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Examining Health Disparities in a Community-Based Sample of Children with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Symptomatology

A Thesis

Presented in

Partial Fulfillment of the

Requirements for the Degree of

Master of Arts

By

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Department of Psychology

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Biography

The author was born in Coral Springs, Florida in June 1997. Chelsea graduated from Coral Springs Christian Academy in 2015. She received her Bachelor of Arts from Florida Gulf Coast University in 2018. Chelsea began the Clinical-Community MA/PhD program at DePaul University in 2018.

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Abstract

Previous literature examining overall health outcomes and outcomes specifically related to adults with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) have found disparities based on sociodemographic characteristics including race/ethnicity, gender, and socioeconomic status. There is currently little information known regarding demographic disparities in health outcomes for youth with ME/CFS symptomatology, though a recent prevalence study found Black and Latinx youth as well as females have higher rates of ME/CFS than White youth and males, respectively. The current study examined 137 youth who screened positive for ME/CFS symptomatology. Multiple linear regressions assessing demographic predictors on fatigue severity, number of symptoms endorsed, and overall physical functioning found females had worse outcomes associated with ME/CFS across all outcome variables and Latinx and Black youth had less fatigue severity compared to White youth. Results provide support for the need to target female youth in future diagnostic and treatment considerations for ME/CFS. Further examination is needed to understand the role of race/ethnicity and socioeconomic status in illness severity for ME/CFS symptomatology in youth.

Keywords: myalgic encephalomyelitis, chronic fatigue syndrome, pediatrics, health disparities

Introduction

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is characterized as a debilitating chronic illness involving extended durations of fatigue as well as symptoms related to pain, sleep, neurocognitive abilities, immune and neuroendocrine functioning, and post-exertional malaise (Fukuda et al., 1994; IOM, 2015; Jason et al., 2006; Reeves et al., 2003). Specifically in pediatric populations, ME/CFS has been found to cause impairments in various domains of life including physical functioning, school achievement, and involvement in activities outside of school such as sports (Josev et al., 2017; Kennedy et al., 2010; Torres-Harding et al., 2006; Walford et al., 1993). Additionally, ME/CFS has been found to significantly debilitate children and adolescents, as only about 14% of those with the illness were able to attend school consistently in a study conducted by Krilov and colleagues (1998). Research has also shown many adolescents diagnosed with ME/CFS will continue to experience symptoms related to the illness and not return to pre-illness levels of functioning over time (Brown et al., 2012).

This evidence suggests ME/CFS in younger populations can cause significant issues in functioning across multiple life domains, and there is a strong need to better understand the disparities and risk factors associated with the illness in this population. Unfortunately, there are few studies addressing the symptomatology and prevalence of ME/CFS in diverse pediatric populations. Many epidemiological studies assessing prevalence and symptom severity rely on participants from tertiary care settings, which excludes those who may not have consistent access to care (Dobbins et al., 1997; Gunn et al., 1993; Lloyd et al., 1990). Therefore, these studies are biased in recruitment methodology and may not provide an accurate picture of those who are most at risk to be diagnosed with the illness. It is important to take into account the disparities

found in health care and diagnosis as well as to use a demographically diverse sample to better understand the presentation of ME/CFS in children and adolescents.

Health Disparities and Access to Care

Due to the debilitating nature of ME/CFS for pediatric populations, it is vital to understand potential risk factors for the illness to better target prevention, diagnosis, and treatment strategies. Understanding the roles health disparities and access to care play in the severity of ME/CFS symptomatology in certain populations is an important first step needed to be taken within the field. Health disparities are differences in health outcomes in which those belonging to disadvantaged groups defined by race, ethnicity, social class, gender, and disability experience worse health than those of more privileged status (Braveman & Barclay, 2009). These health disparities extend past the individual level and may be the result of systemic inequalities surrounding certain individuals' ability to access and utilize medical care on a regular basis. By understanding the impact of race/ethnicity, socioeconomic status, and gender on illness severity for pediatric populations, future research regarding diagnosis and treatment can be specifically tailored for those found to be most at risk.

Race/Ethnicity. Research has shown disparities in the prevalence of illnesses, access to care, and health outcomes for racial/ethnic minority children and adults (Nelson, 2002). A study by Newacheck and colleagues (2002) found children of racial/ethnic minority status with significant health care needs were more likely than White children to not have health insurance, not have access to a regular care source, and not be able to get medical care when needed. Additionally, Latinx and Black children were found to be less likely to be in good health when compared to White children, and these minority children and their parents were more likely to

report dissatisfaction with health care services due to not feeling heard by physicians and receiving referrals to specialists when needed (Flores et al., 2005).

Further, Latinx individuals endorse higher rates of developing diabetes and certain cancers and experiencing job-related injuries, and also report higher mortality rates for HIV, all of which are influenced by lack of access to adequate health care and education (Vega, et al., 2009). Latinx children and adolescents also have the highest rates of obesity (National Center for Health Statistics, 2016). These disparities in prevalence of illnesses are also mirrored in Black populations. For Black individuals, research has shown higher rates of cancer, diabetes, and heart disease when compared to White counterparts (Copeland, 2005; Peek et al., 2007; Singh & Jemal, 2017). Black individuals also have the highest rates of infant mortality and premature births (National Center for Health Statistics, 2016). In regards to access to care, issues regarding stigma associated with fears surrounding prejudice and discrimination have been examined as another barrier for access to care, especially for ethnic minority individuals and accessing mental health care (Gary, 2005). Taken together, this body of research suggests race/ethnicity may be a risk factor for the prevalence of illness and access to care and should be further examined in the context of ME/CFS.

Socioeconomic Status. In conjunction with differences in race/ethnicity, family income and parental education have also been found to associated with health disparities (Braveman, et al., 2001; Dubay & Lebrun, 2012). Adolescents from low-income families were found to have worse health outcomes and access to care than those of middle or high income families (Newacheck et al., 2003). Additionally, a study examining potential for chronic infection in children found children with lower household income and parental education had a higher likelihood of infection (Dowd et al., 2009). Asthma prevalence was found to be highest for Black

children of low-income status and low-income White children also had significant rates of asthma when compared to higher income counterparts (Akinbami et al., 2002). Mortality and incidence rates for cancer were also found to be higher for individuals with low income and lower educational status (Singh & Jemal, 2017). When considering parental education, a study by Chen and colleagues (2006) found there were worse outcomes in terms of overall health and physical activity for children whose parents had lower levels of education, especially for White and Black children.

It is important to note Latinx and Black individuals have been found more likely to be lower income and have lower levels of educational attainment than White individuals, further increasing the risk for health disparities based on socioeconomic status in tandem with racial/ethnic minority status (Kocchar & Cilluffo, 2018; Ryan & Bauman, 2016). Latinx and Black individuals are also more likely to live in unsafe neighborhoods and die by homicide, suggesting environmental factors associated with lower income status may also contribute to disparities in health outcomes (Copeland, 2005; Vega et al., 2009).

Gender. Health disparities have also been found among male and female children, although research is mixed. For males, one study found Black males had the highest risk for strokes, and overall, males had higher rates of fatality for ischemic strokes when compared with females (Fullerton et al., 2003). Additionally, in a study examining childhood chronic illness, males were found to be at higher risk for behavioral problems than females (Gortmaker et al., 1990). A recent review of gender disparities across a variety of domains of health found higher prevalence rates of obesity, autism spectrum disorder, and asthma for males when compared to females (Piccini et al., 2018). For females, this review found higher prevalence for rheumatic diseases and chronic pain conditions when compared to males (Piccini et al., 2018).

Additionally, in a study looking at children with end-stage renal disease (ESRD), female children were 14% less likely to be put on an organ transplant wait list than male children, leading to decreased chance for favorable outcomes related to the disease (Garg et al., 2000). A study by Thomas and colleagues (2011) also found female adolescents were more likely to screen positive for depression than males. There is significantly less research currently on health disparities related to gender for pediatric populations and further research is needed to provide clarity in this area regarding where disparities between males and females occur, especially within the area of chronic illness.

Prevalence and Health Disparities in ME/CFS Literature

Pediatric Prevalence. It is important to understand the occurrence of ME/CFS in pediatric populations in order to best assess where disparities in symptomatology, prevalence, and access to care reside. While there have been numerous prevalence studies conducted to determine ME/CFS in youth populations, the methodology of many of these studies excludes whose who cannot or do not access regular medical care (Gunn et al., 1993; Dobbins et al., 1997; Lloyd et al., 1990) or did not include a medical evaluation, which can negatively impact diagnosis rates of the illness (Nijhof et al., 2011; Bakken et al., 2014; Collin et al., 2016). These studies recruited participants through physician referral which meant the youth had to have already accessed care to be included. Two subsequent studies utilized community-based recruitment methods. The first involved random digit dialing to households in San Francisco, California and found a prevalence rate of 116.4 per 100,000 for ME/CFS-like conditions for adolescents between the ages of 12 and 17 (Dobbins et al., 1997). The second community-based study involved random digit dialing in Wichita, Kansas and reported a prevalence rate of 338 per 100,000 for ME/CFS-like illness in youth (Jones et al., 2004). A limitation across both studies

was there was not a medical evaluation included within the study so actual ME/CFS diagnosis prevalence was not calculated and only the prevalence of ME/CFS-like illness was found. Other prevalence studies including one based in Norway (Bakken et al., 2014) and one in the Netherlands (Nijhof et al., 2011) found pediatric ME/CFS rates of 43 per 100,000 and 111 per 100,000 respectively and neither included a medical examination. A study based in Great Britain found prevalence of 1,900 per 100,000 for 16-year-olds but also did not include a medical examination, again yielding non-definitive results (Collin et al., 2016). In comparison, Jordan and colleagues (2000) incorporated a medical examination in their methodology and found a prevalence rate of 60 per 100,000. However, a significant amount of time elapsed between the initial phone screen and physician examination, which may have impacted the results.

A recent prevalence study with a community-based sample in the Chicagoland area, in which data for the current study were derived, was conducted involving both self-report measures and a medical and psychiatric interview (Jason et al., 2020). Results found the prevalence rate to be 750 per 100,000 for children ages 5-17 and 95% of these youth had not been previously diagnosed with ME/CFS. While this study has more fully encompassed those who may have the illness, the current review of the literature shows prevalence rates for pediatric ME/CFS have widely varied across studies with rates ranging from 2.7 to 1,900 per 100,000 (Lloyd et al., 1990; Gunn et al., 1993; Dobbins et al., 1997; Chalder et al., 2003; Farmer et al., 2004; Jones et al., 2004; Jordan et al., 2006; Rimes et al., 2007; Nijhof et al., 2011; Bakken et al., 2014; Collin et al., 2016). This history of ambiguity in findings suggests less is known about the prevalence and subsequent presentation of the illness in pediatric populations which further supports the need to examine the disparities in prevalence and symptomatology for a diverse, community-based sample.

ME/CFS Disparities. A majority of the aforementioned studies above failed to report on prevalence rates or sample sizes for individual racial/ethnic groups or specific ages (i.e., child versus adolescent) and instead reported aggregated overall prevalence rates. A few studies did report specific rates based on gender (Lloyd et al., 1990; Jordan et al., 2006; Bakken et al., 2014, Jason et al., 2020), and found females to have higher rates of ME/CFS when compared to males. A majority of the studies only included adolescent samples, with the Jason and colleagues (2020) study being the only one to report rates for children as young as seven; results reported prevalence rates to be highest for older adolescents.

The Jason and colleagues' study (2020) and a study by Jordan and colleagues (2000) were the only pediatric studies to report prevalence rates based on race/ethnicity and found Latinx and Black youth to have higher prevalence rates when compared to White youth. Additionally, the Jason and colleagues (2020) study found female participants and adolescents to have higher prevalence rates as compared to males and younger children. Of note, both of these studies were community-based and not tertiary care referrals, reducing barriers to access to care. While the data is scarce in terms of reporting prevalence of ME/CFS for specific sociodemographic categories, there are indications from the two above mentioned studies that the highest occurrence of ME/CFS is seen for racial/ethnic minority individuals, females, and adolescents. Additionally, no studies of differences in symptomatology or fatigue severity were found in the literature based on sociodemographic groupings for youth with ME/CFS symptomatology.

Expanding the examination of sociodemographic differences in prevalence and symptomatology is important to better understand ME/CFS across diverse populations. A prevalence study conducted with an adult community-based sample found Latinx individuals

endorsed the highest prevalence rates across all racial/ethnic groups and females reported the highest rates in terms of gender (Jason et al., 1999). Additionally, this study found fatigue severity scores for both Latinx and Black participants were higher than White participants and there was a significant interaction between ethnicity and socioeconomic status on fatigue severity for this sample, suggesting a compounding effect of disparities (Song et al., 1999; Jason et. al., 2000). A meta-analysis also found Black and Native American individuals had a higher likelihood for CFS and minorities with chronic fatigue reported greater symptom severity (Dinos et al., 2009). A study examining chronic fatigue and sociodemographic correlates found those with lower reported socioeconomic status as well as females and those with a psychological diagnosis had increased risk for CFS (Hickle et al., 1996). In regards to access to care, one study found access to an ME/CFS specialist was significantly lower for participants with lower household incomes and financial barriers were one of the most commonly cited reasons for a lack of access to care for individuals with ME/CFS (Sunnquist et al., 2017).

Some hypotheses have been offered regarding why racial/ethnic minority groups and those with lower socioeconomic status report more severe fatigue and have higher prevalence rates of fatigue. Possible explanations include the risk for poorer overall health status for minority groups due to lack of access to adequate medical care, stress due to outside social factors, and hazardous work experiences and living environments (Jason et al., 2000; Dinos et al., 2009). Additionally, one study posits that increased pressure to take care of one's family due to cultural ideals and stress due to acculturation processes of Latinx populations may also account for increased risk for fatigue and higher fatigue severity (Song et al., 1999). The current study seeks to examine whether the findings reported in adult populations are similar for children in regard to ME/CFS symptomatology and fatigue severity in order to inform understanding of

where health disparities lie and how this may impact affected populations in regards to illness presentation and diagnosis.

Outcomes Related to ME/CFS

Cardinal domains impacted by ME/CFS for pediatric populations include fatigue, sleep, pain, neurocognitive abilities, and immune and neuroendocrine functioning (Jason et al., 2006). Youth with ME/CFS also experience symptoms such as rashes and abdominal pain, a distinct difference compared to adult populations (Jason et al., 2006). Fatigue and other debilitating symptoms can lead to a decrease in physical functioning, with many children with the illness having to take extended leaves from school, being dependent on wheelchairs, or unable to leave the house (Dowsett & Colby, 1997; Rowe et al., 2017). Since ME/CFS can have substantial impacts on functioning due to symptom severity, it is important to examine how severe symptomatology is based on measures such as fatigue severity, quantity of severe symptoms reported, and overall physical functioning, which can be used to understand the impact of the illness in various life domains on youth.

Additionally, there is a lack of consensus regarding a universal case definition for ME/CFS diagnosis in the field. Prominent case definitions used currently for children and adults include the Fukuda (1994) Criteria, the IOM (2015) criteria, and the Pediatric Criteria (Jason et al., 2006). Due to this lack of consistency regarding diagnosis of the illness, it is important to examine how certain demographic variables such as gender, race/ethnicity, and socioeconomic status can influence the likelihood of receiving a diagnosis of ME/CFS across case definitions. Understanding the influence of sociodemographic variables can help to inform future diagnostic processes by illuminating whether certain groups receive diagnoses regardless of how severe their symptomatology is.

Theory: Life-Course Perspective

Previous research on broad health outcomes has revealed ethnic/racial minorities, females, and those with lower socioeconomic status are more at risk for developing a variety of illnesses, including ME/CFS, and having worse outcomes associated with these illnesses. One theory regarding health disparities, the life-course perspective, has provided an understanding for why these differences occur for historically disadvantaged groups (Arcaya et al., 2015; Braveman & Barclay, 2009).

This framework promotes the need to examine multiple life stages and also account for social context when attempting to understand health disparities. Specifically, the life-course perspective acknowledges differences related to social group membership based on race, gender, and socioeconomic status can have an impact on health outcomes beginning in early childhood that may not be reversible even if the individual experiences subsequent positive life events throughout the rest of their lifespan (Braveman & Barclay, 2009). Additionally, even secondhand factors, such as parental education or occupation, can have an impact on health outcomes due to potential for limited social mobility, exposure to violence or hunger, and lack of access to care.

The incorporation of sociodemographic characteristics that impact early childhood experience and potential for exposure to a variety of variables within this framework is useful for examining sociodemographic presentations of ME/CFS symptomatology in pediatric populations as well. Using this framework to examine causes of health disparities of disadvantaged populations as well as previous literature surrounding those with ME/CFS that points to disparities in ME/CFS health outcomes depending on sociodemographic grouping has shaped this study's hypotheses described below.

Rationale

There is no previous research related to symptomatology, fatigue severity and duration, overall physical functioning, and likelihood of an ME/CFS diagnosis for pediatric ME/CFS-like populations that is broken down using sociodemographic categories involving race/ethnicity, socioeconomic status, and gender. Understanding the differences in reports within these domains is essential when working to address health disparities and access to care through intervention and diagnostic strategies. In order to properly address disparities, we have to know where they are prevalent and at what level intervention is needed (i.e., is socioeconomic status more predictive of ME/CFS symptomatology than race/ethnicity, etc.).

The present study seeks to address this gap in the literature by examining the relationship between sociodemographic variables (i.e., race/ethnicity, gender, socioeconomic status) and illness severity through measures of physical functioning, fatigue severity, and frequency of symptoms. A similar examination was conducted using an adult sample and results were used to hypothesize casual mechanisms of disparities and intervention focal points (Jason et al., 2000). Additionally, another study examining an adult sample found interactions in which racial/ethnic minority status and lower socioeconomic status further increased disparities in fatigue severity (Song et al., 1999). Thus, an investigation is imperative for pediatric ME/CFS populations, and the ability to do this is possible with the economically and racially diverse sample utilized in this study. Understanding specific presentations of ME/CFS symptomatology based on sociodemographic variables and their interactions is the first step in developing tailored strategies to help manage and properly diagnose this illness in children and adolescents, which historically has been limited.

Statement of Hypotheses

Hypothesis I. Black and Latinx children with ME/CFS symptomatology will have worse outcomes associated with ME/CFS (i.e., fatigue severity, number of reported symptoms, decreased overall physical functioning, and likelihood of an ME/CFS diagnosis) than White children with ME/CFS symptomatology.

Hypothesis II. Children with ME/CFS symptomatology with lower household income and lower parental educational attainment (some college or lower) will have worse outcomes associated with ME/CFS (i.e., fatigue severity, number of reported symptoms, decreased overall physical functioning, and likelihood of an ME/CFS diagnosis) than children with ME/CFS symptomatology having higher household income and higher parental educational attainment (completed a college degree or higher).

Hypothesis III. Female children with ME/CFS symptomatology will have worse outcomes associated with ME/CFS (i.e., fatigue severity, number of reported symptoms, decreased overall physical functioning, and likelihood of an ME/CFS diagnosis) than male children with ME/CFS symptomatology.

Hypothesis IV. Children with ME/CFS symptomatology who are members of multiple disadvantaged groups (i.e., gender, race, SES) will have worse outcomes related to ME/CFS (i.e., fatigue severity, number of reported symptoms, decreased overall physical functioning, and likelihood of an ME/CFS diagnosis) than those with ME/CFS symptomatology belonging to only one disadvantaged group. Specifically, outcomes will be worse for individuals with lower socioeconomic status especially for Black and Latinx participants.

Method

Participants

Participants were taken from a community-based sample which was diverse across race/ethnicity, gender, and SES, as this was a community-based sample. Participants screened positive for ME/CFS-like symptomatology during an initial screener and 165 youth ages 6-17 were originally included in the current study. After accounting for incomplete demographic data and outliers, a final sample of 137 youth was examined.

Recruitment. Participants for this study were recruited as part of a larger study of the prevalence of pediatric chronic fatigue syndrome (Jason et al., 2020). Phase one of the study involved calling 147,954 households in the Chicagoland area to administer a fatigue screener for youth ages 5-17 within each household. 5,622 households answered the phone and were willing to participate in the screener, resulting in 10,119 screened children and adolescents. To screen positive for ME/CFS symptomatology, parents who completed the screener had to endorse their child had fatigue at a moderate or greater severity and occurring at the least half of the time, at least one symptom related to school performance, and at least four other symptoms characteristic of ME/CFS as measured using the *Pediatric ME/CFS Screening Questionnaire* (Jason & Sunnquist, 2018). Additionally, any youth who had an explanatory reason for fatigue such as illness or intense physical activity were excluded from subsequent stages of the study. Screen positive participants from stage one were invited to participate in stage two of the study. Asymptomatic participants from screen one who were demographically similar based on age, gender, and race/ethnicity were invited to stage two as controls. For the present study, only those who screened positive for ME/CFS-like symptomatology (*N*=165*)* and participated in stage two of the study were included. See **Figure 1** for a flowchart of the complete epidemiological study.

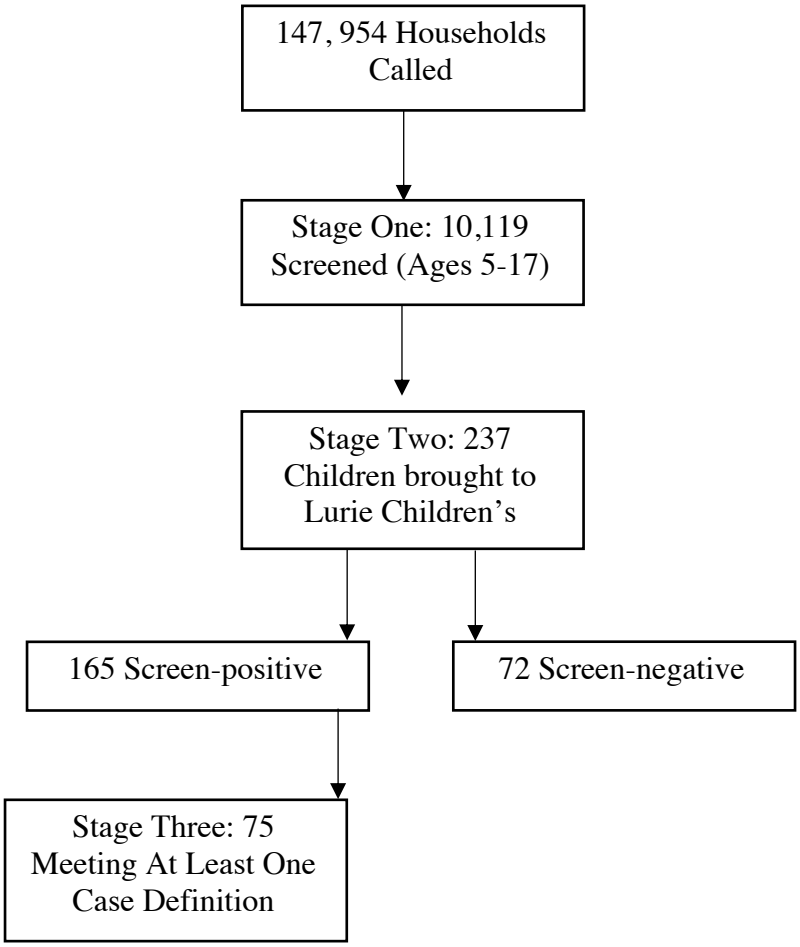

Figure 1. Methodology of Jason et al. (2020) study of pediatric ME/CFS

Materials

Demographics. Parents were asked to complete questions regarding their race, gender, household income, marital status, educational status, household size, and religious affiliation as well as age, gender, race, and educational information regarding their child. Youth were asked to complete questions regarding age, gender, race, education, household size, and religious affiliation.

DePaul Pediatric Symptom Questionnaire (DPSQ). The DPSQ is a measure administered to both parent and youth separately that assesses ME/CFS symptoms and illness

duration/history (Jason & Sunnquist, 2018). For the present study, the child responses were used to maintain consistency across measures. The DPSQ incorporates symptomatology from various case definitions, including the Fukuda et al. CFS criteria (1994), Canadian Clinical Criteria (Carruthers et al., 2003), and Institute of Medicine (IOM, 2015) criteria. The original questionnaire, the DePaul Symptom Questionnaire (DSQ), has been adapted for use with pediatric samples and has shown accurate case definition fulfillment with this population (Jason et al., 2006; Jason et al., 2009; Jason & Sunnquist, 2018).

Respondents were asked to rate the frequency of each of the 49 symptoms listed over the past three months on a Likert scale with 0 = "none of the time," 1 = "a little of the time," 2 = "about half the time," 3 = "most of the time," and 4 = "all of the time." Respondents were also asked to rate the severity of each symptom listed over the past three months on a Likert scale with 0 = "symptom not present," 1 = "mild," 2 = "moderate," 3 = "severe," 4 = "very severe." The frequency and severity score for each symptom was then multiplied by 25, creating 100-point scales. The 100-point score for both frequency and severity was then averaged, creating a final composite score for each symptom. Lastly, respondents were asked to report how many total months they had experienced fatigue and this information was used to determine fatigue duration for fulfilling case definition criteria.

In terms of psychometric properties in adult samples, the DSQ has demonstrated good test-retest reliability for those with ME/CFS and control groups, $\alpha > .70$ for a majority of items, (Jason et al., 2015; Jason & Sunnquist, 2018) and was found to have excellent internal reliability, $\alpha = 0.89\text{-}.96$, while also accurately differentiating between those with ME/CFS and controls (Murdock et al., 2016; Jason & Sunnquist, 2018). Research is currently being conducted to examine psychometric properties for the DPSQ in pediatric populations. For the current sample,

internal consistency was α =.93. For this study, only symptoms reported to be at a threshold level of occurring at least half of the time and of moderate or greater severity were used for analyses regarding number of symptoms reported by the youth.

Child Health Questionnaire (CHQ). The CHQ is a measure completed by the parent and child separately that examines overall physical and psychosocial well-being for the child (Landgraf et al., 1996). The child form (CHQ-CH87) is an 87-item measure and the parent form (CHQ-PF50) is a 50-item measure. Both versions include scales assessing physical functioning, role/social (behavioral, emotional, physical), general health perceptions, bodily pain, and self-esteem. Two additional scales are found on the parent version, "Parent Impact- Emotional" and "Parent Impact-Time". The CHQ has demonstrated good internal consistency, with Cronbach's alphas averaging .72 across indices, and acceptable validity (Raat et al., 2002). The CHQ was also found to discriminate children with clinical conditions from controls, thus being found to have excellent discriminant validity (Landgraf et al., 1996; Raat et al., 2002). For this study, the domain assessing physical functioning was used for analyses as reported by the youth. Higher scores on this domain indicate better physical functioning. For the current sample, internal consistency was α=.85 on the physical functioning domain.

Fatigue Severity Scale (FSS). This self-report scale (Krupp et al., 1989) was administered to children or adolescents and includes 9 statements about fatigue that are rated on 7-point scales: 1 = "Strong disagree," 4 = "Neither agree nor disagree," and 7 = "Strongly agree." Ratings are sensitive to different degrees of fatigue severity. Higher scores on the scale indicate more fatigue for the respondent. The FSS has been found to accurately discriminate between those with ME/CFS, multiple sclerosis, and depression (Pepper et al., 1993). Internal consistency was found to be high for this scale with chronic illnesses, α = .88 (Krupp et al.,

1989) and test-retest reliability was adequate in a sample experiencing chronic pain, ICC = .95 (Takasaki & Treleaven, 2013). The scale was found to differentiate individuals with ME/CFS from controls (Jason et al., 2011). This scale was used to measure overall fatigue severity as reported by the youth and internal consistency for this sample was α=.92.

Case Definitions

Fukuda et al. (1994) criteria. Diagnosis based on this criteria requires relapsing or persistent fatigue for at least six concurrent months and at least four of eight somatic symptoms (cognitive impairment, sore throat, tender lymph nodes, muscle pain, joint pain, headaches, unrefreshing sleep, and post-exertional malaise) that did not begin before the onset of the fatigue. Substantial reduction in functioning is also required and fulfillment of this criteria is assessed through subscales of the CHQ parent and child forms. An example item measuring substantial reduction is "During the past 4 weeks, has it been difficult for you to get around your school, neighborhood, or playground due to health problems?" As defined by Reeves (2003), the child or adolescent could also not have any exclusionary medical or psychiatric conditions such as depression with melancholic features, obesity, or narcolepsy.

Pediatric criteria (Jason et al., 2006). The pediatric criteria was shaped by and adapted for pediatric populations based on the Canadian Clinical Criteria (Carruthers et al., 2003). This case definition requires unexplained or persistent fatigue that is not alleviated with rest and not the result of exertion. Substantial reduction in functioning is required and was measured using questions from the CHQ. Symptoms related to post-exertional malaise, unrefreshing sleep, pain, and neurocognitive difficulties are needed to meet criteria and will be assessed using the DPSQ. Additionally, at least one symptom from at least two of the following categories is required: autonomic, neuroendocrine, or immune. The pediatric criteria has been used with multiple

investigations including one that differentiated severe versus moderate symptomatology (Jason et al., 2009), one that compared diagnoses using the pediatric criteria and Fukuda (1994) criteria and found the pediatric criteria led to less misdiagnosis (Jason et al., 2010), and one that found 21 adolescents with ME/CFS, who had longer time in bed and sleep time, and poorer sleep quality than controls (Josev et al., 2017). While this criteria typically requires three concurrent months of fatigue to meet case definition criteria, a threshold of six months of fatigue was used for this sample to maintain consistency across the three case definitions used. Participants could not have any exclusionary medical or psychiatric conditions in order to meet this criteria.

IOM (2015) criteria. The IOM criteria requires six or more months of concurrent fatigue that is not lifelong, alleviated by rest, or the result of ongoing exertion. Substantial reduction in functioning is required and was assessed using the CHQ. Symptoms associated with post-exertional malaise (i.e., soreness after mild activity, dead/heavy feeling after exercise) and unrefreshing sleep (i.e., need to nap daily, problems failing or staying asleep) must also be present and was measured using symptoms on the DPSQ. Those who meet IOM criteria for ME/CFS must also have symptoms related to at least one of the two following: cognitive impairment (i.e., difficulty paying attention, difficulty finding the right word) or orthostatic intolerance (i.e., dizziness).

Procedure

The study procedures referenced were all approved by the Institutional Review Board of DePaul University. Participants attended a medical appointment at a children's outpatient health center conducted by a pediatrician with expertise involving ME/CFS. The appointment involved a standard physical, a psychiatric interview, and collection of blood, saliva, and urine.

Prior to being seen by the medical doctor, participants and their parents were given consent/assent forms and completed the DePaul Pediatric Symptom Questionnaire (DPSQ; Jason & Sunnquist, 2018), the Fatigue Severity Scale (FSS; Krupp et al., 1989), and the Child Health Questionnaire (CHQ; Landgraf et al., 1996) via an online questionnaire service (REDCap; Harris et al., 2009). While completing the consent forms, participants and their parents were told the study was attempting to estimate the prevalence of chronic fatigue syndrome in children and children with and without fatigue were being examined. After the appointment, participants and their primary care physician received a summary letter from the medical doctor involved in the study detailing the results of the appointment and lab work in the mail.

For stage three of the study, two physicians, not including the physician present at the medical appointments, reviewed each participant's data and determined whether the participant meets case definition criteria for ME/CFS. The dichotomous outcome variable for this study, meets at least one case definition or does not meet any case definitions, was derived from this physician review process.

Statistical Plan

All data was analyzed using SPSS version 23.0 (IBM Corp., 2015).

Assumptions. Data were assessed to ensure it met the assumptions relating to regression analyses including completeness of data, linearity, normality, and homoscedasticity (Osborne & Waters, 2002). Little's Missing Completely at Random test (Little, 1998) was run to determine if missing data for continuous outcome variables could be replaced utilizing imputation. Outliers were examined and removed utilizing the interquartile range method in which those exceed 2.2 times the interquartile range were removed for outcome variables (Hoaglin & Iglewics, 1987).

Skewness and kurtosis values as well as data histograms were analyzed to determine data normality.

Demographic variables. For the race variable, only those participants who endorsed identifying as Latinx, Black, and White were used for analyses due to small sample sizes for other racial categories (i.e., Asian and multiracial; *n*=10). Dummy variables were created and utilized to compare Black participants with White participants, and Latinx participants with White participants. For the parent education variable, participants were collapsed into two groups: lower parental education attainment for those reporting less than a standard college degree and higher parental education attainment for those reporting a standard college degree or higher. Annual household income was operationalized on an ordinal scale, with six income categories ($0-49,999, $50,000-99,999, $100,000-150,000, $150,000-199,999, $200,000-000-249,999, and $250,000 or more). For categorical variables, female was the reference category for the gender variable, lower parental education attainment was the reference category for the education variable, and White was the reference category for race variables.

Hypotheses I, II, and III. Multiple linear regression analyses (Aiken et al., 2003) were conducted with each of the continuous criterion variables separately, including fatigue severity as assessed by the FSS, number of threshold symptoms as assessed by the DPSQ, and overall physical functioning as assessed by the CHQ. This regression procedure allows for an examination of a dependent variable and multiple independent variables that may be continuous or categorical and attempts to model the relationship by constructing a linear model based on observed data. Using linear regression also allows an examination of the individual contribution of variance of each predictor while controlling for all other predictors, which is the main purpose

of this study. Predictor variables for each of these multiple linear regressions included gender, race/ethnicity, household income, and parental educational attainment.

Because the outcome variable for ME/CFS diagnosis was binary (met at least one case definition or did not meet any case definitions), binary logistic regression was used (Walker & Duncan, 1967). This method predicted the odds of a participant having a ME/CFS diagnosis based on the participants' gender, race/ethnicity, household income, and parental educational attainment.

Hypothesis IV. To assess whether belonging to multiple disadvantaged groups had a significant impact illness severity, significant linear regressions used to assess Hypotheses II, III, and IV were re-run with specifications that included interaction effects for variables with significant main effects in initial regression analyses.

Results

Participant Characteristics

165 screen-positive children and adolescents were originally included in the current study. Data were first assessed for missing values. Any participants who selected the answer choice "Prefer not to respond" for the annual income question (n=16) or who identified as multiracial or Asian (n=10) were excluded from all analyses. Outliers were removed if they fell beyond 2.2 times the interquartile range for continuous outcome variables (n=2). This left the final sample size at 137 participants. Participants were average age of 13.6 years (SD=2.6) and about half (54.7%) were female. In terms of race/ethnicity, approximately half (53.3%) identified as White, 21.2% identified as Black, and 25.5% identified as Latinx (Table 1).

Table 1. Demographic Characteristics of Screen Positive Participants

	Screen Positive (*n*=137)
	M (SD)
Age	13.6 (2.6)
	% *(n)*
Gender	
Female	54.7 (75)
Male	45.3 (62)
Race/Ethnicity	
White	53.3 (73)
Black	21.2 (29)
Latinx	25.5 (35)
Parent	
Reported Income	
$0-49,999	26.3 (36)
$50,000 - $99,999	21.9 (30)
$100,000 - 149,999	24.1 (33)
$150,000 - 199,999	21.2 (29)
$200, 000 - 249,999	2.9 (4)
$250,000 or more	3.6 (5)
Highest degree or level of education	
Less than high school	0.7 (1)
High school or GED	12.4 (17)
Partial college or specialized training	18.2 (25)
Standard college degree	38.0 (52)
Graduate or professional degree	30.7 (42)

Preliminary Analyses

Missing Data. Little's Missing Completely at Random (MCAR) test (1998) was not significant, $\chi 2 = 12.36$, $p = 0.09$, indicating data was missing completely at random and expectation maximization imputation methods were utilized using SPSS for the continuous outcome variables Fatigue Severity Score (missing *n*=1), Physical Functioning on Child Health

Questionnaire (missing *n*=2), and Number of Symptoms reported on DePaul Pediatric Symptom Questionnaire (missing *n*=7). Data with imputed values were used for all subsequent analyses. Regarding outcome variables, participants reported a mean FSS total score of 36.28, the mean number of symptoms endorsed on the DPSQ was 11.83, and the mean physical functioning score on the CHQ was 81.68 (Table 2).

Table 2. Descriptive statistics of outcome variables (*n*=137)

Variable	**M**	**SD**	**Range**
Fatigue Severity Scale Total Score	36.275	14.125	9-62
Number of Symptoms at 2/2 on DPSQ	11.830	8.164	0-36
Physical Functioning Score on CHQ	81.680	17.423	26-100

Variable	*% (n)*
Case Definition Fulfillment	
Met at least one ME/CFS Case Definition	48.2 (*66)*
Did not meet at least one ME/CFS Case Definition	51.8 (*71*)

Assumptions. Regarding data normality, q-q plots were examined and skewness and kurtosis values were determined to be within an absolute value of two, indicating data were in an acceptable range for normality (George and Mallery, 2019). Statistical assumptions required for regression analyses were examined utilizing scatter plots, histograms, and variance inflation factor and tolerance scores and all factors were determined to be within normal limits.

Primary Analyses

Model Summaries. Results indicated a significant linear regression model regarding the predictors income, education, race/ethnicity, and gender on the FSS total score (R^2 = .12, $F(5,131) = 3.40$, p = .006; Table 3). The linear regression models regarding the demographic predictors on the number of symptoms reported on the DPSQ (R^2= .07, $F(5,131) = 2.02$, p = .080*;* Table 4), the linear regression model regarding the demographic predictors on physical functioning reported on the CHQ (R^2 = .06, $F(5,131) = 1.80$, p = .118*;* Table 5), and the binary

logistic model predicting case definition fulfillment based on demographic predictors (Nagelkerke R^2 = .05, X^2 (5) = 5.56, p = .352; Table 6) were not significant.

Table 3. Linear regression predicting fatigue severity reported on FSS

Predictors	**β**	**Std. Error**	***t* value**	***p* value**	
(Constant)	38.930	3.844	10.128	0.000	
Household Income	-1.256	1.139	-1.103	0.272	
Parent Education	0.835	2.942	0.284	0.777	
Race: Black	-6.923	3.372	-2.053	0.042	*
Race: Latinx	-7.869	2.934	-2.682	0.008	**
Child Gender	6.500	2.339	2.778	0.006	**

R-square = .115**; * p < .05; ** p < .01; *** p < .001

Table 4. Linear regression predicting number of symptoms reported on DPSQ

Predictors	**β**	**Std. Error**	***t* value**	***p* value**	
(Constant)	10.483	2.275	4.607	0.000	
Household Income	-0.592	0.674	-0.878	0.382	
Parent Education	1.114	1.742	0.640	0.524	
Race: Black	0.500	1.996	0.250	0.803	
Race: Latinx	-0.836	1.737	-0.481	0.631	
Child Gender	4.111	1.385	2.968	0.004	**

R-square = .071; * p < .05; ** p < .01; *** p < .001

Table 5. Linear regression predicting child physical functioning reported on CHQ

Predictors	**β**	**Std. Error**	***t* value**	***p* value**	
(Constant)	83.816	4.875	17.193	0.000	
Household Income	-0.516	1.445	-0.357	0.722	
Parent Education	3.646	3.731	0.977	0.330	
Race: Black	-0.566	4.277	-0.132	0.895	
Race: Latinx	3.406	3.721	0.915	0.362	
Child Gender	-7.358	2.967	-2.480	0.014	*

R-square = .064; * p < .05; ** p < .01; *** p < .001

Table 6. Binary logistic regression predicting case definition fulfillment

Predictors	β	Std. Error	Wald	*p* value	Exp(B)
(Constant)	-0.272	0.690	0.155	0.694	0.762
Household Income	0.123	0.171	0.518	0.472	1.131
Parent Education	-0.345	0.445	0.602	0.438	0.708
Race: Black	0.294	0.512	0.329	0.566	1.342
Race: Latinx	-0.046	0.439	0.011	0.916	0.955
Child Gender	-0.488	0.354	1.897	0.168	0.614

Nagelkerke R-square = .053; * p < .05; ** p < .01; *** p < .001

Hypothesis I. As reported in Table 3, race/ethnicity was found to be a significant predictor in the model assessing the FSS total score outcome for Black participants (β = -6.92, *p* = .042) and Latinx participants (β = -7.87, *p* = .008). The regression coefficients suggest less severity of fatigue as evidenced by lower scores on the FSS for both Black and Latinx groups. Race/ethnicity predictor variables were not significant for any other regression analyses. These findings do not support the hypothesis that racial/ethnic minority participants would experience worse outcomes related to ME/CFS when compared to White participants.

Hypothesis II. Socioeconomic status was not found to be a significant predictor for total FSS score, physical functioning on the CHQ, number of symptoms endorsed on the DPSQ, or probability of ME/CFS case definition fulfillment. This lack of findings does not support the hypothesis that lower household income or parent education attainment would contribute to worse outcomes associated with ME/CFS.

Hypothesis III. Gender was a significant predictor across all regression models with continuous outcome variables, including one predicting total score on FSS (β=6.50, *p* = .006; Table 3) in which the entire model was significant. Regression coefficients show female participants had higher total scores on the FSS when compared to males, indicating worse fatigue severity. Additionally, gender was a significant predictor for total number of symptoms at a

moderate threshold on the DPSQ (β = 4.11, *p* = .004; Table 4), with females reporting more symptoms and physical functioning on the CHQ (β = -7.36, *p* = .014; Table 5), with females reported decreased physical functioning. These results support the hypothesis that females would experience worse outcomes related to ME/CFS than males, even for nonsignificant models.

Hypothesis IV. Regression analyses were re-run including interaction effects for race by gender for the regression model predicting FSS due to significant main effects of gender and race. There were no significant interaction effects for any of the variables in the model (Table 7). This finding does not support the hypothesis that there would be a combined effect of multiple minority group identifications contributing to worse ME/CFS outcomes. Due to non-significance of main effects for any other predictors in all other regression analyses, interactions were not assessed.

Table 7. Linear regression predicting fatigue severity with interactions

Predictors	**β**	**Std. Error**	***t* value**	***p* value**	
(Constant)	39.510	4.049	9.759	0.000	
Household Income	-1.181	1.162	-1.016	0.311	
Parent Education	0.584	3.007	0.194	0.846	
Race: Black	-8.303	4.662	-1.781	0.077	
Race: Latinx	-8.900	4.170	-2.134	0.035	*
Child Gender	5.407	3.290	1.644	0.103	
Gender by Race: Black	2.671	6.069	0.440	0.661	
Gender by Race: Latinx	1.943	5.716	0.340	0.734	

R-square = .117*; * p < .05; ** p < .01; *** p < .001

Discussion

The current study is the first to examine the potential for health disparities in ME/CFS illness severity for a pediatric, community-based sample of screen positive participants. The results highlighted in this study provide a good starting point for future research examinations

regarding sociodemographic factors and their impact on functioning and symptomatology of ME/CFS.

Results of this study supported the hypothesis that female participants would exhibit worse functioning on ME/CFS illness severity outcome variables including number of symptoms reported, overall physical functioning, and fatigue severity when compared to males. Females reported more symptoms on the DPSQ, decreased physical functioning on the CHQ, and higher fatigue severity on the FSS. These results align with previous findings in adults with ME/CFS in that overall prevalence and illness severity are more severe for female participants (Hickle, et al., 1996; Jason et al., 1999; Jason et al., 2000, Song et al., 2002; Song et al.,1999). This finding expands on previous knowledge relating to pediatric ME/CFS highlighting females have higher prevalence rates of the illness (Lloyd et al., 1990; Jordan, et al., 2006; Bakken et al., 2014, Jason et al., 2020) by showing females also have worse illness severity and functioning as compared to males. Taken together, these results point to the need for increased attention on females exhibiting symptoms characteristic of ME/CFS at both diagnostic and treatment levels as females are more likely to have the illness *and* more likely to report more severe symptomatology, increased fatigue, and diminished physical functioning when compared to males. Regarding clinical implications of this finding, clinicians should carefully consider gender as a risk factor for diagnosis of ME/CFS and should assess illness severity across various aspects in order to develop an appropriate diagnosis and treatment plan accounting for disparities evidenced in female youth with ME/CFS symptomatology. As noted within the life-course perspective (Braveman & Barclay, 2009), disparities present within early childhood can have negative impacts throughout the life span. Thus, early detection and attention to disparities such as those found with gender in this study are vital initial steps for addressing differences in illness

presentation in youth populations. A notable finding was that none of the demographic variables, including gender, successfully predicted ME/CFS case definition fulfillment in this sample. Perhaps this points to a greater need for clinician sensitivity and thorough analysis of patient symptomatology and functioning, as demographic risk factors alone do not predict likelihood of diagnosis.

The hypothesis that Black and Latinx youth would report worse outcomes related to ME/CFS than White youth was not supported in this study. Latinx and Black identity did significantly predict fatigue severity on the FSS; however, both groups reported less fatigue severity than White participants. This finding suggests that while Black and Latinx youth have higher prevalence rates of ME/CFS (Jordan et al., 2000; Jason et al., 2020), fatigue severity is not following this same pattern. This also does not align with findings in studies examining adults with ME/CFS, with Latinx and Black participants reporting higher fatigue severity than White participants (Song et al., 1999; Jason et. al., 2000). One potential reason for this disparity in findings may be lack of cultural validity for the FSS in racial/ethnic minority youth with ME/CFS symptomatology. There are currently no validation studies examining the use of the scale with racially/ethnically diverse youth. Therefore, differences in the understanding of ME/CFS or the concept of fatigue may be contributing to the finding that Latinx and Black youth report less fatigue severity than White youth. Disparities in access to health insurance and regular health care for racial/ethnic minority youth (Newacheck et al., 2002) may have also influenced youth reporting on illness severity, potentially due to unfamiliarity with health care systems or not feeling comfortable disclosing severity of symptoms.

A recent study by Grossman and colleagues (2020) found similar findings, with Black youth with a diagnosis of Crohn's disease reporting less fatigue and anxiety than White youth

with this illness even though Black youth were found to have a more severe disease trajectory. The authors suggest potential reasons for this disparity include increased stigma regarding reporting on mental health, presence of resilience for Black youth, or differences in knowledge of the illness. This parallel in findings across two different chronic illnesses, Crohn's disease and ME/CFS, suggest the need for more research in this area to better understand if factors such as stigma, resilience, or illness knowledge may play a role in reporting fatigue and other symptomatology in pediatric ME/CFS. Additionally, validating measures such as the FSS for diverse samples is imperative to understand whether differences in understanding of concepts like fatigue impact reporting.

The hypothesis that youth with lower socioeconomic status would report worse outcomes related to ME/CFS than youth with higher socioeconomic status was not supported. Similar to the potential for lack of access to healthcare or understanding of the illness in explaining findings for racial/ethnic minority groups, this may also be the case for youth with lower socioeconomic status, who may have underreported or conceptualized ME/CFS questionnaires differently when compared to youth with higher socioeconomic status. Findings from the Jason and colleagues' (2020) pediatric prevalence study found only 4.8% of those diagnosed with ME/CFS had a prior diagnosis, suggesting a larger issue of underdiagnosis for the illness in pediatric populations. This highlights strong potential for lack of knowledge about illness symptomatology at time of reporting, which may be further impacted by other sociodemographic disparities described.

Additionally, lack of significant findings across original regression models led to an inability to test most interaction effects between demographic variables. Future research with larger sample sizes should explore whether interactions among sociodemographic variables exist when significant main effects are found.

Limitations. The current study had several limitations which may have influenced the results. First, data for these analyses were derived from youth self-report measures. While internal consistency and other psychometric properties of the measures were acceptable, including other types of observable measures, such as biomarkers or physical tests of functioning during the medical appointment, would be a good direction for future studies. Additionally, all illness severity data was obtained by youth to maintain reporter consistency, as the FSS was only collected from youth participants. Incorporating parent reported data could also present a different perspective on youth's illness severity, as previous work with a subset of this sample has found discrepancies in youth and parent reporting for ME/CFS symptomatology (Holtzman et al., 2018).

This sample included a broad range of youth regarding illness severity, as those included only had to screen positive for ME/CFS symptomatology. While this allowed for the examination of predicting case definition fulfilment via binary logistic regression, this may have also been a limitation because it included those who did not ultimately receive a diagnosis for ME/CFS. Future research should attempt these analyses with a larger sample of those meeting case definition criteria for ME/CFS to determine if the impact of sociodemographic characteristics changes with a purely diagnosed sample.

Finally, variables assessing socioeconomic status for this sample could be improved. A more robust measure of socioeconomic status by incorporating a more specific measure of income, household size, parental education, and insurance status may yield different results. Future studies should incorporate a more nuanced approach to socioeconomic status to determine its relationship to pediatric ME/CFS symptomatology.

Future Directions. Taking into account the life-course perspective and findings of this study, it is vital to continue to examine contextual factors which may be influencing reporting of illness severity. As Braveman & Barclay (2009) report, secondhand factors, such as parent education and income status as examined here, often play a role in health disparities. Thus, the need for a more nuanced approach to measuring socioeconomic status continues to be vital from a theory perspective. Additionally, other social factors such as stigma or resilience may also impact perception or reporting of illness for underrepresented groups. Continued examination of how social factors may impact reporting from a life-course perspective lens is warranted.

It is important to note number of symptoms reported, overall physical functioning, and fatigue severity do not encompass all potential aspects of illness severity that can be measured. Future research should explore other measures of illness severity, such as emotional functioning, coping with illness, impact on school, and more to further understand how sociodemographic variables may influence those with ME/CFS symptomatology.

The biggest finding of this study was that females reported worse outcomes related to ME/CFS across all measures of illness severity. It is imperative for clinicians and researchers to take this finding into account when designing diagnostic measures and piloting treatments to ensure those at risk for more severe symptomatology are targeted appropriately. Continued research regarding race/ethnicity and socioeconomic status can help illuminate other necessary considerations for diagnosis and treatment of diverse populations.

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