CHRONIC FATIGUE SYNDROME: HOLISTIC UNDERSTANDING AND THE IMPACT OF SOCIAL SUPPORT ON DISTRESS

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Abstract

Background: Chronic fatigue syndrome (CFS) is a debilitating illness that results in many functional impairments, with individuals who experience it being unable to work, and even becoming bedridden for years at a time. However, there continues to be confusion regarding the population of individuals with CFS, the etiology, and the treatment options.

Study One: In Study One, I attained a profile of the sociodemographic characteristics of adults with CFS in a Canadian sample using the Canadian Community Health Survey – Mental Health 2012 (Statistics Canada, 2013). Individuals with CFS were more likely to be female, 45-64, living alone, unmarried, unemployed, low income, have psychiatric diagnoses and have a history of childhood maltreatment than people without CFS.

Study Two: I re-examined the data from Study One to determine the level of social support and distress in individuals with CFS. Further, I explored the predictive ability of specific social support domains on distress with individuals with CFS, women with CFS, and men with CFS, and of overall social support after controlling for the significant demographic and mental health variables from Study One. For women with CFS, social integration and guidance support uniquely predicted distress; for men with CFS, social integration uniquely predicted distress. After controlling demographic and mental health variables, social support was found to predict 10.4% of the variance in distress.

Discussion: These findings are integrated to explore the possible etiological implications of childhood maltreatment, the importance of a holistic biopsychosocial approach to illness for this population, and how such an approach may provide greater treatment opportunities for individuals with CFS.

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List of Abbreviations

ADHD: attention-deficit/hyperactivity disorder

CBT: cognitive behavioural therapy

CCHS-MH: Canadian Community Health Survey – Mental Health 2012

CEQ: childhood experiences questionnaire

CFS: chronic fatigue syndrome

DSM-5: Diagnostic and Statistics Manual of Mental Disorders: 5th edition

HPA: hypothalamic-pituitary-adrenal

K10: Kessler Psychological Distress Scale

MDD: major depressive disorder

OR: odds ratio

PTSD: posttraumatic stress disorder

SD: standard deviation

SPS-SF: Social Provisions Scale – Short Form

SSRD: somatic symptom and related disorder(s)

Chronic Fatigue Syndrome: Holistic Understanding and the Impact of Social Support on Distress

Forward

Words matter. The nomenclature I use for chronic illnesses and syndromes matters. The illness described and discussed herein as chronic fatigue syndrome has gone by a number of different names, even over the course of the last 10 years (Bested & Marshall, 2015; Bonner et al., 1994; Carruthers et al., 2011; Escobar et al., 2002; Statistics Canada, 2013; Zavestoski et al., 2004). It has been referred to, as described here, as chronic fatigue syndrome, but also as myalgic encephalomyelitis, systemic exertion intolerance disease, Gulf War syndrome, and historically as neurasthenia, or nervous exhaustion. Some researchers have simply opted to classify it more broadly as medically unexplained symptoms (Escobar et al., 2002; Park & Knudson, 2007).

It is recognized that many living with the condition and also in this field of research may object to the nomenclature used in this study, as it may be seen as an outdated framing of the disease state described herein, and is also fraught with associated stigma (McInnis et al., 2015). I was of two minds in the selection to use the name "chronic fatigue syndrome" in this document. On one hand, I wanted to best represent the population I am discussing who often object to the use of this name, as I truly hope that the findings of this research will serve them as opposed to hindering them. On the other hand, I considered that with each renaming of disease, carried with it is the stigma associated with a lack of understanding. Shedding the name has not seemed to shed the views of the public. Ultimately, the deciding factor was the choice by Statistics Canada (2013) to use the nomenclature of chronic fatigue syndrome in the collection of the data

used herein. I am hopeful that any criticism of the choice to use this framing will not outweigh the content of the findings.

Chapter 1: General Introduction

Reports of illnesses akin to chronic fatigue syndrome (CFS; often referred to as myalgic encephalomyelitis) have been detailed since at least the 1800s as "neurasthenia" and "nervous exhaustion" (Bonner et al., 1994). As with these earlier documented conditions, both mental and physical exhaustion have been implicated in CFS, and the disease burden cannot be understated (Wessely & Powell, 1989). Twenty-five percent of individuals with CFS have been found to be unable to get out of bed, leave their homes, or work, and a further 33% have been found to be able to work only part-time hours even when of a working age (Komaroff & Buchwald, 1991; Pendergrast et al., 2016). Additionally, the reported length of illness ranges from between three to 30 years in a community sample (Wilson et al., 1994).

Diagnostic Criteria

Difficulty in determining a direct cause has also resulted in difficulty establishing diagnostic criteria. There have been a number of different diagnostic criteria used over the last 30 years (see Table 1), all of which were somewhat similar, though different enough to result in widespread confusion, and significant differences in the reported prevalence rates of CFS (Johnston et al., 2013). Some consensus has been achieved in recent years by way of an international panel of experts who indicate that diagnosis should include significant fatigue symptoms which results in a minimum of 50% reduction in activity level, in addition to a minimum of one neurocognitive impairment (e.g. difficulties with memory, sleep, or pain), one immune/gastrointestinal/genitourinary impairment (e.g.

increased susceptibility to infection, nausea, or changes in urinary frequency), and one energy production/transportation impairment (e.g. heart palpitations, light headedness, or laboured breathing) (Carruthers et al., 2011). Individuals with CFS have been found to experience equivalent fatigue to those with mood disorders, and significantly more fatigue than individuals with neuromuscular disorders (Wessely & Powell, 1989). However, while 10.4% of individuals in Great Britain report having had significant fatigue for over a month, the estimated prevalence of CFS is much lower, ranging between 0.2%-3.28% of the population depending on the diagnostic criteria in use, and whether it was clinician-assessed or self-reported (Johnston et al., 2013; Steele et al., 1998). A recent meta-analysis placed the prevalence at a mean of 0.89% when using the Fukuda (1994) criteria, and 1.14% when completing an interview (Lim et al., 2020).

Economic Implications

Given the functional limitations associated with this illness, the burden on afflicted individuals and their supports is quite significant as is the impact on healthcare systems and government services. As individuals with CFS often spend years being unable to maintain employment, they are typically supported by government subsidies, and face continued reliance on the healthcare system (Bonner et al., 1994). The economic loss of productivity in the United States is estimated to be roughly 9.1 billion dollars annually based on both employment and household labour, with estimates of double the loss of economic productivity as compared to individuals with chronic fatigue who do not meet criteria for CFS (McCrone et al., 2003; Reynolds et al., 2004). When considering the increased reliance on the healthcare system, the cost of CFS may increase two to three times, estimated between 18 and 24 billion dollars annually (Jason et al., 2008). Such

economic and productivity losses have served to exacerbate significant stigma, and public and health-professional misperceptions about the disorder. This is of concern as negative perceptions and responses further contribute to the distress and debilitation associated with the CFS disease state (McInnis et al., 2015; Verspaandonk et al., 2015). Such confusion also permeates the literature with respect to the origins and etiology of illness in this population.

Etiology

While a number of possible causes have been explored, none have been able to independently account for the onset or maintenance of CFS. As such, it has been proposed that CFS be considered a set of symptoms rather than the result of one particular disease state (Holmes et al., 1988). This has also resulted in difficulty classifying CFS, and disagreements in the conceptualization of CFS amongst experts.

Historically, questions have repeatedly surfaced as to whether CFS may be best conceptualized as a somatic symptom or related disorder (SSRD) as per the diagnostic category in the Diagnostic and Statistical Manual of Mental Disorders (5th edition; DSM-5; American Psychiatric Association, 2013) due to the frequent classification of CFS as being medically unexplained (Escobar et al., 2002; Park & Knudson, 2007; Zavestoski et al., 2004). This category of psychiatric disorders had previously been solely reserved for disorders involving physical symptoms with no medical or biological basis (American Psychiatric Association, 2013). However, with the newest iteration of the DSM-5, there is greater acknowledgement for physical symptoms with a medical basis that create significant distress or psychological impairment, as well as the importance of considering the inseparable nature of the body and mind (American Psychiatric Association, 2013).

Additionally, there have been concerns among healthcare professionals that the presence of CFS is simply a new label for the same or similar symptoms in patients who have had medically unexplained somatic symptoms and who continue to search for a medical cause in spite of continual negative findings (Stewart, 1990). Unfortunately, the fact that the diagnosis of CFS has been based on *negative* diagnoses for other disease states, as opposed to a *positive* diagnosis for CFS (Zavestoski et al., 2004), perpetuates its unexplained perception, which ultimately may encourage individuals to continue this search.

The classification of CFS as being possibly psychiatric in nature has resulted in significant backlash from CFS sufferers (Escobar et al., 2002). Specifically, this classification has been blamed for delegitimizing the illness state, with increased concern around stigma, lack of access to medical services and treatment, and inability to access financial support (Escobar et al., 2002; Zavestoski et al., 2004). From a health practitioner perspective, the presentation of CFS is another form of somatization which means that continued medical investigations, and searching for biological causes of symptomology, will perpetuate symptoms and illness beliefs, and prevent individuals with CFS from accessing psychological services which could be of great benefit in alleviating symptoms and illness burden (Escobar et al., 2002; Wessely, 1995b; Zavestoski et al., 2004). However, in spite of this conceptualization, various studies have implicated a number of possible biological markers of CFS in illness onset (Bonner et al., 1994; Esfandyarpour et al., 2019).

The controversy within the CFS literature is certainly reflective of its complexity, and justifies a need for a more comprehensive approach toward developing an

understanding of illness onset beyond what the biomedical model can provide; in other words, a biopsychosocial perspective is required (Bayliss et al., 2014; Engel, 1977), which incorporates a holistic view of the individual including the biological, psychological, and social factors.

While such an approach has also been the recommended model for physicians for understanding and treating CFS, it has not been without its criticisms (Geraghty & Esmail, 2016; National Institute for Health and Care Excellence, 2017). It has been suggested that poor care for individuals with CFS has been a direct result of this perspective (Geraghty & Esmail, 2016). Nonetheless, in keeping with this model, researchers have identified a variety of factors which interact and contribute to the onset and maintenance of the disease state in CFS (Bonner et al., 1994). Specifically, this model (Engel, 1977) might consider biological factors such as genetic predisposition, bacterial or viral infection, and/or physiological responses within the body which have often been identified as possible precipitating factors in CFS onset (Esfandyarpour et al., 2019; Twisk, 2014; Wessely, 1995b; Wessely & Powell, 1989). Psychologically, relevant factors might include beliefs and expectations, personality structure, and mental/emotional health, of which comorbidities have been explored with CFS including major depressive disorder (MDD), anxiety disorders, posttraumatic stress disorder (PTSD), and attention-deficit/hyperactivity disorder (ADHD) (Bonner et al., 1994; Heim et al., 2006; Janssens et al., 2015; Mariman et al., 2013; Wessely et al., 1996). Social factors might involve family environment throughout development, social support, and culture, which have had limited exploration including the prevalence of childhood

maltreatment in CFS, and interpersonal difficulties (Heim et al., 2006; Kempke et al., 2013; Krzeczkowska et al., 2015; van Houdenhove et al., 2009; Wessely, 1995a).

Objectives

The confusion associated with this illness is reflected in the findings above. While CFS has a significant impact on the individuals experiencing it, as well as on society at large in the economic and healthcare implications noted, this appears to be the only thing that is agreed upon. The etiology is far from consistent, the demographic data are sparse and discrepant across findings, and the factors influencing outcome are largely unknown.

The studies herein aim to provide some clarity regarding CFS. Given the significant impact of CFS as agreed upon across the existing body of literature, it is imperative I gain a better understanding of this population, both in terms of who they are, as well as their general experience. The objectives of the current research were to increase the understanding of the demographic profile of individuals with CFS, including a better understanding of socioeconomic status, education, marital status, household size, sex, age, and psychiatric comorbidities through a comparison of individuals with and without CFS. Second, I looked into the level of social support and distress in this population, specifically examining the role social support has in predicting distress even after controlling for demographic and mental health characteristics. Finally, through the discussion, possible etiology is explored in the prevalence of childhood maltreatment in individuals with CFS, and how this is reflected in the symptomology.

Chapter 2: Study 1 – Demographic Profile of Individuals with CFS

The disease state known herein as chronic fatigue syndrome (CFS) has gone by many names over the years, including myalgic encephalomyelitis, systemic exertion intolerance disease, Gulf War syndrome, historically as neurasthenia/nervous exhaustion, or simply medically unexplained symptoms (Bested & Marshall, 2015; Bonner et al., 1994; Carruthers et al., 2011; Escobar et al., 2002; Park & Knudson, 2007; Zavestoski et al., 2004). Along with the changes in nomenclature, have come many iterations of diagnostic criteria as documented in Table 1. As the name suggests, CFS results in significant mental and physical exhaustion on the part of the individual (Wessely & Powell, 1989), specifically resulting in a 50% reduction in activity level (Carruthers et al., 2011). However, this is just one of many symptoms that individuals with CFS must contend with. They also experience a range of immune and gastrointestinal symptoms, energy production and transportation impairment, and neurological symptoms including pain, cognitive decline, sleep disturbances, and sensory concerns (Carruthers et al., 2011) which can last for decades (Wilson et al., 1994), resulting in a significant disease burden for this population.

As the diagnostic criteria have varied over the years, it has been difficult to fully establish demographic and socioeconomic characteristics of individuals with CFS, with heterogeneous findings across the current body of literature. This can be seen in the variability of prevalence rates within the existing body of literature which ranges between 0.2% to 3.28% depending on the criteria used and whether it was clinician-assessed or self-reported (Johnston et al., 2013; Steele et al., 1998). Nonetheless, women have been found to be 1.5-2.7 times more likely to experience CFS depending on the particular

diagnostic criteria considered (Komaroff & Buchwald, 1991; Pawlikowska et al., 1994). Further, depending on the severity of illness, and given its pervasive nature, many individuals with CFS become so compromised by their symptoms that they are unable to maintain employment, may require reduced hours, and are often housebound (Komaroff & Buchwald, 1991; Pendergrast et al., 2016). While there have been findings of CFS amongst high socioeconomic status households (Wessely, 1995b), the limitations of employment and activity level have more frequently been found to limit personal and household income such that CFS is more often found within middle class households, households with an income discrepancy of $20,000 per year, or with total household incomes less than $40,000 per year (Carruthers et al., 2003; Moss-Morris et al., 1996; Pawlikowska et al., 1994; Reeves et al., 2007; Reid et al., 2000; Steele et al., 1998). It is unclear as to whether these income discrepancies have any relationship to academic attainment by individuals with CFS as there is some evidence that the highest prevalence of CFS is among well-educated white women (Moss-Morris et al., 1996); however, this reflects a limited finding within the larger body of literature as other findings suggest that CFS is found equally across races and ethnicities (Reid et al., 2000).

The socioeconomic and employment difficulties documented by individuals with CFS often result in increased stigma on the part of the public and even health professionals. Such stigma is of great concern for this population as negative perceptions have been found to exacerbate the severity of illness for individuals with CFS (Carruthers et al., 2003; Moss-Morris et al., 1996; Pawlikowska et al., 1994; Reeves et al., 2007; Reid et al., 2000; Steele et al., 1998). This stigma is also perpetuated by the confusion surrounding the etiology of illness for this population.

Etiology

While a number of possible causes have been explored, none have been able to independently account for the onset or maintenance of CFS. As such, it has been proposed that CFS be considered a set of symptoms rather than the result of one particular disease state (Holmes et al., 1988). This has also resulted in difficulty with the classification of CFS, and disagreements in the conceptualization of CFS amongst experts as to whether it is best captured as biological or psychological in origin.

There is ongoing debate in the literature as to whether CFS may be best classified within the category in the DSM-5 of SSRD (American Psychiatric Association, 2013). Under this conceptualization of illness, many healthcare professionals view CFS as a new label for the same or similar symptoms in patients who have had medically unexplained somatic symptoms but continue to search for a medical cause in spite of continual negative findings (Stewart, 1990). However, there have also been various biological findings related to illness in CFS.

Biological factors. With regard to biological bases of disease, while 72% of individuals diagnosed with CFS believed their illness was related to a viral infection, only 33% were able to specifically verify such a history (Wessely & Powell, 1989). Viruses implicated in onset include enterovirus, Epstein-Barr virus, influenza, Hepatitis A, and toxoplasmosis, but such physical causes alone are insufficient to completely account for CFS onset and maintenance (Wessely, 1995a). CFS sufferers have also been found to be immuno-compromised, have increased cellular stress linked to aging, and have gastro-intestinal difficulties prior to the onset of illness (Twisk, 2014). Further, in an effort to find a biomarker of CFS, the electrical conduction of blood cells were analyzed, with the

blood cells of individuals with CFS demonstrating a significantly different electrical resistance pattern from the control group which may be unique to CFS (Esfandyarpour et al., 2019). While there have been findings of biological bases and physiological markers of illness, it is of particular interest that individuals who believe their CFS has a biological basis experience significantly more functional impairment than those who report other causes, such as psychological or social (Pendergrast et al., 2016; Scheeres et al., 2008; Wilson et al., 1994).

Psychological factors. There has also been a focus on potential psychological and social influences with respect to the onset of CFS. Comorbidity of CFS with major depressive disorder (MDD), for instance, has led to suggestions that the manifestation of CFS is the experience of a psychiatric disorder primarily characterized by fatigue (Bonner, Ron, Chalder, Butler, & Wessely, 1994; Wessely, Chalder, Hirsch, Wallace, & Wright, 1996). This interpretation stems from the overlap in physical symptoms seen in CFS and depressive mood disorders including fatigue, loss of energy, difficulty sleeping, and difficulty concentrating (American Psychiatric Association, 2013) but is perpetuated by several findings. Individuals with CFS have been found to present with significantly more symptoms of depression, and with greater symptom severity than individuals who are healthy and those with autoimmune disorders (McInnis et al., 2014). Further, upon treatment, the remission of symptoms of CFS often occurs in conjunction with remission of depressive symptoms, and the return of symptom severity of CFS occurs when depressive symptoms return (Bonner et al., 1994).

Individuals with CFS also report significantly more traumatic life events, and greater perceived stress than non-fatigued controls in the year leading up to onset and

diagnosis (Heim et al., 2006; Nater et al., 2011). They are also more likely to report clinically significant symptoms of PTSD than non-fatigued controls (Heim et al., 2006).

Of particular interest is the prevalence of early childhood trauma in this population. Not only have CFS sufferers been found to be significantly more likely than the general public to have experienced emotional, physical, and/or sexual trauma during childhood, but the presence of childhood trauma has repeatedly been observed to predict fatigue, fatigue severity, and overall symptom severity in this population (Heim et al., 2006; Kempke et al., 2013; Krzeczkowska et al., 2015; van Houdenhove et al., 2009).

In addition to depressive and trauma-related disorders, several other psychiatric comorbidities have been implicated in the development and maintenance of CFS. Anxiety disorders, including social anxiety disorder and panic disorder have been observed to be significantly more prevalent among those with CFS than healthy controls, or individuals with other chronic health conditions (Janssens et al., 2015; Mariman et al., 2013). Attention-deficit/hyperactivity disorder (ADHD) has also been found to be significantly more prevalent among CFS sufferers, as well as substance-related disorders, and sleep-wake disorders (Mariman et al., 2013; Sáez-Francàs et al., 2014). Further, a linear relationship between somatic symptoms and psychological symptoms has been demonstrated in individuals with CFS suggesting greater distress could result in increased severity of disease (Wessely et al., 1996). This finding would be consistent with the view of CFS as being possibly a SSRD whereby psychological distress presents in individuals as physiological symptoms (Escobar et al., 2002). However, not all individuals with CFS have a comorbid psychiatric disorder, and as such has been insufficient in accounting for the prevalence of CFS (Bonner et al., 1994; Wessely et al., 1996).

Psychosocial factors. Those with CFS have been found to differ from those with MDD due to the high motivation found in individuals with CFS (Wessely, 1995a). This has been related to specific personality characteristics found amongst individuals with CFS including higher conscientiousness, perfectionistic tendencies, over-achieving, and being "over-active" prior to the onset of illness (Besharat et al., 2011; Wessely, 1995a). A biological attribution helps alleviate self- and other-stigma by medically legitimizing the physiological limitations involved in CFS, circumnavigating the social difficulties associated with psychiatric illness (Wessely, 1995a). Individuals with CFS report greater negative beliefs about emotional expression with increased emotional suppression of negative emotions related to concern around social perception (Brooks et al., 2017; Rimes et al., 2016; Rimes & Chalder, 2010). There is also evidence to suggest that CFS serves a social function, accounting for distress that would otherwise be unacceptable to those with CFS, allowing this population to slow down and be less busy, without adding a stigma (both self- and socially inflicted) associated with "being lazy" (Wessely, 1995a).

The views related to a social function of symptomology in CFS are consistent with the perspective that CFS may best be classified as a SSRD. It would suggest that the symptoms of CFS may not have a biological origin, but instead result from another source such as the presentation of physical symptoms resulting from psychological distress, consistent with the symptoms of conversion disorder/functional neurological symptom disorder (American Psychiatric Association, 2013). This is not to say they are any less real, but instead that they would be a functional difficulty as opposed to a structural difficulty associated with biological changes.

Study One Objectives and Rationale

The objective of the Study One pertains to obtaining a holistic perspective on the population of individuals with CFS. To the best of my knowledge, there has never been a nationwide analysis of the prevalence and sociodemographic qualities of individuals with CFS. Previous research has consisted of small samples, with the largest cohort study conducted state-wide in Georgia in the U.S. (Reeves et al., 2007), and one meta-analysis examining prevalence related to differing diagnostic criteria (Johnston et al., 2013).

Additionally, to date, data have been conflicting regarding the sociodemographic factors of individuals diagnosed with CFS. Some studies have indicated that those who experience CFS are more likely to be white, middle-upper class women, and others indicating CFS is found equally across race, with significant variability in findings for gender and socioeconomic statues (Komaroff & Buchwald, 1991; Moss-Morris et al., 1996; Pawlikowska et al., 1994; Reeves et al., 2007; Reid et al., 2000; Wessely, 1995a).

The disagreement among researchers in this area is indicative of the poor understanding of both CFS, and those diagnosed with the disorder and the importance of further exploration of this disorder. In an effort to understand, diagnose, and better manage/treat CFS, gaining a better understanding of the population diagnosed with this disorder is imperative. Additionally, given the purported psychological involvement in the onset and maintenance of CFS, psychological comorbidities and prevalence of childhood maltreatment will be examined as compared to those without CFS.

Method

Participants

Participants in this study were selected from the Canadian Community Health Survey – Mental Health 2012 (CCHS-MH), a national cross-sectional survey containing data from 25,113 individuals across the 10 Canadian provinces (Statistics Canada, 2013). Individuals living in the Canadian territories and on First Nations reserves, full-time members of the Canadian Forces, and individuals who were institutionalized during data collection were excluded from this process. The Public Use Microdata File includes data on individuals aged 15 to 80 years of age and older. For this study, those aged 15 to 19 years, and 65 years and over were excluded as Canadian adults with CFS were of primary interest. Of the 25,113 individuals who completed the CCHS-MH 2012, there were 16,972 respondents between the ages of 20-64. The target group consisted of all those individuals who have indicated they have been diagnosed with CFS by a physician. Previous research indicates that it is very unlikely for individuals with chronic fatigue to self-diagnose with CFS when they have not been diagnosed by a physician, suggesting this is a reliable indicator of diagnosis (Pawlikowska et al., 1994).

Data Collection

Data were collected via the CCHS-MH questionnaire, using computer assisted interviewing to ensure participants were asked only those questions which would pertain to them based on previous answers (Statistics Canada, 2013). Participants were selected using random-digit dialing across Canada using pre-selected regions. The majority of interviews were completed in person, with the remainder conducted by telephone.

Additional information about this procedure has been detailed by Hesson and Fowler (2015).

Materials

Sociodemographic Measure. For the present study, variables of interest include age (five-year intervals from 20-64), sex (male and female), race (white versus not white), province of residence, marital status, household size, work status, source of household and personal income (split into employment income, employment insurance/workers' compensation/welfare, seniors benefits, and other), socioeconomic status (broken into five household income brackets ranging from less than $20,000 to above $80,000, and five personal income brackets between less than $10,000 to above $50,000), and highest level of education by the respondent (ranging from less than secondary school to postsecondary school graduation). Additionally, an exploration of psychiatric diagnoses was completed including mood disorders, anxiety disorders, ADHD, PTSD, and childhood maltreatment was conducted.

Childhood Experiences Questionnaire (CEQ). The CEQ is a six question self-report scale used to measure the experience of physical and sexual violence before age 16 (Statistics Canada, 2013; Walsh et al., 2008). It assesses experiences of witnessing violence, experiencing various types of physical violence (e.g., spanking, slapping, hitting, punching, biting) by an adult, experiencing physical touching by an adult, and forced sexual activity by an adult. There is also a calculation of the number of types of childhood maltreatment experienced by the individual which ranges from having experienced none (0) to having experienced all types asked about (6). It has strong test-retest reliability (Walsh et al., 2008).

Statistical Analyses

The current study reflects secondary data analysis using the CCHS-MH (2012). Data were analyzed using SPSS version 25. Descriptive statistics (i.e., frequencies and percentages) were reported to indicate prevalence in terms of demographic variables noted above. Additionally, chi-square tests and odds ratios (OR) were calculated to examine differences between individuals with CFS as compared to the rest of the CCHS-MH (2012) sample with respect to sociodemographic information and mental health characteristics.

Results

Frequency data were examined to determine how many people reported having been diagnosed with CFS by a physician. Of the 16,972 individuals in our sample, 277 individuals reported a diagnosis of CFS, for a prevalence rate of 1.63% among Canadian adults. Of these individuals, n = 194, or 70% were female. Individuals with CFS were proportionally distributed across the 10 provinces, consistent with the distribution of those without CFS as reported in Table 2.

Demographic Information

A series of chi-squared and OR effect size analyses, which compare the likelihood of particular responses among individuals with CFS with the likelihood of these responses in individuals without CFS, were conducted to obtain a better understanding of the population of individuals with CFS in Canada. Odds ratios of 1.5 to 2.5 were considered small effect sizes, 2.5 to four were considered medium effect sizes, and greater than four were considered large effect sizes (Rosenthal, 1996). Comparisons between individuals with CFS and individuals without CFS related to age, sex, race, marital status, household

size, working status, household income, personal income, difficulty meeting basic expenses, and highest level of education attained by the respondent are presented in Table 2. As the table indicates, significant differences were found between individuals with CFS and individuals without CFS for all variables except race.

Individuals with CFS were significantly more likely to be without employment than individuals without CFS ($\chi^2 = 230.185$, $p < .001$, OR = 5.298), and if they were working, they were significantly more likely to be working only part-time hours than individuals without CFS ($\chi^2 = 8.240$, $p = .004$, OR = 1.899). This had implications for income as well, with individuals with CFS being significantly more likely to have a household income totalling less than $40,000 per year ($\chi^2 = 185.931$, $p < .001$, OR = 4.121), a personal income totalling less than $20,000 per year ($\chi^2 = 123.166$, $p < .001$, OR = 2.689), and were significantly more likely to report difficulty meeting expenses ($\chi^2 = 237.358$, $p < .001$, OR = 5.463). This also appears to be unrelated to level of education, as individuals with CFS were equally as likely as individuals without CFS to report post-secondary graduation (OR = 1.198).

Individuals with CFS were also significantly more likely to report being unmarried (i.e., single, divorced, separated, or widowed) than the individuals without CFS ($\chi^2 = 79.767$, $p < .001$, OR = 1.923). They are also significantly more likely to be living alone, having a household size of one, than individuals without CFS ($\chi^2 = 51.955$, $p < .001$, OR = 2.116).

Mental Health Information

A series of chi-squared and OR effect size analyses were conducted to obtain a better understanding of the mental health of individuals with CFS in Canada.

Comparisons were made between individuals with CFS and individuals without CFS related to a variety of psychiatric diagnoses and risk factors including mood disorders, anxiety disorders (including panic disorder, specific phobia, or obsessive-compulsive disorder), PTSD, and ADHD; as well as whether they have experienced childhood maltreatment, and the number of types of childhood maltreatment experienced by the individual (See Table 3). Comparisons of mental health variables amongst individuals with CFS versus individuals without CFS revealed significant differences for all variables.

Individuals with CFS were significantly more likely to report childhood maltreatment than individuals without CFS ($\chi^2 = 37.160$, $p < .001$, OR = 2.217), and multiple forms of childhood maltreatment than individuals without CFS ($\chi^2 = 216.427$, $p < .001$, OR = 2.935). In terms of comorbidities, individuals were significantly more likely to report ADHD (OR = 3.821), anxiety disorders (OR = 7.806), and mood disorders (OR = 9.954). Perhaps most strikingly, individuals with CFS were significantly more likely to report PTSD ($\chi^2 = 478.680$, $p < .001$, OR = 14.339).

Discussion

Study One

Sociodemographic characteristics. The objective of the present study was to obtain a holistic understanding of the sociodemographic and mental health characteristics of the population of individuals with CFS, and how they compare to individuals without CFS. Within our sample, $n = 277$ respondents identified they have received a diagnosis of CFS by a healthcare professional, for a prevalence rate for CFS of 1.63% in Canada. This fits nicely within the spectrum of findings on prevalence previously documented in the

literature as being between 0.2-2.6% of the population (Steele et al., 1998; Wessely et al., 1997). I found that individuals with CFS in Canada are significantly more likely to be between the ages of 45-64, female, living alone, and single/divorced/separated/widowed than individuals without CFS. They are equally as likely to be white/racial minorities as individuals without CFS.

With respect to socioeconomic factors, individuals with CFS are significantly more likely to have a household income of less than $40,000 than individuals without CFS. They are also more likely to be without employment or if they are working, working part-time hours, which is consistent with the finding that they are almost three times more likely to have a personal income less than $20,000, and roughly three times more likely to have a personal income of less than $30,000. Taken together with their employment status and personal income, it is unsurprising that individuals with CFS are over five times more likely to have difficulty meeting expenses with their household income. However, based on this employment status and income, it is somewhat surprising to find that they are only slightly more likely to have less than secondary school education than individuals without CFS, and equally as likely to have post-secondary graduation as individuals without CFS.

As compared with the previous literature on demographic data, our findings help to increase the consistency found therein. In keeping with our findings, the existing body of literature identifies that women are significantly more likely to have a diagnosis of CFS than men (Komaroff & Buchwald, 1991; Pawlikowska et al., 1994). Our findings are also consistent with the findings of Reeves and colleagues (2007) that individuals with CFS are equally as likely as the rest of the population to be of a racial minority.

Our findings also help to provide some clarity to discrepant findings related to socioeconomic status within the pre-existing literature. Across Canada, individuals with CFS are found to have a significantly lower income than the rest of the country, consistent with some of the findings throughout the literature (Steele et al., 1998; Wessely et al., 1997). Further, the data regarding work status and source of personal income are consistent with those in the literature suggesting that individuals with CFS are less able to work than their counterparts without CFS (Jason et al., 2008). The discrepancy in income cannot be attributed to differences in level of education as individuals with CFS are equally as likely to have graduated from postsecondary institutions as individuals without CFS in Canada. In combination, these findings reflect the severity of disability experienced by individuals with CFS, as they are not able to maintain full-time, or in many cases any, employment due to their health status.

Mental health characteristics. In terms of mental health characteristics, individuals with CFS in Canada were almost 10 times more likely to have a mood disorder, almost eight times more likely to have an anxiety disorder, almost four times more likely to have ADHD, and over 14 times more likely to have PTSD than individuals without CFS. They were also more than twice as likely to report having experienced childhood maltreatment, and roughly three times more likely to report having experienced multiple types of childhood maltreatment than individuals without CFS. These findings are consistent with the existing body of literature, where individuals with CFS have been found to present with significantly greater prevalences of psychiatric diagnoses, including mood disorders, histories of childhood trauma, PTSD, and ADHD (Bonner et al., 1994; Heim et al., 2006; Janssens et al., 2015; Kempke et al., 2013; Mariman et al., 2013;

McInnis et al., 2014; Sáez-Francàs et al., 2012; Wessely et al., 1996). Nonetheless, these findings remain striking when all examined together given the sheer volume of psychiatric comorbidities found within this population. Such findings speak to the importance of considering CFS as more than simply a set of physical symptoms in need of treatment, but also examining psychological components of symptomology and how psychological intervention may aid in alleviating symptomology (Stewart, 1990).

Clinical Implications

The discrepancies in socioeconomic status between individuals with CFS and individuals without CFS have stark implications for current and future health status. Socioeconomic status is often associated with health behaviours, such that individuals from lower socioeconomic status households often report lower health-promoting behaviours than individuals in higher socioeconomic status households. Individuals from lower socioeconomic status households are less likely to adhere to dietary recommendations (Lagström et al., 2019), likely due to an inability to regularly access more expensive foods such as fresh produce and lean protein sources. Further, they engage in less physical activity than individuals of high socioeconomic households, and are less likely to attend healthcare appointments than individuals in high socioeconomic status households (Sahekbar et al., 2018; Sninsky et al., 2015). Given the limitations already experienced by individuals with CFS on activity levels, it is likely that this discrepancy in socioeconomic status could further perpetuate poor health in this population making poor health outcomes more likely. People with CFS may also experience difficulties accessing health services and treatment options as a result of low

income due to being unable to access services in the private sector which could be cost prohibitive for this population.

The discrepancy in household income is made larger by the fact that individuals with CFS are much more likely to be living alone, and single/divorced/separate/widowed than individuals without CFS. Living alone has also been found to have potential negative consequences for health, and health behaviours. Individuals who live alone are more likely to experience negative health outcomes including greater instances of cardiac concerns, worsening of mental health, and even mortality at an earlier age in certain populations (O'Keefe et al., 2019; Tamminen et al., 2019). However, there is some evidence to suggest that living alone is actually confounded with social isolation and lack of social support in these instances (Holt-Lunstad et al., 2010; Sakurai et al., 2019). As a result, it is important to investigate the possible social impact of CFS on sufferers.

The findings related to prevalence of PTSD and childhood maltreatment in individuals with CFS are striking, as endorsing more symptoms of PTSD has been associated with disorganized attachment (O'Connor & Elklit, 2008), and 82% of children who have experienced maltreatment demonstrate disorganized attachment (Carlson et al., 1989), such that they have a poor view of both self and others (Bartholomew & Horowitz, 1991). Disorganized attachment has been linked to lower social competence, decreased reliance on others, lower romantic involvement, and hostility in romantic relationships (Bartholomew & Horowitz, 1991; Sroufe, 2005). I see indications of these difficulties in individuals with CFS through examining the differences in marital status, and household size. Individuals with CFS are significantly more likely to be living alone, and

single/divorced/separated/widowed than individuals without CFS, consistent with lower romantic involvement.

Limitations

While the findings of the present study provide insight into a better understanding of the population as a whole, and some of the difficulties experienced by this population, there are of course limitations to the study. Primarily, the nature of the project is such that it is limited in scope, and as a result there are areas that I simply did not explore or incorporate which could reflect important aspects of functioning in individuals with CFS. This includes such things as comorbid health conditions, and many premorbid factors which could provide greater insight into the etiology of illness in this population.

As this information reflects only a snapshot in time, and the data analyzed reflect data collected several years ago, it is possible that the data reflected herein are not reflective of the current criteria used in diagnosing CFS, or the mental illness diagnoses captured by the analysis. I are unable to speak to the criteria used to diagnose the individuals captured herein with CFS, and as a result it is unclear exactly which symptoms the individuals surveyed would have endorsed at the time of data collection. Further, the data collected here reflect mental health diagnoses which were likely made prior to the release of the DSM-5 (American Psychiatric Association, 2013), and as a result, may not reflect the most up to date understanding of these diagnoses. As a result, it is important to understand the findings of this study in this context, and demonstrates the importance of continued research with this population.

Further, with secondary data analysis I are limited in the analysis and interpretation of certain variables such as childhood maltreatment as the measure used

does not capture emotional abuse or neglect which has similar implications for physical and psychological functioning as compared with physical abuse or neglect, sexual abuse, and witnessing violence (Spertus et al., 2003; Zurbriggen et al., 2010). Had I been able to examine this variable, our results may have reflected that a greater population of individuals with CFS experienced childhood maltreatment, or that the childhood maltreatment captured herein could be a distinguishing factor for individuals with CFS. I were also unable to capture certain psychological variables which could be underlying some of the findings herein and acting as mediating variables. In particular, I were unable to capture attachment style. Given the findings related to childhood maltreatment, and the findings related to household size and marital status, an understanding of attachment style could reflect an important underlying factor pertinent to onset and treatment in this population (Waldinger et al., 2006).

Conclusions

The results of this study have important implications for the population of individuals with CFS. The socioeconomic discrepancies appear to reflect the severity of illness and poor health status of this population, particularly given that individuals with CFS are equally likely to have achieved post-secondary graduation as individuals without CFS. This discrepancy may also serve to perpetuate poor health as people from lower socioeconomic status households often experience difficulty accessing higher cost foods such as vegetables and lean meats (Lagström et al., 2019), in addition to being less likely to engage in other health promoting behaviours (Sahekbar et al., 2018; Sninsky et al., 2015).

Living alone and the high likelihood of reporting being unmarried or without a common-law partner also may provide some insight into the mental health difficulties experienced by this population. Living alone has been found to be related to poor health outcomes in other populations (O'Keefe et al., 2019; Tamminen et al., 2019); however, this could be related to a lack of social support as opposed to the size of household (Holt-Lunstad et al., 2010; Sakurai et al., 2019). This is a particularly important area of exploration for this population given the high prevalence of childhood maltreatment, and comorbidity of PTSD in individuals with CFS. These findings have implications for attachment styles, and in particular the increased likelihood of disorganized attachment within this population (Carlson et al., 1989; O'Connor & Elklit, 2008). Taken with the propensity for individuals with CFS to live alone, may indicate significant interpersonal difficulties on the part of CFS sufferers which could further compromise their health and outcomes.

Chapter 3: Study 2 – Social Support and Distress in CFS

Chronic fatigue syndrome (CFS) is a debilitating illness characterized by significant exhaustion on the part of the individual (Wessely & Powell, 1989). Individuals with this illness experience a 50% reduction in activity level, and significant impairment across neurological, immune, gastrointestinal, and energy production/transportation functioning (Carruthers et al., 2011). These impairments often result in an inability to maintain employment, with many people being unable to even leave their homes or get out of bed (Komaroff & Buchwald, 1991; Pendergrast et al., 2016). Further, CFS has been found to last upwards of 30 years, suggesting that these limitations may also impact sufferers throughout their adult lives (Wilson et al., 1994).

The employment challenges experienced by individuals with CFS have important implications for the social perception of illness by this population. Individuals with CFS contend with significant stigma from both the public, and also healthcare professionals (McInnis et al., 2015; Raine et al., 2004; Wessely, 1995a). Further, they report greater stigmatization than individuals with other conditions such as autoimmune diseases (McInnis et al., 2015).

The stigma associated with CFS is believed to be related to and worsened by the confusion regarding etiology. There has been debate in the literature as to whether CFS may be best conceptualized as a SSRD per the diagnostic category in the DSM-5 (American Psychiatric Association, 2013) due to the frequent classification of CFS as being medically unexplained (Escobar et al., 2002; Park & Knudson, 2007; Zavestoski et al., 2004). It has often been seen as a form of somatization which means that continued medical investigations, and searching for biological causes of symptomology will

perpetuate symptoms and illness beliefs, and prevent individuals with CFS from accessing psychological services which could be of great benefit in alleviating symptoms and illness burden (Escobar et al., 2002; Wessely, 1995b; Zavestoski et al., 2004). However, the findings in this regard are mixed, as various studies have implicated a number of possible biological markers of CFS in illness onset including blood-markers, and both bacterial and viral infections (Bonner et al., 1994; Esfandyarpour et al., 2019). When examined holistically, these findings may reflect the gaps associated with the use of a more biomedical model, and reflect the importance of examining CFS through the lens of the biopsychosocial model (Bayliss et al., 2014; Engel, 1977)

The stigma associated with this illness may in part account for the finding from the first study that individuals with CFS are significantly more likely to live alone, and be unmarried or without a common-law partner. Living alone has been related to poor health in other populations (O'Keefe et al., 2019; Tamminen et al., 2019), though this is thought to be more in keeping with a lack of social support than with the size of the household (Holt-Lunstad et al., 2010; Sakurai et al., 2019). As a result, it is imperative that social support in individuals with CFS be investigated as a contributing factor to illness.

The impact of social support on individuals with CFS is a particularly important area of study given the high prevalence of childhood maltreatment and comorbidity with PTSD within this population (Heim et al., 2006; Kempke et al., 2013; Krzeczkowska et al., 2015; Nater et al., 2011; van Houdenhove et al., 2009). A high prevalence of childhood maltreatment and PTSD have implications for the attachment styles of individuals with CFS such that they may be more prone to having insecure, and specifically disorganized, attachment (Carlson et al., 1989; O'Connor & Elklit, 2008).

Difficulty with attachment may have a significant impact on interpersonal relationships, and ultimately the ability of individuals with CFS to access social support.

Social Support

Social support is not considered to be one sole construct, but rather a combination of different domains of socialization, each of which may have a different impact on the individual (Prins et al., 2004). There have been a number of different conceptualizations of the domains of social support, all of which are reflective of what one is receiving from a particular social relationship such as guidance (advice/instruction), attachment/emotional support (somebody who can be relied upon to support emotions), tangible support (providing acts of service), reassurance of worth, and/or a sense of belonging (Cutrona & Russel, 1987). Any social relationship may provide different types of social support at different times.

Various populations have been found to respond differently to the domain types of social support, with age, gender, and personality factors also being predictive of the impact of each domain (Perera, 2016; Reevy & Maslach, 2001; Shumaker & Hill, 1991; Tinajero et al., 2015). For example, older individuals experience significantly fewer cognitive issues with increased emotional social support, whereas tangible support does not predict cognitive functioning in this population (Seeman et al., 2001).

When I examine the differential impact of social support by gender, increased global perceived social support has been found to protect against depressive symptoms and correlate with increased life satisfaction in women (Chiu et al., 2016; Razurel et al., 2013). This is also consistent across all domains of social support (Chiu et al., 2016). When looking at specific domains, women experience increases in health-related

activities with greater reassurance of worth and social integration (Ulvick & Spink, 2015) However, while women have typically been found to experience a benefit from emotional social support, such as attachment and reassurance of worth, in some age brackets, emotional social support has been found to negatively impact health outcomes in women (Shumaker & Hill, 1991).

Men have also been found to find benefit in increased social support. For example, men entering college experience fewer depressive symptoms when they perceive greater support from friends (Lee et al., 2020), and male athletes identify greater sport engagement with greater social support (Atkinson & Martin, 2020). Further, emotional and affectionate support have been found to mediate the relationship between childhood maltreatment and psychological distress in incarcerated men (Wolff & Caravaca Sánchez, 2019). However, there is also evidence to suggest that societally ingrained gender roles can have a detrimental effect on men accessing their supports. Men who feel self-stigma related to their health status, or who see emotionality as compromising their masculinity exhibit difficulty accessing these types of supports (Cole & Ingram, 2020; Wester et al., 2007).

In spite of these findings regarding the relationship between gender on social support, there have been few studies investigating the gender differences associated with specific domains of social support. Men have alternately been found to report greater and lesser perceived social support as compared to women, globally and across domains (Duncan et al., 1993; Lee et al., 2020; Perera, 2016; Tinajero et al., 2015). However, these limited findings are insufficient for determining the specific relationships between gender and domains of social support.

Social support in chronic illness. The benefits of social support in healthy populations also appears to carry over to illness populations as well. Social support by both health professionals, and friends/family, has been positively correlated with speed of recovery/remission, and compliance with treatment (Artemiadis et al., 2011; Cobb, 1976; Edwards, 2006). Further, social support has been negatively correlated with distress in individuals with chronic illness, as well as those in recovery (Bogart, 2015; Gallant, 2003). In chronic illness populations, including epilepsy and diabetes, social support has been found to be positively related to self-management of the illness and self-efficacy beliefs, suggesting that the availability of social support enhances one's belief that they have the personal resources to be able to manage their illness (Gallant, 2003).

While there are significant benefits to social support, people with chronic illnesses are also greatly affected by drawbacks related to negative social interactions. Symptoms of depression have also been found to predict negative social interactions and reductions in positive social interactions in individuals with rheumatoid arthritis (Ray, 1992). This has also been repeatedly observed across various chronic illnesses, with the effects of negative social interactions believed to counteract any benefit of social support and positive social interaction (Prins et al., 2004). Individuals with chronic illness may actually experience an increase in stress with receiving social support due to the difficulty within the support network to adapt to the individual's illness such as through changes in diet, increased anxiety, and treating the person differently (Gallant, 2003).

In addition to differences experienced within the contexts of chronic illness, men and women with chronic illnesses have been found to report different levels of perceived social support by domain. For example, men and women with PTSD have been found to

differ in their report of perceived attachment support, with men reporting significantly less than women (Fowler et al., 2020). Additionally, men with bipolar disorder experience a protective factor against psychological distress with increased reassurance of worth, while women with bipolar disorder do not experience this same benefit (Walsh & Fowler, 2019).

Social support in SSRD. There has been very little research into the role of social support in SSRD. However, adolescents with conversion disorder report poorer social support, particularly within their families, as compared to healthy adolescents (Yilmaz et al., 2016). Additionally, individuals with psychogenic non-epileptic seizures have been found to report significantly greater distress related to social functioning (Testa et al., 2012) indicative of the difficulty individuals with SSRD have with social interactions. While individuals with psychogenic non-epileptic seizures have been found to have nonsignificant differences from individuals with epilepsy and healthy controls in terms of utilizing social support for coping (Testa et al., 2012), the increased distress they experience related to social functioning may reflect reduced benefit from utilizing social support as a coping strategy. Reduced benefit from social support would be consistent with the finding that individuals with psychogenic non-epileptic seizures are significantly more likely to demonstrate a disorganized attachment style, viewing both themselves and others in a negative light (Bartholomew & Horowitz, 1991; Holman et al., 2008), and ultimately impacting on their perception of stressful situations (van der Kolk, 2003).

Social support in CFS. In individuals with CFS, positive social interactions have been negatively correlated with symptoms of anxiety, while negative social interactions have been positively correlated with both symptoms of anxiety, and symptoms of

depression (Ray, 1992). This finding is concerning as individuals with CFS have been found to experience significantly lower social support prior to the onset of illness than individuals experiencing other chronic illnesses (Prins et al., 2004). Further, compared to a healthy control population, individuals with CFS experience significantly more unsupportive social interactions by way of distancing, minimizing of experience, disbelief about illness, and inability to accept the illness (Anderson & Ferrans, 1997; McInnis et al., 2014), indicative of the impact of stigma within this disorder.

Even beyond the bounds of the individual's personal life, stigma may also compromise the care received by individuals with CFS. Physicians, for instance, have been found to interact with individuals with CFS differently than individuals with irritable bowel syndrome, potentially translating into a different treatment response (Raine et al., 2004). Specifically, physicians tend to report patients with CFS as being a "burden" to treat, lacking stoicism, and taking advantage of the sick role as compared to individuals with irritable bowel syndrome. Ultimately, this would likely impact treatment recommendations, consistent with the finding that physicians report they would not refer individuals with CFS to a mental health practitioner as it could further disrupt the relationship with the patient, even in spite of the acknowledgment that mental health services could benefit the patient (Raine et al., 2004).

When social support is able to be accessed by individuals with CFS, it appears to play a large role in mitigating the stigma associated with the illness. Women with CFS, for example, have been found to experience significantly less perceived stigma when immersed in a high social support environment, unlike women with other chronic

illnesses including multiple sclerosis, rheumatoid arthritis, and osteoarthritis (McInnis et al., 2015).

People with CFS report greater difficulty and lower satisfaction with their social support than individuals with other illnesses and people who are healthy (Jason et al., 2003); however, in situations where social support is sought out in this population, they report lower dysfunction, and greater adjustment to illness (Heijmans, 1998; Jason et al., 2010; Moss-Morris et al., 1996; Schoofs, Bambini, Ronning, Bielak, & Woehl, 2004). The salutary impact of social support can also be seen in the finding that individuals with CFS report less functional impairment with a partner who is optimistic about their course of illness, and significantly greater functional impairment with difficult interpersonal relationships (Heijmans, de Ridder, & Bensing, 1999; Prins et al., 2004).

Psychological Distress

When considering overall functioning, psychological distress is often used as an indicator of impact of illness on an individual, and is seen as a form of stress response resulting from the psychological impact of internal and external stimuli (Kessler et al., 2002). Stress has been defined as anything which threatens homeostasis in an organism in response to a stressor (Selye, 1956). Acute stress is something that most are able to manage through the physiological activation of the “alarm system” which involves increased responding of the adrenal system, and more generally changes in the hypothalamic-pituitary-adrenal (HPA) axis (Selye, 1975). Such changes may result in alterations to sleep, pain, and immune response dependent on the specific vulnerability of the individual in question.

This stress response evolved as a helpful reaction to physical threats to homeostasis. However, the stress response is acutely reactive to psychological and emotional "threats" as well, and should the stressor become more chronic in nature, the body's attempt to adapt may involve a blunting or dysregulation response of the HPA axis (Kempke et al., 2016; Selye, 1956). These alterations impact a variety of biological processes, as well as onset of disease in various aspects of body systems (Schneiderman et al., 2005; Selye, 1975).

With psychological and emotional stressors, cognitive appraisal is a key factor in determining stress response (Lazarus & Folkman, 1984). Cognitive appraisal is the determination the individual makes about whether they are capable of managing the stressor in their environment. However, if one believes they are unable to manage or cope, an increased stress response will occur, and ultimately psychological distress (Lazarus & Folkman, 1984). Hence, psychological distress is the impact that the inability to cope with acute and chronic stressors has on an individual's mental and physical health, their relationships, and overall well-being (Drapeau et al., 2011). The inability to cope arises through a taxing of personal resources, which are comprised of both internal (e.g., skills and traits) and external (e.g., social network and income) factors (Drapeau et al., 2011). So long as an individual persists in seeing themselves as incapable of managing the stressors they are confronted with, the stress response will persist, resulting in the onset of fatigue and exhaustion (Selye, 1956).

Throughout the literature, psychological distress has been implicated in the development and maintenance of disease in individuals with CFS. Even in otherwise healthy populations, increased distress has been significantly related to increased fatigue

(Pawlikowska et al., 1994) consistent with a persistent physical stress response (Selye, 1956). Given this physiological fatigue, and the impact on immune response, the impact of distress in individuals with chronic illness may serve to expedite onset, and exacerbate symptoms.

Distress in chronic illness. In addition to the distress experienced by said healthy population, individuals with chronic illness must also contend with psychological distress related to their illness (Fisher et al., 2014). This increased distress is an expected emotional response to health threats, and the uncertainty this can provoke with regard to future prospects (White et al., 2008). For example, in individuals with multiple sclerosis, the reduced functional capacity caused by symptoms such as fatigue, as well as exacerbation of those symptoms has been demonstrated to result in significantly greater distress in this population (White et al., 2008).

Health perception has been found to have a significant impact on distress and symptomology as well, with poorer health perception being indicative of increased distress, and onset of health decline (Farmer & Ferraro, 1997). Further, when individuals experience distress during a period of acute illness which is unrelated to the illness, their perceived health status worsens (Farmer & Ferraro, 1997). This is consistent with the findings that having a sense of mastery in life generally improves health perceptions (Folkman et al., 1986), as do feelings of control over the course of illness (Mystakidou et al., 2015). Of particular interest is the finding that one's peer group moderates the perception of health regardless of symptomology (Cockerham et al., 1983). This is indicative of the role social support plays in onset, maintenance, and possible exacerbation of distress in individuals facing chronic illness. Further, social support can

actually help facilitate adaptation to illness through supporting an illness identity, ultimately reducing distress in individuals with multiple sclerosis (Bogart, 2015).

Distress in SSRD. Similar to the influence of chronic medical illness on distress, there is a notable impact of SSRD on distress levels. In addition, people experiencing SSRD must also contend with difficulties and distress associated with acquiring a diagnosis, navigating the healthcare system to rule out various conditions, and the stigma of medically unexplained symptoms (Zavestoski et al., 2004). Furthermore, the confusion inherent in having such a disorder in terms of etiology, presentation, and treatment can serve to reduce the sense of control and mastery those with SSRD feel around managing their symptomology (Zavestoski et al., 2004), which could elevate distress, consistent with the findings of chronic illness populations (Folkman et al., 1986; Mystakidou et al., 2015).

The distress associated with the experience of SSRD may also be exacerbated by stressful life events (Brown & Reuber, 2016; LaFrance et al., 2013), further complicated by noted difficulties with emotion regulation (Pick et al., 2019). As a result, those with SSRD could be at higher risk for interpretation of stressors as being beyond their means of coping, which could result in even greater distress on a day to day basis (Pick et al., 2019).

Specific Impact of Distress in CFS. In individuals with CFS, distress has been repeatedly found to predict fatigue and disease severity. In a community sample in Great Britain, for instance, distress was found to be moderately correlated with fatigue, and was the second-most cited reason for fatigue, second only to psychosocial variables including work, family, and lifestyle (Pawlikowska et al., 1994). Studies have further revealed that

72% of individuals with CFS have a comorbid psychiatric illness, and in a primary care setting, between 50–85% of individuals with CFS report developing depression and/or anxiety (Komaroff & Buchwald, 1991; Wessely & Powell, 1989). These secondary diagnoses are indicative of the significant distress experienced by the majority of the population of individuals with CFS. At a one-year follow-up, for example, individuals who continued to meet criteria for CFS had repeatedly experienced significantly greater distress than those experiencing remission of symptoms (Bonner et al., 1994). This is unsurprising considering that individuals with CFS often attribute the onset of illness to greater distress in their lives in the time leading up to the development of symptoms (Nater et al., 2011).

Fatigue also appears to create significant distress, both for those with CFS and other chronic illnesses. Individuals with CFS have been found to experience significantly greater distress than people with chronic illnesses with less reported fatigue, such as rheumatic diseases (Ali et al., 2017). High levels of distress can also be seen within other chronic illness populations such as multiple sclerosis where fatigue is a significant factor in symptomology (White et al., 2008). As social support has been demonstrated to mediate such distress in other populations with chronic illness who experience significant fatigue (Folkman et al., 1986; Gay et al., 2010; Jean et al., 1997), it is expected that similar results would be found for individuals with CFS.

Impact of Social Support on Distress in Individuals with CFS

Previous research has indicated that having supportive social relationships inversely predicts secondary depressive symptoms in individuals with CFS, and suggested a significant protective factor with regard to distress levels in this population

(Jackson & MacLeod, 2017). Similarly, a primary care study which paired undergraduate "buddies" with CFS sufferers, demonstrated that emotional and tangible social support predicts a significant reduction in fatigue compared to "non-buddied" counterparts (Jason et al., 2010). While individuals with CFS in this study did not indicate less stress at the end of the four-month period (Jason et al., 2010), the reduction in fatigue symptoms suggests social relationships may indirectly impact on the overall distress of this population. Given that pre-existing literature suggests reduced fatigue predicts reduced distress for those with CFS (Bonner et al., 1994), it is surprising that reduced stress was not observed at the end of this study (Jason et al., 2010). However, it is important to recognize that the buddies spent only two hours a week with those with CFS throughout the study period. As a result, the individuals with CFS may not have perceived a change in social support, as they may not have seen this as being a close or even a social relationship given the foundation of the relationship was research. Further, the exact benefit of the various domains of social support went unmeasured, and thus it cannot be determined from this research how each type of social support could impact the levels of distress found in individuals with CFS. Additionally, even were these relationships perceived by the individuals with CFS to be supportive in nature, it is possible that the particular domains of social support provided by the "buddies" may be unhelpful and unrelated to alleviating distress in this population.

While the impact of social support has been examined within the context of CFS, few have accounted for demographic characteristics in analysis. Further, no study has examined the varying impact of different domains of social support, nor has social support been examined in relation to distress experienced by CFS sufferers. Additionally,

much of the literature on social support has focused on the impact of social support for women with CFS, while there has been relatively little about the comparative impact of social support for men with CFS. Given the large body of research into the impact of social support and distress on health quality, chronic illness, and disease management in CFS, further research into the impact of social support on distress in this population is warranted and necessary.

Study Two Objectives and Rationale

The objective of the study two is to obtain a better understanding of the maintaining factors in CFS. Although it has been suggested by other researchers as an avenue for future research, to the best of my knowledge, the impact of social support on distress in a population of individuals with CFS has not been examined. Distress has previously been demonstrated to be a possible contributing factor in the onset and maintenance of CFS (Komaroff & Buchwald, 1991; Nater et al., 2011; Wessely & Powell, 1989). In other populations, social support has previously been demonstrated to moderate the relationship between distress and illness outcome (White et al., 2008).

With regard to CFS, positive and negative social interactions have been found to be significantly related to stress (Ray, 1992); however, the impact of the various domains of social support on distress has not been explored in this population. As a result of the significant impact social support can have on health outcomes (Jackson & MacLeod, 2017; Jason et al., 2010; Prins et al., 2004), as well as the clear impact of distress on the development and maintenance of disease in individuals with CFS (Komaroff & Buchwald, 1991; Nater et al., 2011; Wessely & Powell, 1989), it is imperative I investigate the possible relationship between the domains of social support and distress in

individuals with CFS, particularly as it compares to the general population. A better understanding of the mechanisms which contribute to the onset and maintenance of illness will provide insight into the etiology of disease in individuals with CFS, as well as serve to indicate possible treatment options to aid in recovery.

In this study, differences in distress and social support domains between individuals with CFS and those without CFS was examined. Further, potential differences between men and women with CFS in distress and social support domains will be explored. Given the significant illness burden, and the sociodemographic findings of Study One, it is expected that individuals with CFS will experience significantly more distress than those without CFS, and report significantly less perceived social support across domains than individuals without CFS. Further, as men have typically been found to report less perceived social support than women, it is expected that men with CFS will report less perceived social support than women with CFS globally and across domains.

The predictive ability of social support as it relates to psychological distress in individuals with CFS were investigated. This specifically involved regressing the domains of social support on psychological distress for the population of individuals with CFS overall, and women and men with CFS separately to determine whether — and which — social support subtypes might be predictive of psychological distress in this population. Given our sample of individuals with CFS is made up of roughly two-thirds women, it is expected that the results for women will be comparable to the results for the overall population, with both differing from men in terms of the domains of social support which predict distress.

We will also be examining the predictive value of social support for distress in individuals with CFS after controlling the sociodemographic and mental health variables which are demonstrated to be significantly different from those without CFS as described in study one. These variables include age, sex, factors related to socioeconomic status, source of household income, marital status, household size, childhood maltreatment, and diagnoses of mood disorders, anxiety disorders, PTSD, and ADHD. Given the apparent importance of social relationships for individuals with CFS, it is expected that social support will be an important factor in predicting distress, even after controlling for demographic and mental health variables.

Method

Participants

Participants in this study were the same as those described in Study One, as selected from the CCHS-MH (Statistics Canada, 2013). As described in Study One, there were 16,972 respondents between the ages of 20-64. The target group consisted of all those individuals who have indicated they have been diagnosed with CFS by a physician, which consisted of 277 people, for a prevalence of 1.63% as found in Study One. Previous research indicates that it is very unlikely for individuals with chronic fatigue to self-diagnose with CFS when they have not been diagnosed by a physician, suggesting this is a reliable indicator of diagnosis (Pawlikowska et al., 1994).

Materials

Sociodemographic Measure. For the present study, the same sociodemographic information was re-examined as laid out in Study One.

Childhood Experiences Questionnaire (CEQ). The CEQ is a six-question self-report scale used to measure the experience of physical and sexual violence before age 16 (Statistics Canada, 2013; Walsh et al., 2008). For more information on this measure, please refer to Study One.

Kessler Psychological Distress Scale (K10). The K10 is a 10-question self-report scale used to measure distress, conducted as part of the CCHS-MH (Kessler et al., 2002; Statistics Canada, 2013). It assesses symptoms of anxiety and depression over the preceding 30 days using five-point Likert scales ranging from *none of the time (0),* to *all the time (4).* Higher scores represent greater distress experienced by the respondent. It has strong test-retest reliability, and has established construct validity in measuring global psychological distress (Kessler et al., 2002).

Social Provisions Scale – Short Form (SPS-SF). The SPS-SF is a 10-item self-report measure used to assess five dimensions of social support across a variety of populations, conducted as part of the CCHS-MH (Cutrona & Russel, 1987; Statistics Canada, 2013). Each question involved a four-point Likert scale ranging from *none of the time (1),* to *all of the time (4).* Higher scores on this scale and each of its subscales are representative of greater support. The five dimensions of social support assessed as part of this measure include guidance (providing advice/information), reliable alliance (assurance that others will provide tangible support), reassurance of worth (recognition of competence and value by others), attachment (emotional closeness which provides security), and social integration (a sense of belonging), each assessed using four items of the measure (Cutrona & Russel, 1987). Each of the scales have demonstrated discriminant

and construct validity, including with a chronic illness population, as well as internal reliability across populations (Chiu et al., 2016; Cutrona & Russel, 1987).

Statistical Analyses

Data were analyzed using SPSS version 25. Descriptive statistics (i.e., frequencies and percentages) were reported to indicate prevalence in terms of demographic variables noted above.

In order to test our hypotheses regarding social support and distress in CFS, a series of one-sample t-tests were used to determine the differences between individuals with CFS and those without CFS in psychological distress and domains of social support. Additionally, a series of independent-samples t-tests were conducted to identify any possible differences between women with CFS and men with CFS in distress and domains of social support. Levene's test of significance was conducted to determine whether variance was significantly different between groups, and when significant, the statistics reflect more conservative estimates where equal variance was not assumed.

Next, a series of correlations were carried out to determine the relationship between each domain of social support and overall K10 score among individuals with CFS, followed by stepwise regressions to determine the predictive power of the SPS-SF domains (guidance, reliable alliance, reassurance of worth, attachment, social integration) on the K10 distress scale in individuals with CFS, women with CFS, and men with CFS.

Third, a hierarchical regression was conducted to determine the predictive value of the social support domains on distress in this population after controlling for relevant demographic and mental health variables. In this analysis, the sociodemographic and psychiatric variables determined to be significantly different in individuals with CFS than

those without CFS in Study One were entered in the first two blocks respectively, with the domains of the SPS-SF entered in the third block to determine the impact of social support on distress in this population after accounting for the differences previously demonstrated in this population.

Results

Comparisons of Distress and Domains of Social Support

Comparisons between individuals with CFS and those without CFS. A series of one-sample t-tests were conducted to determine if there were differences between individuals with CFS, and the entire CCHS adult sample in terms of psychological distress, and social support domains. The population psychological distress and social support means used for the one-sample t-tests were calculated using the CCHS sample of 16,972 people aged 20-64. For the purposes of calculating the Cohen's *d* effect sizes, the overall standard deviations (*SD*) were used as the population standard deviations for each respective comparison. Cohen's *d* effect sizes of 0.2 to 0.5 were considered small effect sizes, 0.5 to 0.8 were considered medium effect sizes, and greater than 0.8 were considered large effect sizes (Rosenthal, 1996). Comparisons were made for the overall score of distress on the K10, the overall score of social support on the SPS-SF, and each of the five domains of social support as measured in the SPS-SF. The results of these comparisons can be found in Table 4. Significant differences were found between individuals with CFS and those without CFS for all comparisons. In particular, individuals with CFS reported 2.5 times more psychological distress than those without CFS ($t = 17.550$, $p < .001$, $d = 1.464$). Individuals with CFS perceived less social support on all domains than those without CFS with differences nearing or reaching a medium

effect size; the overall difference in social support was also a medium effect size (t = -7.071, p < .001, d = 0.564).

Comparisons between women with CFS and men with CFS. A series of independent-samples t-tests were conducted to determine if there were differences between CFS women and men. As there were more than twice as many women as compared to men (n = 194 and n = 83 respectively) in our sample, Cohen's d effect sizes were calculated using the more conservative (larger) *SD* in an effort not to overestimate these effects. Comparisons were made for the overall score of distress on the K10, the overall score of social support on the SPS-SF, and each of the five domains of social support as measured in the SPS-SF, and the results of these comparisons can be found in Table 5. Significant differences between CFS men and women were observed for the overall score of social support (t = -2.286, p = .023, d = 0.297), and the domain of attachment (t = -3.305, p = .001, d = 0.398). The difference on the domain of reassurance of worth approached significance as well (t = -1.949, p = .052, d = 0.251).

Predictive Power of Social Support on Distress in Individuals with CFS

Correlations between social support domains and distress in individuals with CFS. A series of Pearson correlations were conducted to determine the relations between each domain of the SPS-SF and the K10 overall score in individuals with CFS. All domains of social support were found to be significantly related to K10 scores. Pearson's r correlations and significance for domains of social support and overall K10 scores can be found in Table 6.

Stepwise regressions of social support domains on K10 distress in individuals with CFS. Three separate stepwise regressions were conducted with individuals with

CFS to determine the best predictors of distress amongst domains of social support in this population. In this series of regressions, I examined first the overall population of individuals with CFS, then women with CFS, and lastly men with CFS. The five domains of social support as classified in the SPS-SF were entered into a forward stepwise regression to predict the overall K10 score. Domains found to be significant in the comparisons have been noted in Table 7, with overall R^2 and significance for these models detailed as well. For both the analyses examining all individuals with CFS, and women with CFS, reassurance of worth and guidance support were found to significantly predict distress ($R^2 = .212$ and $R^2 = .228$ respectively). Whereas in the analysis of men with CFS, only social integration was found to uniquely predict distress ($R^2 = .199$).

Hierarchical regression of social support on K10 distress in individuals with CFS. A hierarchical regression was conducted with individuals with CFS to determine the predictive power of social support for distress after controlling for demographic and mental health variables. Demographic variables were entered in block one, and included age, sex, household size, working status, household income, source of personal income, whether they had difficulty meeting expenses, and level of education based on the significant findings as outlined in Table 2/Study One. Mental health variables were entered in block two and included diagnosis of ADHD, PTSD, mood disorder, anxiety disorder (including panic disorder, phobia, and obsessive-compulsive disorder), and types of childhood maltreatment including witnessing caregiver violence, experiencing physical violence by an adult, and experiencing sexual violence by an adult based on the significant findings as outlined in Table 3/Study One. Domains of social support were entered in block three and included the five domains of the SPS-SF. R^2/ R^2 change and

significance values for this analysis can be found in Table 8. There was a medium effect size for the predictive power of social support on distress even after controlling for demographic and mental health variables, with an overall R^2 for the model of .686.

Discussion

Study Two

The objective of Study Two was to gain a better understanding of the level of social support and distress in individuals with CFS within Canada, in addition to exploring the impact of social support on distress in this population. Within our sample, I had a prevalence rate for CFS of 1.63% in Canada, as established in Study One, which was consistent with previous research (Steele et al., 1998; Wessely et al., 1997).

Level of distress in individuals with CFS. As compared with those without CFS, individuals with CFS were found to be significantly more distressed, with scores roughly 2.5 times higher than those without CFS. Further, their scores were consistent with individuals with moderate to severe psychiatric illness (Kessler et al., 2003). This finding is consistent with the literature on distress in chronic illness, and experience of stressors in individuals with CFS specifically (Ali et al., 2017; Nater et al., 2011; Walsh & Fowler, 2019). It also suggests that individuals with CFS experience equivalent levels of distress as found in other chronic illness populations.

Within the population of individuals with CFS, males and females were found to experience equivalent levels of distress. This contrasts with the general literature on distress in the general public where women are often found to experience significantly greater distress than men (Drapeau et al., 2011). This discrepancy from the overall literature on distress suggests that the illness burden of CFS may serve to override the

typical gender difference in distress noted in the literature, consistent with other chronic illness populations (Fowler et al., 2020; Walsh & Fowler, 2019), in much the same way that sociodemographic factors, such as ethnicity and marital status, have been demonstrated to eliminate the gender difference of distress in other populations (Drapeau et al., 2011).

Level of social support in individuals with CFS. In terms of social support, individuals with CFS were found to report significantly less overall social support as compared to those without CFS, with significant differences and roughly medium effect sizes across all domains of social support as well. The finding that individuals with CFS receive less overall social support is consistent with previous findings (Prins et al., 2004). The findings that each domain of social support was also lower amongst individuals with CFS as compared to those without CFS are also unsurprising given the overall illness burden of CFS; however, these present as novel findings within the existing body of literature. These findings are in keeping with the understanding that health status has a global impact on social support (Artemiadis et al., 2011; Edwards, 2006), and that CFS in particular has a global impact on social support (Prins et al., 2004). Further, it is demonstrative of the interconnectedness of biopsychosocial factors of illness and the inability to isolate any one factor from the overall model (Engel, 1977).

We also examined any differences in social support between men and women with CFS. Women were found to receive more overall social support, consistent with the previous literature on the subject (Cutrona & Russel, 1987; Shumaker & Hill, 1991; Walsh & Fowler, 2019). Women with CFS were also found to receive more social support in the domains of attachment and reassurance of worth than men with CFS,

consistent with some previous findings (Tinajero et al., 2015; Walsh & Fowler, 2019), and inconsistent with others (Duncan et al., 1993). This may be reflective of the fact that males tend to rely more on partners for such emotional support, whereas females tend to utilize all types of interpersonal relationships for all types of social support (Shumaker & Hill, 1991), and based on the findings of Study One, the population of individuals with CFS is much more likely to be living without a partner than individuals without CFS. While these differences had small effect sizes, they are clinically meaningful in terms of possible best approaches to treatment.

Impact of social support on distress in CFS. ***I*** examined the relationship between distress and the five domains of social support in individuals with CFS using Pearson's correlations. All domains of social support were significantly related to one another, suggesting that individuals with CFS who are able to ascertain one form of social support are likely better able to ascertain other forms of social support as well. Additionally, all five domains of social support were significantly related to distress in individuals with CFS, indicative of the importance of social support in this population.

We then examined the predictive power of the domains of social support on distress using stepwise regressions for the overall population, women with CFS, and men with CFS. In the overall population, reassurance of worth and guidance were found to account for 21.2% of the variability in distress. This was consistent with the model examining the predictive power of social support on distress in women with CFS where reassurance of worth and guidance were found to account for 22.8% of the variability in distress. These findings may reflect shifting roles with the onset of illness as well as the difficulty in adapting to illness with CFS. As individuals become symptomatic, they may

be unable to fulfill their previous roles in the lives of those around them, and as a result may perceive themselves to be of less worth to those in their social network, and may actually receive fewer words of appreciation or reassurance that they are valued consistent with findings on adaptation to illness in other chronic illness populations (Bogart, 2015). This finding is particularly concerning as reassurance of worth has also been found to be significantly related to self-efficacy in other chronic illness populations (Chiu et al., 2016), and may help explain the predictive power of guidance in individuals with CFS. As they adapt to illness, individuals with CFS may experience a decline in reassurance of worth from their social network, lowering their self-efficacy, and ultimately increasing the importance of guidance as they navigate new symptomology and management.

Men with CFS differed from women in terms of the specific domains of social support which predicted distress. The only domain which significantly predicted distress in the model was social integration, which accounted for 19.9% of the variability in distress in men with CFS. This is consistent with previous findings that men are more likely to adhere to an exercise regimen when experiencing greater social integration (Duncan et al., 1993), but reflects the first study to demonstrate that social integration predicts distress in men, to the best of our knowledge. To this point, there has been very little research into the impact of social support on distress in men with CFS, and this is an important finding for healthcare practitioners to consider when treating this population as the existing body of literature has tended to focus on women when examining CFS. This may reflect the tendency for men to engage a larger circle of individuals than women, but for women to engage fewer people in a deeper manner (Shumaker & Hill, 1991). Further,

this may be indicative of a protective factor for men with CFS, as individuals with CFS have a propensity to live without a partner, and social integration is typically ascertained through peer or friend networks as opposed to romantic partnerships (Cutrona & Russel, 1987). However, it could also present as a risk factor, as social integration demonstrated the largest difference between individuals with CFS as compared with those without CFS, with individuals with CFS experiencing significantly less social integration than those without CFS.

We then used a hierarchical regression analysis to examine the predictive power of overall social support on distress in individuals with CFS after controlling for sociodemographic and mental health characteristics. After controlling for sociodemographic and mental health characteristics, which accounted for 36.6% of the variability in distress, social support was found to predict an additional 10.4% of the variability in distress in individuals with CFS. This is indicative of the important role social support plays in CFS, consistent with previous findings that increased social support predicts lower dysfunction in this population (Moss-Morris et al., 1996). Further, as distress has been found to predict symptom severity in individuals with CFS (Pawlikowska et al., 1994; Wessely et al., 1996), this finding also reflects the importance of considering a holistic, biopsychosocial approach with CFS. The additional impact of social support indicates that non-physiological factors may be impacting on functioning in individuals with CFS and are important considerations in examining disease onset, maintenance, and treatment of CFS.

Clinical Implications

The lack of social support for individuals with CFS, and the impact this has on distress, are indicative of poor health outcomes in this population. Social isolation has been previously found to have implications for worsening health, and even mortality in other populations (Holt-Lunstad et al., 2010; O'Keefe et al., 2019; Sakurai et al., 2019; Tamminen et al., 2019). Given previous findings that individuals with CFS are unable to maintain employment and even leave their homes (Komaroff & Buchwald, 1991; Pendergrast et al., 2016), the lack of social support reported by individuals with CFS may reflect a maintaining factor in illness which may serve to worsen symptoms. This may be a consideration for treatment, and indicate that group psychotherapy and peer support groups may benefit this population.

The differential predictive ability of domains of social support on distress by gender may have implications for treatment options as well. Where women experience benefit of guidance and reassurance of worth, men with CFS are more likely to benefit from a sense of belonging. As a result, women may benefit from psychoeducation related to their illness, and working toward an intrinsic sense of value/worth (Bartholomew & Horowitz, 1991), whereas men may be more likely to benefit from involvement in group activities more broadly (Duncan et al., 1993).

Given the importance of social support in this population, the relationship all healthcare providers have with individuals with CFS is important to consider in treatment. This is of particular interest for this population given the difficulties reported by healthcare providers in their experience with this population. General practitioners who work with individuals with CFS have identified that they see this population as lacking in

work ethic and stoicism (Raine et al., 2004). Further, they identified finding treatment of this population to be burdensome, and that they are reluctant to refer them for mental health services in spite of acknowledging a mental health component of illness (Raine et al., 2004). This is consistent with the finding that the physician-patient relationship is the largest predictor of whether a physician will make a referral to a psychologist (O'Barto-Trainer, 2017), and reflects the impact of healthcare relationship on treatment for individuals with CFS. In one study, the view that CFS was "all in the patient's head" was related to lack of knowledge about the illness on the part of the healthcare provider suggesting that the difficulties experienced may be ameliorated by further education (Brimmer et al., 2010).

Limitations

Though these are important findings, there are also limitations to the current study. The first is the difficulty of examining data that are cross-sectional. The information collected and analyzed in this study reflects only a snapshot of the experience of the individuals for whom data were collected. This has implications in terms of interpretation of the data analysis as I are limited in speaking about causality. While there are strong relations amongst the variables captured by this study, I are unable to determine whether these factors reflect causality in terms of onset and maintenance of illness in individuals with CFS, and are simply able to speak to the differences that exist for this population as compared with individuals without CFS, as well as the relations that exist between variables and possible mechanisms behind such correlations.

Further, with secondary data analysis, I were unable to capture certain psychological variables which could be underlying some of the findings herein and acting

as mediating variables. In particular, I were unable to capture attachment style. Given the importance of social support in this population, an understanding of attachment style could reflect an important underlying factor pertinent to onset and treatment in this population (Waldinger et al., 2006).

Conclusion

The findings herein have important implications for the population of individuals with CFS. The inherent difficulty in accessing social support by individuals with CFS due to the limitations associated with their health status reflect a significant concern due to the clear importance of social support for this population. This may reflect an overlooked area for intervention which could help to alleviate symptomology for individuals with CFS. In particular, the differential findings by sex demonstrate the importance of considering all biopsychosocial factors in the treatment of illness; treatments that may benefit women may not have the same impact for men, and vice versa. Additionally, these findings reflect important considerations for healthcare practitioners, as they demonstrate the importance of the therapeutic relationship in treatment.

Chapter 4: General Discussion

In an effort to examine the findings of these studies holistically, I would like to present the possible underpinnings of the role of social support and distress in this population utilizing the results found in Study One. In conceptualizing this population as a whole, I largely see individuals between the ages of 45–64, who live alone, are unable to work, and are financially insecure. When considering the availability of sources of social support available to this population, I find that they are not supported by partners, nor do they have co-workers. Further, the severity of illness in this population is such that they are often unable to work, and previous findings demonstrate that they are often housebound and even bedbound related to their illness (Komaroff & Buchwald, 1991; Pendergrast et al., 2016). As a result, it is unlikely that they are managing to afford or engage meaningfully in social relationships which involve regularly scheduled recreational activities, in keeping with the difficulties in this domain experienced by other chronic illness populations (Tabuteau-Harrison et al., 2016). Based on these constraints, it becomes apparent that social support would likely be limited in this population, and individuals with CFS likely must rely on family and pre-existing friendships for social support. However, much like in other chronic illness populations, pre-existing relationships are often lost or changed following onset of illness, and may actually become unsupportive (Tabuteau-Harrison et al., 2016; Yilmaz et al., 2016). Taken together, the reduced social support reported by individuals with CFS as compared with those without CFS follows from the sociodemographic characteristics of this population taken in the context of chronic illness.

Individuals with CFS experience a wide range of mental health concerns, which likely are impacting on the social support they are able to access. Most particularly, they are over 14 times more likely to have PTSD, over twice as likely to have witnessed or experienced physical violence in their homes, or experienced sexual violence in childhood, and are roughly three times more likely to have experienced more than one form of childhood maltreatment. With the presence of childhood maltreatment in individuals with CFS, taken with the finding that individuals with chronic illness often experience, and are greatly affected by, negative and unsupportive social interactions (Ray, 1992; Yilmaz et al., 2016), it is consistent that I would see difficulties with social support, and particularly in the domains of attachment, guidance, and social integration in this population. It is of great interest then that I see such a high correlation between the two social support domains of guidance and attachment ($r = .834$). The overlap of guidance support and attachment support may be indicative of such negative and unsupportive social interactions experienced by this population within their support network, as they report significantly less support in these domains compared to individuals without CFS. Previous attempts to reach out in ostensibly safe and secure relationships for advice with negative or unsupportive responses may reduce the safety and security felt within those relationships, and at the same time reduce the perception of that relationship as being available for guidance support.

When considering interpersonal relationships and social support, the findings related to prevalence of PTSD and childhood maltreatment in individuals with CFS are striking, as 82% of children who have experienced maltreatment demonstrate disorganized attachment, such that they have a poor view of both self and others

(Bartholomew & Horowitz, 1991). Disorganized attachment has been linked to lower social competence, decreased reliance on others, lower romantic involvement, and hostility in romantic relationships (Bartholomew & Horowitz, 1991; Sroufe, 2005). These difficulties, while not measured in our study, may be reflected through examining the differences in marital status, household size, and social support domains. Individuals with CFS are significantly more likely to be living alone, and single/divorced/separated/widowed than individuals without CFS, consistent with lower romantic involvement.

Further, the global discrepancy in social support across all domains reflects the difficulties in accessing social support and social relationships within this population. This is particularly concerning as lower perception of social support has been found to predict development and perpetuation of insecure attachment in women over a period of two years (Cozzarelli et al., 2003), and the constraints on individuals in this population would reduce their ability to access social support. Such constraints related to health status would ultimately perpetuate insecure attachment and difficulties in social relationships. This could ultimately lead to a cyclical impact of social support and childhood maltreatment in this population, whereby childhood maltreatment may result in disorganized attachment, which perpetuates interpersonal difficulties and disruption of social support, which perpetuates insecure attachment, and so on. When an additional factor, such as chronic illness, is added to this situation, I expect to see a further detrimental impact on interpersonal relationships.

Additionally, the prevalence of childhood maltreatment and PTSD in this population lends some possible understanding into the distress experienced by individuals

with CFS. When viewing distress as a chronic stress response, the role of childhood maltreatment and trauma can be seen as that of the stressors. Consistent with the work of Selye (1956), the impact of chronic stressors and chronic stress, I would expect to see a dysregulation impact on the brain's HPA axis, ultimately impacting a variety of biological processes including sleep, pain, and immune responses. These underpinnings of distress have been previously demonstrated in the literature examining the long-term impacts of childhood maltreatment and trauma.

Clinical Implications

Importance of the biopsychosocial model. The implication of these findings demonstrates the importance of the biopsychosocial model in exploration of symptomology in CFS. The history of this illness reflects a desire to place it in the context of either biological or psychological in origins, but not both. However, this prevents a holistic understanding of disease, and the importance of recognizing the bidirectional relationships of biological, psychological, and social factors. Ultimately, CFS does not have to be classified as either biological or psychosocial in nature, and may in fact be best understood as having biological, psychological, and social implications, all of which are important in conceptualization and treatment (Bayliss et al., 2014).

When I consider other disorders, even those that are considered to be "purely psychiatric," such as functional neurological symptom disorders (e.g., psychogenic nonepileptic seizures), they demonstrate a biological impact exhibited by neurological differences (LaFrance et al., 2013). Then, when reflecting on those disorders that are considered to be biological in origin — such as multiple sclerosis, epilepsy, and amyotrophic lateral sclerosis — psychological variables such as distress and emotion

regulation often have striking impacts on symptomology (Artemiadis et al., 2011; Houpt et al., 1977; van Campen et al., 2015)

There is also a clear relationship between premorbid stressors and development of CFS symptomology when I examine the existing literature and findings herein (Heim et al., 2006; Kempke et al., 2013; Nater et al., 2011). I see that individuals with CFS experience increased life stressors leading up to onset of symptomology, and that chronic stressors from childhood, such as childhood maltreatment, present as risk factors for illness onset in this population. However, this does not negate the physical symptomology of the illness and the emerging evidence of biomarkers related to diagnosis in individuals with CFS (Carruthers et al., 2011; Esfandyarpour et al., 2019). In fact, when I consider these factors to be reflective of chronic stress, and reflect on the impact of chronic stress on the body, it is only natural that there would be physical symptoms resultant from these factors (Selye, 1956). As a result, it is important to consider how all predisposing, precipitating, and perpetuating factors contribute to disease in individuals with CFS, which can only be done by ensuring all biopsychosocial factors are captured in our understanding.

While the concerns and criticisms about the biopsychosocial perspective of CFS come from a good place, in terms of trying to ensure clinicians remain patient-centred (Geraghty & Esmail, 2016), it would be reductive and irresponsible not to consider the impact of all factors in understanding the onset in, and exploring treatment options for, individuals with CFS (Engel, 1977). While the self-stigma of having psychological factors contribute to illness in this population may be distressing for certain individuals with CFS, by discounting psychological factors in illness, healthcare providers and

researchers would ultimately be contributing to and perpetuating said stigma (Corrigan & Watson, 2004; Engel, 1977; Raine et al., 2004; Thachuk, 2011). This would indicate that there is something invalid about such factors, and could in fact be more distressing and invalidating in instances where a biological basis for illness cannot be established. This impact would be particularly concerning as it has been previously established that individuals with CFS who insist on a biological basis of disease experience greater impairment in the long term than those who are open to the impact of psychosocial factors (Wilson et al., 1994). Further, discounting psychological factors would limit research which could ultimately be helpful in preventing and treating CFS as it would limit our understanding of illness (Engel, 1977).

Hints into etiology and the role of trauma. While this is a cross-sectional study exploring primarily current circumstances of the participants, meaning I are limited in the exploration of etiology, there is one aspect within our study which allows us to consider possible etiology in development of CFS. As individuals with CFS are significantly more likely to have experienced childhood maltreatment, and multiple forms of childhood maltreatment, it is important to consider how such premorbid experiences might impact an individual's development of CFS later in life, and how this might occur.

When considering the biopsychosocial factors in illness onset and etiology, trauma and childhood maltreatment are often considered to be captured within the psychological and social spheres as they are related to such things as environmental factors, interpersonal relationships, emotions, view of self, psychiatric diagnoses, and attachment style (Krzeczkowska et al., 2015; Ogle et al., 2015; Pick et al., 2019). There is

certainly reason for this, and the findings herein reflect these factors in the results related to social support.

Individuals with CFS are significantly more likely to have experienced childhood maltreatment, and also identify significantly less social support than those without CFS. These findings demonstrate a possible connection between childhood maltreatment and later interpersonal relationships and attachments in individuals with CFS. This may reflect the difficulty individuals who have experienced childhood maltreatment have in forming healthy relationships, trusting in relationships, and accessing social support (Courtois et al., 2012; van der Kolk, 1996). It is clear from the findings that individuals with CFS experience difficulty with social support, and that this has implications for levels of distress; it may be that childhood maltreatment reflects a mediating factor in this relationship.

Further, given the limitations associated with this illness, including being without work, and often being housebound (Komaroff & Buchwald, 1991; Pendergrast et al., 2016), accessing social support already would present a challenge to individuals with CFS. The social implications of childhood maltreatment on attachment style and perception of relationships may prove to be too large a barrier to overcome given these pre-existing limitations of illness. However, this does not capture the full picture of the impact of childhood maltreatment.

In examining the biological impact of trauma, I see changes which could have implications for the onset of CFS. Individuals who have experienced childhood maltreatment demonstrate significant differences in the structure and function of their HPA axis as compared to individuals who have not experienced childhood maltreatment

(Bunea et al., 2017; Heim et al., 2002; Kaess et al., 2018; McCrory et al., 2011). The structural differences include smaller hippocampal volume, and changes in pituitary volume, while the functional differences reflect increased adrenocorticotropic hormone response, and differences in cortisol levels following a stressor. Moderate stress in childhood has been connected to blunted cortisol levels in response to stressors at older ages (Kaess et al., 2018; Parker et al., 2004), while severe stress in childhood, and more instances of childhood maltreatment, has been connected to a heightened and lengthened cortisol response to stressors, taking greater time to return to baseline (Ouellet-Morin et al., 2019). These differences are consistent with the neurological changes found in individuals with CFS, whereby there have been findings of blunted or dysregulated cortisol response, as well as decreased neuronal density in the hippocampus (Chen et al., 2008; Tomas et al., 2013). Further, this is consistent with our finding that individuals with CFS are three times more likely to have experienced multiple types of childhood maltreatment than individuals without CFS.

Of interest in considering the onset of CFS is the impact the biological implications of childhood maltreatment could have on systems implicated in CFS symptomology. With dysregulation in these structures related to childhood maltreatment, I could see the immune system become compromised, increased inflammation, disruptions in sleep, muscle weakness and pain, abdominal pain, cognitive-perceptual disruptions, and most notably, fatigue (Tomas et al., 2013), reflecting the symptomology of CFS as outlined in Table 1. Further, HPA axis dysregulation has also been demonstrated to be found in individuals with CFS with consideration for the involvement in onset and maintenance of the disease state (Poteliakhoff, 1981). These impacts are also

consistent with early literature regarding the impact of chronic stress. Selye (1975) identified that such things as hereditary predisposition and environment play a role in which systems and organs will be implicated in the chronic stress response, and will most readily be affected. This reflects the heterogeneous presentation of CFS, as each individual would be affected in a different manner by chronic stress based on their genetics and environment.

Treatment implications. The implications of the findings within this study related to mental health diagnoses, childhood maltreatment, difficulties with social support, and significant distress are such that psychological treatment would likely be of benefit for this population. This is further supported when these findings are placed in the larger context of the existing body of literature related to the impacts of chronic stress, and consistency with attachment insecurity.

Consistent with much of the literature related to the efficacy and effectiveness of psychotherapy more generally in recent years, cognitive behavioural therapy (CBT) has been examined for its utility with individuals with CFS. While the early research regarding CBT with individuals with CFS demonstrated promising results, more recent literature has called into question the benefits of CBT, suggesting that the functional improvements are minimal and not sustained following completion of treatment (Geraghty & Blease, 2018). There has also been a question regarding the cognitive-behavioural conceptualization of CFS. This conceptualization identifies that the belief in a biological basis of illness reflects an avoidance into the true nature of illness, and an avoidance of responsibility for one's care (Geraghty et al., 2019). The criticisms of this model identify that there has been a growing body of literature with evidence presenting

physiological markers of CFS, and biological bases of illness onset in CFS. As a result, these criticisms identify that this conceptualization is lacking in evidence and contrary to the existing body of literature. This has brought with it criticism into the claim of a psychological component of illness in individuals with CFS. However, as previously discussed, when considering the bidirectional relationship of psychosocial and biological factors impacting on one another, presenting an illness such as CFS as entirely biological or entirely psychological may in fact be reductionistic, and dismissive of the true nature of physiological and psychological processes as interactive and inseparable.

The criticisms of CBT for individuals with CFS also do not consider the significant portion of individuals with CFS who do report benefit following treatment with CBT. These individuals identify a reduction in physical symptoms of CFS, improvement in functioning, greater quality of life, improved illness management, and even no longer identifying themselves as having CFS at long-term follow ups (Clark, 2019; Janse et al., 2017).

In addition to CBT, further exploration of alternative therapies may also be warranted when considering the findings related to childhood maltreatment, PTSD, and even social support in this population. Individuals with a history of childhood maltreatment and trauma often have difficulties with forming and maintaining healthy relationships (Courtois et al., 2012; van der Kolk, 1996). As a result, more relationally-focused interventions may also be beneficial in the treatment of individuals with CFS. Further, with the history of childhood maltreatment and possible implications toward attachment insecurity, there may be a tendency toward somatization in this population above and beyond any biological basis of illness (Waldinger et al., 2006). As a result,

examining treatments which have proven successful for individuals with SSRD, may be of benefit for individuals with CFS. One such intervention is intensive short-term dynamic psychotherapy which has demonstrated efficacy in psychological and physical symptom reduction in individuals with somatic disorders (Town & Driessen, 2013). Given this beneficial impact with similar medically unexplained symptoms (Abbass, 2005), it may be of benefit to explore this therapeutic modality with individuals with CFS.

Beyond the specific form of psychotherapy, the findings of this study reflect the importance of relationships with mental healthcare providers. There is a clear relationship between social support on distress in this population, even above and beyond the impact of demographic and mental health factors. In psychotherapy, the therapeutic relationship has been repeatedly found to be one of the biggest predictors of change, regardless of treatment modality, accounting for twice as much variance than the techniques of particular types of therapy (Norcross & Lambert, 2011). For individuals with CFS, the therapeutic relationship may be of even greater importance in psychological treatment following from the finding that social support is significantly lower in this population than individuals without CFS, and also significantly related to distress across all domains, even after controlling for demographic and mental health variables.

Future Directions.

There are a number of areas of study which would provide greater insight into the conceptualization and treatment of illness with individuals with CFS. One such way would be to conduct follow up research, even using the existing dataset, to examine the possible role of physical health comorbidities, and overlap in other conditions which have

HPA axis involvement such as autoimmune conditions and cardiac concerns (Gold et al., 2005; Ranabir & Reetu, 2011). This would allow us to determine possible information about onset and maintenance of illness in CFS, as it is often considered a set of symptoms as opposed to one particular illness (Holmes et al., 1988). Greater insight into these comorbidities could allow for improved treatment with this population, as well as to establish possible subgroups within the population of individuals with CFS.

Further, with this database, I could explore the relationship between access of various services in the preceding twelve months and social support with individuals with CFS. As previously noted, relationships with healthcare providers would likely be especially important with this population given that social support was found to significantly predict distress above and beyond demographic and mental health factors. It has also been established that general practitioners have described individuals with CFS to have undesirable qualities (Raine et al., 2004). As a result, exploring how individuals with CFS have utilized services, and any noted reasons for either not accessing, or ceasing access to services could provide insight into how this population could be better served in the healthcare system, and any barriers to treatment. This would also be particularly beneficial given the findings regarding general practitioners' impressions of individuals with CFS as having mental health involvement but not referring for mental health services (Raine et al., 2004). Such analyses would allow for an understanding as to whether this issue is reflected in a Canadian sample, or if the differences in the healthcare system create a positive difference for this population. These research questions may also be explored using the upcoming annual CCHS which will also be asking respondents

about a diagnosis of CFS, engagement with healthcare practitioners, and barriers to these services (Statistics Canada, 2020).

It will also be important to consider new research with this population beyond the scope of this database. Given the limited ability to explore etiology with this study, it is important to consider more longitudinal studies, and also to ensure such variables as length of illness, age at onset, and severity of symptoms are captured in future research. This would allow greater understanding in onset of illness, and also possible opportunities for prevention of onset and early identification/intervention in other chronic illness populations.

As mentioned, I were unable to capture certain psychological variables which could provide a deeper conceptualization and improved insight into treatment for individuals with CFS. In particular, it would be beneficial to examine the attachment styles of this population given the prevalence of childhood maltreatment, and importance of social support found in this study. Individuals who experience somatization of emotions, with similar symptom presentations as individuals with CFS, frequently are found to be insecurely attached, and to even have disorganized attachment (Abbass, 2005; Holman et al., 2008; Waldinger et al., 2006). Disorganized attachment has also been linked to several psychosocial factors consistent with what is seen in individuals with CFS including lower social competence, decreased reliance on others, and lower romantic involvement (Bartholomew & Horowitz, 1991; Sroufe, 2005). Further, in animal models, attachment disruption is also found to result in HPA axis dysregulation (Rincón-Cortés & Sullivan, 2014), consistent with that seen in individuals with CFS (Tomas et al., 2013). Given these similarities between individuals with CFS and individuals with disorganized

attachment styles, it is possible that attachment style is mediating the relationship between social support and distress, and could even be a contributing factor in illness perpetuation with beliefs about the self, others, and interpersonal relationships resulting in significant distress, and ultimately exacerbating dysregulation in the HPA axis in this population.

However, not all individuals with CFS present with childhood maltreatment or psychiatric diagnoses. As a result, it may also be of benefit to explore differences between individuals with CFS with and without presentations of childhood maltreatment and psychiatric diagnoses. This may provide information about possible subtypes of illness with differing etiologies and illness trajectories. One study completed a cluster-analysis finding five possible subtypes based on co-morbidities which may present as a jumping off point for this sort of future investigation (Castro-Marrero et al., 2017). Further, there may be specific protective factors for those without psychiatric diagnoses which could shed light into specific skills that would be beneficial to develop for individuals with CFS who have comorbid psychiatric diagnoses.

Finally, the information derived in this study related to mental health in CFS reflects the importance of examining additional treatment options for this population, and the importance of holistic treatment through the use of an interdisciplinary team approach. Interdisciplinary group treatment has been previously found to benefit individuals with CFS with respect to improvement of quality of life, and fatigue severity suggesting that interdisciplinary team treatment may be both of benefit and also cost effective in managing CFS. Further, exploration of additional psychotherapy modalities which have been demonstrated to have efficacy for individuals with somatization, and

similar symptom presentations as individuals with CFS may be warranted both given the possible benefits to individuals with CFS in exploring new options, and also given the continued difficulty in reaching symptom remission in this population (Abbass, 2005; Town & Driessen, 2013)

Conclusion

The current research reflects what is, to the best of our knowledge, the first nationwide study into a) the demographic factors of CFS, b) the perceived social support for individuals with CFS, and c) the relationship between social support and distress across domains in individuals with CFS. As the prevalence of CFS reflects greater than 1.5% of the population, there is a relative dearth of research in this area. The prevalence of CFS reflects a larger proportion of individuals than many of the illnesses for which comparisons were made within this document, including multiple sclerosis, amyotrophic lateral sclerosis, and seizure disorders (Hirtz et al., 2007); however, its presence in the literature does not reflect this. This is likely, and sadly, a practical reflection of the lack of social support experienced by individuals with CFS.

The inherent difficulty in accessing social support by individuals with CFS due to the limitations associated with their health status reflect a significant concern due to the clear importance of social support for this population. This may reflect an overlooked area for intervention which could help to alleviate symptomology for individuals with CFS. In particular, the differential findings by sex demonstrate the importance of considering all biopsychosocial factors in the treatment of illness; treatments that may be of benefit for women may not have the same impact for men and vice versa. Additionally,

these findings reflect important considerations for healthcare practitioners, as they demonstrate the importance of the therapeutic relationship in treatment.

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Table 1

Diagnostic criteria of CFS throughout the years

Author	Year	Criteria
Holmes et al.	1988	Must have new onset of persistent or relapsing fatigue with no previous history of similar symptoms that does not resolve with rest, and impairs functioning below 50%, which is not better accounted for by another condition. An additional 8 of following must be present: mild fever, sore throat, painful lymph nodes, unexplained muscle weakness, muscle discomfort/myalgia, prolonged fatigue post-exercise, headaches, arthralgia without swelling or redness, neuropsychologic complaints, sleep disturbance, development over a few hours to a few days. Further, two of the following must also be documented by a physician: fever, pharyngitis, tender lymph nodes.
Fukuda et al.	1994	Chronic (persistent or relapsing) fatigue for a minimum of six months, as well as four of the following: impaired memory/concentration, sore throat, tender lymph nodes, muscle pain, multi-joint pain, new headaches, unrefreshing sleep, post-exertion malaise
Carruthers et al.	2003	New onset, unexplained, persistent, or recurrent fatigue, post-exertional malaise, sleep dysfunction, and pain. Additionally, at least two cognitive symptoms, and at least one symptom from two of the following categories: autonomic, neuroendocrine, immune manifestations.
Carruthers et al.	2011	Post-exertional exhaustion which lasts for a minimum of 24 hours, at least one neurological impairment (cognitive, pain, sleep disturbance, sensory/perceptual/motor), at least one immune/gastrointestinal/genitourinary impairment, at least one energy production/transportation impairment.

Note. These are the most commonly used definitions. Those which have not been used in the review of relevant literature have not been included.

Table 2

Sociodemographic comparisons between individuals with CFS versus without CFS

	Overall χ^2	*p*	OR Comparison	OR
Province of Residence	16.729	.053		
Age	60.988	<.001	>45 with CFS versus without CFS	2.526**
Sex	30.268	<.001	Female with CFS versus without CFS	2.038*
Race (White vs. Non-white)	1.071	.301		
Marital Status	79.767	<.001	Single/Divorced or separated/Widowed with CFS versus without CFS	1.923*
Household Size	51.955	<.001	1 person with CFS versus without CFS	2.116*
Worked at a Job/Business	230.185	<.001	No with CFS versus without CFS	5.298***
If Working: Full-time or Part-time	8.240	.004	Part-time with CFS versus without CFS	1.899*
Main Source Household Income	229.788	<.001	Not employment income with CFS versus without CFS	4.880***
Total Household Income	185.931	<.001	<$40,000 with CFS versus without CFS	4.121**
Main Source Personal Income	82.100	<.001	Not employment income with CFS versus without CFS	3.655**
Total Personal Income	123.166	<.001	<$20,000 with CFS versus without CFS	2.689**
			<$30,000 with CFS versus without CFS	3.195**

Difficulty Meeting Expenses with Household Income	237.358	<.001	Yes with CFS versus without CFS	5.463***
Highest Level of Education by Respondent	14.140	.003	Less than secondary school graduation with CFS versus without CFS	1.790*
			Post-secondary graduation without CFS versus with CFS	1.198

Note: * = small effect size; ** = medium effect size; *** = large effect size

Table 3

Mental health comparisons between individuals with CFS versus without CFS

	Overall χ^2	*p*	OR Comparison	OR
Has a Mood Disorder	513.714	<.001	Yes with CFS versus without CFS	9.954***
Has an Anxiety Disorder	346.626	<.001	Yes with CFS versus without CFS	7.806***
Has ADHD	47.978	<.001	Yes with CFS versus without CFS	3.821**
Has PTSD	478.680	<.001	Yes with CFS versus without CFS	14.339***
Experienced Childhood Maltreatment	37.160	<.001	Yes with CFS versus without CFS	2.217*
Number of Types of Childhood Maltreatment	216.427	<.001	Two or more with CFS versus without CFS	2.935**

Note: * = small effect size; ** = medium effect size; *** = large effect size

Table 4

T-test comparisons between individuals with CFS and those without CFS

	Population Mean (*SD*)	CFS Mean (*SD*)	*t*	*p*	Cohen's *d*
K10 Distress	5.783 (5.799)	14.272 (7.977)	17.550	<.001	1.464***
SPS (overall)	36.016 (4.429)	33.517 (5.686)	-7.071	<.001	0.564**
SPS (attachment)	7.255 (1.013)	6.771 (1.328)	-5.999	<.001	0.478*
SPS (guidance)	7.316 (1.021)	6.810 (1.411)	-5.876	<.001	0.496**
SPS (reliable alliance)	7.366 (0.938)	6.923 (1.299)	-5.626	<.001	0.472*
SPS (social integration)	6.991 (1.111)	6.244 (1.491)	-8.167	<.001	0.600**
SPS (reassurance of worth)	7.022 (1.030)	6.466 (1.373)	-6.581	<.001	0.540**

Note: * = small effect size; ** = medium effect size; *** = large effect size

Table 5

T-test comparisons between men with CFS and women with CFS

	Male Mean (*SD*)	Female Mean (*SD*)	*t*	*p*	Cohen's *d*
K10 Distress	13.812 (7.673)	14.466 (8.115)	-.615	.539	0.081
SPS (overall)	32.286 (5.900)	34.038 (5.528)	-2.286	.023	0.297*
SPS (attachment)	6.370 (1.436)	6.942 (1.244)	-3.305	.001	0.398*
SPS (guidance)	6.568 (1.449)	6.914 (1.385)	-1.855	.065	0.239*
SPS (reliable alliance)	6.732 (1.258)	7.005 (1.311)	-1.598	.111	0.208*
SPS (social integration)	6.139 (1.206)	6.289 (1.597)	-.835‡	.405‡	0.094
SPS (reassurance of worth)	6.215 (1.429)	6.573 (1.338)	-1.949	.052	0.251*

Note: ‡ = Levene's test significant/equal variances not assumed; * = small effect size; ** = medium effect size; *** = large effect size

Table 6

Pearson's r correlations between domains of SPS-SF and K10 in individuals with CFS

	SPS-SF attachment	SPS-SF guidance	SPS-SF reliable alliance	SPS-SF social integration	SPS-SF reassurance of worth
Overall K10	-.383*	-.382*	-.359*	-.364*	-.418*
SPS-SF attachment		.834*	.690*	.641*	.724*
SPS-SF guidance			.744*	.579*	.631*
SPS-SF reliable alliance				.588*	.635*
SPS-SF social integration					.663*

Note: * = p <.001

Table 7

Stepwise regressions examining the impact of social support on distress in CFS

Population	Domains of SPS-SF in model	F	df	*p*	R^2
Individuals with CFS	Reassurance of worth, guidance	34.264	2, 255	<.001	.212**
Women with CFS	Reassurance of worth, guidance	26.219	2, 178	<.001	.228**
Men with CFS	Social integration	18.628	1,75	<.001	.199**

Note: * = small effect size; ** = medium effect size; *** = large effect size

Table 8

Hierarchical regression examining the impact of social support on distress in CFS

Block	F change	df	*p*	R^2 change
1: Demographic variables	3.422	16, 236	<.001	.188**
2: Mental health variables	9.199	7, 229	<.001	.178**
3: Social support	8.813	5, 224	<.001	.104**

Note: * = small effect size; ** = medium effect size; *** = large effect size