

# Invisible and Visible Symptoms of Multiple Sclerosis: Which Are More Predictive of Health Distress?

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**Abstract:** The purpose of this study was to examine whether it is the invisible or the visible symptoms or signs of multiple sclerosis (MS) that are associated with greater health distress. Visible symptoms include the use of assistive devices, problems with balance, and speech difficulties, while invisible symptoms include fatigue, pain, depression, and anxiety. In a sample of 145 adults with MS, participants reported on these symptoms and their current level of self-reported health distress. Hierarchical regression analyses were used to determine whether invisible or visible symptoms were more predictive of health distress. When visible symptoms were added as the first step in the regression, 18% of the variance in health distress was explained. When invisible symptoms were added as the first step, 53% of the variance was accounted for. The invisible symptoms of pain and depression were the most significant predictors of distress. For a subset of the sample that had had MS for more than 11 years, pain and depression continued to be important predictors, but assistive-device use and fatigue were also important. Nurses should be aware that invisible symptoms may be more troubling to patients than visible symptoms and should ensure that adequate screening and treatment are provided for those with MS.

In recent years, increased attention has been given to the invisible symptoms of multiple sclerosis (MS), such as fatigue, pain, depression, and anxiety. However, when first diagnosed, patients often imagine that the worst symptoms they will have to deal with are visible physical limitations that would require the use of assistive devices, such as walkers or wheelchairs (Isaksson & Ahlström, 2006; Johnson, 2003; Koopman & Schweitzer, 1999). For the purpose of this study, *invisible symptoms* are defined as those symptoms that are life limiting but not readily discernible to others (Davis, 2005). It is critical that individuals with MS and healthcare professionals consider the invisible symptoms of MS because these symptoms might be unidentified, mislabeled, or left untreated (Marshak, Seligman, & Prezant, 2001). Because they are often not discussed or attended to, invisible symptoms may allow the individual to be in denial about his or her MS and the necessity of beginning or continuing disease-modifying treatment. In addition, individuals with invisible disabilities often struggle to convince others that they do not seek an unfair advantage, such as using a handicapped parking spot (Davis). In social interactions, those with invisible symptoms have to decide whether they will forgo needed assistance and accommodations or explain the invisible symptoms and potentially endure disbelief, rejection, humiliation, or social disapproval

(Stone, 2005). The purpose of this investigation was to ascertain whether the visible or the invisible symptoms of MS are associated with an individual's increased distress about his or her health.

## Background

Talcott Parsons' notion of the sick role (1951) and Erving Goffman's (1963) concept of stigma are two possible theoretical orientations that could be used to hypothesize about the outcomes of invisible and visible symptoms in MS. Unfortunately, the two theories would hypothesize conflicting outcomes for visible and invisible symptoms. In Parsons' sick role, visible symptoms would elicit more social support and provide a visual validation that the individual has a reason to be excused from normal responsibilities, whereas an individual with invisible symptoms may be seen as malingering and

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may not receive empathy and social support from others (Chamberlain, 2006). The concept of stigma (Goffman) suggests that an individual who has outward visible signs of illness demonstrates something unusual, different, or bad, and as a result, others may discredit and stigmatize him or her (Joachim & Acorn, 2000). Those with invisible symptoms can “pass for normal” and decide how and when they will disclose their symptoms (Hodgman et al., 1979; Joachim & Acorn). Once an individual discloses invisible symptoms, there is the threat of being stigmatized and the possibility of not receiving needed social support. However, if the invisible symptoms are not stigmatized, the individual could receive the necessary assistance. Figure 1 illustrates the differences between Parsons’ and Goffman’s theories in relation to positive outcomes, with a plus sign (+) indicating that the theory hypothesizes that the individual would experience positive outcomes and a minus sign (–) signifying that the theory hypothesizes negative outcomes for the individual.

Discussion of invisible and visible symptoms in the medical literature is limited, with only passing reference to the terms in MS literature (Cross & Rintell, 1999). Individuals who have fibromyalgia, wherein symptoms are entirely invisible, have reported that no one believed that they were ill because they looked well; they felt that the invisibility of the illness created dilemmas for them (Sturge-Jacobs, 2002). In women with rheumatoid arthritis or myalgic encephalomyelitis, the invisibility of symptoms prompted others, including healthcare

professionals, to label these patients as “slackers” (Moss & Dyck, 2002). Hearing loss (Hallberg & Jansson, 1996; Levene, 1983; Lipkin & Williams, 1986; Randall, 1973; Sherlock, 2005; Shohet & Bent, 1998); mental illness (Stewart, Ricci, Chee, Hahn, & Morganstein, 2003); and neurological conditions, such as epilepsy (Hodgman et al., 1979), traumatic brain injury (Chamberlain, 2006), and hemorrhagic stroke (Roding, Lindstrom, Malms, & Ohman, 2003; Stone, 2005) are other conditions for which the concept of invisible symptoms has been discussed. Because of the connection between MS and the neurological conditions previously mentioned, this research will be briefly reviewed.

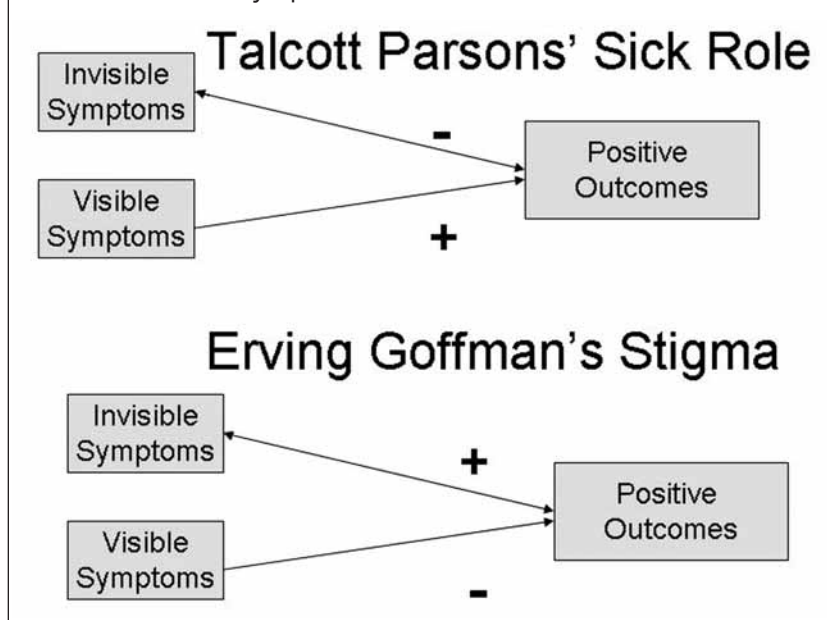
In a sample of adolescents with seizure disorders, Hodgman and colleagues (1979) reported that those who have relatively “mild defects involving social disability may be more troubled than those with more apparent defects” (p. 309). The authors speculated that adolescents with a visually apparent disability might have an obvious explanation as to why they are unable to drive or swim, while those with more invisible impairments do not have an obvious, visually apparent reason to be excused from certain age-appropriate behavioral expectations.

Chamberlain (2006) interviewed 60 survivors of traumatic brain injury 1 year after sustaining their injuries. The majority of the survivors showed no physical evidence of their injuries, and 45 of the 60 survivors mentioned the concept of invisibility. Some were distressed by the lack of empathy from healthcare providers, especially for their invisible symptoms. Others felt that they were withdrawing from society because of the embarrassment about what they felt others thought of them and their invisible disabilities.

Two studies (Roding et al., 2003; Stone, 2005) investigated young survivors of hemorrhagic stroke. Both studies had small samples. Roding and colleagues’ sample consisted of two women and three men who suffered a hemorrhagic stroke between the ages of 37 and 54 years, while Stone’s sample included 22 women who suffered a hemorrhagic stroke between the ages of 8 and 49 years. Roding and colleagues reported that participants felt that because their handicaps were invisible, they were not as legitimate as other forms of handicaps. A quote from one participant illustrated this belief:

I usually say that it might have been easier if my arm was paralysed [sic] and hanging or if I had trouble with speech. Then it would have been easier for my family to understand why mommy cannot unload the dishwasher or why she cannot pack a gym bag (Roding et al., 2003, p. 871).

**Fig 1.** Comparison of Talcott Parsons’ and Erving Goffman’s Theories and the Potential Impact of Invisible and Visible Symptoms



Stone's (2005) research found that young survivors of hemorrhagic stroke felt that they had to continually explain themselves and their invisible disabilities and expressed frustration that their able-looking bodies gave others expectations about what they should be able to do—expectations that they could not always meet. As a result, the women tried not to enter into situations where they would have difficulties. Even others who were close to the women (e.g., family members and close friends) would commonly forget or deny the invisible disabilities.

As can be seen from the aforementioned studies, those with neurological problems that are not clearly visible felt the need to explain themselves and their disabilities, which appears to be distressing to them. These findings are in line with Parsons' sick role, because those without obvious physical limitations are held to conventional expectations of behavior and may be more distressed by the health symptoms that are not as obvious.

Three visible symptoms of MS, specifically, (a) the use of assistive devices, (b) problems with balance, and (c) problems with speech, and four invisible symptoms of MS, (a) fatigue, (b) pain, (c) depression, and (d) anxiety, were considered in this study. The outcome measure for individuals with MS was a low level of health distress. A brief overview of each of these symptoms and the outcome measures are provided in the following sections.

## Visible MS Signs or Symptoms

### Use of Assistive Devices

Because it is a progressive neurological disease, many with MS will require the use of assistive devices to maintain their mobility and independence as the disease progresses (Blake & Bodine, 2002; Finlayson, Guglielmello, & Liefer, 2001; Freeman, 2001). Across all types of MS, Pittcock and colleagues (2004) reported that the time from diagnosis to reaching scores of 3 (*moderately disabled*) and 6 (*use of a cane*) on the Expanded Disability Status Scale (EDSS) was 17 years and 24 years, respectively. Half of the patients with secondary-progressive MS (SPMS) were expected to reach EDSS scores of 3, 6, and 8 (*use of a wheelchair*) within 3 years, 10 years, and 38 years, respectively. The progression of disability was much more rapid for those with primary-progressive MS (PPMS), with the median time from diagnosis to reaching EDSS scores of 6 and 8 being 3 years and 25 years, respectively. In conducting a secondary data analysis of existing cross-sectional data from a survey mailed to 906 members of the Multiple Sclerosis Society of Canada, Finlayson and colleagues (2001) examined the factors associated with increased use of assistive devices. Variables associated with

greater disability, such as having a progressive type of MS, having MS for a longer period, and having more symptoms and limitations on activity, were predictive of assistive-device use.

### Balance

In a random sample of persons with MS in northern California, Goodin and the Northern California MS Study Group (1999) found that 47.6% of respondents indicated that they had moderate or severe difficulties with balance. In a study of balance performance involving 124 MS patients (28 with PPMS, 34 with SPMS, and 62 with relapsing-remitting MS [RRMS]) and 31 healthy controls, several balance items were evaluated, including the results of steady-stance tests (i.e., eyes opened and closed, feet apart and together, stride stance, tandem stance, and single stance), self-generated perturbations (i.e., functional-research, arm-raise, and step tests), external perturbations, Tinetti-gait, and 10-meter-gait time tests (Soyuer, Mirza, & Erkorkmaz, 2006). MS patients had impaired balance in many of the items (i.e., tandem stance, single-leg stance, self-generated perturbations, external perturbations, Tinetti-gait, and 10-meter-gait time tests). Those with SPMS and PPMS had more balance impairments than those with RRMS. In a much smaller sample ( $N = 14$ ), with no differentiation between types of MS, there was no difference between persons with MS and healthy controls on standing balance (i.e., feet apart, feet together, or stride stance), but there were differences in tandem stance and single-leg stance (Frzovic, Morris, & Vowels, 2000).

### Speech

Few studies have described the speech characteristics in persons with MS (Hartelius, Runmarker, & Andersen, 2000). It is estimated that between 40% and 55% of persons with MS have, at one time or another, experienced dysarthria, or speech characterized by slowness, slurring, or difficulties in production or comprehension (Hartelius et al.; Hartelius & Svensson, 1994; Klugman & Ross, 2002). There may also be problems controlling the pitch, loudness, rhythm, and voice qualities of speech. Hartelius and colleagues found that the frequency and severity of speech problems were variable and dependent upon individual characteristics of the disease. In a small sample of MS patients ( $N = 30$ ), 56.7% reported speech problems and 63.3% reported language difficulties (Klugman & Ross). One of the most commonly reported speech problems is impaired verbal fluency (Friend et al., 1999; Henry & Beatty, 2006; Klugman & Ross; Pozzilli et al., 1991), a symptom that would be clearly noticeable to others.

## Invisible MS Symptoms

### **Fatigue**

Fatigue can manifest as a lack of motivation to perform certain mental or physical tasks, an inability to sustain continuous activity, or an inability to perform multiple tasks over time (Bakshi, 2003; Kaasa, Loge, Knobel, Jordhoy, & Brenne, 1999). About 80% of MS patients report that they experience fatigue (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994; Freal, Kraft, & Coryell, 1984), and it is estimated that 10%–40% of MS patients report that it is their most common and debilitating symptom (Krupp, 2003; Krupp, Alvarez, LaRocca, & Scheinberg, 1988). Fatigue has been reported to cause distress and to have detrimental effects on activities of daily living, social and occupational obligations, and individuals' overall quality of life (Bakshi; Strober & Arnett, 2005).

Although the specific etiology (Colombo, Annovazzi, & Comi, 2006) and pathophysiology of fatigue in MS are not well understood (Colombo et al.; Egg, Högl, Glatzl, Beer, & Berger, 2002), it has been suggested that causes of MS fatigue may be multifactorial (Schwid, Covington, Segal, & Goodman, 2002). Causes may include psychological factors such as depression, loss of control over one's environment, or coping skills, whereby the person is unable to meet external demands (Bakshi, 2003; Clark et al., 1992; Krupp, 2003; Schwid et al.; Strober & Arnett, 2005); physical factors, including pain and disabilities, such as impaired balance or coordination that prevent activities, independent of fatigue (Bakshi; Kaasa et al., 1999; Krupp); and physiological factors, such as sleep disturbances (Clark et al.; Strober & Arnett). Although the relationship between fatigue and depression is still under debate (Colombo et al.), Schreurs, deRidder, and Bensing (2002) found that mental fatigue was associated with depression; in another investigation (Strober & Arnett), depression was a strong predictor of fatigue. Pain and fatigue also have been found to be correlated (Kaasa et al.).

### **Pain**

Various studies have used different methodologies and samples to assess the prevalence, severity, and impact of pain on activities of daily living in persons with MS (Beiske, Pedersen, Czujko, & Myhr, 2004; Ehde et al., 2003). These studies clearly indicate that chronic pain in persons with MS is not only common but can also be severe and often goes untreated (Beiske et al.; Goodin & the Northern California MS Study Group, 1999; Kalia & O'Connor, 2005; Österberg, Boivie, & Thuomas, 2005). Some studies have found that pain prevalence or severity was associated with the age of the individual, disease duration, or gender; however, the majority of

studies have not found such associations (Archibald et al., 1994; Beiske et al.; Ehde, Osborne, & Jensen, 2005; Österberg et al.). Österberg and colleagues reviewed eight previous pain studies and reported that the percentage of MS patients indicating they had experienced pain ranged from 29% to 86%. Kalia and O'Connor found that pain was more often nonneurogenic than neurogenic, with 56.6% of persons with MS reporting nonneurogenic pain, compared with 17.2% reporting neurogenic pain. The severity of pain in MS is similar to other chronic conditions that are characterized by severe pain, such as rheumatoid arthritis and osteoarthritis (Kalia & O'Connor). Pain severity was related to anxiety and depression (Archibald et al.; Kalia & O'Connor) and associated with reduced health-related quality of life, indicated primarily through low scores in mental-health tests (Archibald et al.; Kalia & O'Connor). Pain has also been related to higher levels of distress (Archibald et al.).

### **Depression and Anxiety**

A high comorbidity of mental-health challenges, specifically depression and anxiety, has been found in persons with MS (Gilchrist & Creed, 1994; Lynch, Kroencke, & Denney, 2001; Minden & Schiffer, 1990, 1991; Mohr & Goodkin, 1999; Schubert & Foliart, 1993). A meta-analysis of the literature on depression and MS found that MS patients have higher rates of depression than either the general population or people with other medical or neurological illnesses (Schubert & Foliart). People with MS also score high on measures of anxiety (Maurelli et al., 1992).

## Outcome Variables

### **Health Distress**

Fear and uncertainty about one's health and future abilities are common in persons with MS (Kroencke, Denney, & Lynch, 2001; Thorne, Con, McGuinness, McPherson, & Harris, 2004). Devins and Seland's (1987) review of the literature on depression and emotional stress identified two situations for MS patients that are related to increased emotional distress. The first is functional loss caused by increased physical disabilities. This functional loss could also include fatigue, which can greatly impact daily life (MacAllister & Krupp, 2005). The second is that patients reported distress from disease activity caused by exacerbation or progression of MS symptoms. Patients experiencing an exacerbation reported four times the emotional distress levels of patients in remission (Dalos, Rabins, Brooks, & O'Donnell, 1983). Thus, an exacerbation that brings new symptoms, symptoms that do not resolve, the necessity of starting or changing treatment, and the unpredictability of MS could all be causes for

emotional distress and uncertainty (Minden & Schiffer, 1991).

### Purpose of the Study

The purpose of this study was to examine the effects of visible and invisible symptoms on individuals with MS to determine which is more important in predicting their health distress. Based on a review of the existing medical literature, it was hypothesized that invisible symptoms would be associated with higher levels of health distress. This hypothesis fit more closely with Parsons' (1951) ideas about a sick role than with Goffman's (1963) concept of stigma, in that invisible symptoms of MS would be less obvious to family, friends, and healthcare professionals. Individuals with MS who have invisible symptoms do not appear to be ill but nonetheless may experience symptoms that cause them distress and that most likely require attention and treatment from healthcare professionals.

### Method

#### Subjects

The participants in this study were part of a larger study that examined the impact of living with MS. They were recruited through a Midwestern chapter of the National Multiple Sclerosis Society (NMSS). The chapter requested a random sample of 1,000 names and addresses affiliated with their chapter from the NMSS national database. The initial mailing consisted of a letter introducing the study and a form that potential participants completed, indicating that they had received a definite diagnosis of MS and whether they preferred to complete the study by telephone, Internet survey, or a mailed pencil-and-paper survey. Ninety-two of these mailings were returned as undeliverable; 185 individuals returned the form for an initial response rate of 20%. Of these 185, two were family members of MS patients and one had probable MS; these three respondents, therefore, were not included in the study. Data were obtained from 145 individuals (i.e., 78% of those who desired to participate).

Twenty individuals requested a telephone interview. These individuals had severe vision problems or difficulty writing. Telephone interviews typically were 1–2 hours in length (although a few were completed in two sessions when the participants reported becoming fatigued). The response rate for the telephone interview was 100%.

Paper-and-pencil surveys were mailed to 137 individuals. The survey questions were contained in two booklets and took approximately 1 hour to complete. Reminder postcards were sent to those

who did not return the survey after 3 weeks, and follow-up telephone calls were made to those who did not respond to the postcard reminder. Of the original 137 individuals, 7 withdrew (one participant had died; others had had an increase in health problems, and others did not like the questions), 27 did not return the booklets for various reasons (participants had other things going on, or the survey had gotten lost in the mail), and 103 returned completed booklets. The overall response rate for pencil-and-paper surveys, including those who withdrew, was 75%.

Based on a review of the existing medical literature, it was hypothesized that invisible symptoms would be associated with higher levels of health distress.

An e-mail with a link to the Internet survey form was delivered to participants, and they were given 3 weeks to complete the survey. Of the 24 people who received the Internet survey, one declined after reading the questions and one e-mail address was undeliverable, yielding a response rate of 92%.

Respondents who requested telephone interviews (a) were older (53.8 years versus 44.8 years) and (b) reported more physical limitations (16.3 versus 22.1 on the Short Form 36<sup>®</sup> [SF-36] Physical Functioning Scale, with lower scores reflecting more limitations) than those who requested to complete the survey over the Internet. Given that no significant differences were found for other demographic or outcome variables, we concluded that differences in mode of administration did not bias the results in any systematic way.

Table 1 summarizes the demographics of the participants. Seventy-four percent were female ( $n = 107$ ); they ranged in age from 25 years to 82 years (median age = 50;  $SD = 11.05$ ), and most (92%) were European Americans. In terms of type of MS, 66% indicated that they had been diagnosed with RRMS, 12% with PPMS, and 9% with SPMS. Thirteen percent indicated that they did not know what type of MS they had or selected "other" (e.g., "stabilized quad"). Participants had had MS for an average of 10.8 years (range = 1 year to 38 years).

Approximately two-thirds of the sample was married (62%), and most did not have children living at home with them (65%). Participants reported household incomes that were fairly evenly distributed across the six income categories (median income range = \$40,000–\$59,000) and were an educated group (some high school or high school graduate,

**Table 1.** Demographic Characteristics of Participants

Characteristics	<i>n</i>	%
<b>Sex</b>		
Male	38	26
Female	107	74
<b>Type of MS</b>		
Relapsing-remitting	95	66
Primary-progressive	17	12
Secondary-progressive	13	9
Other	14	10
Not sure	4	3
<b>Race/Ethnicity<sup>a</sup></b>		
American Indian/Alaska Native	1	1
Asian or Pacific Islander	1	1
African American	3	2
Mexican American	2	1
European American	132	92
Other	5	3
<b>Relationship status</b>		
Dating	5	3
Engaged	2	1
Remarried	10	7
Married	90	62
Living together	4	3
Divorce/Annulment	10	7
Separated	4	3
Widowed	4	3
Not in relationship	16	11
<b>Income<sup>b</sup></b>		
\$0–\$19,999	28	21
\$20,000–\$39,999	25	19
\$40,000–\$59,999	29	22
\$60,000–\$79,999	26	19
\$80,000–\$99,999	11	8
\$100,000 and above	15	11
<b>Education</b>		
Some high school	4	3
Completed high school	31	21
Some college	59	41
Completed college	21	14
Some graduate work	7	5
Completed master's degree	22	15
Completed doctorate degree	1	1

<sup>a</sup> Not all participants answered this question; *n* = 144.

<sup>b</sup> Not all participants answered this question; *n* = 134.

24%; some college or college graduate, 55%; some postdegree or completed postdegree, 21%). The majority of participants was either on disability (33%) or employed full time (30%), and most identified their religion as either Protestant (60%) or Catholic (14%).

## Measures

### Visible Symptoms

Three questions inquired about visible symptoms of MS. The first question, which participants could answer yes or no, was “During the past 4 weeks,

have you used an assistive device?” The responses were dummy coded so that *no* = 0 and *yes* = 1. Balance and speech were the second and third visible symptoms of MS used in the analysis. The balance question was assessed by a Likert-type question: “During the past 4 weeks, how often have you altered your activities because of problems related to balance?” The speech question was identical, except that it inquired about problems related to speech. Respondents could select 1 = *not at all*, 2 = *once*, 3 = *two to four times*, 4 = *more than weekly but not daily*, and 5 = *daily*.

### Invisible Symptoms

Four invisible symptoms, including fatigue, pain, anxiety, and depression, were measured. The Modified Fatigue Impact Scale, which is part of the Multiple Sclerosis Quality of Life Inventory (Ritvo et al., 1997), a 5-item Likert-type scale, was used to assess fatigue. This scale included statements such as “Because of my fatigue during the past 4 weeks, I have been limited in my ability to do things away from home” and “I have had trouble concentrating.” Participants responded with 1 = *never*, 2 = *rarely*, 3 = *sometimes*, 4 = *often*, and 5 = *almost always*. Internal consistency for the fatigue items was .87. Pain was measured with the Pain Effects Scale (Ritvo et al.), a 6-item Likert-type scale. Examples of questions included “During the past 4 weeks, how much did pain interfere with your mood?” and “During the past 4 weeks, how much did pain interfere with your ability to move around?” Respondents could indicate 1 = *not at all*, 2 = *a little*, 3 = *moderately*, 4 = *quite a bit*, and 5 = *to an extreme degree*. The alpha coefficient was .92 for the Pain Effects Scale. The Mental Health Inventory (MHI) was used to assess anxiety and depression in this study; it has been widely used in other MS studies (Vickrey, 1995). Two of the four subscales on the 18-item MHI were used: (a) anxiety (“Have you been a very nervous person?”) and (b) depression (“Have you felt downhearted and blue?”). Participants were asked to consider the time frame of the past 4 weeks. The internal-consistency alpha coefficients for the anxiety and depression subscales were .85 and .86, respectively.

### Outcome Measures

Health distress was measured by a 4-item Likert-type scale from the Multiple Sclerosis Quality of Life-54 (Vickrey, 1995). Questions on this scale included: “How much of the time during the past 4 weeks were you discouraged by your health problems?”; “Were you frustrated about your health?”; “Was your health a worry in your life?”; and “Did you feel weighed down by your health problems?” Respondents could indicate 1 = *all of the time*, 2 = *most of the time*, 3 = *a good bit of the time*, 4 = *some*

of the time, 5 = a little of the time, or 6 = none of the time. A standardized score was created from the average of each item, with higher scores indicating greater health distress. Internal consistency for the health-distress items was .93.

### Analysis

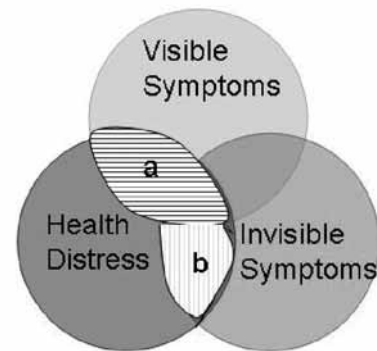
Hierarchical regression was used in the analysis. In hierarchical regression, independent variables are entered into the regression analysis in the order specified by the researcher (Tabachnick & Fidell, 1996). In the first model, visible symptoms were entered first, followed by invisible symptoms (Fig 2). The second hierarchical-regression model reverses the order in which invisible and visible symptoms are added in the regression; that is, invisible symptoms were entered first, followed by visible symptoms (Fig 3). If more variance was explained by the first step (indicated by the shaded area *a* in Figures 2 and 3), then that set of symptoms (either visible or invisible) was a more important predictor of health distress.

Another strategy for determining which set of variables is more important is to examine the additional variance explained by the second set of variables added to the regression equation. The set of variables entered last that contributes above and beyond the variance explained by the first set of variables is a stronger predictor of the outcome. Therefore, the shaded area *b* in Figures 2 and 3 was examined to determine which set of variables added more predictive ability after the first step when explaining health distress.

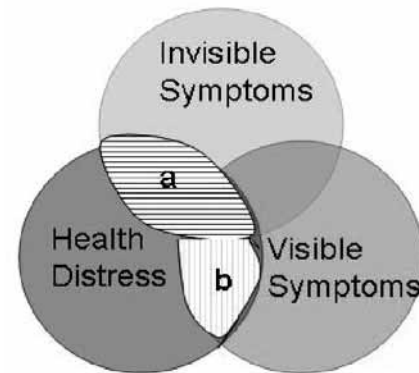
### Results

Table 2 presents the bivariate correlations, means, standard deviations, and ranges for the three visible and four invisible symptoms. The use of assistive devices was positively correlated with greater problems with balance ( $r = .43, p < .001$ ), and higher levels of fatigue ( $r = .29, p < .001$ ) and pain ( $r = .30, p < .001$ ). Greater problems with balance were positively associated with more speech difficulties ( $r = .42, p < .001$ ), higher levels of fatigue ( $r = .48, p < .001$ ), pain ( $r = .29, p < .001$ ), and depression ( $r = .17, p < .05$ ). Speech difficulties were positively correlated with higher levels of fatigue ( $r = .36, p < .001$ ), pain ( $r = .22, p < .01$ ), depression ( $r = .28, p < .001$ ), and anxiety ( $r = .32, p < .001$ ). Higher levels of fatigue were positively associated with greater pain ( $r = .50, p < .001$ ), depression ( $r = .32, p < .001$ ), and anxiety ( $r = .30, p < .001$ ). More pain was positively correlated with higher rates of depression ( $r = .28, p < .001$ ) and anxiety ( $r = .34, p < .001$ ). Depression and anxiety were highly correlated ( $r = .74, p < .001$ ), such that higher levels of depression would be associated with higher levels of anxiety.

**Fig 2.** Venn-Diagram Representation of Hierarchical Regression with Visible Symptoms Entered First



**Fig 3.** Venn-Diagram Representation of Hierarchical Regression with Invisible Symptoms Entered First



**Table 2.** Bivariate Correlations Between Visible and Invisible Symptoms

Variable	1	2	3	4	5	6	7
Visible Symptoms							
1. Assistive Device	—						
2. Balance	.43***	—					
3. Speech	.09	.42***	—				
Invisible Symptoms							
1. Fatigue	.29***	.48***	.36***	—			
2. Pain	.30***	.29***	.22**	.50***	—		
3. Depression	-.08	.17*	.28***	.32***	.28***	—	
4. Anxiety	-.09	.12	.32***	.30***	.34***	.74***	—
<i>M</i>	0.51	3.31	1.79	15.84	13.84	27.61	33.24
<i>SD</i>	0.50	1.69	1.27	4.76	6.09	21.03	20.67
Range	0–1	1–5	1–5	2–25	6–28	0–90	0–96

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Simultaneous to conducting regression analyses, data were evaluated to determine whether the underlying assumptions of multiple regression—that of normality, lack of multicollinearity, and multivariate outliers—had been met. After examining skewness and kurtosis, it was determined that the data

were generally univariately normally distributed, except for the dummy-coded variable use of assistive devices. Using collinearity statistics generated by the Statistical Package for the Social Sciences (SPSS) Version 14.0, variance inflation factors were small, suggesting that multicollinearity among the independent variables was not a problem. With respect to multivariate outliers, six respondents had multivariate observations outside of  $\pm 2$  standard deviations on regression standardized residuals, but only one respondent had residuals greater than  $\pm 3$  standard deviations and was removed from the regression analyses.

Two hierarchical regression models were used to examine the proportion of explained variance from visible symptoms (i.e., use of assistive devices, balance, and speech problems) and invisible symptoms (i.e., fatigue, pain, depression, and anxiety) in health distress. In the first model (Fig 2), visible symptoms was the first step entered into the regression equation and invisible symptoms was the second step. The second model (Fig 3) reversed the order of the first and second steps so that invisible symptoms were entered first, followed by visible symptoms. The results of these two regression models appear in Table 3.

When visible symptoms were added first into the regression equation (Model 1), 18% of the variance in predicting health distress was explained ( $F = 10.13$ ,  $p < .001$ ). By comparison, when invisible symptoms were the first step in the regression (Model 2), 53% of the variance was accounted for ( $F = 35.20$ ,  $p < .001$ ). In comparing the second step, Model 1 added invisible symptoms second, the amount of explained variance increased to 55%, and the change in  $R^2$  was .37 ( $F = 25.18$ ,  $p < .001$ ). Model 2 contributed to a change in  $R^2$  of .03 ( $F = 2.78$ ,  $p < .05$ ). It is clear that invisible symptoms, whether they were included in the first or second step of the model, explained a greater portion of the variance. After Steps 1 and 2 were added, only pain ( $\beta = 1.00$ ,  $t = 2.97$ ,  $p < .01$ ) and depression ( $\beta = 0.57$ ,  $t = 4.79$ ,  $p < .001$ ) were significant variables, meaning that when all of the variables were considered together, pain and depression were the most important in predicting health distress.

Because of the process of disease progression, it may be that the impact of visible and invisible symptoms on health distress changes the longer one has had MS. To examine this, the same two hierarchical regression models were computed on individuals who had had MS for 10 or fewer years ( $n = 74$ ) and

**Table 3.** Two Models with Visible and Invisible Symptoms Entered in (Alternating) Hierarchical Regression Steps Used to Predict Health Distress

	Model 1			Model 2		
	Adj. $R^2$	$\Delta R^2$	$F$ change ( $df$ )	Adj. $R^2$	$\Delta R^2$	$F$ change ( $df$ )
Step 1: Visible Symptoms	.18	.20	10.13*** (3, 121)	Step 1: Invisible Symptoms	.53	.54 35.20*** (4, 120)
Step 2: Invisible Symptoms	.55	.37	25.18*** (7, 117)	Step 2: Visible Symptoms	.55	.03 2.78* (7, 117)
<b>Final Model</b>						
			$\beta$	$SE \beta$	$t$	
			Assistive Device	5.36	3.92	1.37
			Balance	1.85	1.29	1.44
			Speech	1.16	1.56	0.74
			Fatigue	0.75	0.47	1.59
			Pain	1.00	0.34	2.97**
			Depression	0.57	0.12	4.79***
			Anxiety	0.05	0.13	0.39

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

those who had had MS for 11 or more years ( $n = 60$ ). For those who had had MS for 10 or fewer years, the results were similar to those described in the previous paragraph; that is, invisible symptoms explained more variance than visible symptoms, and pain and depression were the two variables that had significant predictive power in explaining health distress. The results were slightly different for those who had had MS for 11 or more years. As can be seen in Table 4, the first and second steps of invisible and visible symptoms explained 65% of the variance when predicting health distress. Reflecting the increased predictive power of visible symptoms for those who had had MS for 11 or more years, use of assistive devices ( $\beta = 17.10, t = 2.95, p < .01$ ) was a significant variable, as were fatigue ( $\beta = 1.46, t = 1.98, p < .05$ ), pain ( $\beta = 1.36, t = 3.08, p < .01$ ), and depression ( $\beta = 0.71, t = 4.93, p < .001$ ).

## Discussion

In this study, invisible symptoms were more predictive of health distress than visible symptoms. In fact, the four invisible symptoms explained 53% of the variance in predicting health distress when entered into the regression equation as the first step, whereas the visible symptoms accounted for only 18% of the variance. Pain and depression were the two invisible symptoms that had significant  $t$ -scores. For those who had had MS for 11 years or longer, fatigue, pain, and depression were the three invisible symptoms that had significant  $t$ -scores. These data support the notion that invisible symptoms are more distressing to persons with MS than visible symptoms. These quantitative data support the qualitative research with adolescents with seizure disorders (Hodgman et al., 1979) and adults with traumatic brain injuries (Chamberlain, 2006) or early strokes (Roding et al., 2003; Stone, 2005), which reports that invisible symptoms cause a great deal of distress for the individual.

For chronic neurological conditions such as MS, invisible symptoms clearly are distressing. They should be identified through screening and adequately treated by healthcare professionals. While most people newly diagnosed with MS may be most focused on the physical ramifications that might require the use of assistive devices such as wheelchairs or walkers (Isaksson & Ahlström, 2006; Johnson, 2003; Koopman & Schweitzer, 1999), our data suggested that this fact may not contribute significantly to health distress for those living with the illness during the first 10 years after diagnosis. Invisible symptoms, such as depression and pain, appear to be more salient variables in predicting health distress.

As part of the block of invisible symptoms, fatigue, pain, depression, and anxiety were important

contributors to predicting health distress. It is possible, however, for the  $R^2$  to be significant as a block, even though not all individual variables would be significant because of the variance shared by the variables. Given that fatigue is a common complaint of persons with MS (Fisk et al., 1994; Freal et al., 1984; Krupp, 2003), it is surprising that it was not one of the significant individual variables for the entire sample. However, fatigue and pain ( $r = .50$ ) and fatigue and depression ( $r = .32$ ) are significantly correlated, and in a multivariate analysis, the variance shared by pain and depression in predicting health distress partially accounted for variance that would be explained by fatigue. Fatigue was a significant predictor of health distress only for those who had been living with MS for 11 or more years.

Depression, not anxiety, was the most significant individual predictor of health distress. Depression frequently has been identified as a comorbid condition with MS (Mohr & Goodkin, 1999; Schubert & Foliart, 1993; Siegert & Abernethy, 2005), and this study supports those findings. Because anxiety has been reported in other research (Maurelli et al., 1992) as a mental-health problem for people with MS, it may be that in this study, anxiety overlapped with depression and therefore is not an individual significant predictor. In fact, the high correlation between depression and anxiety ( $r = .74$ ) would support this explanation. Given the prevalence of depression in MS of about 20% annually (Siegert & Abernethy), it is essential for healthcare providers to screen for and treat depression.

The findings from this study indicate that pain is also an important predictor of health distress. Recently, research has pointed out the prevalence

**Table 4.** Regression Model with Invisible (Step 1) and Visible (Step 2) Symptoms Entered for Persons Who Have Had Multiple Sclerosis for 11 or More Years

	Adj. $R^2$	$\Delta R^2$	$F$ change ( $df$ )
Step 1: Invisible Symptoms	.57	.60	18.64*** (4, 49)
Step 2: Visible Symptoms	.65	.09	4.80** (7, 46)
	$\beta$	SE $\beta$	$t$
Assistive Device	17.10	5.81	2.95**
Balance	0.78	1.75	0.44
Speech	3.11	2.47	1.26
Fatigue	1.46	0.74	1.98*
Pain	1.36	0.44	3.08**
Depression	0.71	0.14	4.93***
Anxiety	-0.19	0.17	-1.12

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

and severity of pain in people with MS (Beiske et al., 2004; Goodin & the Northern California MS Study Group, 1999; Kalia & O'Connor, 2005). Ehde and colleagues (2003) concluded that "disability due to pain may be more important than previously recognized" (p. 605). To keep health distress at a minimum, it is important that healthcare professionals assess and aggressively treat the invisible symptom of pain.

Only after a patient has lived with MS for 11 or more years do the visible symptoms of decreased mobility and the need to use an assistive device become significant predictors of health distress. Previous research has identified that the type of MS and the length of time since diagnosis can predict EDSS scores and when persons with MS need to begin to use assistive devices (Finlayson et al., 2001; Pittock et al., 2004). In general, these studies show that few individuals have EDSS scores that indicate assistive-device use within the first 10 years after diagnosis. In our sample, only 34.2% of those who had had MS for 10 or fewer years used an assistive device, compared with 71.2% who had had MS for 11 or more years.

The analysis used in this study allowed for several variables to be examined simultaneously, thereby allowing a determination of which of the individual variables were significant when the other variables were accounted for. Because the sample size limited the number of variables that could be included in the analysis, we chose to focus on those variables commonly described in the MS literature as frequent and troublesome symptoms of MS. It is likely that the results would be different if a larger sample were used and more invisible symptoms were included. However, we would probably hypothesize that adding additional invisible symptoms would only increase the ability to explain additional variance when predicting health distress.

One of the methodological shortcomings of this study was that it was a cross-sectional sample of individuals with MS, so it is not known whether the longitudinal trajectory of any given person would find the same symptoms to be significantly associated with health distress. Given the variable course of MS, it would be interesting to follow the same individual beginning shortly after diagnosis and throughout the ensuing years to determine which symptoms are associated with health distress in the same individual. A second shortcoming was that this was a relatively small sample of individuals with MS who lived in the Midwest, belonged to the NMSS, and felt that they had the physical ability to respond to an online or paper-and-pencil survey or telephone interview. The study should be replicated with other populations. For example, individuals with severe MS who are experiencing extreme paralysis and are wheelchair bound may respond differently concerning invisible and visible symptoms.

The third shortcoming was that the present analysis did not consider whether the cumulative impact of symptoms is important in explaining health distress. Thus, it may be that the total number of MS symptoms is more distressing than the presence of just one or two of the major symptoms.

## Summary and Implications

In this study, the invisible symptoms of MS, especially pain and depression, clearly caused distress to the individuals living with these symptoms. In light of this finding, it is important that, with each visit to the neurologist or neurological clinic, neurological nurses screen the level of pain, fatigue, and depression in patients with MS and evaluate their level of distress with respect to these symptoms. Effective interventions and pharmacological treatments can then be discussed with the patient. In addition, follow-up visits should review the interventions and treatments to determine whether they were successful. Future research should be conducted to determine whether attention to and treatment of the invisible symptoms of MS reduce the health distress in individuals with MS.

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## References

- Archibald, C. J., McGrath, P. J., Ritvo, P. G., Fisk, J. D., Bhan, V., Maxner, C. E., et al. (1994). Pain prevalence, severity and impact in a clinic sample of multiple sclerosis patients. *Pain, 58*, 89–93.
- Bakshi, R. (2003). Fatigue associated with multiple sclerosis: Diagnosis, impact, and management. *Multiple Sclerosis, 9*, 219–227.
- Beiske, A. G., Pedersen, E. D., Czujko, B., & Myhr, K. M. (2004). Pain and sensory complaints in multiple sclerosis. *European Journal of Neurology, 11*, 479–482.
- Blake, D. J., & Bodine, C. (2002). An overview of assistive technology for persons with multiple sclerosis. *Journal of Rehabilitation Research and Development, 39*, 299–312.
- Chamberlain, D. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing, 54*, 407–417.
- Clark, C. M., Fleming, J. A., Li, D., Oger, J., Klonoff, H., & Paty, D. (1992). Sleep disturbance, depression, and lesion site in patients with multiple sclerosis. *Archives of Neurology, 49*, 641–643.
- Colombo, B., Annovazzi, P., & Comi, G. (2006). Understanding fatigue in multiple sclerosis: New insights in causes and assessments. *Neurological Science, 27*, 304–306.
- Cross, T., & Rintell, D. (1999). Children's perceptions of parental multiple sclerosis. *Psychology, Health and Medicine, 4*, 355–360.
- Dalos, N. P., Rabins, P. V., Brooks, B. R., & O'Donnell, P. (1983). Disease activity and emotional state in multiple sclerosis. *Annals of Neurology, 13*, 573–577.
- Davis, N. (2005). Invisible disability. *Ethics, 116*, 153–215.
- Devins, G. M., & Seland, T. P. (1987). Emotional impact of multiple sclerosis: Recent findings and suggestions for future research. *Psychological Bulletin, 101*, 363–375.

- Egg, R., Högl, B., Glatzl, S., Beer, R., & Berger, T. (2002). Autonomic instability, as measured by papillary unrest, is not associated with multiple sclerosis fatigue severity. *Multiple Sclerosis*, 8, 256–260.
- Ehde, D. M., Gibbons, L. E., Chwastiak, L., Bombardier, C. H., Sullivan, M. D., & Kraft, G. H. (2003). Chronic pain in a large community sample of persons with multiple sclerosis. *Multiple Sclerosis*, 9, 605–611.
- Ehde, D. M., Osborne, T. L., & Jensen, M. P. (2005). Chronic pain in persons with multiple sclerosis. *Physical Medicine and Rehabilitation Clinics of North America*, 16, 503–512.
- Finlayson, M., Guglielmo, L., & Liefer, K. (2001). Describing and predicting the possession of assistive devices among persons with multiple sclerosis. *American Journal of Occupational Therapy*, 55, 545–551.
- Fisk, J. D., Pontefract, A., Ritvo, P. G., Archibald, C. J., & Murray, T. J. (1994). The impact of fatigue on patients with MS. *Canadian Journal of Neurology Science*, 21, 9–14.
- Freal, J. F., Kraft, G. H., & Coryell, J. K. (1984). Symptomatic fatigue in MS. *Archives of Physical Medicine and Rehabilitation*, 65, 135–138.
- Freeman, J. A. (2001). Improving mobility and functional independence in persons with multiple sclerosis. *Journal of Neurology*, 248, 255–259.
- Friend, K. B., Rabin, B. M., Groninger, L., Deluty, R. H., Bever, C., & Grattan, L. (1999). Language functions in patients with multiple sclerosis. *Clinical Neuropsychologist*, 13, 78–94.
- Frzovic, D., Morris, M. E., & Vowels, L. (2000). Clinical tests of standing balance: Performance of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, 81, 215–221.
- Gilchrist, A. C., & Creed, F. H. (1994). Depression, cognitive impairment and social stress in multiple sclerosis. *Journal of Psychosomatic Medicine*, 38, 193–201.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Goodin, D. S., & the Northern California MS Study Group. (1999). Survey of multiple sclerosis in northern California. *Multiple Sclerosis*, 5, 78–88.
- Hallberg, L. R., & Jansson, G. (1996). Women with noise-induced hearing-loss: An invisible group? *British Journal of Audiology*, 30, 340–345.
- Hartelius, L., Runmarker, B., & Andersen, O. (2000). Prevalence and characteristics of dysarthria in a multiple-sclerosis incidence cohort: Relation to neurological data. *Folia Phoniatrica et Logopaedica*, 52, 160–177.
- Hartelius, L., & Svensson, P. (1994). Speech and swallowing symptoms associated with Parkinson's disease and multiple sclerosis: A survey. *Folia Phoniatrica et Logopaedica*, 46, 9–17.
- Henry, J. D., & Beatty, W. W. (2006). Verbal fluency deficits in multiple sclerosis. *Neuropsychologia*, 44, 1166–1174.
- Hodgman, C., McAnarney, E., Myers, G., Iker, H., McKinney, R., Parmelee, D., et al. (1979). Emotional complications of adolescent grand mal epilepsy. *Journal of Pediatrics*, 95, 309–312.
- Isaksson, A. K., & Ahlström, G. (2006). From symptom to diagnosis: Illness experiences of multiple sclerosis patients. *Journal of Neuroscience Nursing*, 38, 229–237.
- Joachim, G., & Acorn, S. (2000). Stigma of visible and invisible chronic conditions. *Journal of Advanced Nursing*, 32, 243–248.
- Johnson, J. (2003). On receiving the diagnosis of multiple sclerosis: Managing the transition. *Multiple Sclerosis*, 9, 82–88.
- Kaasa, S., Loge, J. H., Knobel, H., Jordhoy, M. S., & Brenne, E. (1999). Fatigue: Measures and relation to pain. *Acta Anaesthesiologica Scandinavica*, 43, 939–947.
- Kalia, L. V., & O'Connor, P. W. (2005). Severity of chronic pain and its relationship to quality of life in multiple sclerosis. *Multiple Sclerosis*, 11, 322–327.
- Klugman, T. M., & Ross, E. (2002). Perceptions of the impact of speech, language, swallowing, and hearing difficulties on quality of life of a group of South African persons with multiple sclerosis. *Folia Phoniatrica et Logopaedica*, 54, 201–222.
- Koopman, W., & Schweitzer, A. (1999). The journey to multiple sclerosis: A qualitative study. *Journal of Neuroscience Nursing*, 31, 17–26.
- Kroencke, D. C., Denney, D. R., & Lynch, S. G. (2001). Depression during exacerbations in multiple sclerosis: The importance of uncertainty. *Multiple Sclerosis*, 7, 237–242.
- Krupp, L. B. (2003). Fatigue in multiple sclerosis: Definition, pathophysiology and treatment. *CNS Drugs*, 17, 225–234.
- Krupp, L. B., Alvarez, L. A., LaRocca, N. G., & Scheinberg, L. C. (1988). Fatigue in multiple sclerosis. *Archives of Neurology*, 45, 435–437.
- Levene, B. (1983). Hearing loss—The invisible disability. *Nursing*, 2, 525–529.
- Lipkin, M., & Williams, M. E. (1986). Presbycusis and communication. *Journal of General Internal Medicine*, 1, 399–401.
- Lynch, S. G., Kroencke, D. C., & Denney, D. R. (2001). The relationship between disability and depression in multiple sclerosis: The role of uncertainty, coping, and hope. *Multiple Sclerosis*, 7, 411–416.
- MacAllister, W. S., & Krupp, L. B. (2005). Multiple sclerosis-related fatigue. *Physical Medicine and Rehabilitation Clinics of North America*, 16, 483–502.
- Marshak, L. E., Seligman, M., & Prezant, F. (2001). *Disability and the family life cycle*. New York: Basic.
- Maurelli, M., Marchioni, E., Cerretano, R., Bosone, D., Bergamaschi, R., Citterio, A., et al. (1992). Neuropsychological assessment in MS: Clinical, neurophysiological and neuroradiological relationships. *Acta Neurologica Scandinavica*, 86, 124–128.
- Minden, S. L., & Schiffer, R. B. (1990). Affective disorders in multiple sclerosis: Review and recommendations for clinical research. *Archives of Neurology*, 47, 98–104.
- Minden, S. L., & Schiffer, R. B. (1991). Depression and mood disorders in multiple sclerosis. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, 4, 62–77.
- Mohr, D. C., & Goodkin, D. E. (1999). Treatment of depression in multiple sclerosis: Review and meta-analysis. *Clinical Psychology: Science and Practice*, 6, 1–9.
- Moss, P., & Dyck, I. (2002). *Women, body, illness: Space and identity in the everyday lives of women with chronic illness*. Lanham, MD: Rowman & Littlefield.
- Österberg, A., Boivie, J., & Thuomas, K. A. (2005). Central pain in multiple sclerosis—prevalence and clinical characteristics. *European Journal of Pain*, 9, 531–542.
- Parsons, T. (1951). *The social system*. Glencoe, IL: The Free Press.
- Pittcock, S. J., Mayr, W. T., McClelland, R. L., Jorgensen, N. W., Weigand, S. D., Noseworthy, J. H., et al. (2004). Disability profile of MS did not change over 10 years in a population-based prevalence cohort. *Neurology*, 62, 601–606.
- Pozzilli, C., Passafiume, D., Bernardi, S., Pantano, P., Incoccia, C., Bastianello, S., et al. (1991). SPECT, MRI and cognitive function in multiple sclerosis. *Journal of Neurology, Neurosurgery and Psychiatry*, 54, 110–116.
- Randall, J. (1973). Hearing loss—The invisible disability. *Australian Nurses' Journal*, 2, 18.
- Ritvo, P. G., Fischer, J. S., Miller, D. M., Andrews, H., Paty, D. W., & LaRocca, N. G. (1997). *Multiple sclerosis quality of life inventory: A user's manual*. New York: National Multiple Sclerosis Society.
- Roding, J., Lindstrom, B., Malms, J., & Ohman, A. (2003). Frustrated and invisible—Younger stroke patients' experiences of the rehabilitation process. *Disability and Rehabilitation*, 25, 867–874.
- Schreurs, K. M. G., deRidder, D. T. D., & Bensing, J. M. (2002). Fatigue in multiple sclerosis: Reciprocal relationships with physical disabilities and depression. *Journal of Psychosomatic Research*, 53, 775–781.
- Schubert, D. S., & Foliart, R. H. (1993). Increased depression in multiple sclerosis patients: A meta-analysis. *Psychosomatics*, 34, 124–130.
- Schwid, S. R., Covington, M., Segal, B. M., & Goodman, A. D. (2002). Fatigue in multiple sclerosis: Current understanding and future directions. *Journal of Rehabilitation Research and Development*, 39, 211–224.
- Sherlock, L. (2005). An invisible disability. *FDA Consumer*, 39, 40.
- Shohet, J. A., & Bent, T. (1998). Hearing loss: The invisible disability. *Postgraduate Medicine*, 104, 81, 87–90.
- Siebert, R. J., & Abernethy, D. A. (2005). Depression in multiple sclerosis: A review. *Journal of Neurology, Neurosurgery and Psychiatry*, 76, 469–475.
- Soyuer, F., Mirza, M., & Erkorkmaz, U. (2006). Balance performance in three forms of multiple sclerosis. *Neurological Research*, 28, 555–562.
- Stewart, W. F., Ricci, J. A., Chee, E., Hahn, S. R., & Morganstein, D. (2003). Cost of lost productive work time among U.S. workers with depression. *Journal of the American Medical Association*, 289, 3135–3144.

- Kuzis, G., Sabe, L., Tiberti, C., Merello, M., Leiguarda, R., & Starkstein, S. E. (1999). Explicit and implicit learning in patients with Alzheimer disease and Parkinson disease with dementia. *Neuropsychiatry, Neuropsychology, and Behavioral Neurology*, 12(4), 265–269.
- Lawton, M. P. (2001). Physical environment of the person with Alzheimer's disease. *Aging and Mental Health*, 5(Suppl. 1), S56–S64.
- Mace, N. L., & Rabins, P. V. (1991). *The 36-hour day* (Rev. ed.). Baltimore: Johns Hopkins University Press.
- Madori, L. L. (2007). *Therapeutic thematic arts programming for older adults*. Baltimore: Health Professional Press.
- Nebes, R. D. (1992). Cognitive dysfunction in Alzheimer's disease. In F. I. M. Craik & T. A. Salthouse (Eds.), *The handbook of aging and cognition* (pp. 373–446). Hillsdale, NJ: Erlbaum.
- Nielsen, N. C., Hein, N., Reynolds, F. E., Miller, A. L., Karff, S. E., Cochran, A. C., et al. (1983). *Religions of the world*. New York: St. Martin's Press.
- Nordin, S., & Murphy, C. (1996). Impaired sensory and cognitive olfactory function in questionable Alzheimer's disease. *Neuropsychology*, 10(1), 113–119.
- Peters, J. M., Hummel, T., Kratzsch, T., Lotsch, J., Skarke, C., & Frolich, L. (2003). Olfactory function in mild cognitive impairment and Alzheimer's disease: An investigation using psychophysical and electrophysiological techniques. *American Journal of Psychiatry*, 160(11), 1995–2002.
- Poldrack, R. A., & Gabrieli, J. D. E. (1997). Functional anatomy of long-term memory. *Journal of Clinical Neurophysiology*, 14(4), 294–310.
- Reisberg, B., Franssen, E. H., Souren, L. E., Auer, S. R., Akram, I., & Kenowsky, S. (2002). Evidence and mechanisms of retrogenesis in Alzheimer's and other dementias: Management and treatment import. *American Journal of Alzheimer's Disease and Other Dementias*, 17(4), 202–212.
- Samanta, M. K., Wilson, B. M., Santhi, K., Kumar, K. P., & Suresh, B. (2006). Alzheimer's disease and its management: A review. *American Journal of Therapeutics*, 13(6), 516–526.
- Speedie, L. J., Brake, N., Folstein, S. E., & Bowers, D. (1990). Comprehension of prosody in Huntington's disease. *Journal of Neurology, Neurosurgery, and Psychiatry*, 53, 607–610.
- Stolley, J. M., Koenig, H., & Buckwalter, K. C. (1999). Pastoral care for the person with dementia. *Journal of Health Care Chaplaincy*, 8(1–2), 7–23.
- U.S. Department of Labor, Bureau of Labor Statistics. (2006). *Occupational outlook handbooks (OOH), 2006–2007 Edition*. Retrieved March 1, 2006, from www.bls.gov/oco.
- Vance, D. E. (2004). Procedural and emotional religious activity therapy: Cognitive and spiritual aspects of dementia. *Activities, Adaptation and Aging*, 29(1), 27–45.
- Vance, D. E., Burgio, L. D., Roth, D. L., Stevens, A. B., Fairchild, J. K., & Yurick, A. (2003). Predictors of agitation in nursing home residents. *Journal of Gerontology*, 58B, P129–P137.
- Vance, D. E., & Crowe, M. (2006). A proposed model of neuroplasticity and cognitive reserve in older adults. *Activities, Adaptation and Aging*, 30(3), 61–79.
- Vance, D. E., & Johns, R. N. (2002). Montessori improved cognitive domains in adults with Alzheimer's disease. *Physical and Occupational Therapy in Geriatrics*, 20(3/4), 19–36.
- Vance, D. E., & Porter, R. J., Jr. (2000). Cognitive benefits from using Montessori in Alzheimer's day cares. *Activities, Adaptation and Aging*, 24(3), 1–22.
- Yaari, R., & Corey-Bloom, J. (2007). Alzheimer's disease. *Seminars in Neurology*, 27(1), 32–41.

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- Stone, S. (2005). Reactions to invisible disability: The experiences of young women survivors of hemorrhagic stroke. *Disability and Rehabilitation*, 27, 293–304.
- Strober, L. B., & Arnett, P. A., (2005). An examination of four models predicting fatigue in multiple sclerosis. *Archives of Clinical Neuropsychology*, 20, 631–646.
- Sturge-Jacobs, M. (2002). The experience of living with fibromyalgia: Confronting an invisible disability. *Research and Theory for Nursing Practice: An International Journal*, 16, 19–31.
- Tabachnick, B. G., & Fidell, L. S. (1996). *Using multivariate statistics* (3rd ed.). New York: Harper Collins.
- Thorne, S., Con, A., McGuinness, L., McPherson, G., & Harris, S. R. (2004). Health care communication issues in multiple sclerosis: An interpretive description. *Qualitative Health Research*, 14, 5–22.
- Vickrey, B. G. (1995). *Multiple sclerosis quality of life inventory-54 instrument*. Los Angeles: University of California at Los Angeles.

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