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Housebound versus nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome

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Abstract

Objectives—The objective of this study was to examine individuals with myalgic encephalomyelitis and chronic fatigue syndrome who are confined to their homes due to severe symptomatology. The existing literature fails to address differences between this group, and less severe, nonhousebound patient populations.

Methods—Participants completed the DePaul Symptom Questionnaire, a measure of myalgic encephalomyelitis and chronic fatigue syndrome symptomology, and the SF-36, a measure of health impact on physical/mental functioning. ANOVAs and, where appropriate, MANCOVAS were used to compare housebound and nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome across areas of functioning, symptomatology, and illness onset characteristics.

Results—Findings indicated that the housebound group represented one quarter of the sample, and were significantly more impaired with regards to physical functioning, bodily pain, vitality, social functioning, fatigue, postexertional malaise, sleep, pain, neurocognitive, autonomic, neuroendocrine, and immune functioning compared to individuals who were not housebound.

Discussion—Findings indicated that housebound patients have more impairment on functional and symptom outcomes compared to those who were not housebound. Understanding the differences between housebound and not housebound groups holds implications for physicians and researchers as they develop interventions intended for patients who are most severely affected by this chronic illness.

Keywords

Chronic illness; housebound; chronic fatigue syndrome; myalgic encephalomyelitis; severely ill

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Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) affect more than one million people in the United States.[1] Many patients face difficulties including identity loss, disconnection from social networks and issues accessing medical care.[2,3] The prognosis for patient recovery is relatively poor.[4–7] In addition, patients' quality of life is severely affected in areas such as marital and family relationships, financial security, daily routines, hobbies, and stamina.[8,9] In a study of several chronic diseases including cancer, stroke, schizophrenia, and renal failure, patients with ME and CFS had the lowest median quality of life.[10] Patients report functional limitations that are as debilitating as, or even more so, than Type II diabetes mellitus, congestive heart failure, multiple sclerosis, and end-stage renal disease.[9,11] Only 13% of patients are able to maintain full-time employment, and 25% or more are confined to their homes (housebound) or completely bedbound.[12,13]

Only about 0.5% of the ME and CFS literature focuses on patients who are housebound.[14] The few studies in this area have small sample sizes, or investigate patients across multiple illnesses.[2,6,15] Illustrative of these studies, Hill et al.[6] found that housebound patients had a poor prognosis for recovery, and illness outcome was not related to mode of onset, psychiatric illness, or chemical sensitivities. The study's findings are limited, as the sample size only included 23 patients. Wiborg et al.[15] also sampled patients with CFS and found those who were housebound had increased impairment, levels of daily fatigue, patterns of passive activity, and somatic attributions than those who were not housebound. These findings are also limited by their small sample of housebound patients ($N = 15$). These sample size limitations might be due to the difficulties these patients have in traveling to the researchers' laboratory settings. Regardless of the reasons, the absence of scientific literature in this area has limited understanding of housebound patients.

A limited number of studies of patients with ME and CFS who are housebound have been drawn from larger population sizes, obtained through questionnaires distributed by advocacy organizations. In these studies, respondents reported considerable difficulties accessing basic services, social isolation, a lack of sympathy/acceptance of their condition, misdiagnosis, and ineffective treatment options.[16,17] While this information with larger data sets is useful in constructing a framework for understanding the experience of housebound patients, this research varies in quality and comprehensiveness, and has not been published in peer reviewed journals.

There has been one published study with a robust sample size of 124 severe patients.[18] This study assessed premorbid personality components as well as pre-illness exposure, occupation, immunizations, allergies, and infections. Additionally, researchers evaluated the effects of early stage illness management and relationship with medical practitioners. Findings from this study indicated numerous risk factors for severe ME and CFS, including being a homemaker or student, a family history of ME or CFS, and reported exposure to chemicals in the home.[19] However, the personality testing instrument used in this study had not been validated for use by people with ME or CFS, nor was it designed for use with achonically ill sample.[20,21] Participants were instructed to reflect on their prediagnosis personality, but this introduces self-report and recall bias considering many patients had been sick for years or decades. Most importantly, this study did not assess multiple domains

of symptomology (neurocognitive, postexertional malaise, bodily pain, etc.) and functionality (social, physical, and emotional).

The present research focuses on the differences in symptoms and functionality between housebound and not housebound patients with ME and CFS. Understanding the functional and symptomatic differences and similarities between housebound and not housebound patients is of importance given the paucity of research in this area. The objective of the present study was to evaluate a larger sample of housebound patients and contrast them with those who were not housebound. It was predicted that the housebound sample would have more impairment on functional and symptom outcomes than those who are not housebound.

Method

Participants

Approval for the present study was received from the DePaul University review board (#LJ071012PSY). Participants in the study were derived from one United States (US), one United Kingdom (UK), and two Norwegian samples. The US sample, referred to as the DePaul sample, was derived from a convenience sample of adults who self-identified as having ME and/or CFS. The sample from the UK, referred to as the Newcastle sample, was comprised of participants referred to the Newcastle-upon-Tyne Royal Victoria Infirmary clinic by primary care physicians. The first Norwegian sample, referred to as Norway 1, was derived from a sample of adults enrolled in a CFS self-management program. The second Norwegian sample, referred to as Norway 2, was derived from inpatients and clinic patients at a multidisciplinary ME/CFS Center.

DePaul sample—This sample was drawn from adults self-identifying as having CFS, ME, and ME/CFS. In order to accommodate participants unable to attend a clinic, a variety of Institution Review Board-approved recruitment methods were implemented. These methods included posting on internet forums, visiting support groups, and contacting individuals who had expressed interest in past or future research studies at DePaul. Participants chose from three options to complete measures: electronic survey, hard-copy survey, or verbal survey over the telephone. Participants were able to complete the survey at their discretion, as this illness can be unpredictable and symptoms can fluctuate from day to day. The first one hundred individuals to complete the survey received a $5.00 gift card to Amazon.com for their participation. Participants were at least 18 years of age, capable of reading and writing in English, and reported a current diagnosis of ME, CFS, or ME/CFS. Participants completed the study electronically, verbally over the telephone or as a hard copy. One participant was excluded due to incomplete data, and 216 participants were included in the present study. The majority of participants identified as female (84.2%), and 15.8% identified as male. Participants identified primarily as Caucasian (97.7%), with 1.9% identifying as other, and 0.5% as Asian. The mean age of sample participants was 52.0 (SD = 11.3). With regard to work status, over half of participants (56.7%) were on disability and 13.5% reported working full-time or part-time. In terms of education status, almost half (40.5%) of the sample held a graduate or postgraduate degree, 34.4% had obtained a college

degree, 18.1% had attended college for at least one year and 7.0% had completed high school or obtained a GED.

Newcastle sample—This sample was obtained from participants who had been referred for medical evaluation at the Newcastle-upon-Tyne Royal Infirmary Clinic on a suspected CFS diagnosis. Participants were evaluated by a physician and those who met eligibility criteria were invited to participate in the study and completed an informed consent process prior to participating. A total of 103 participants completed a hard copy questionnaire and three were excluded due to incomplete data. Participants in the Newcastle sample identified as almost entirely Caucasian (99.0%), with 1.0% identifying as multiracial. This sample identified as 82.5% female and 17.5% male. The mean age of the sample was 45.6 (SD = 14.0). With regard to work status, 37.5% of participants were working full-time or part-time with 30.2% of participants reported being on disability. Within the Newcastle sample, 20.9% of participants held a graduate or professional degree, 29.7% had a college degree, 24.2% had attended at least one year of college; 14.3% held a high school degree, and 11.0% had not completed high school.

Norway 1 sample—The first sample from Norway was obtained from participants in a randomized trial of a CFS self-management program. Participants were recruited from various sources, including physicians, waiting lists for patient education programs, and CFS patient organizations in the communities surrounding Oslo. Participants were required to be at least 18 years old with a diagnosis of CFS by a physician. Of the 176 participants, 175 were included in this study with one participant excluded due to missing data. Participants from the Norway 1 sample identified as predominantly Caucasian (99.4%), and only one participant identified as Other. Participants identified as 86.8% female and 13.2% male with an average age of 43.4 (SD = 11.7). In terms of work status, the majority of participants (84.0%) reported that they were currently receiving disability and only 9.7% of participants reported that they were currently working. With regards to education, 9.9% of participants had a graduate or professional degree, 40.1% had obtained a college degree, and 41.9% had obtained a high school degree. The remaining participants (8.1%) had not completed high school.

Norway 2 sample—The second Norway sample was composed of inpatients medical and outpatients at a multidisciplinary ME/CFS Center. Eligible participants were between 18 and 65 years of age and capable of reading and writing in Norwegian. Participants received a medical examination, including medical history and consultation by a psychologist. The examinations were conducted in order to rule out potential exclusionary conditions. Participants completed a written informed consent process, and the study measures were completed in hard copy form. Of the 65 total participants, 63 were included in this study; one was excluded due to missing data. Participants identified as predominantly Caucasian (95.1%), with 3.3% identifying as Other, and 1.6% identifying as Asian. The majority of participants identified as female (82.5%) with only 17.5% identifying as male. Many participants reported being on disability (76.2%) and 19.0% reported they were currently working. The mean age of the sample was 34.9 (SD = 11.6). With regard to education,

11.1% held a graduate or professional degree; 25.4% had obtained a college degree; 46.0% had a high school degree; and 17.5% had not completed high school.

Materials

The DePaul Symptom Questionnaire—Participants completed the DePaul Symptom Questionnaire (DSQ), a 99-item self-report measure of ME and CFS symptomology that measures symptoms and relevant health items related to the Clinical Canadian Criteria, ME International Consensus Criteria, and Fukuda et al. criteria.[22–25] The questionnaire includes questions regarding demographic information as well as medical, social and occupational history. The DSQ is available in the shared library of Research Electronic Data Capture (REDCap), hosted at DePaul University: https://redcap.is.depaul.edu/surveys/?s=tRxytSPVVW.

Housebound status—The DSQ includes a measure that asks participants to describe their fatigue/energy related illness.[25] Participants that responded either "I am not able to work or do anything, and I am bedridden," or "I can walk around the house, but I cannot do light housework," were classified as Housebound. Participants that responded "I can do light housework, but I cannot work part-time," or indicated more functioning (participating in family responsibilities, working part-time or full-time) were classified as not housebound. This item on the DSQ had a test–rest agreement of 77% and a good kappa coefficient, $K = 0.68$, $p < 0.001$.

Symptoms—The DSQ contains a 54-item self-report measure of symptomology.[25] Participants rated symptom frequency over the past six months on a 5-point Likert scale: 0 = none of the time, 1 = a little of the time, 2 = about half of the time, 3 = most of the time, and 4 = all of the time. Participants rated symptom severity on a 5-point Likert scale: 0 = symptom is not present, 1 = mild, 2 = moderate, 3 = severe and 4 = very severe. Frequency and severity scores were multiplied by 25 to create 100-point scales. These 100-point scales were averaged yielding one composite score for each symptom. The DSQ demonstrated strong construct, convergent, and discriminant validity as well as good test-retest reliability when used to identify individuals with CFS or ME.[26,27] A factor analysis of these symptoms resulted in a three-factor solution, and these factors evidenced good internal consistency.[26]

Perceived energy quotient and expenditure—The DSQ asked participants to rate perceived daily and weekly energy and perceived expended energy on a 100-point scale (0 = no energy; 100 = abundant energy).[25] An energy quotient score was calculated by dividing the perceived energy by the perceived expended energy and multiplying by 100. Scores greater than 100 reflected a participant who pushed themselves beyond their energy resources. The perceived energy quotient measure has been found to have good test–retest reliability.[28] Additionally, participants reported the number of hours they spent doing household, social/recreational, family-related, and work-related activities in the past month.

Postexertional malaise—Participants responded to five items from the DSQ that were related to postexertional malaise.[25] These questions included questions such as "If you rest, how long until your fatigue/energy goes away?" and "If you feel worse after activities, how

long does this last," to which participants had the option to respond with various lengths of time. These items had good test–retest reliability.

Course of illness—One item regarding illness onset from the DSQ was included.[25] Participants were asked to indicate whether or not their illness began after one or more of the following: infectious illness, accident, vacation, immunization, surgery, severe stress, or an unspecified reason. Participants were also asked to specify over what period of time their illness developed; rapid (less than 1 month), gradual (less than 1 year) or slow (more than 1 year). A DSQ item that asked participants to describe the course of their illness was also included. Participants responded with one of the following answers: "Constantly is Improving," "Symptoms Persist/No change," "Symptoms Relapse," "Symptoms Fluctuate," or "No Symptoms Present." This item on the DSQ had a test–rest agreement of 77% and a good kappa coefficient, $K = 0.68$, $p < 0.001$. Participants were also asked to indicate their perceived cause of illness by choosing from the following: "Definitely Physical," "Mainly Physical," "Equally Physical and Psychological," or "Mainly Psychological." This item on the DSQ had a test–rest agreement of 80% and a good kappa coefficient, $K = 0.70$, $p < 0.001$.

Comorbidities—One item regarding comorbid conditions from the DSQ was included.[25] Participants indicated whether or not they had ever been diagnosed with one or more of the following: major depression, bipolar disorder, anxiety, schizophrenia, eating disorders, substance abuse, chemical sensitivities, fibromyalgia, or allergies. These measures demonstrated good test–retest validity, $K = 0.48–0.90$ or 100% agreement.

Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36 or RAND Questionnaire)—SF-36, or RAND Questionnaire, measures the impact of health on physical and mental functioning.[29] The SF-36 includes one multi-item scale that assesses this impact across eight different areas: physical functioning (limitations in physical activities because of health problems), role physical (limitations in usual roles due to physical health problems), bodily pain, general health, social functioning, mental health (psychological well-being), role emotional (limitations in usual roles due to emotional problems), and vitality on a 0–100 scale, where a higher score indicated better functioning. The SF-36 has demonstrated psychometric soundness in both the short and long term.[30] This measure had been found to have strong internal consistency as well as good discriminant validity as a measure of mental health and physical functioning across a variety of patient populations.[31,32]

Statistical analysis—All statistical analyses were performed by the DePaul group. An analysis of variance was conducted in order to determine any significant differences of demographics between DePaul, Newcastle, Norway 1, and Norway 2 groups. In order to explore the differences between severely ill, and less severely ill patients with ME and CFS, differences in functionality and symptoms between housebound and not housebound groups were compared. Due to unequal sample sizes and variances, Welch's F tests and Games-Howell post hoc tests were conducted to compare the RAND-36 scores and 100-point symptom scores of these groups, age was controlled for as a covariate. A chi-square analysis

was performed on measures pertaining to perceived energy quotient and expenditure, post-exertional malaise, course of illness, and psychiatric comorbidities.

Results

Demographics

Table 1 includes demographic data for all four samples, displayed separately. There was an overall significant difference between the groups on mean age, $F(3, 542) = 36.81$ at a significance of $p < 0.001$, with the exception of the Newcastle and Norway 1 groups. Chi-square analyses revealed significant differences in work status between groups χ^2 (18, $N = 550$) = 129.77, $p < 0.001$, as well as significant differences in education between all groups except Norway 1 and Norway 2, χ^2 (18, $N = 542$) = 247.18, $p < 0.001$.

Table 2 includes demographic data for all samples, comparing the results of housebound and not housebound groups. Previous literature has examined the differences in patients with CFS from the US and the UK. The UK sample was significantly more impaired with regard to role emotional and mental health measures on the SF-36 compared to the US sample.[33] The UK sample was significantly more symptomatic at the 0.05 level in 8 of 54 symptoms, indicating that illness experience may vary slightly between samples.[25] However, there were no significant differences on these measures between housebound and not housebound groups.

In the present study, there were no significance differences between groups with regards to age, race, education, or gender. Chi-square analyses revealed that the housebound group had a higher proportion of individuals who were currently receiving disability (86%) compared to not housebound individuals (57.2%), χ^2 (6, $N = 542$) = 44.94, $p < 0.001$.

Activity level

An analysis of covariance controlling for age and level of education revealed that housebound patients spent significantly less time on household tasks, $F(1, 352) = 37.87$, $p < .001$. Individuals who were housebound spent significantly less time at work, $F(1, 352) = 21.94$, $p < .001$ (See Table 3).

Individuals who were housebound reported less perceived available daily energy $F(1, 352) = 59.02$, $p < .001$. Housebound individuals reported more perceived fatigue than not housebound individuals, $F(1, 352) = 7.26$, $p < .001$. Individuals who were not housebound expended more perceived daily energy compared to housebound individuals $F(1, 352) = 32.27$, $p < .001$.

A chi-square test of independence was performed to examine the relationship between housebound/not housebound status and effectiveness of rest on fatigue/energy. The relationship between these variables was significant, χ^2 (3, $N = 537$) = 29.67, $p < 0.001$; 58.6% of housebound individuals reported that their fatigue/energy was not improved by rest while 40.7% of not housebound individuals reported that their fatigue/energy was not improved by rest. Regarding whether or not fatigue worsens after minimal physical effort, a significant effect was found, χ^2 (2, $N = 538$) = 15.56, $p < 0.001$ with 99% of housebound

participants answering “Yes” to this question and 86.9% of not housebound participants answering “Yes” to this question.

Course of illness

Regarding the course of illness, a significant effect was found χ^2 (5, N = 533) = 39.48, p < 0.001; 72.7% of individuals who were not housebound reported symptoms that relapsed or fluctuated while only 51.5% of housebound individuals reported symptoms that relapsed or fluctuated. There were no significant differences between housebound and not housebound patients with regards to cause of illness onset or length of time of illness onset. There were no significant differences in duration of illness at time of survey between housebound and not housebound groups. Finally, regarding illness attribution, a significant effect was found, χ^2 (5, N = 529) = 39.53, p < 0.001, with 83.4% of housebound individuals indicated they believed their illness definitely had a physical origin, compared to 52.9% of not housebound individuals.

Comorbid health conditions

There were no significant differences between housebound and not housebound individuals with regards to psychiatric illness, substance abuse, chemical sensitivities, fibromyalgia, or allergies.

Symptoms

Table 4 includes specific data on all symptom domains and associated composite symptom frequency and severity scores. Housebound individuals reported significantly higher symptoms compared to not housebound individuals across all symptom domains after controlling for participant age and level of education: fatigue, F(1, 340) = 39.98, p < .001; postexertional malaise, (F(1, 340) = 62.76, p < .001; sleep, F(1, 340) = 15.77, p .000; pain, F(1, 340) = 11.38, p < .001; neurocognitive, F(1, 340) = 11.49, p < .01; autonomic, F(1, 340) = 17.55, p < .001; neuroendocrine, F(1, 340) = 14.65, p < .01; immune, F(1, 340) = 28.20, p < .001.

Medical Outcomes survey

Housebound individuals reported significantly more limitations in physical activities due to health problems F(1, 494) = 140.78, p < 0.001, and more bodily pain F(1, 494) = 30.28, p < 0.001, compared to not housebound individuals. Housebound individuals reported significantly less vitality F(1, 494) = 14.82, p < 0.001, and significantly poorer general health, F(1, 494) = 44.67, p < 0.001 as well as poorer social functioning F(1, 494) = 85.43, p < 0.001 compared to not housebound individuals. There were no significant differences between housebound and not housebound individuals with regards to mental health functioning or limitations due to emotional problems.

Discussion

Consistent with previous findings, nearly 25% of participants in this study reported being too ill to leave their homes.[13,18] Based on previous epidemiological literature, it can be estimated that approximately 250,000 people are housebound due to ME and CFS in the

United States.[1] This housebound group consistently demonstrated significant impairment in functionality and amplified symptomatology compared to individuals who were not housebound. The housebound group's significantly increased symptoms across all domains supports patient narratives, accounts written by severely ill patients' families, and postings on various patient advocacy websites such as Action for ME, ME Association, and The 25% M.E. Group.[16,33] These results indicated that housebound patients consistently experience more frequent and more severe symptoms than their nonhousebound counterparts.

Patients have identified several concerns with regards to the general practitioner/patient relationship including failure to recognize and believe patients' experiences, failure to make appropriate referrals, and failure to appropriately diagnose the illness.[33] The present findings are key to cultivating an understanding of housebound patients within the healthcare community as these patients demonstrate significant differences in illness presentation. Previous research has demonstrated that a good relationship with general practitioners from the onset of illness is essential to avoiding severe presentation of the illness, yet current levels of acceptance and knowledge regarding ME and CFS among doctors are largely minimal and unsatisfactory to patients with ME and CFS.[18,35,36]

Based on responses to the SF-36 Medical Outcomes survey, the housebound sample was significantly more impaired with respect to functionality. Housebound respondents were significantly worse with regards to general health functioning, physical activities due to health problems, social functioning due to health problems, vitality, and bodily pain compared to not housebound individuals. These findings support previous literature that found housebound patients fared worse than outpatients across three dimensions; fatigue, daily functioning, and physical activity.[15] Additionally, these results are consistent with previous literature that suggested severely ill patients with ME and CFS face social isolation.[18] The significant differences in functionality between housebound and not housebound individuals is likely reflected in the comparable differences in energy availability and level of fatigue. Housebound individuals reported significantly more fatigue, prolonged post-exertional malaise and less energy than individuals who were not housebound. Similarly, housebound individuals found rest less effective to mitigate their fatigue, even if they rested for longer periods of time. Housebound individuals were more likely to experience a worsening of fatigue triggered by minimal physical or mental effort than not housebound individuals.

Housebound patients' increased impairment with regards to functionality may affect prognosis, illness severity, and recovery. The impaired physical activity and social functioning reported by housebound individuals may explain the difficulties faced by housebound patients as they try to get medical attention for their illness. A survey by Action for ME revealed that the most severely affected patients with ME receive the worst level of support, with less than 50% of bedridden patients monitored by a medical practitioner and 60% sometimes too unwell to travel to a clinic.[34] Impairment in physical activity due to severe symptoms may increase difficulty faced by severe patients with ME and CFS who attempt travel to a clinic. Impairment in social functioning due to severe symptoms may decrease the ability of a severely ill patient to access their social network for assistance traveling to a medical appointment. These findings indicate a potentially self-perpetuating

circle of severe illness and lack of access to care; with greater illness severity comes decreased access to care.

Analyses revealed no significant differences in prevalence rates of comorbid psychiatric conditions (major depression, bipolar disorder, anxiety, schizophrenia, eating disorders, and substance abuse) between individuals who were housebound and those who were not housebound. Results from the medical outcomes survey demonstrated that the housebound sample was not significantly more impaired with regards to mental health functioning or limitations in usual roles due to emotional problems. These results corroborate previous literature that found housebound and not housebound patients did not differ on most scales of psychological well-being, nor did emotional distress relate to general illness severity in patients with ME and CFS.[15,37] These results indicate mental health or problems with daily activities as a result of emotional problems are not predictive of whether or not an individual with ME or CFS will become housebound. Rather, the significant differences in functionality between housebound and not housebound individuals are reflected in physical functioning, bodily pain and problems with daily activities as a result of physical health.

One limitation of the present study is the lack of diversity with regards to race in all samples. The four samples were chiefly composed of individuals identifying as White. This may affect the generalizability of the present findings considering previous community-based epidemiology literature suggests a greater proportion of individuals from minority populations, namely Latino women, make up the overall prevalence for this illness.[38] Further research should be conducted with more ethnically diverse ME and CFS samples.

In an effort to produce a robust sample size of patients who are housebound, researchers in the current study combined four samples. This aggregation could represent a limitation of the study, however it does provide a more generalizable view of the data. The DePaul sample was collected from individuals who self-reported a diagnosis of ME, CFS, or ME/CFS that was eventually confirmed by endorsement of symptoms on the DSQ. The Newcastle sample was comprised of patients who were referred by a general practitioner to a specialist on the suspicion of a ME, CFS, or ME/CFS diagnosis. The Norway 1 sample was recruited from a CFS self-management program and the Norway 2 sample was recruited from a clinic. These samples may include individuals who are especially motivated and able to take part in research, which may distinguish them from the general population. Considering that previously reported findings from advocacy groups suggest severely ill housebound patients have difficulty accessing medical care, our recruitment methods may not include the most severely ill of patients. Therefore, our samples may not be representative of the entire continuum of severely ill patients, and future research should utilize research methods capable of including these severely ill patients (i.e., home visits; shortened measures to prevent participate fatigue) as well as place an emphasis on internal validity.

There were significant differences between the DePaul, Newcastle, Norway 1, and Norway 2 samples with regards to mean age, work status, and education. In order to account for these differences, analyses of the DePaul Symptom Questionnaire and Medical Outcomes Survey were repeated with age as a covariate. When age was controlled for, the results of analyses still demonstrated numerous significant differences between participants who were

housebound compared to those who were not. As an additional precaution, samples were separated and comparative analyses of housebound and not housebound groups were repeated. The pattern of results held (patients who were housebound experienced more severe symptoms and functional limitations compared to patients who were not housebound), however there was some loss of statistical power due to reduced sample sizes. In support of the hypothesis of the present research, these results suggest that differences between housebound and not housebound group are due to differences in functionality and severity of illness. The heterogeneity of the samples with regards to age, work status and education increases generalizability of the findings; however, future research should improve internal validity by utilizing similar recruitment methods for all data collection sites as well as improve generalizability by including more participants from lower income/educated and minority groups.

The present study corroborated the exploratory findings of previous literature that illustrated differences between housebound and not housebound individuals, namely that this group makes up about 25% of the total patient population and experiences a significantly more severe illness across all domains related to physical activity and functioning. Results of the current study demonstrated significant differences in both functionality and symptomology between housebound and not housebound patients and no significant differences on validated measures of psychiatric comorbidity, or mental health between these groups. Housebound patients consistently demonstrated a more severe illness. This severity has many potential consequences for both patients and health care providers; namely, it produces obstacles for housebound patients to access medical care. The practical implications for these findings include the need to develop interventions that are better tailored to the severely ill subset of patients, as their illness experience and functional limitations are significantly worse than those patients who are not housebound. Future research should examine the potential effects of tailored medical attention or established specialist services (including outreach services for the home) aimed at those who are housebound by ME and CFS. In order to better understand how to aide this severely ill population, programs need to be developed that provide services and resources to the homes of those that are not able to travel to obtain medical services or basic needs such as food and needed household supplies.

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Table 1

Demographics of participant groups (DePaul, Newcastle, Norway 1, and Norway 2).

	DePaul ***M*** **(SD)**	**Newcastle** ***M*** **(SD)**	**Norway 1** ***M*** **(SD)**	**Norway 2** ***M*** **(SD)**	**Sig.**
Age	**51.9 (11.3)**^{bcd} **N (%)**	**45.9 (14.1)**^{ad} **N (%)**	**43.5 (11.9)**^{ad} **N (%)**	**35.2 (11.9)**^{abc} **N (%)**	***
Gender					
Female	182 (83.9)	80 (81.6)	150 (85.7)	51 (81.0)	
Male	34 (15.7)	18 (18.4)	24 (13.7)	12 (19.0)	
Race					
White	211 (97.2)	97 (99.0)	174 (99.4)	58 (95.1)	
Asian/Pacific Islander	1 (0.5)	0 (0.0)	0 (0.0)	1 (1.6)	
Other	4 (1.8)	1 (1.0)	1 (0.6)	2 (3.3)	
Marital status					
Married	116 (53.5)	49 (50.0)	101 (57.5)	30 (47.6)	
Separated	3 (1.4)	2 (2.0)	4 (2.3)	0 (0.0)	
Divorced	39 (18.0)	14 (14.3)	16 (9.1)	4 (6.3)	
Widowed	0 (0.0)	0 (0.0)	4 (2.3)	1 (1.6)	
Never married	53 (24.4)	32 (32.7)	49 (28.0)	27 (42.9)	
Education					***
Some high school or less	0 (0.0)	2 (2.0)	14 (8.0)	11 (17.5)	
High school/GED	15 (6.9)	21 (21.4)	73 (41.7)	29 (46.0)	
Partial college	39 (18.0)	22 (22.4)	0 (0.0)	0 (0.0)	
College degree	74 (34.1)	27 (27.6)	68 (38.9)	15 (23.8)	
Graduate school	87 (40.1)	19 (19.4)	17 (9.7)	8 (12.7)	
Work status					***
On disability	123 (56.7)	30 (30.6)	147 (84.0)	49 (77.8)	
Student	6 (2.8)	8 (8.2)	5 (2.9)	3 (4.8)	
Homemaker	6 (4.1)	1 (1.0)	2 (1.1)	0 (0.0)	
Retired	25 (11.5)	18 (18.4)	4 (2.3)	0 (0.0)	
Unemployed	24 (11.1)	5 (5.1)	1 (0.6)	0 (0.0)	
Working part-time	17 (7.8)	21 (21.4)	14 (8.0)	10 (15.9)	

	DePaul *M* (SD) N (%)	Newcastle *M* (SD) N (%)	Norway 1 *M* (SD) N (%)	Norway 2 *M* (SD) N (%)	Sig.
Age	**51.9 (11.3)*[bcd]***	**45.9 (14.1)*[ad]***	**43.5 (11.9)*[ad]***	**35.2 (11.9)*[abc]***	***
Working full-time	12 (5.5)	13 (13.3)	2 (1.1)	1 (1.6)	

[a] Differed significantly from DePaul group.

[b] Differed significantly from Newcastle group.

[c] Differed significantly from Norway 1 group.

[d] Differed significantly from Norway 2 group.

*** $p > .001$,

** $p > .01$,

* $p > .05$.

Table 2

Demographics of housebound (H) and not housebound (NH) groups.

	H *N* = 128 *M* (SD)	NH *N* = 409 *M* (SD)	Sig.
Age	**44.5 (15.1)** ***N* (%)**	**44.1 (12.6)** ***N* (%)**	
Gender			
Female	109 (84.5)	348 (85.1)	
Male	20 (15.5)	66 (16.1)	
Race			
White	125 (96.8)	408 (99.7)	
Asian/Pacific Islander	0.8 (1)	1 (0.2)	
Other	1.6 (2)	5 (1.2)	
Marital status			*
Married	58 (44.9)	234 (57.3)	
Separated	1 (0.8)	7 (1.7)	
Divorced	15 (11.6)	58 (14.2)	
Never married	51 (39.5)	108 (26.4)	
Education			
Some high school or less	11 (8.6)	25 (6.1)	
High school/GED	28 (21.7)	98 (23.9)	
Partial college	17 (13.2)	44 (10.8)	
College degree	45 (34.9)	137 (33.4)	
Graduate school	26 (20.2)	104 (25.4)	
Work status			***
On disability	111 (86.0)	234 (57.2)	
Student	3 (2.3)	19 (4.6)	
Homemaker	1 (0.8)	11 (2.7)	
Retired	8 (6.2)	39 (9.5)	
Unemployed	4 (3.1)	26 (6.4)	
Working part-time	2 (1.6)	59 (14.4)	
Working full-time	0 (0.0)	27 (6.6)	

*** $p > .001$,

** $p > .01$,

* $p > .05$.

Table 3

Illness experience of housebound (H) and not housebound (NH) patients.

	H *N* = 125 *N* (%)	NH *N* = 411 *N* (%)	Sig.
Illness began after			
Infectious illness	95 (76.0)	272 (66.2)	*
An accident	6 (4.8)	22 (5.4)	
A trip or vacation	9 (7.2)	28 (6.8)	
An immunization	17 (13.6)	41 (9.9)	
Surgery	18 (14.4)	41 (9.9)	
Severe stress	33 (26.4)	158 (38.4)	*
Other	36 (28.8)	95 (23.1)	
Illness developed			
Rapidly (<1 month)	53 (42.4)	135 (32.9)	
Gradually (<1 year)	28 (22.4)	115 (27.9)	
Slowly (>1 year)	41 (31.8)	151 (36.7)	
Patient has been diagnosed or treated for			
Major depression	34 (26.9)	73 (21.5)	
Major depression with melancholic or psychotic features	3 (2.4)	4 (1.1)	
Bipolar disorder	2 (1.6)	6 (1.8)	
Anxiety	31 (24.6)	86 (25.3)	
Schizophrenia	0 (0.0)	0 (0.0)	
Eating disorder	6 (4.8)	15 (4.4)	
Substance abuse	5 (3.9)	2 (0.6)	
Chemical sensitivities	17 (13.5)	37 (10.9)	
Fibromyalgia	48 (38.1)	107 (31.5)	
Allergies	60 (47.6)	186 (54.7)	
Cause of illness attribution			***
Definitely physical	106 (83.4)	213 (52.9)	
Mainly physical	16 (12.6)	119 (29.6)	
Equally physical and psychological	4 (3.1)	60 (14.9)	
Mainly psychological	0 (0.0)	7 (1.8)	
No problem with fatigue	1 (0.1)	2 (0.5)	
	M (SD)	*M* (SD)	
In the past month, how many hours did patient spend on			
Household-related activities[a]	2.8 (3.1)	7.8 (7.5)	***
Social/recreational activities[a]	2.9 (6.4)	4.5 (6.8)	
Family-related activities[a]	3.1 (6.3)	5.7 (7.5)	*
Work-related activities[a]	0.5 (2.4)	7.3 (13.8)	***
Perceived energy available yesterday[a]	13.9 (9.5)	31.1 (18.3)	***
Perceived energy expended yesterday[a]	19.1 (20.5)	31.9 (20.9)	**

	H ***N* = 125** ***N* (%)**	**NH** ***N* = 411** ***N* (%)**	**Sig.**
Perceived fatigue had yesterday[a]	75.8 (23.8)	64.9 (22.5)	**
Perceived energy available in past week[a]	17.3 (15.4)	33.5 (17.7)	***
Perceived energy expended in past week[a]	21.5 (18.9)	38.1 (22.1)	***
Perceived fatigue had in past week[a]	79.4 (19.3)	66.5 (20.6)	***
Energy quotient (yesterday)[a]	182.5 (310.3)	113.8 (109.3)	**
Energy quotient (last week)[a]	104.6 (105.6)	101.3 (59.3)	
Duration of illness (years)[a]	9.1 (7.9)	8.1 (7.7)	
If patient rests, how long until fatigue goes away	N (%)	N (%)	***
<30 min	2 (1.6)	8 (2.9)	
30–59 min	1 (0.8)	35 (12.9)	
1–2 h	5 (3.9)	56 (20.6)	
>2 h	54 (42.2)	172 (63.3)	
No answer	66 (51.5)	140 (33.9)	
If patient rests, does problem with fatigue/energy go away?			***
Entirely	0 (0.0)	7 (1.7)	
Partially	40 (31.3)	235 (57.0)	
Fatigue/energy not improved by rest	75 (58.6)	168 (40.7)	
No issues with fatigue/energy	0 (0.0)	2 (0.2)	
No answer	2 (1.6)	0 (0.0)	
Does patient experience a worsening of fatigue/energy			
After engaging in minimal physical effort?	127 (99.3)	358 (86.9)	***
After engaging in mental effort?	122 (95.3)	373 (90.5)	*
Length of postexertional malaise			***
<1 h	2 (1.6)	7 (1.7)	
2–3 h	2 (1.6)	31 (7.5)	
4–10 h	2 (1.6)	39 (9.5)	
11–13 h	1 (0.8)	8 (1.9)	
14–23 h	10 (7.8)	69 (1.67)	
>24 h	102 (79.7)	239 (58.0)	

[a]Age controlled for as covariate.

***$p > .001$,

**$p > .01$,

*$p > .05$.

Table 4

Comparison of housebound and not housebound symptom severity, and functionality controlling for age and education.

	H *N* = 127 *M* (SD)	NH *N* = 412 *M* (SD)	Sig.
Fatigue	87.3 (13.5)	74.4 (17.6)	***
Postexertional malaise	86.5 (12.4)	66.5 (20.5)	***
Dead, heavy feeling	84.5 (25.2)	68.6 (27.7)	***
Next day soreness	89.4 (14.4)	66.8 (22.8)	***
Mental tiredness	78.3 (19.6)	58.8 (26.1)	***
Minimum exercise	91.8 (13.5)	71.1 (24.4)	***
Sick after mild activity	89.9 (12.7)	66.4 (24.9)	***
Muscle weakness	76.1 (23.4)	57.9 (28.0)	***
Sleep	59.8 (12.4)	51.1 (17.5)	***
Unrefreshed waking up	87.3 (16.9)	79.5 (20.8)	**
Nap daily	58.8 (34.2)	55.2 (31.9)	
Falling asleep	72.8 (26.7)	55.1 (32.8)	***
Staying asleep	67.0 (32.8)	58.3 (31.1)	
Waking up early	50.4 (32.8)	44.4 (33.1)	
Sleeping all day	26.5 (33.2)	14.9 (25.1)	***
Pain	53.4 (16.8)	44.8 (19.4)	***
Muscle pain	73.6 (26.0)	65.6 (28.0)	**
Joint pain	64.3 (32.6)	55.8 (32.4)	
Eye pain	42.8 (28.5)	33.7 (28.1)	**
Chest pain	33.6 (24.4)	25.6 (24.0)	*
Bloating	51.5 (28.7)	46.3 (28.7)	
Stomach pain	49.2 (28.3)	40.6 (29.3)	*
Headaches	58.7 (27.3)	50.8 (26.6)	
Neurocognitive	62.2 (15.6)	52.7 (18.0)	***
Muscle twitches	37.3 (26.1)	31.4 (25.7)	
Sensitivity to noise	70.3 (26.6)	59.3 (29.5)	*
Sensitivity to bright lights	64.1 (28.9)	54.2 (29.2)	
Problems remembering things	72.5 (26.4)	66.9 (23.7)	
Difficulty paying attention	81.9 (20.2)	70.8 (25.7)	*
Difficulty expressing thoughts	68.9 (24.8)	60.6 (25.2)	*
Difficulty understanding things	56.3 (26.9)	44.8 (27.1)	*
Can only focus on one thing at a time	77.9 (23.2)	49.9 (30.2)	***
Unable to focus vision and/or attention	55.4 (26.7)	41.4 (27.9)	**
Loss of depth perception	26.9 (32.3)	23.4 (30.2)	
Slowness of thought	65.2 (24.7)	54.6 (26.1)	**
Absentmindedness or forgetfulness	65.6 (28.7)	58.8 (26.6)	
Autonomic	47.6 (18.7)	36.5 (18.1)	***

	H *N* = 127 *M* (SD)	NH *N* = 412 *M* (SD)	Sig.
Bladder problems	37.6 (35.3)	28.9 (32.2)	
Irritable bowel problems	57.7 (30.6)	47.7 (33.8)	**
Nausea	46.0 (26.6)	32.7 (25.4)	***
Feeling unsteady on feet	53.9 (30.0)	38.7 (25.9)	***
Shortness of breath	50.1 (30.1)	36.3 (27.5)	***
Dizziness or fainting	52.9 (26.4)	38.4 (26.1)	***
Irregular heartbeats	39.6 (30.4)	31.7 (26.9)	
Neuroendocrine	43.6 (15.1)	37.4 (16.8)	***
Losing or gaining weight without trying	48.5 (35.7)	39.1 (35.1)	
No appetite	34.3 (28.4)	22.8 (25.8)	**
Sweating hands	19.3 (27.0)	15.5 (24.8)	
Night sweats	40.3 (29.8)	34.6 (30.2)	
Cold limbs	56.4 (29.9)	54.7 (31.2)	
Feeling chills or shivers	50.2 (28.8)	40.9 (29.0)	*
Feeling hot or cold for no reason	61.0 (26.1)	52.9 (28.3)	*
Feeling like you have a high temperature	51.2 (32.4)	35.7 (30.3)	***
Feeling like you have a low temperature	31.4 (31.1)	30.6 (29.9)	
Alcohol intolerance	45.9 (40.7)	41.4 (37.1)	
Immune	48.5 (16.5)	36.3 (19.9)	***
Sore throat	44.9 (23.2)	36.1 (27.3)	*
Tender/sore lymph nodes	45.9 (29.7)	33.8 (29.3)	***
Fever	25.9 (24.7)	17.4 (23.1)	**
Flu-like symptoms	67.4 (23.3)	50.8 (27.6)	***
Sickened by smell, food, meds, chemicals	59.3 (37.1)	41.3 (35.2)	***
Physical functioning[a]	17.1 (15.0)	42.0 (21.9)	***
Role physical[a]	2.9 (12.4)	7.7 (20.1)	*
Bodily pain[a]	28.9 (23.8)	42.4 (23.0)	***
General health functioning[a]	19.1 (12.5)	30.8 (17.2)	***
Vitality[a]	13.2 (14.8)	19.6 (16.3)	***
Social functioning[a]	10.2 (13.7)	30.7 (23.9)	***
Role emotional[a]	74.4 (41.1)	75.7 (38.9)	
Mental health functioning[a]	68.7 (19.4)	70.4 (17.8)	

[a] Lower scores on RAND-36 items indicate poorer functionality.

*** $p > .001$,

** $p > .01$,

* $p > .05$.