a neuropsych evaluation. I'd had an assessment with…a functional employment specialist. So, I'd had all this stuff done and all their assessments basically said the same thing, which was I'm not capable of sustaining regular employment at that time. And I went to the hearing and the judge asked me one question, and that was, "Did you really run 100 miles?" And I said, "Yes." That was the only thing he asked me at the hearing. It was the only question… I could hardly speak and I'm crying, but he [the judge] was just like, "Did you actually run 100 miles? All right then…" It was just ridiculous…I was furious. I was so mad – it was several weeks before we got the decision – but I knew the second we walked out of the courtroom based on his lack of questions that it didn't matter…And my lawyer was basically like, "He dismissed everything that your doctors are saying. He's not even considering it. He had his mind made up the minute he read your file and he's not even listening, which is not his job. His job is to take the information from your doctors and from the diagnostics and use that information. It's not to deny your diagnosis."

However, that is exactly what the judge did. Piper further explained how the judge's interpretation of her ability was a common lay misperception about mTBI, saying:

> I would have people comment and say, ‘Gosh, it’s so great to see you running. I’m so glad to see you doing so well.” And I just think I’m not doing so well. I’m actually doing terrible…And I get it. From a logical standpoint, if you don’t understand the process and you just look at that and go, “You ran 100 miles, but you’re telling me you can’t hold down a job?” And I can see how a lot of people would think I was trying to milk the system. And they don’t get it [brain injury]. Running doesn’t take a lot of brain power. But that was it; that’s why I got denied.

Despite multiple doctors’ opinions that Piper had a debilitating brain injury, the judge used other social frames to make a determination about Piper’s disability status. Piper said, “I felt [pause] so belittled and people just thought I was faking it. It was really hurtful.”

Furthermore, the court ignored the doctors’ identification of severe cognitive fatigue, and despite having a doctorate degree in veterinary medicine, recommended that she “could be a parking lot attendant or a house cleaner.” Piper described being “furious” about this suggestion because it made her question her own embodied epistemology, saying, “It almost made me start to question my own reality. Am I really [disabled]? Could I hold down a job? Am I overplaying this?” She noted that she eventually reaffirmed her own knowledge, explaining that while she had the ability to do such jobs for short periods of time, she did not have the stamina to do them for enough hours in the day that would bring in sufficient income to support herself. She said:

> [I’m a] Doctor of Veterinary Medicine. At the time there was part of me that’s like, “You’ve got to be kidding me.” But at the same time, I’m like, “If that’s really *all* I was capable of then fine.” But the problem is, it’s not that I suddenly became uneducated. It’s not like that knowledge suddenly disappeared. It’s that my mental stamina wasn’t there. So, I could go be a veterinarian for a few hours or I could go be a parking lot attendant for a few hours. It has nothing to do with the knowledge. It was the stamina. And then I couldn’t go do anything all week…There was no way that I was going to go be a parking lot attendant. That wasn’t going to happen. I definitely looked at other jobs – other part-time jobs, like, “Okay, what else could I do?” And so... I never considered myself above doing anything, but I also didn’t want to just do mindless work. That wasn’t going to help me get any better. And that was just going to exhaust me so that I didn’t have time to work on the things that I needed to work on [to get better].

Piper and her lawyer ultimately made a federal appeal. She said, “But, I’m not holding my breath on anything.” Piper was one of my first interviews, but it quickly became apparent that this was common within the mTBI community – so common, in fact, that the women were advised by other patients “to lawyer up right away if you want any shot at getting approved” (Lisa). This recommendation was supported in my interviews as the women who did not have lawyers during their first application process ultimately hired lawyers for appeals, consistently reporting issues with their mTBI diagnoses being accepted by the courts. None of the women I interviewed had their claims accepted on the first submission, and many of them were still in the process, either having the process prolonged or having been previously rejected and now petitioning their cases. Based on the women’s experiences pursuing legal claims related to their mTBI, I argue that current legal policies are not sensitive to the unique circumstances and forms of disablement that women with mTBI experience.

DISCUSSION

This chapter focused on reintegration post-injury. However, this does not represent the experiences of all women in this study because there were about a third of the women for whom these pathways were closed or for whom (re-)entry was not the goal (e.g., previously retired women or stay-at-home moms). Despite the average time since injury at the time of the interview being about four years – enough time for a determination to be made whether this would be a permanent condition – many of the women had not moved forward with pursuing any of these three pathways. Pursuing legal disability status was a contingency plan for women who could not successfully reintegrate through return to learn or to work. However, many women were not learning or working at the time of their injuries, whether because they were retired or were stay-at-home moms. Consequentially, some women could not apply for SSDI because they had not worked long enough or recently enough to be eligible. Similar to the women who pursued legal disability status, these women's symptoms prevented them from reintegrating through education or employment. These women, and those who pursued legal disability status, maintained the sick role that they had adopted in the acute phase of their injury, as discussed in the prior chapter. Another important lesson from this inquiry is that we lack measures of recovery for individuals who are not involved in sports, education, or employment, such as those who are retired or are stay-at-home parents. This presents a significant challenge for measuring recovery among individuals who are older or childbearing-aged women since we know that women are more likely to be primarily responsible for their children's care than men (Craig and Mullan 2011).

Extant scholarship has long established that women fare worse economically than men, across race/ethnicity and educational attainment (Bureau of Labor Statistics 2020; Kroeger and Gould 2017). However, that is not to say that race/ethnicity and education do matter, but rather that the gendered pattern persists across other social dimensions. There are important patterns of stratification wherein multiply marginalized groups experience lower incomes and higher rates of poverty, what Maroto et al. (2019) refer to as "hierarchies of disadvantage." Amongst those with disabilities, women of color with less education earn the least and have the highest poverty rates. Women are more likely to live in poverty, especially single women with children. This trend is assiduous, establishing the feminization of poverty. Disability only magnifies this trend with women with disabilities having higher poverty rates, lower household incomes, and lower employment rates than men with disabilities (American Community Survey 2003 - 2007). Even among those receiving public disability benefits, disabled women receive less money in disability benefits than disabled men. SSDI benefits are based on one's work history and prior income. Since women are more likely to have interrupted or no work history and to have lower lifetime earnings than men, they tend to receive less money through the disability benefits system even when their claims are successful.

In the sections above, I outlined three pathways the women took to manage mTBI as a chronic illness and disability: returning to learn, returning to work, and pursuing legal disability status. These pathways were not mutually exclusive, as women sometimes pursued more than one simultaneously (as was the case with SSI) or successively (as was the case when women pursued one pathway but found it closed to them). The legitimacy deficit that women with mTBI faced in earlier stages of the disease process (i.e., diagnosis and illness) persisted into the encounters women had with formal institutions (i.e., education, employment, and law) while they found pathways to coping with mTBI as a chronic condition. I showed the extensive impression management and self-advocacy work women engaged in to be successful in their pursuits of education, employment, and legal disability support. I showed the salience of the invisible nature of the condition, as well as the lack of understanding about mTBI specifically but also invisible disabilities generally. I also identified how women's social positions made them more or less able to successfully navigate systemic barriers to accessing resources that would improve their quality of life. Profound inequalities are created when there is a failure to equalize access to care; legitimacy deficits effectively operate as barriers to sufficient and appropriate care for women. Formal institutions serve as gatekeepers for accessing important forms of support (e.g., accommodations and financial resources) through their power to authorize some conditions as disability. Therefore, it is crucial to increase awareness of the "miserable minority" to improve quality of life and prognosis. Whether women in the "miserable minority" return to learn, return to work, or pursue support through SSDI/SSI, the failure to grant legitimacy to their conditions negatively impacted their quality of life and prognosis.

CHAPTER 6

BEING A MAN WITH MTBI

[W]hat's often missing from the media's discussion of the topic is a recognition that the concussion problem is not merely a health issue; it's also a social issue… Ideas about gender even influence how we define the scope of the concussion problem…Some analysts have pointed to how men could be more likely to "play through" a concussion to live up to masculine ideals of toughness… Most [sports] commentators will concede that the era of shaking off a head injury as "getting your bell rung" is over. But the concussion issue should force us to rethink the value systems that make violence and playing through pain manly symbols of toughness (Matt Ventresca 2015, The Washington Post).

Scholarship on men, masculinity, and disability consistently finds that men with illness or impairment struggle with issues related to masculinity both personally and socially. This is explained by the characteristics that are associated with being a patient being in direct opposition to those associated with being a man. Hegemonic masculinity is defined by aptitude, strength, toughness, power, self-reliance, rationality, and bravery in risk-taking (Connell 1985; Courtenay 2000). Men and women also talk about pain and illness in different, gendered ways (Charteris-Black and Seale 2010; Jaworska and Ryan 2018). Because masculinity is a privileged status and disability is a marginalized one, many disabled men will strongly identify with masculinity to access its associated privileges and minimize their disability and its associated stigma. To do so, they may strive to perform masculine roles and/or reformulate these roles to better suit their bodies and abilities (Gerschick and Miller 1995). However, for many men with disabilities, accessible pathways to outlets for enacting hegemonic masculinity may be closed due to their lack of individual resources. Thus, rather than embracing or reformulating hegemonic masculinity, some men might reject hegemonic masculinity altogether. The intersection of masculinity and disability may yield different outcomes depending on class, race, age, and sexuality (Shuttleworth, Wedgewood, and Wilson 2012). Gender differences in symptom reporting and care-seeking may also contribute to observed gendered health disparities in diagnosis and prognosis of some conditions (see Ladwig et al. 2000; Barsky, Peekna, and Borus 2001). My analysis offers a partial explanation for the observed gender gap in mTBI prognosis by highlighting important points of divergence in men's and women's experiences with mTBI. On the whole, men faced fewer barriers to diagnosis, recovery, and reintegration, which suggests that the gendered disease frame aided their recoveries; however, gendered social organization and beliefs about masculinity still posed challenges to men with mTBI.

Extant literature has identified several barriers to men's identification of and reporting of concussions (Delaney et al. 2002; McCrea et al. 2004; King et al. 2014; Kroshus et al. 2014; Register-Mihalik et al. 2013), but they have yet to consider the gender system as a driving mechanism, or how gender acts in subsequent stages of the disease process to further compound health disadvantages across men from different social positions. In this chapter, I draw on 14 interviews with men to show that, in the case of mild traumatic brain injury (mTBI), masculinity is a double-edged sword; simultaneously operating as a *barrier* to health care because of how men enact gender through health while also serving as a *resource* for legitimizing men's claims to the diagnosis and facilitating the recognition of men as credible patients.

MASCULINITY, THE MTBI DISEASE FRAME, AND THE DIAGNOSTIC MOMENT

Diseases are sociomedical in that there is a bidirectional relationship between medicine and cultural ideologies. Medicine is classed, raced, and gendered. Gendered language in medicine is well documented in extant scholarship and more attention has been given to gendered disease language recently (see Bordo 2004; Riska 2004; Almeling 2011; Kempner

2014; Shim 2014). While medical disease language cannot prevent or negate stigmatization, language nonetheless contributes to the stigma and discrimination of conditions (Corrigan 2016).

Normalization and Gendered Rhetoric

Medicine influences health outcomes, disease classifications, and social restrictions and roles. Gender pervades nearly all aspects of medicine to affect health influencing who becomes a provider (and consequently who patients interact with and the form of that interaction); who can access medicine; who gets afforded the sick role through diagnosis; what pharmaceutical treatments are developed; who engages in health promoting behaviors; how illness is experienced; and even the process of disease discovery itself. Medicine shapes perceived risk, too. For example, using the case of coronary heart disease (CHD), Riska (2004) argues that medicine's construction of men's disease risk draws on stereotypes of hegemonic masculinity about stress, emotionality, and work-ethics.

Similarly, in the case of mTBI, doctors and patients alike embrace a hypermasculinized disease profile. Physicians have understood concussion to be a condition predominantly for men since its discovery in medicine. Assumptions about men and masculinity remain deeply embedded within the language of the diagnosis, suggesting a relationship between the legitimacy deficit, disease frame, and the production of medical knowledge. The stereotypical portrayal of brain injury patients as tough, brave, risk-taking men suggests that the understanding of this injury is rooted in masculinity. The type of person associated with mTBI – characterized by strength, risk, courage, bravery, and athleticism – is admired. For example, popular media tends to depict men who are veterans and athletes as the types of people who have brain injuries, and much of the discussion about mTBI in the medical literature has focused on these groups.

Moreover, cultural beliefs about the common causes and symptoms of concussion are associated with strength, a characteristic that is associated with masculinity; and yet, the same symptoms, when found among women, are pathologized, suggesting psychological weakness. Masculinity serves as a resource from which men may draw on to gain status and legitimacy – the benefits of which are both substantial and substantiated. Such benefits may help to explain how the clear masculinization of concussion has endured despite growing evidence that women make up an increasing portion of concussion patients.

While concussions are increasingly being treated more seriously with a rise in concussion protocol implementation and more stringent restrictions, previous generations were still raised under the belief that it is a mundane, minor injury. Declan, a 30-year-old veteran, conveys this, saying, "[I]t's expected; no one asks *if* you got one, they ask *when* you got it." Common sayings like "getting your bell rung" similarly reflect this sentiment. Theo, a 21-year-old who had multiple concussions throughout his hockey career, said, "I stayed in the game and continued to play, just like, 'Eh, I'm okay.' It's kind of swept under the rug, like it's a normal occurrence. Like, you're just going to push through." Thus, masculinity also prevented men from receiving proper treatment; that is, the men and others tended to believe that they should just "toughen up" or "man up" or "play through the pain" after concussion.

This situation is connected to an intriguing paradox where men have relatively higher status and greater resources, yet experience health disadvantages across various measures, including decreased life expectancies and higher rates of preventable causes of deaths. One well-documented factor contributing to men's health disadvantages is greater levels of engagement in risky behaviors and lower levels of health care seeking practices (Courtenay 2000, 2003; Starfield, Shi, and Macinko 2005). Substantial scholarship finds that men avoid health care partly because they associate masculinity with invulnerability and independence (Courtenay 2000; Galdas, Cheater, and Marshall 2005; O'Brien, Hunt, and Hart 2005). Courtenay (2000) argues that gendered health-related beliefs and behaviors are important contributors to men's poor health outcomes; specifically, dominant social constructions of masculinity promote behaviors that work against health. Men use these health-negative social practices as signifiers of masculinity and tools in their negotiation of social power and status. Some of these practices contributing to men's poor health outcomes include men being less likely than women to make use of primary care services, to engage in proactive help-seeking behavior, to participate in exercise, maintain a healthy diet, and avoid "risky" behaviors like drinking, smoking, violence, and fast driving. This further means that health-related beliefs and behaviors are contexts where individuals "do gender" (West and Zimmerman 1987). The ways in which men "do health" also demonstrates their masculinity (Saltonstall 1993). Thus, the body serves as a canvas and vehicle for both gender and health accomplishments. Connell (2012) argues that these are, in fact, not distinct accomplishments but rather linked. In this way, health behaviors are just like any other gendered social practices, underlining how health behaviors are shaped by and (re)produce gender. This helps to explain why men with mTBI who have certain kinds of privilege are able to draw on the masculinity embedded in the social framing of concussion and TBI but still face challenges in recovery.

This may also be partially explainable by the fact that cultural stereotypes are more durable than the power of new biological knowledge, what Ludwik Fleck calls "the self contained" nature of scientific thought (1979: 38). As Kempner (2014) says, "Gender is persistent; even as we try to alter power relations in medicine, the universal patient is embedded within a broader sociocultural gender system that promotes gender essentialism in medicine" (p.

157). This is evident in the different rates at which men and women are diagnosed with the controversial and feminized diagnosis of persistent concussive symptoms or post-concussion syndrome (PCS); men are much less likely to be diagnosed with PCS. In this section, I show how gender beliefs get written into the social framing of brain diseases; specifically, how mTBI gets framed as a brain disease for men and of masculinity.

The Glass Slipper Effect: Masculinity as a Source of Status and Resource for mTBI Legitimacy

Because activities that tend to be associated with concussion and TBI are often gender-typed masculine, men are granted a kind of courtesy association as potential participants in such activities, and this lends them credibility as patients. Said differently, because arenas where concussions are believed to be prevalent – such as professional sports or the military – are male dominated, then it seems likely that a patient who has a concussion is a man. A helpful theory for understanding this comes from the literature on occupations. Ashcraft (2013) theorizes the concept of "collective occupational identity" to explain how (dis)advantage is accrued through association with occupational identities. Building off the classic "glass" metaphors of the "glass ceiling" (Powell 1999), the "glass cliff" (Ryan and Haslam 2007), or the "glass escalator" (Williams 1992), Ashcraft uses the metaphor of the "glass slipper" to represent how occupations are thought to be "naturally" better suited to certain people and incongruous for others. This could also be extended beyond the kinds of things people do for pay to include other activities people participate in, like sports. Despite women's entries into male-dominated and concussion-common activities like football and military combat, these fields remain gender-typed masculine (see Irvine and Vermilya 2010). This is to say that even though statistically men are actually not at greater risk or more likely to incur concussion within certain activities, the cultural belief that they are nonetheless persists.

This occupational gender stereotyping of concussion was a theme in the ten interviews with men whose injuries were not related to sports or combat. For example, Bennett, a 61-year-old whose mTBI was caused by a motor vehicle collision, said that when he would tell people he had a brain injury, they would sometimes ask if he was a veteran. He would clarify with them that he was injured on one of his construction sites. Bennett chuckled and told me, "I never had to explain further than that I guess." While his specific occupation was identified incorrectly, his actual occupation fit within a masculine-typed occupation, so it fit the concussion schema and did not warrant further credentialing. Thus, men experienced "the glass slipper effect" that meant their brain injuries were not suspect but instead seemed legitimate.

Men reported needing to offer explanations for their conditions less often than the women in this study did. On the occasions that men did feel the need to offer explanations, they framed these explanations as friendly reminders rather than cases of proving credibility. For example, Alex, a 41-year-old, reported people simply "forgetting" he had incurred a concussion because of the time that had passed since the injury, not that they did not believe his condition. He said, "And so I'll say something, like 'Yeah, but remember my concussion?' And then they're like, 'Oh yeah, you did have a concussion.' You know? So, it's just that I gotta remind people that this is what I'm dealing with." Thus, the interactional challenges men encountered were different from women's in that others did not question the seriousness of the men's conditions and, as such, the men did not experience a legitimacy deficit.

The Diagnostic Moment

Men did not report any legitimacy deficits related to their initial diagnoses of concussion or mTBI even when asked directly. However, hegemonic masculine ideals pervaded every stage of the disease process, starting with the pre-diagnosis phase and the sentiment that men can – and should – just “walk it off”; that is, men, unlike women, should have the mental fortitude and pain tolerance to overcome any physical pain or deficits and persevere. This sentiment permeated the diagnostic moment, too. Of this mentality, Alex said, “The doctor that I went to two weeks [after] my head injury, he was like, ‘Yeah, you can go back to work.’” He further explained that he had also incurred a laceration that required staples with his fall, so the doctor was basing his recommendation on the healing process of that laceration and being able to remove the staples prior to him returning to his manual labor job but made no mention of his concussion. Alex reported needing to remind the physician of his concussion and explicitly ask about whether he should return to work when he was still experiencing severe symptoms, like dizziness, vestibular disfunction, memory deficits, headaches, and insomnia. His doctor told him to “take another week off then and see how [he felt].” Thus, while his symptoms were not dismissed, they also were not treated with the same level of concern as the laceration, suggesting that concussion is relatively lower in the hierarchy of medical conditions. Similarly, the men reported “surprise” from physicians when their symptoms persisted. For example, Ben, a 43-year-old, said, “not like skeptical like he thought I was lying or nothing, just more like surprise, you know, ‘cause they usually are gone in like a couple days or weeks or whatever.” This has important consequences for men’s recoveries as they were less likely to advocate for themselves to pursue care.

Many of the men reported that the health promoting behaviors they did engage in were not voluntary. Rather, their initial clinical encounters were obligatory because their injuries occurred during a formal organized activity, such as in sports or on the worksite, where there were policies to respond to injury. For example, while working as a locomotive mechanic, Alex fell several feet to the ground and was taken to the hospital via ambulance because his supervisor called 911. This illustrates how organizations’ policies supported men’s health outcomes.

Organizational practices further supported the men's recoveries through encouraging follow-up care in their return-to-play, return-to-learn, and return-to-work policies requiring documentation from a physician confirming that they could safely return. Thus, the men had to seek follow up care if they wanted to return to work, which they all did. As I discuss later, the importance of returning to work for the men was paramount. The motivation to return to work supported follow-up care through organizational requirements but, in some cases, it also encouraged men to neglect their care as they minimized and ignored symptoms to accomplish gender by proving their masculinity through invincibility and fulfilling the breadwinner role by earning an income.

My analysis suggests that the legitimacy deficit is smaller for men with mTBI than for women in large part because mTBI is gendered masculine. Like the women with mTBI, the men with mTBI faced barriers to accessing resources and experienced a legitimacy deficit when communicating the severity of their illness to others; but, unlike the women, the men could rely on the masculinity embedded in the social construction of their diagnosis as a resource to aid their efforts of legitimating the persistence of their symptoms. They similarly generalized their specific diagnosis to "brain injury" more broadly, thereby deploying neurobiology as an additional resource in resisting others' interpretations of their conditions as mundane. Doing so supported one of their primary aims: avoiding feminized attacks and being labelled a "sissy." Men with mTBI embraced the highly masculinized disease profile of concussion and TBI, drawing on the same images of soldiers and professional football players that were rather detrimental to the women, to bolster their claims. I argue that masculinity is inscribed into the concussion diagnosis through diagnostic language and gender-typed activity identity association and serves as a resource for legitimacy among men.

ROLE CONFLICT

Despite being legitimized as mTBI sufferers, men with mTBI experienced role conflicts as patients, fathers, and providers. Role conflict occurs when the expectations of two or more social statuses are incompatible or competing. Murphy (1990) maintains that men with (physical) disabilities experience what he calls “embattled identities” because the expectations of them as men are not just different but opposed to the expectations of them as people with disability. Disability conflicts with the power typically afforded to men (Gerschick and Miller 1995). Masculinity is traditionally defined through strength and power. Men are stereotyped as providers, independent, rational, aggressive, and powerful (Kimmel 1996). Disability, though, suggests dependence and incompetence and, therefore, it can have an emasculating effect. As I discuss in this section, while the men I interviewed did not face obstacles to diagnosis, they did encounter obstacles to receiving adequate care that would expedite and maximize their recoveries. While the women in this study encountered external obstacles to accessing care, the men struggled with internal counterincentives to pursuing care: feeling compelled to prove their masculinity and experiencing anxiety about their failures to meet societal gender norms.

Social Support

Gendered norms about the experience and communication of vulnerabilities negatively impacted men’s mental health and prevented them from gaining access to resources (Evans et al. 2011). Caleb, a 53-year-old, said:

> When I do talk to people about it – the few people that I do trust and know – I get things like, “Why now?” Or “Just pull yourself up, damn it,” and “Quit being sad,” and “You’ll be fine.” So, I tend to push those people off a little bit. And it makes me less willing to open up to other people. As a single person, it would be nice to go on a date, or something – it’s been a long time. But how do you explain that kind of stuff to a potential partner? Not on the first date, obviously. Third date? Like, I don’t know.

Theo similarly noted that the “worst part of this” was that he did not get many opportunities to talk about his injury with other people. He explained how the legitimacy afforded to him as a man with mTBI limited the questions people had about his condition “for better or worse.” Theo explained how while it was nice not to have to prove his condition to other people, not having to explain his condition also meant fewer opportunities to talk about his experience. This lack of connection and social support contributed to him feeling isolated and experiencing depression post-injury. He also explained how he and other men were uncomfortable talking about their vulnerabilities, which include impairment and illness, so it was not easy to find other men who had similar experiences with whom to connect, and he had a difficult time expressing his needs. These factors, as well as their somatic symptoms, inhibited the men’s abilities to make new social connections. For instance, Theo entered college soon after his most significant concussion, one which left him with lingering symptoms. Of his transition to college life, he said:

> Everyone made friends that way [going out to bars and parties]. But I never made the same friends as them. I don’t really go out as often as other people do because I just don’t feel like it because my head…There’s some days where I’m just completely shut down, I’m not talking to anyone, not going on my phone or anything, or socializing at all. So, I think it affected the amount of friends I was able to make.

Theo later explained that having a smaller social circle helped him avoid needing to provide explanations for declined or cancelled plans. This is in stark contrast to the women who commonly reported their absences from social life contributing to their suffering. This gender difference may be explainable in part by gendered expectations of communication and care work that do not expect men to do as much communicating or as much care work as women.

Likely because others did not doubt their conditions, none of the men reported feeling like they could ever *not* get help from those in their social networks, including family, friends, and even coworkers. The one man who hinted at needing more help, Alex, said that he was certain that if he ever did ask for help from his ex-wife or friends, they would help. He explained that it was "not 'cause nobody would have helped me but that I didn't think about asking them…And I want to be with my kids when I can, you know, I don't want someone else watching them." While Alex did experience constrained choices (Bird and Rieker 2008), his lack of support was not a result of others denying his requests; rather, it was a consequence of his failure to ask for help. His experience contrasts significantly with the experiences of women, who largely reported feeling under-supported because their requests for help had been rejected. This difference further supports my argument that the legitimacy deficit is a product of gendered social processes.

Family Roles

According to Parsons, the sick role is modeled on the traditional male role as a family "breadwinner." If a man falls ill, he must do all possible to restore his productivity to its normal level or risk not being recognized as legitimately sick. While Parsons' ideal type has been critiqued for failing to account for the social position women occupy in society, it is also important to point out that this is an idealistic presumption for men's recoveries that does not consider variation among men's social positions, particularly socioeconomic status. This expectation of the sick role is a double-edged sword for men: while the traditional "breadwinner" role may offer men greater flexibility to dedicate time to recovery, the expectation to provide for their families can also be detrimental to their prognosis through pressure to return to work sooner than would be ideal for recovery.

For example, when I asked Ethan why he went to work the day after his injury despite being symptomatic, he said:

> If I would've been better off financially, would I have gone back? No, most definitely not. I would've been able to not stress about that because it was important that I worked

> and made the money because I was the only income at the time. So, yeah, I think that was, that was probably a big chunk of [why I returned to work the next day] – you know, just not really sure what else to do with the fear of probably losing my job if I didn't show up.

Ethan explained that he did not have the "luxury of being able to call in sick" because he was the family's "breadwinner." His family of five was living paycheck to paycheck, and he did not have paid time off or paid sick leave available to him. This was a common narrative among the men – they either needed to return to work for the income or to ensure a future prosperous career.

Some fathers in this study were concerned about the impact their injuries would have on their families beyond financial support, thus challenging traditional gendered parenting expectations that define being a "good" father as being a "good" breadwinner. Alex emphasized the constraints that being a parent had on his recovery and the constraints that being a patient had on providing support for his children.

> I went back to work 'cause, you know, I definitely gotta make sure my kids are okay and taken care of, you know. So, I felt like work could take advantage of that because they knew I needed the money and didn't have the money to go after them. And then people would be all like, "How come you didn't get a second opinion?" And I'm like, I don't even remember that I *should* get a second opinion, let alone actually find a doctor who will take me and to make an appointment. And then it's like I still gotta drive to these places! And I don't got no help, you know, and I still got young kids, and all this other stuff, and I didn't have any help. And then it's like, "Well, how come your wife didn't do this?" But it's like we ain't really together no more, and too, like, if she's with me, helping me, then who's gonna watch the kids?

Thus, the men sought to avoid any negative impacts that their conditions may have on their children, whether these were financial or time related. Even when the parenting men had wives, they did not want to take the "one functioning parent away from the kids, too," as Bennett said. He further explained that he wanted his wife to be there for the children in his absence since he could no longer make his son's lacrosse games or his older daughter's volleyball tournaments. The fathers in this study worried that they were taking time away from their children by asking their wives to instead help them in their recoveries. Thus, rather than using time that could be devoted their own recoveries, the men instead opted to allocate that time to their children.

An important way that the men's and women's narratives about parental roles diverged was that the married fathers constructed their roles as "helpers" in the childrearing process, whereas mothers constructed their roles as primary caregivers for their children. For instance, in Bennett's example above, his wife was taking over the "helping" duties he previously had of driving kids to their extracurriculars. Married fathers relied on their wives to compensate for their reduced availability, and single fathers relied on their older children to do the same, whereas married mothers asked their husbands to "help" more and single mothers continued in their preexisting roles unchanged.

For example, after Bennett's separation, his first-born (a son) and his middle-child (the eldest daughter) lived with him most of the time. His eldest daughter took up much of his care and much of the housework, which he said he "still worries about to this day [because]… it made her grow up too fast and lose some of her childhood." Bennett worried that because he was no longer able to be self-sufficient after his injury and relied on his eldest daughter for many day-to-day things, that she and others may see him as a bad father. Caleb echoed this concern about how one's disability affects parenting, saying:

> It impacts my parenting. It's one of those things that I'm constantly feeling self-conscious about because you get looked at differently as a single parent, and because I had an injury, as well. So, I worry about someone thinking I'm not doing a good job and, especially as a single *father*, I worry about getting reported and him [his son] getting taken away from me.

Caleb's account reflects the feminized role of parenting that precludes men from being perceived as being as good of parents as women. Such prejudice is compounded for low-income fathers (Edin and Nelson 2013), like Caleb. In addition to being a father and low-income, he worried that his disability status would only exacerbate others' assessments of him as an unfit father, in part due to his reduced emotional regulation post-injury. He worried that others may be more sensitive to his emotionality – particularly angry emotions – and, because he is a man, interpret him to be dangerous.

Conflicts with parenting expectations were not the only family issues men experienced, however. Of the five men who were in marriages at the time of their injuries, only one was still married at the time of the interview. Bennett was one of the men who experienced divorce, which he directly attributed to his injury.

> I was the stereotypical breadwinner, and that was what we [him and his ex-wife] had planned on; that's what she signed up for – being a stay-at-home mom. That's what I promised her. So, when all of a sudden I couldn't manage my company and I couldn't do really anything around the house and needed her to drive me and do pretty much everything for me, not only was I losing my multi-million-dollar company but she was basically gaining a fourth child.

He explained that this created significant discord in their relationship, and they eventually separated three years later, followed by a divorce after two more years. In these ways, men faced significant role conflict as mTBI patients when trying to balance the expectations of being a partner, a father, and a provider.

EDUCATION, EMPLOYMENT, AND DISABILITY

Gendered disparities in access to good jobs and health resources yield a lifetime of cumulative advantages for men's health, relative to women's, due to institutional arrangements in occupational and family care roles (Moen and Chermack 2005). Two main pathways through which gender influences health is through systemic socioeconomic disparities and exposure to gender-specific stressors and coping resources. The relationship between gender and health is complex. For this reason, Bird and Rieker (2008) argue that it is not theoretically appropriate to simply add gender into other models of fundamental social causes like race or socioeconomic status. Instead, they develop a more sensitive understanding of gendered health outcomes that relies on the concept of "constrained choice," arguing that gender determines the availability of opportunities and choices through decisions and actions taken by families, communities, and governmental policies. Thus, social position frames the personal experience of health.

Overall, men faced fewer challenges when reintegrating into education and employment post-TBI than did the women in this study. However, not all the men shared the same privileges and, therefore, the same experiences of mTBI. In the sections that follow, I parse out how social difference contributed to different experiences of mTBI, focusing on how different occupation types mattered; jobs in the service sector and blue-collar jobs were less friendly to men with mTBI than those in white-collar institutions. Men who were unable to (re-)enter education or employment ultimately pursued formal disability status for financial support through the state. Compared with the women in this study, the men experienced fewer difficulties in the courtroom and increased success in pursuing disability claims.

Reintegration into Education and Employment

White-collar occupations and higher education institutions offered greater flexibility for mTBI patients than many other jobs in the service sector or blue-collar occupations. Theo, for instance, explained how he did not need to seek formal accommodations at his university for either his coursework or his research assistantship. He explained that:

> I would just tell them I'd had all these concussions before in hockey and, you know, that I now have all these issues from that, and they've all been really understanding and let me take more time on papers or do quizzes late or whatever. And then the professor I'm working under, he's really lax. He said, "Just get the work done when you can." He's not enforcing strict hours on me. And if I'm not feeling well, I can just go home.

This experience starkly contrasts with both women's experiences accessing accommodations in education and the workplace, and with men's experiences in blue-collar industries and service sectors. Women experienced difficulties because they were not believed and, consequently, faced obstacles in accessing accommodations in education and the workplace. Theo's experience accessing accommodations as a student in college contrasts that of Harper, who had to not only formally request accommodations through the college and provide substantial documentation in doing so, but then had to repeatedly petition their rejections of her requests.

Workplace resources for paid leave and other financial resources while unable to work, such as workers compensation, were often just as problematic for men as it was for women, but in different ways. For example, Alex explained how his job duties were not compatible with his injury or his recovery. He said:

> When I got to work, they didn't put me on easy jobs. Like, they put me on regular work, and everything hurt. I wasn't healed when I went to work, and nobody cared. So, it's like I had to go to work, and I couldn't heal. I can't do my job. I can't remember certain things or I'm not retaining information as fast as everyone wants me to, or at least the supervision wants me to. So, it's like I beat myself up or have to try writing stuff down. It's like a handicap but there's no place and no time for handicaps in [my occupation]. This is an unforgiving work environment. And it's like maybe I can't do my job or maybe there's something else that I should be doing.

When I asked Alex why he "had" to go back to work, he explained that he had kids and a wife, who he was separated from but still supporting for the kids, so he was paying for two households now and needed the income. He explained that he "didn't quite qualify for [his company's] disability" because he had not met the employment requirement of one year of full-time employment prior to his injury that would have qualified him for his company's short-term disability coverage. He said:

> Since I hadn't worked quite up to that full year yet when I had the accident, I didn't qualify like other people who would still be off work recovering right now. They would've gotten their full check every week. Like even the people who hurt their finger

> or something, like they can be off for months, but because I'd been there less than a year when I got hurt, I wasn't getting any money. If I had qualified for disability, I believe that I could have healed longer, which could have done more for my brain.

Thus, like most of the women in this study, the three men who were in service sector and blue-collar industries (i.e., not white-collar jobs) faced barriers to accessing financial support through workers' compensation programs or short- and/or long-term disability through their companies. An important distinction in the men's experiences, however, was that it was not due to a legitimacy deficit but rather to systemic workplace practices and policies.

The most significant stratifying factor in the men's experiences was their occupational fields in the workforce (i.e., blue-collar, service sector, or white-collar). This has significant consequences for workers with illness or injury because workers must choose between providing for their families or their health. My interviews with men in blue-collar occupations suggest that their jobs are detrimental to recovery because they tend to be characterized by hypermasculinity and do not offer flexibility in the workplace (e.g., flexible work schedules, hourly pay without paid time off, and available reasonable accommodations). Alex, for example, described his job as a locomotive mechanic as being "unforgiving" with "no time for handicaps in the railroad." He explained how there are "no backups or nobody to help you – it's just you, and if you can't do the work, then you gotta go. You know, we're all working our asses off out there." Ben, an auto mechanic, described his workplace similarly, saying, "It's just all us guys out there in the shop, so nobody's checking on you all the time asking how you're feeling or anything. And I sure as hell wasn't gonna be the one whining about a headache." Ben's comment illustrates Rochelle's (2019) finding that men are especially reluctant to share their symptoms with others in the workplace because their symptoms, like headaches, were "minor." After trying to "tough it out" for the first couple weeks, Ethan, who worked in the service sector, submitted a request to the restaurant’s manager for a role change. He ultimately quit his job after being told by his supervisor that they “can’t do anything, and to stick it out or quit.” These men also reported the most challenges during recovery and the least favorable outcomes in terms of reintegration compared to the men in white-collar occupations.

Extant literature finds that masculinity beliefs shape health behaviors, and a few studies have examined how this relationship is impacted by occupation. Springer and Mouzon (2011) argue that masculinity partially explains the paradox of men’s decreased life expectancy despite working in white-collar jobs, finding that typically health-promoting factors – like education, wealth, and income – are mutable by strong masculinity beliefs. Another important factor to consider is the gendered context that men are embedded in at their workplaces. Men working in blue-collar occupations may be embedded in workplace cultures that promote hypermasculinity more than white-collar jobs. This may explain the similarities and differences I noticed with blue-collar workers who fared worse in their recoveries; however, additional research is needed.

Understanding men’s challenges in the workplace is important for theoretical reasons but may also provide practical implications for policy. There are robust findings that men with disability experience higher rates of un-/underemployment and poverty, as well as lower rates of labor force participation and lower incomes compared to men without disability (American Community Survey 2003 – 2007; Kidd, Sloane, and Ferko 2000; Campolieti 2002; Wilkins 2004). Their labor force exclusion stems from the ideological connection of disability and dependency; that is, others assume that people with disabilities are not capable of being independent. In the labor force, this translates into not being self-sufficient workers, thereby preventing people with disabilities from being attractive candidates to potential employers who do not see them as economically profitable employees. It is important to note that their rates of participation in the labor force are still higher than women's (both with and without disability); thus, disabled men still accrue relative privilege. This relative privilege, however, seemed to have an occupational and socioeconomic gradient wherein those with non-manual labor jobs and higher socioeconomic status seemed most insulated from the negative consequences of disablement; they were best able to cope, resulting in better recoveries.

The experience of Alex, as described earlier, contrasts starkly with that of William, a 56-year-old former doctor who is married with three adult children and identified himself as upper class. After his fall, William received extensive treatment through an outpatient program at a traumatic brain injury (TBI) treatment center. Contrasted with all the other men in this study, William reported having "probably too much treatment." I asked William to clarify what he meant by "too much treatment," thinking that perhaps it was overwhelming due to fatigue or worsening symptoms, but he responded that it "was just overkill." He felt that he had recovered as best he possibly could with current medical knowledge and technology. He never felt pressured to return to work, and he reported that his family and colleagues were all supportive of his recovery and ultimate departure from the medical practice. While he is no longer able to practice medicine due to his mTBI, he continues to work as a writer, consultant, and brain injury advocate. These two cases starkly contrast with each other, showing how outcomes of mTBI are moderated in part by the preexisting protective factors and flexible resources. In contrast to the women and men like Alex and Caleb who were working class single fathers of dependent children, William was well versed in the healthcare system and had ample social and economic resources from which he could rely on to help minimize the impact of his disability on his financial, social, and emotional well-being.

Pursuing Social Security Disability Insurance (SSDI)

The two men who had completed the Social Security Disability Insurance (SSDI) claims process, Caleb and Ben, were both successful. Neither of them reported the judges questioning the seriousness of their condition. A third man, Ethan, was still in the process of filing for SSDI but identified his greatest concern as being able to properly complete the paperwork. As such, he had recently hired a lawyer to manage his case. Unlike the women who hired lawyers for their legal expertise to combat doubt about the seriousness of the mTBIs, Ethan hired a lawyer due to practical concerns resulting from his visual and cognitive impairments.

There is an important socioeconomic and education gradient in men's experiences in the workplace post-injury, and whether they pursued SSDI. A handful of the men I interviewed had never applied for disability because they were able to maintain or find new employment. Some men, like Levi, a 53-year-old with a bachelor's degree, and Elliot, a 43-year-old with a graduate or professional degree, were able to pivot occupational trajectories and pursue jobs that allowed for the accommodations they needed to return to work. Two other men pursued alternative means of income by investing in properties, companies, and/or stocks. However, when men were unable to return to work or find new streams of income, they sought SSDI. Two of the three men who were receiving or pursuing SSDI identified as poor, and the third identified as middle class. Caleb, who identified as middle class and was a 53-year-old veteran, was also receiving Veterans Affairs disability compensation because his impairment occurred during service. He was also married, and his wife was working, bringing in a second income. In contrast, SSDI was the only source of income for Ben, a former mechanic and a single father to a teenager, and Ethan, a 31-year-old whose wife was also disabled and was raising three young kids. Ben and Ethan worked in blue-collar and service industries, which left little room for accommodations to be implemented for them to continue working in their jobs. They also had high school educations, which may have limited their options for alternative employment that could offer more flexibility in workplace environments and accommodations, as we saw earlier in Theo's case at college.

DISCUSSION

In this chapter, I showed how the mTBI diagnosis is constructed as masculine and thus affords men the "glass slipper" by which they are endowed a privileged patient status through an imagined association with male dominated concussion-common activities. I demonstrated how the gendered social frame may be drawn on as a resource for legitimacy by men with mTBI, but also that adherence to masculine norms can discourage them from engaging in health promoting behaviors. While men certainly faced struggles related to their condition, such as maintaining employment, these stemmed from their symptoms and impairments rather than their recognition as patients with significant and real symptoms. Despite most men seeking little to no care post-injury, their somatic symptoms nonetheless manifested role conflicts that created further strain that was detrimental to their recoveries and personal lives. Finally, I showed how men navigated a new "normal" with chronic illness and disability in education and employment, or when unable to return to learning or working, sought legal disability status.

My analysis in this chapter demonstrates the gendered legitimacy of disease frames and extends existing theories on biopolitics by drawing attention to the relationship between gendered diagnoses and patient gender (in)congruency. My findings provide an important intervention in the literature on masculinity and health, as the case of men with mTBI demonstrates that even in cases where the condition is less stigmatized, and in some ways even seen as evidence of men's strength, men still minimally pursue treatment. This suggests that while men may have fewer difficulties claiming the mTBI diagnosis and being recognized as credible and worthy patients, they nonetheless experience serious barriers to care in their recoveries because *any* diagnosis identifies dysfunction and thus vulnerability, which is incompatible with hegemonic masculinity. The case of men with mTBI is an interesting one that warrants further exploration as there is conflict between the diagnosis itself which is masculine – even a badge of honor for men – and the role of being a patient, which is feminized. Impairment threatens not only the individual man's masculinity (Shakespeare 1999; Shuttleworth et al. 2012) but the larger gender order in society (Murphy 1990), which may partly explain why men face barriers to treatment: they do not want to emasculate themselves by showing weakness and asking for help; gender norms also mean that family, friends, colleagues, and medical caregivers do not know how to or do not want to discuss men's impairment; and finally, institutional exclusion – such as in the workplace – may create a self-fulfilling prophecy with disability being equated to incapability and subsequently unproductivity. Thus, being diagnosed with mTBI is still stigmatizing for men, leaving substantial room for interventions to improve men's prognosis.

CHAPTER 7

CONCLUSION

In this dissertation, I compared the experiences of women and men with mild traumatic brain injury (mTBI) to identify the social determinants contributing to mTBI resilience in order to explain the observed gender gap in prognosis. Through the analysis of interviews with 52 mTBI patients, I argued that there are multiple co-occurring and divergent social forces that contour the cultural status and illness experience of mTBI that give way to gendered disparities. I began by briefly introducing brain injury and this study's theoretical framing in the first chapter, followed by a discussion of my methodological decisions in the second. In my first analytic chapter, "Chapter 3: Getting Diagnosed," I examined how women go through each stage of the diagnostic process, highlighting the role of gender in physicians' diagnostic assessments, and using the negative space to show where other women who never received a diagnosis were likely to fall out of the diagnostic search. To better understand how the illness experience of mTBI is shaped by the legitimacy deficit, in "Chapter 4: Being Brain Injured" I show how patients "do" and "know" disease (Mol 2002:12). In doing so, I offered an intersectional analysis in outlining the social determinants of mTBI to show how resilience is especially sensitive to social capital under circumstances of doubt. In "Chapter 5: Navigating a New Normal," I showed how mTBI poses condition-related and gender-specific challenges for women when pursuing education or employment, or when defaulting to legal disability. In my final analytic chapter, "Men with mTBI," I showed how masculinity serves as both a resource for legitimacy through the disease frame and an impediment to recovery through negative health behaviors. Taken together, these findings suggest that there are multiple co-occurring and divergent social forces that contour the cultural status and illness experience of disease that give way to gendered disparities.

The case of mTBI shows that legitimacy depends on more than medicine's recognition: even though it is recognized as a medical disease, some patients (i.e., women) continue to have difficulty convincing their physicians that they have one and that their symptoms are serious. Even those lucky enough to garner medical support of their condition still face doubt in other social arenas, like in social gatherings or the workplace. Thus, the legitimization of concussion takes on a gendered and moral dimension as patients must prove that they are credible. While there have been stakeholders in the concussion community working towards increasing awareness of concussion, these efforts have failed to address the risks of lasting disability and to provide inclusive representations of patients. Thus, mTBI has had increased recognition as an acute condition (i.e., concussion) but still lacks authority as a chronic illness or disability (i.e., post-concussion syndrome/persistent concussive symptoms (PCS)). Risk is narrowly focused among boys and men, so whether concussion is widely recognized is a moot point for a large part of the patient population (i.e., women) if they are not recognized as potential sufferers or are not believed when they do incur concussions.

This leads to a critical question about how gender gets inscribed into conditions that are not sex specific. As Kempner rightfully asks, "What makes the idea of a hysteric, neurotic women or a strong, stoic man so compelling that it gets reinscribed into the body…and inscribed into the brain?" (2014: 164). The persistence of gender, and its varied forms of inequality, continues to be a significant area of investigation amongst feminist scholars. In the case at hand, Ridgeway's (2011) theorizing offers a helpful framework for reconciling the gaps between medical science as an institution and as culture. Ridgeway argues that gender inequality persists because of gendered social framing that makes specific status characteristics more prominent in certain contexts where gender is perceived to be relevant, and that these “activate” gender stereotypes. This was a salient feature in my research as others relied on women’s gender as a relevant frame for interpreting their condition in the absence of readily observable indicators of illness or disability. Ridgeway identified a two-pronged solution to gender inequality that also seems appropriate in the specific context of mTBI given my analysis: reduce gender status beliefs and reduce the range of contexts where gender is culturally perceived as sufficiently relevant to measurably shape status.

CONTRIBUTIONS

I outlined how the institution of medicine and cultural narratives of gender interact beyond diagnosis and throughout the disease process. In doing so, I showed how concepts of health, illness, and disability are uniquely applied to conditions of the brain. I explicated how the brain is socially constructed by showing how neurological technology and medical science is shaped by and shapes social and cultural forces. Thus, this work contributes to the growing body of scholarly work on neurosociology. This dissertation further contributes to a breadth of bodies of scholarship, including medical sociology, science, knowledge and technology studies, sociology of health and illness, disability studies, social psychology, sociology of mental health, body and embodiment, and gender studies.

This research also contributes to the health disparities literature, offering a less common meso-level analysis of psychosocial factors by showing that successfully overcoming barriers to recognition as a patient was vital to quality of life and prognosis. To address the theoretical and methodological critique that population health studies lack integrated intersectional approaches that focus on the power dynamics contributing to health inequalities (see Bauer 2014; Mulinari et al. 2018), I examined the relationship between social categories and power through process and structure (see Bauer 2014; Mulinari et al. 2018); explicitly discussed the role of theory (see Krieger 2003; Bartley 2004; Bauer 2014); and highlighted context, or social positionality, to retain the texture of people's lives that is manifested by the complex, interweaving of social systems (see Raphael and Bryant 2003).

By connecting "upstream" causes and "downstream" mechanisms, my analysis further demonstrates the importance of socioeconomic status, flexible resources, and social capital as predictors of prognosis across genders, though acting differently for each. Using Shim's (2010) concept of cultural health capital, I showed how patients' social positionality interacts with the healthcare setting to affect diagnosis and recovery. My findings support Shim's argument that these interactions accumulate to produce systemic differences in care and, consequently, health disparities within the patient population. Given the important consequences of doctor-patient interactions, medical education programs ought to advance their curriculum on mTBI to improve patient outcomes. While not sufficient, increased medical authority may also help to create social change in cultural narratives that stigmatize mTBI and other invisible disabilities. To this end, more information and knowledge about the potential long-term consequences of mTBI are needed for the lay audience, including patients and the public.

The contested illness literature would suggest that diagnosis alone is sufficient to help a patient overcome legitimacy deficiencies and gain medical authority. And yet, the findings I presented here demonstrate that this is not so in the case of concussion diagnosis. Whereas prior research explored the interplay between unexplained symptoms and labels in the case of conditions that are characterized by an absence of specific etiology (e.g., Barker 2002; Dumit

2006; Zavestoski, McCormick, and Brown 2004), this study examined a diagnosis with observable incidents of injury or known causes. Other well studied invisible pain conditions are, by contrast, mostly measured by patients' subjective self-reports of pain levels. While concussion cannot always be diagnosed by diagnostic imagery of the brain, unlike other contested illnesses, it can be effectively diagnosed using functional tests of vision, the vestibular system, cognitive and motor functioning, and more.

Because literature on contested illness is predicated on a lack of diagnosis, it falls short of offering sufficient theoretical frameworks for understanding mTBI. That is, mTBI is widely accepted as a medically legitimate diagnosis and condition but not all patients have equal access to the benefits the diagnosis confers; not all sufferers are equally seen as legitimate mTBI patients. Thus, there is a lacuna that generally neglects the experiences of patients who have a legitimate, medically recognized diagnosis, yet are still subject to suspicion and doubt and, consequently, experience barriers to accessing resources to aid in their recovery to wellness. Thus, my research conceptualizes a contested sick role, rather than a contested illness. In this respect, my focus on contested sick roles diverges from dominant approaches to studying medical authority: I shift the focus of legitimacy from the authority of the diagnosis itself to the interaction between it and the patient: the space in which disease is a label and is lived.

To understand why different patients with the same diagnosis experience dramatic differences in their illness experiences, I employed an intersectional approach where gender was the primary frame of analysis. This allowed me to examine gender (in)congruence between diagnosis and patient. Departing from studies that examine conditions like headaches and migraines (e.g., Kempner 2014) or ME/FMS (Barker 2005) where there is gender congruency between the majority patient population and the gendered social framing of the disease, (i.e., women patients with feminized conditions), I examined gender *in*congruence. While Kempner (2014) considered gender differences between comparable but differently gendered diagnoses (i.e., headache – a feminized condition where women make up the majority of the patient population – and migraine – a masculinized condition where men make up the majority of the patient population), her analysis still examines gender congruence between the patient population and the gendered disease frame. Such analyses fail to consider how a subjugated patient population fares with a condition that is constructed for the dominant class. Thus, this study provides a critical account by demonstrating how womanhood is pernicious to a masculine diagnosis. In my analysis, I argued that medicine intersects with the gender system in the disease frame to produce a legitimacy deficit among women patients with mTBI due to gender incongruence between the disease frame and the patient's gender. In the process, I further developed theories of legitimacy by expanding on how patients' social positionality, principally gender, contributes to legitimacy deficits. By doing so, I emphasized the role of embodiment in diagnosis, arguing that the body is fundamental to understanding the intersections of gender, health, and disability, including lived experiences of bodies, cultural ideas about bodies, and strategies of regulating bodies to bring them under normative prescriptions (Siebers 2008).

In addition to contributing to understandings of women's illness experiences, my findings also provide important interventions in the literature on masculinity and health by identifying some of the health disadvantages or determinants of men's health – an area that has received relatively less attention. The case of men with mTBI demonstrates that even in cases where the condition is less stigmatized, and in some ways even revered as evidence of men's strength, the men in this study still minimally pursued treatment. This suggests that while men may have fewer difficulties claiming the mTBI diagnosis and being recognized as credible and worthy patients, they nonetheless experience serious barriers to care in their recoveries because any diagnosis identifies dysfunction and hence vulnerability, which is incompatible with hegemonic masculinity. This is a particularly interesting case because there is conflict between the masculine diagnosis and the feminized role of being a patient. I showed how impairment threatens not only the individual man's masculinity (Shakespeare 1999; Shuttleworth et al. 2012) but also the larger gender order in society (Murphy 1990), which may partly explain why men face barriers to treatment. These findings highlight how being diagnosed can be stigmatizing for men in gendered ways. This leaves substantial room for interventions to improve men's prognoses. This study also contributes to the relatively smaller body of works on masculinity and chronic illness.

In this dissertation, I showed how dominant gender stereotypes were used to reinforce stereotypes about illness and disability. Both women and men in this study contended with stereotypes that labelled them as weak, incompetent, and dependent. For women, these stereotypes were intensified (see Nario-Redmond 2010). Women experienced "rolelessness" (Fine and Asch 1988), as they were neither able to fulfill the traditional feminine role of nurturer nor the traditional masculine role of worker or provider. In trying to claim or legitimate their conditions, the women had to fail at gender performances. Unlike many physically disabled women who fear the negative consequences of failing to perform gender adequately, the women with mTBI in this study feared that any successful gender performances, either in presentation or performance of roles, would discredit their disability status; the goals and means were entirely reversed. For example, in Fannon's (2016) study of women with visual impairments, an interviewee said, "you have to look healthy" because people were quick to assume that blind people were sick or incompetent and the women wanted to bolster others' belief in them as capable individuals. This is in stark contrast to the women in my study who noted conscious decisions to avoid looking healthy or looking put together. Men dealt with "embattled identities" (Murphy 1990) where their disability directly opposed traditional expectations of hegemonic masculinity. I further showed how masculinization raises the status of mTBI and how masculinity serves as a resource for men to draw from to gain legitimacy and status through the "glass slipper" effect (Ashcraft 2013), the benefits of which are both substantial and substantiated. However, this was a double-edged sword as gendered norms about experiencing and communicating vulnerabilities negatively impacted men's mental health and prevented them from gaining access to resources that could have promoted healing (Evans et al. 2011).

Furthermore, scholars have found that disability can discredit gender performances (e.g., Gerschick and Miller 1995; Siebers 2008). However, such analyses have been uni-directional in that they only consider how disability (de)legitimizes individuals' gender, thereby failing to consider how gender can also (de)legitimize disability. This is further reflective of disability's dominantly narrow conceptualization as this phenomenon may only be relevant in the context of invisible disabilities. This is becoming an increasingly contentious debate among scholars, with some arguing that such standpoints are unfounded (see Stefan 2002b; Davis 2005; Chaudoir, Earnshaw, and Andel 2013); in many ways, invisible disabilities are just as stigmatizing and isolating, despite variation in content. In an era that is increasingly attending to mental health and other nonvisible conditions, there has been more research dedicated to this area. Under conditions of equal disclosure, the stigma of invisible disabilities, especially psychological ones, may be worse as their very existence is challenged through claimsmaking about the character of the individual – a process that does not occur with someone who uses a wheelchair for mobility due to quadriplegia. My research provides further support of such arguments as the women's conditions were often psychologized and they reported more extensive stigmatization than the men, whose conditions were accepted as “real” or having neurobiological etiologies.

Thus, another contribution of this research is that it provides an account of how gendered conceptualizations of the brain are employed as the mind (subjective, feminine) and the body (objective, masculine). Such gendering manifested as the increased psychologization of women’s conditions. This research is particularly germane given the neurological era of chronic traumatic encephalopathy (CTE) and dementia-related diseases. The emergence of CTE and the introduction of *mortality* risk from head injury – further evidence of neurobiological causes of concussion – has had a modest clarifying effect on the public’s understanding of concussion and on effacing hypergendered representations of it. Thus, this research provides further evidence that the authority of a disease is multi-level, occurring at the institutional level, cultural or interactional level, and individual level.

These findings further establish the need to problematize the very concept of invisible disability. In lay discourse, it is a concept being used to unite and propel social movements, but it is not a valueless concept. By deploying it, it furthers the “othering” consequences by reinforcing the notion that because we use the qualifier “invisible,” that then by default, disability is physical with readily apparent visual indicators. While the term may serve its purpose for the time being, its potential risks ought to be considered now to shape the trajectory of a successful politicized collective identity. However, doing so potentially reifies what Gerschick (2000) and other scholars have presented as essentially a hierarchy of disabilities, suggesting that “[t]he type of disability, its visibility, its severity, and whether it is physical or mental in origin mediate the degree to which the body of a person with a disability is socially compromised” (p. 164). Gerschick argues that physical disabilities like “having quadriplegia and using a wheelchair for mobility is highly visible, is perceived to be severe, and frequently elicits invalidation." (2000: 164). Such proponents argue that because they are not readily apparent, invisible disabilities avoid stigma. Thus, this dissertation further develops social models of (invisible) disability.

Furthermore, while this is increasingly being addressed in public advocacy as well as scholarly activity, it is worth mentioning here that disability is relative, and it is also contextual. The same may be said of health. Chronic illness challenges the standard definitions of what it means to be "healthy," and whom for. In this dissertation, I also showed how current binary understandings of health/illness and abled/disabled are insufficient to address the full experience of embodiment. The case of mTBI illustrates how fluid these concepts can be and, consequently, how equally problematic they are because of the rhetorical effects on ideologies and institutional organization. Concussion is the acute condition of mTBI – that is, symptoms resolve, and the patient returns to their state of health pre-injury. Persistent concussive symptoms or post-concussion syndrome (PCS) is established when concussion symptoms do not resolve within about three months. Symptoms may still resolve after that – a month, six months, a year or even five years later – but they may also be chronic. Thus, it is very difficult to identify the exact point within the disease process where patients move from being in recovery (being ill) to having permanent impairments (being disabled). Another way in which mTBI challenges dominant conceptions of illness and disability is that symptoms, and thus impairment, may be episodic.

Additionally, this research contributes to suicidology as I addressed issues related to belongingness (Joiner 2005), connectedness (Klonsky and May 2015), cultural scripts (Canetto 1993; Mueller 2017; Abrutyn et al. 2019), and normative capacity (Gould et al. 2004; Nock et al. 2010; Phillips and Luth 2020). My analysis highlighted the concepts of connectedness and rolelessness, which align with Durkheim's (1951) concepts of integration and regulation, respectively. Integration is typically defined as how many and close ties are within one's social network, and regulation refers to how much attitudes and behaviors are controlled and organized to provide moral and social guidance. The women in this study simultaneously experienced loss or distancing of social ties *and* lost their sense of purpose by losing many of their roles and the activities they had participated in pre-injury. This has significant implications for policy. Scholars argue that collective public projects are more efficacious for reducing suicide than interventions that focus on the individual (Pescosolido 1992; Joiner 2005; Hall and Lamont 2009) because of their power to create sufficient organizational change to effectively insulate against suicide (Pescosolido 1992; Hall and Lamont 2009). While it would be ideal to improve both integration and regulation, as I outlined in "Chapter 5: Navigating a 'New' Normal," there are many barriers to reintegrating post-TBI, including impairments for which we presently lack the medical technology to accommodate. Thus, a more efficient intervention at present would be to improve patients' sense of connectedness and belonging (i.e., integration) since belonging "is so powerful that, when satisfied, it can prevent suicide" (Joiner 2005: 118). The findings of this study underscore the importance of mental health care for mTBI patients to improve prognosis and prevent suicide. With recent quantitative studies finding strong correlations between traumatic brain injury (TBI) and suicide (Madsen et al. 2018; McIntire et al. 2021), the findings presented here offer some texture by revealing information about the processes underlying these trends. None of the men I interviewed discussed suicidality but many of the women did. These findings lend further support of McIntire et al.'s (2021) finding of gendered risk patterns and offers some preliminary findings on differences in symptoms.

This study offers many insights critical to health interventions that may improve prognosis and reduce the burden of disability through policy and programming. Social programming interventions, or community-based prevention, through public programming have been found to have significant positive effects across a variety of health measures (Williams et al. 2008; Committee on Valuing Community-Based, Non-Clinical Prevention Programs and Wellness Strategies). The evidence I presented here provides a strong case for the potential of such impacts on mTBI outcomes, with the greatest needs across genders being financial access to treatment, access to transportation, affordable childcare, and patient care coordinators/advocates to manage patients' treatment plans.

This study also has implications for research funding. I demonstrated how a diagnosis' patient subpopulations can be stratified by moral worthiness based on social characteristics and the disease frame. Kahn Best (2012) identified how disease politics and research funding are tightly coupled, with more stigmatized disease receiving less funding. Disease advocacy shapes funding practices so that policymakers, organizations, and private donors allocate resources based on the perceived worthiness of the patient population rather than objective merits of the research. If women are seen as illegitimate mTBI patients, then funding will be scarce, knowledge discovery will be stymied, and women will continue to have poorer outcomes.

STUDY LIMITATIONS AND FUTURE RESEARCH

This study is not able to capture an important stage where many cases fall out of the observed disease rates: pre-diagnosis. In "Chapter 3: Getting Diagnosed," I suggested where potential patients may be falling out of surveillance in healthcare by identifying the challenges of those who were successfully diagnosed. However, it is not possible to assert with confidence that the negative cases are fully captured here. Prospective studies are needed to understand cases that never get diagnosed and go undetected. This is imperative to understanding the pre-diagnosis and diagnostic processes. Under ideal research circumstances, a study that followed patients from injury for a specified number of months using participant journaling, multiple interviews, or ethnographic field work would provide a better understanding of selection into the patient population, as well as yield richer and more reliable data given that memory can be unreliable years out, especially with a patient population for whom memory issues are common.

Additionally, this research drew on patient reports and the limited extant scholarly research on the culture of concussions to assert a masculinized disease frame. However, this area would benefit from a deeper exploration of the contents and mechanisms of concussion culture through ethnographic research that interrogates the institution of medicine as well as interviews with physicians. Addressing both the illness experience of mTBI at the individual level and how knowledge is produced and practiced in medicine as an institution would yield a more integrated framework of embodiment and epistemology that bridges the lay-science divide. Doing so would provide more details about the interactive process between “lay/alternative knowledge” and “scientific knowledge” (Hess 2004: 699) that could better illuminate how the disease politics of mTBI “get into the brain” to produce disparities.

A more extensive study is needed to offer a fully intersectional analysis that captures greater diversities in race/ethnicity, geography, gender, sexuality, education, socioeconomic status, and parental roles. Despite significant efforts to compose a demographically diverse sample, this research is unable to offer a fully intersectional analysis given its generally homogenous and relatively small sample. I was unable to recruit participants who did not identify within the sex and gender binaries, leaving an important subpopulation unrepresented in a context where gender was the primary frame of analysis. Sexuality may be especially relevant in this area of research because of the salience of gender. Gender (in)congruency between partners may shape gendered beliefs about mTBI, as well as the household division of labor that may make patients' roles substantively different (see Kelly and Hauck 2015). Health research has identified critical disparities in health behaviors and access to health resources by race (see Williams and Sternthal 2010), socioeconomic status (see Pampel, Krueger, and Dennery 2010), and geography (see Meit et al. 2014). While my data suggests some interesting patterns related to socioeconomic status, more data is needed to strengthen these findings.

This study was not sensitive enough to control for the severity of symptoms and impairment within mTBI. Additional research is also needed to evaluate the generalizability of these findings within the broader diagnostic category of TBI to study the relevance of severity (i.e., mild, moderate, and severe) or across etiologies (i.e., traumatic versus non-traumatic). There is some indication in extant literature, such as Dale Stone's (2005) research on hemorrhagic stroke among young women, that these findings may hold true within non-traumatic acquired brain injuries as well. Future research would also benefit from purposively sampling specific TBI subpopulations such as athletes, active military members and veterans, domestic violence survivors, and the elderly. This would offer the opportunity to test the legitimacy deficit in different subcultures and at different stages of the life course. Similarly, another limitation of this study is that these findings are based on self-reports that occurred at varied stages in the disease process. Because my interviews occurred at varied stages within the recovery process, a longitudinal study would better capture disease course-sensitive and life course-specific dynamics.

Finally, based on the interview data from this study and findings in extant research, there are important connections between TBI and substance (ab)use and TBI and mental health that ought to be qualitatively investigated to better understand process. While I addressed the salience of such concerns amongst my participants in this study, I lacked sufficient data to explore these themes fully. For example, I did not explicitly ask participants about suicidality, so it is important that future research addresses suicidality explicitly. These are important issues that warrant independent research dedicated to fully extrapolating the social forces that contribute to the decline of mental health and uptake of substance use amongst TBI patients.

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APPENDIX A

INTERVIEW GUIDE

I. Demographics
    A. In what month and year were you born?
    B. What gender do you identify with?
    C. What is your race/ethnicity?
    D. What is your highest level of education?
    E. Where would you place yourself in social class? If it helps, you can think of a ladder, where would you place yourself on a 10-rung ladder in terms of your socioeconomic standing?
    F. What is your marital status?
    G. Do you have any dependent children?
II. Medical Hx
    A. Date of trauma(s)
    B. Diagnosis
    C. Prognosis
    D. Are you seeing any health professionals being seen for treatments relating to your brain injury?
III. Did you have insurance at the time of injury? Have you had injury during any part of the treatment or recovery process?
IV. What did a typical day look like for you before your concussion? After the injury?
V. At the time of the trauma, were you working outside the home?
    A. If yes, what was your occupation?
    B. Have you continued to work at the same capacity?
        1.If no, how has your work changed?
    C. Are you working now?
        1.If yes, to what extent compared with your work at the time of the trauma?
VI. What is your household like?
VII. Can you tell me about your social support network?
VIII. How many usable hours on average per day would you say you have?
    A. What do you spend this time doing?
    B. What have you noticed makes your symptoms better or worse? (e.g. baby crying, thinking about financial stress, etc.)
IX. How did your concussion happen? If you've had more than one, please tell me about the most recent injury.
X. What was the most challenging for you post-injury?
XI. What were you most surprised by post-injury?
XII. What was the most beneficial post-injury?
XIII. What has your treatment been like? (regimen, professionals, access – finding and financial)
XIV. Can you tell me about your recovery process?
    A. What were your symptoms like immediately following the trauma? And now?
    B. What impairments have you experienced?

        1. Have you had any formal or professional evaluations of the impact of the trauma?
    C. From 0-100%, where do you think you are now with your recovery?
    D. What have been the greatest barriers in your recovery process?
    E. What has been the most helpful in your recovery process?
    F. What did you worry about during your recovery?
    G. What did you miss as a result of your brain injury?
    H. What do you appreciate about your recovery experience?

XV. Where do you see yourself in five years?

XVI. What advice would you offer to someone just starting their recovery process?

XVII. Do you feel that your treatment or recovery has been affected by anything other than your biology or physiology? Such as gender, religion, race/ethnicity, sexuality, wealth, employment, residential area/geography…

XVIII. Is there anything else that is important for me to know about your experience with brain injury?

APPENDIX B

PARTICIPANT DEMOGRAPHICS

Pseudonym	**Age**	**Years Passed**	**Gender**	**Race/Ethnicity**	**Socioeconomic Status**	**Educational Attainment**	**Marital Status**	**Dependents**	**Cause**	**Region**
Piper	44	6	Woman	White	Middle	Graduate or Professional Degree	Married	No	Vehicle-related collisions	West
Sheryl	51	2	Woman	White	Lower Middle	High School Graduate	Single	Yes	Vehicle-related collisions	South
Felicity	35	1	Woman	White	Middle	Bachelor's Degree	Married	Yes	Fall	West
Phoebe	51	5	Woman	White	Middle	Graduate or Professional Degree	Single	No	Vehicle-related collisions	West
Serena	60	4	Woman	White	Middle	Graduate or Professional Degree	Married	No	Vehicle-related collisions	West
Emma	38	3	Woman	White	Middle	Graduate or Professional Degree	Married	Yes	Fall	West
Lisa	47	3	Woman	White	Poor	Bachelor's Degree	Single	No	Violence	West
Hannah	53	2	Woman	White	Middle	High School Graduate	Single	No	Fall	West
Avery	56	20	Woman	White	Upper Middle	Bachelor's Degree	Married	Yes	Vehicle-related collisions	Northeast
Harper	23	5	Woman	White	Upper Middle	High School Graduate	Single	No	Vehicle-related collisions	Northeast
Maya	32	9	Woman	White	Middle	Graduate or Professional Degree	Single	No	Fall	West
Margo	58	28	Woman	White	Middle	Graduate or Professional Degree	Married	Yes	Violence	West
Natalie	67	8	Woman	White	Upper Middle	Bachelor's Degree	Married	No	Vehicle-related collisions	South
Eliza	64	1	Woman	White	Middle	Graduate or Professional Degree	Married	No	Fall	West
Alice	53	2	Woman	White	Middle	Graduate or Professional Degree	Married	No	Violence	West
Sadie	38	8	Woman	White	Lower Middle	Graduate or Professional Degree	Married	Yes	Vehicle-related collisions	South
Iris	20	3	Woman	White	Middle	High School Graduate	Single	No	Fall	Canada
Evelyn	34	4	Woman	White	Middle	Graduate or Professional Degree	Married	No	Combat injuries	Midwest
Lorelei	41	5	Woman	White	Middle	Bachelor's Degree	Single	No	Vehicle-related collisions	West
Gabriella	39	6	Woman	Hispanic	Poor	Bachelor's Degree	Married	Yes	Vehicle-related collisions	West
Lydia	47	9	Woman	White	Upper Middle	Bachelor's Degree	Married	Yes	Sports injuries	West

Stella	49	10	Woman	White	Middle	High School Graduate	Married	Yes	Fall	West
Chloe	39	9	Woman	White	Poor	High School Graduate	Single	No	Violence	South
Clara	27	1	Woman	White	Upper Middle	High School Graduate	Married	No	Sports injuries	Midwest
Audrey	41	5	Woman	White	Working	Bachelor's Degree	Single	No	Vehicle-related collisions	Northeast
Naomi	60	7	Woman	White	Middle	High School Graduate	Married	No	Vehicle-related collisions	South
Ivy	65	2	Woman	Hispanic	Upper Middle	Graduate or Professional Degree	Married	No	Fall	South
Abigail	71	7	Woman	White	Middle	High School Graduate	Divorced	No	Fall	South
Maeve	35	2	Woman	White	Middle	Bachelor's Degree	Single	No	Sports injuries	South
Charlotte	43	26	Woman	Native American	Upper	Graduate or Professional Degree	Married	Yes	Violence	South
Nora	32	13	Woman	White	Working	High School Graduate	Divorced	Yes	Fall	West
Camila	62	5	Woman	Hispanic	Poor	Graduate or Professional Degree	Single	No	Vehicle-related collisions	West
Gianna	37	21	Woman	White	Poor	Less than High School	Single	Yes	Fall	Midwest
Scarlett	58	2	Woman	White	Upper Middle	High School Graduate	Married	No	Vehicle-related collisions	Midwest
Layla	27	4	Woman	White	Working	Bachelor's Degree	Single	No	Vehicle-related collisions	West
Madison	39	13	Woman	White	Middle	Bachelor's Degree	Married	Yes	Vehicle-related collisions	West
Aurora	46	2	Woman	White	Middle	Bachelor's Degree	Married	Yes	Vehicle-related collisions	Canada
Violet	31	4	Woman	White	Poor	Bachelor's Degree	Single	Yes	Vehicle-related collisions	West
Owen	61	22	Man	White	Middle	High School Graduate	Married	Yes	Vehicle-related collisions	West
Declan	30	11	Man	White	Middle	High School Graduate	Married	No	Combat injuries	West
Theo	21	6	Man	White	Middle	High School Graduate	Single	No	Sports injuries	Canda
Caleb	53	33	Man	White	Middle	High School Graduate	Married	Yes	Combat injuries	West
Ben	43	4	Man	White	Poor	High School Graduate	Single	Yes	Fall	West
Alex	41	1	Man	African American	Middle	High School Graduate	Married	Yes	Fall	Midwest
Ethan	31	2	Man	White	Poor	High School Graduate	Married	Yes	Sports injuries	West
Levi	53	9	Man	White	Middle	Bachelor's Degree	Married	No	Vehicle-related collisions	West
Elliot	43	25	Man	White	Middle	Graduate or Professional Degree	Married	Yes	Vehicle-related collisions	Northeast
William	62	3	Man	White	Upper	Graduate or Professional Degree	Married	No	Fall	West

Gabe	37	19	Man	White	Middle	Bachelor's Degree	Single	No	Vehicle-related collisions	Midwest
Luke	64	2	Man	Native American	Middle	High School Graduate	Married	No	Fall	West
Jack	63	19	Man	White	Middle	Bachelor's Degree	Married	Yes	Fall	West
Bennett	61	13	Man	White	Middle	Bachelor's Degree	Married	No	Vehicle-related collisions	West

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