**Research Article**

# The Depressing Truth about Depression Scales for People with Chronic Invisible Illness

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## Abstract

**Background:** Depression screening instruments are commonly used in research and the clinic. Aim: This study seeks to determine whether several common depression scales might be contaminated by somatic symptoms, thus overestimating depression in people with chronic invisible illness. **Method:** 685 chronically ill women with postural orthostatic tachycardia syndrome, chronic fatigue syndrome/myalgic encephalomyelitis, mast cell activation syndrome, Ehlers-Danlos syndrome and/or fibromyalgia took the Beck Depression Inventory-II (BDI-II). For a broader look at major self-report scales that assess depression in adults, we also investigated seven additional instruments listed on the American Psychological Association webpage. **Results:** In this sample, 38.5% appeared to have major depression as measured by the BDI-II, but this number decreased to 8% when somatic symptoms were removed. Further, there was a 31.2% increase in the number of participants in the minimal depression category of the BDI-II-Mood. Finally, 75% of the adult depression scales that we assessed had at least 40% of the score related to somatic symptoms. **Conclusion:** Care must be taken when assessing depression in people with chronic invisible illnesses to prevent artificial over-inflation of scores based on somatic complaints.

**Keywords:** Chronic invisible illness; Depression; Somatic symptoms; Postural orthostatic tachycardia syndrome (POTS); Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME); Fibromyalgia

## Introduction

Obtaining an accurate measure of depression in people with chronic invisible illnesses like postural orthostatic tachycardia syndrome (POTS), chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), Ehlers-Danlos syndrome (EDS), mast cell activation syndrome (MCAS), and fibromyalgia is complicated. Most current self-report depression instruments use a combination of questions that assess somatic complaints in addition to those describing depressive mood. While many physically healthy individuals have somatic symptoms accompanying depression [1], in chronically ill individuals it is often difficult to separate physical manifestations of their disorder from the somatic symptoms of clinical depression [2].

These self-report depression scales, often used in research and the clinic, could cause the over-diagnosis of depression in this population with two possible ramifications. First, the majority of people with these chronic invisible illnesses are first diagnosed with depression and/or anxiety or told that their symptoms are "all in their head" [3]. When depression instruments weigh somatic symptoms heavily, it is possible that the practitioner will not look past depression for another possible diagnosis, and therefore the physical illness may not be diagnosed. Second, for those with chronic illness and depression, the level of depression may be over-estimated by these instruments. In this case, people might be overly medicated for depression or have freedoms removed (placed on suicide watch) when their depression scores on these

instruments have been inflated by the physical symptoms of POTS, CFS/ME, EDS, MCAS, fibromyalgia or other chronic invisible illnesses.

## Objectives

First, one self-report depression scale was assessed to determine the potential for over-diagnosis of depression in women with chronic invisible illnesses. Second, several well-known and often used self-report measures of depression were evaluated for contamination with somatic symptoms.

## Hypothesis

We hypothesize that chronically ill women will be overrepresented in the moderate and major depression categories due to their somatic symptoms. We further hypothesize that many self-report depression instruments utilize multiple somatic symptoms as markers for depression.

## Method

This project utilizes a mixed-methodological approach. First, we explore the impact of somatic symptoms on one's likelihood to be categorized as depressed in a sample of women with chronic illness. In the second part of this research, we conduct a content analysis to explore the

frequency of somatic symptoms in commonly used self-report adult depression instruments.

## Participants

Participants in this study were females who were at least 18 years old and reported a physician diagnosis of POTS, CFS/ME, EDS, MCAS, fibromyalgia or another chronic invisible illness.

## Procedure

All data were collected electronically via the StandingUptoPOTS.org website. Participants became aware of the online survey through the Standing Up to POTS® social media accounts and online support groups. Participants were prompted to complete the electronically signed informed consent form before beginning the survey, which was both voluntary and confidential. Participants completed several demographic questions and the Beck Depression Inventory-II. A debriefing statement was provided at the end of the survey that included contact information for the National Suicide Prevention Lifeline (phone) and HOPELINE (text). The study protocol was approved by the Wittenberg University Institutional Review Board.

## Variables

The survey included demographic questions on gender, age, years chronically ill, and physician diagnoses of chronic invisible illnesses. Because multiple diagnoses are typical for this population, the respondents were instructed to check "all that apply" to the diagnosis question. Respondent's age, number of years with chronic illness, and total number of diagnoses were measured as continuous variables.

## Instruments

Beck Depression Inventory-II [BDI-II; 4]. This 21-item survey has a series of titles with four possible responses (scored 0-3). The sum of all scores gives the total score, with a possible range from 0-63. Higher scores reflect higher levels of depression, with minimal depression 0-13, mild depression 14-19, moderate depression 20-28, and major depression 29-63 on the BDI-II. The BDI-II was found to be reliable when tested for internal consistency (Cronbach's $\alpha = 0.89$).

Beck Depression Inventory-II Mood (BDI-II-Mood). While the BDI-II is a 21-item inventory used to assess depression, seven health indicators used in the scale measure common physical changes experienced by those with chronic illness [Agitation, Appetite, Concentration, Energy, Fatigue, Irritability, and Sleep; 5] were removed to create the BDI-II-Mood. This new scale assessed how somatic symptoms impact the likelihood that a person with chronic invisible illness is mislabeled with higher levels of depression. The BDI-II-Mood was found to be reliable when tested for internal consistency (Cronbach's $\alpha = 0.88$).

Removing the seven items reduced the total score available for participants on the BDI-II-Mood (from 63 to 42) and the score range for each depression category (minimal, mild, moderate, and major). We did not readjust the score range for each depression category used in the BDI-II because our goal is to compare results on each instrument to better understand if and how somatic symptoms impact one's score on the BDI-II. It is not our intent to suggest that the BDI-II-Mood should replace the BDI-II as an instrument.

## Analysis Plan

The data were analyzed with jamovi 1.6.23 (Sydney, Australia) after excluding male, nonbinary, and transgender participants to ensure only females were included in the sample (n=685). Descriptive statistics and frequencies were calculated for age, years ill, total number of diagnoses, and primary and other diagnoses. Two scales were created in jamovi for this analysis, BDI-II and the BDI-II-Mood. Using the depression categories associated with the BDI-II, we found the percentage of respondents within each depression category (minimal, mild, moderate, and major as labeled by the BDI-II) on the BDI-II scale as well as our modified BDI-II-Mood scale.

Following this, we completed a content analysis reviewing seven additional adult depression scales listed on the American Psychological Association page (https://www.apa.org/depression-guideline/assessment) to better understand the frequency and use of somatic symptoms in assessing depression more broadly. These scales were assessed for composition of questions, with each question placed into one of three symptom categories: somatic, depressive, and other. Somatic symptoms were defined as bodily symptoms that could be explained by a physical chronic invisible illness like POTS, CFS/ME, EDS, MCAS or fibromyalgia, and included questions regarding appetite, weight change, heart palpitations/tachycardia, energy, fatigue, slowness of movement, mental clarity, concentration, agitation, irritability and hypochondria. Depressive symptoms were defined as assessing depressed mood and included questions about sadness, happiness, loneliness, enjoyment and hopefulness. Questions that did not fall into either somatic or depressive were placed in the other category.

## Results

On average, participants were 36.9 years old, had been ill for 12.7 years, and reported 2.5 diagnoses (Table 1). These women had been diagnosed with a variety of chronic invisible illnesses by a physician (Table 2), including POTS (81%), EDS (29%), fibromyalgia (28%), CFS/ME (26%), and MCAS (23%).

### Assessing Depression in Chronic Invisible Illness Using the BDI-II

As expected, the mean of the BDI-II was nine points higher than the BDI-II-Mood, indicating that somatic symptoms associated with chronic illness can potentially increase one's likelihood of being mislabeled as depressed (Table 1).

| Independent Measures | Median | Mean | Mode |
|---|---|---|---|
| Age (18-76) | 36 | 36.9 | 22 |
| Years Ill (1-34) | 9 | 12.7 | 3 |
| Total Diagnoses (1-6) | 2 | 2.5 | 1 |
| BDI-II (21 Items) | 26 | 25.0 | 21 |
| BDI-II-Mood (14 Items) | 15 | 15.7 | 17 |

**Note:** Removal of 7 questions for the BDI-II-Mood could drop BDI-II scores between 0 and 21 points.

**Table 1:** Descriptive statistics for continuous variables & self-report scales (n=685).

| Diagnosis | Primary Diagnosis | Other Diagnoses |
|---|---|---|
| | N (%) | N (%) |
| Postural orthostatic tachycardia syndrome | 405 (59.1) | 150 (21.9) |
| Ehlers-Danlos syndrome | 105 (15.3) | 94 (13.7) |
| Chronic fatigue syndrome/myalgic encephalomyelitis | 41 (6.0) | 135 (19.7) |
| Mast cell activation disorder | 23 (3.4) | 136 (19.9) |
| Vasovagal syncope/neurocardiogenic syncope | 19 (2.8) | 121 (17.7) |
| Fibromyalgia | 16 (2.3) | 176 (25.7) |
| Lupus | 9 (1.3) | 20 (2.9) |
| Sjogren's syndrome | 3 (0.4) | 40 (5.8) |
| Lyme disease | 3 (0.4) | 27 (3.9) |
| Orthostatic hypotension | 2 (0.3) | 113 (16.5) |
| Chiari malformation | 2 (0.3) | 28 (4.1) |
| Addison's disease | 1 (0.1) | 7 (1.0) |
| Multiple sclerosis | 1 (0.1) | 3 (0.4) |
| Mitochondrial disease | --- | 14 (2.0) |
| Crohn's disease | --- | 13 (1.9) |
| Ulcerative colitis | --- | 13 (1.9) |
| Other | 55 (8.0) | 30 (4.4) |

**Note:** Sum of diagnoses > 685 because many participants reported multiple diagnoses.

**Table 2:** frequency & percentages of primary & other diagnoses (n=685).

Most participants scored in the major depression category of the BDI-II, but interestingly, most were in the minimal depression category of the BDI-II-Mood (Table 3). Results indicate an overrepresentation of participants in the moderate and major depression categories as a result of their somatic symptoms. For example, 38.5% of participants appeared to have major depression as measured by the BDI-II. After removing somatic symptoms, this number decreased to 8.0% on the BDI-II-Mood, a 30.5% decrease that may be attributed to physical symptoms of their chronic illness. On the other end of the scale, 13.9% of participants appeared to have minimal depression on the BDI-II, but this number increased to 45.1% in the BDI-II-Mood once somatic symptoms were removed.

| BDI-II Depression Category | BDI-II (%) | BDI-II-Mood (%) | Percent Difference |
|---|---|---|---|
| Minimal (0-13) | 13.9 | 45.1 | +31.2 |
| Mild (14-19) | 17.4 | 24.4 | +7.0 |
| Moderate (20-28) | 30.2 | 22.5 | -7.7 |
| Major (29-63) | 38.5 | 8.0 | -30.5 |

**Note.** Removal of 7 questions for the BDI-II-Mood could drop BDI-II scores between 0 and 21 points.

**Table 3:** Comparison of percent of participants within categories of the BDI-II and BDI-II-Mood.

## Prevalence of Somatic Symptoms on Common Depression Instruments

To better understand the impact of somatic symptoms on depression scores more broadly, we reviewed seven additional adult depression instruments listed on the American Psychological Association website (Table 4). We examined all 130 items, or indicators, used in these instruments to measure depression. The publication year ranged from 1965 (Zung Self-Rating Depression Scale) to 2016 (Clinically Useful Depression Outcome Scale). The number of items on each scale varied from 9 (Patient Health Questionnaire, 2001) to 21 (BDI-II, 1996), with a mean of 16 questions.

| Instrument | Year | Total Items | Somatic | Depressive | Other |
|---|---|---|---|---|---|
| Center for Epidemiological Studies Depression Scale | 1977 | 20 | 4 (20%) | 15 (75%) | 1 (5%) |
| Beck Depression Inventory II | 1996 | 21 | 7 (33%) | 13 (62%) | 1 (5%) |
| Montgomery-Asberg Depression Rating Scale | 1978 | 10 | 4 (40%) | 6 (60%) | 0 |
| Clinically Useful Depression Outcome Scale | 2016 | 18 | 8 (44%) | 9 (50%) | 1 (6%) |
| Zung Self-Rating Depression Scale | 1965 | 20 | 10 (50%) | 4 (20%) | 6 (30%) |
| Hamilton Depression Rating Scale | 1980 | 17 | 9 (53%) | 6 (35%) | 2 (12%) |
| Patient Health Questionnaire | 2001 | 9 | 5 (55%) | 4 (45%) | 0 |
| Quick Inventory of Depressive Symptomology-Self-Report | 2008 | 16 | 12 (75%) | 4 (25%) | 0 |

**Note.** Somatic symptoms included questions on appetite, weight change, energy, fatigue, slowness of movement, agitation, irritability, heartbeat, mental clarity, concentration, and hypochondria that could be related to diagnosed physical illness rather than depression. Depressive symptoms were defined as assessing depressed mood and included questions about sadness, happiness, loneliness, enjoyment and hopefulness. Questions that did not fall into either the somatic or depressive category were placed in the other category. Organized from least to most inclusion of somatic symptoms within the instrument.

**Table 4:** Common depression scales used clinically and in research.

All instruments examined used somatic symptoms as a measure of depression. Somatic symptoms were defined as bodily symptoms that could be explained by a physical chronic invisible illness like POTS, CFS/ME, EDS, MCAS or fibromyalgia, and included questions regarding appetite, weight change, heart palpitations/tachycardia, energy, fatigue, slowness of movement, mental clarity, concentration, agitation, irritability, and hypochondria. The Center for Epidemiological Studies Depression Scale (1977) used only four somatic questions (20%), the smallest proportion in this sample. In comparison, the Quick Inventory of Depressive Symptomology Self-Report used 12 somatic items (75%), the largest proportion in this sample. The BDI-II used 7 items reflecting somatic symptoms (33%). Of the 130 items examined for this analysis, 45.4% measured somatic symptoms.

All the depression instruments we analyzed included items measuring symptoms related to a depressed mood. This included questions about sadness, happiness, loneliness, enjoyment and hopefulness. The number of depressive items used in each scale varied across the sample. Only four of the instruments utilized depressive items for a majority of the questionnaire (Table 4). The Center for Epidemiological Studies Depression Scale (1977) used the most items measuring depressive mood, with 15 questions (75%). In comparison, the Quick Inventory of Depressive Symptomology Self-Report used only four depressive mood items (25%). The BDI-II used 13 items (62%) reflecting a depressive mood. Of the 130 items examined for this analysis, only 47.0% reflected depressive mood.

In our sample, five scales (out of eight) included at least one question we coded as other because it did not easily fall into either the somatic or depressive category. For example, the Zung Self-Rating Depression Scale (1965) had the most other items with 6 questions (30%). Examples of other items measured in the Zung scale include "morning is when I feel best" and "I find it easy to make decisions." The BDI-II had one question we categorized as other which asked about one's interest in sex. The Hamilton Depression Rating Scale (1980) similarly used sex as an item asking if the person experienced menstrual disturbances or lack of libido. Of the 130 items examined for this analysis, 7.6% were judged to not be directly related to either somatic symptoms or depressed mood.

## Discussion

In this study, 68.7% of participants with chronic invisible illnesses including POTS, CFS/ME, EDS, MCAS and fibromyalgia were diagnosed with moderate to major depression using the BDI-II. When somatic symptoms were removed, 38.2% of those participant's scores dropped significantly. This demonstrates that somatic symptoms, commonly associated with POTS and other chronic illnesses, impact scoring on the BDI-II, increasing the likelihood that participants with these symptoms will be categorized as having depression. This indicates that in this population, depression is likely being overestimated using standard adult depression scales due to the prevalence of somatic questions. Unfortunately, when we surveyed other commonly used depression screening instruments, the BDI-II was one of the better scales with 33% of their questions related to somatic symptoms (range 20-75%). Sadly, many of these tools may misidentify people with chronic invisible illness as depressed based primarily on their somatic symptoms.

Somatic symptoms of depression significantly overlap with those of several chronic invisible illnesses. Using POTS as an example, increased heart rate (upon standing) and palpitations are common in POTS but also occur with depression. POTS also commonly present with fatigue, sleep disturbance, gastrointestinal issues, and pain syndromes [6], all of which are common somatic symptoms assessed on many depression scales. In addition, POTS can affect mental clarity, alertness, attention and concentration [7] and patients often have a low body mass index [8], perhaps indicating a decrease in appetite or issues in digesting or absorbing nutrients that might account for changes in weight. Again, these somatic symptoms are common both for POTS patients and assessed on many depression scales. Finally, people in the chronic invisible illness community are often accused of being hypochondriacs or having psychological issues before being properly diagnosed, especially when blood, urine, and other testing is normal.

While people with these physical chronic illnesses can certainly suffer from depression, we believe that many in this community are over diagnosed with depression based on the symptoms of their physical illness. One large study found that 77% of POTS patients were initially told by a physician that their symptoms were likely due to a psychiatric or psychological problem, while after a POTS diagnosis only 37% continued to have a diagnosis of depression or anxiety [3]. It's likely that the somatic symptoms of these chronic invisible illnesses, including appetite, weight change, sleep disturbances, and fatigue, etc., inflate depression scores when screenings are conducted. In people with MCAS, depression scores were elevated as the symptoms of their illness increasingly affected activities of daily living [9], indicating that these somatic symptoms may inflate depression scores. Further, 13-63% of people with fibromyalgia are diagnosed as depressed [10] with those having more major physical symptoms and functional limitations showing higher depression scores [11]. In contrast, a large study of people with neurological disorders including stroke, amyotrophic lateral sclerosis, migraine, and Parkinson's disease found very little impact of somatic symptoms on depression scores for most individuals [12]. It is possible that the somatic symptoms of these disorders do not match those on the depression screening scales as closely as the illnesses that we are discussing, although clearly these disorders have significant somatic symptoms.

There are a wide variety of depression instruments available that are regularly used both in research and clinical practice. We assessed the questions for eight common depression scales used in young and middle-aged adults and found that 75% of the screening tools had at least 40% of their total questions asking about somatic symptoms. These symptoms, including gastrointestinal issues, fatigue and musculoskeletal pain, were linked with increased depression scores on the Patient Health Questionnaire in a large community sample in Japan [13]. In the multiple sclerosis community, elevating the cutoff for depression on the Patient Health Questionnaire from 5 to 10 points accounted for bias due to somatic symptoms [14]. While we understand that somatic symptoms can be indicators of depression in the general population, it is problematic when trying to assess depression in people with these chronic invisible illnesses.

## Limitations of the Study

There are many limitations to this study. We used an online survey to assess depression using the BDI-II without access to medical records for diagnosis of depression or the chronic illnesses our participants reported. Our data may be skewed toward women with more severe symptoms of POTS and other chronic invisible illnesses who might be more likely to join online support groups or follow Standing Up to POTS® on social media. Our participants only took the BDI-II, so while we assessed questions on the other seven adult depression screening tools, we did not directly assess participant responses on these other scales. These depression screening tools were assessed using three loosely described categories: somatic, depressive, and other. For a few items, evaluators might categorize questions differently. We did not assess pediatric or geriatric depression scales.

## Conclusions

People with chronic invisible illnesses like POTS, CFS/ME, EDS, MCAS, and fibromyalgia have numerous and often severe somatic symptoms related to their illness that may over-inflate their depression scores on many common screening instruments. This leads to the possible over-diagnosis of depression in this community, further hindering individuals with chronic invisible illness when seeking treatment.

## Recommendations

Our study demonstrates the need for better depression instruments for those with chronic illness. Practitioners using self-report depression scales should be cautious when using these instruments with chronically ill populations and when possible choose an instrument with minimal weight given to somatic symptoms. In addition, focusing on questions related to mood will provide a more accurate overall measure of depression. When developing instruments to measure depression, researchers should consider the needs of patients with somatic symptoms from underlying issues like chronic invisible illness and adjust the instrument and/or its scoring to better meet the needs of this group.

## Ethical Standards

The study protocol was approved by the Wittenberg University Institutional Review Board and has been performed in accordance with the ethical standards described in the 1964 Declaration of Helsinki. All participants gave informed consent prior to their inclusion in this research study.

## Conflict of Interest

The authors state that there is no conflict of interest. This research did not receive any specific grant from funding agencies in public, commercial, or not-for-profit sectors.

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