Predictors of Help-Seeking Behavior in Adults with Multiple Sclerosis

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Abstract

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Introduction: Multiple sclerosis (MS) is a physically, emotionally, and financially taxing disease. Education, support and wellness programs offered through consumer organizations have been shown to reduce symptom burden and improve overall quality of life. The purpose of this analysis was to predict help-seeking behavior in MS patients in the states of Alaska, Montana and Washington.

Methods: This analysis was part of a cross-sectional needs assessment conducted with the National MS Society, Greater Northwest Chapter of MS Society Members. Our research was guided by Anderson's Behavioral Model of Health Services Use. Predictive variables chosen were based on Anderson's three categories of influence: *predisposing* (age, sex, time since diagnosis, and education), *enabling* (receiving Medicaid, income, social support, relationship status, living in a rural area and use of accessible transportation) and *need* factors (MS type, anxiety, depression, fatigue, pain and mobility). Univariate logistic regression models were conducted to determine predictors of help-seeking behavior. Significance was set using a Bonferroni correction at $p<0.004$.

Results: 437 adults with MS participated in the survey. Participants had a mean age of 52.5 years, 69.3% were female, 59.6% had a relapsing-remitting MS type, 32.3% reported a progressive MS type and average time since diagnosis was 14.6 years. 62.5% of all participants reported not having attended any MS programs or services in the last 2 years. Results from our logistic regression showed years since diagnosis, education, receiving Medicaid, use of accessible transportation and lower mobility to be associated with help-seeking behavior.

Conclusions: Individual differences, ecological factors and disease characteristics serve as barriers to help seeking behavior. Creating options for participation for MS patients with lower income, lower education and those with mobility limitations should be a primary goal. Greater outreach about positive outcomes associated with seeking-help should be conducted.

I. Introduction

A 27-year-old woman has been having dizzy spells for months, but this is not an uncommon symptom for her. However, this time her dizziness is accompanied by a feeling of "pins and needles" in her left hand, as though her circulation has been cut off. Worried, she visits her primary care physician who refers her to a neurologist for further testing. The referral was unexpected; she was hoping for an easy answer and not the barrage of tests the followed: a series of MRIs, spinal taps and tests of response to electrical stimuli. Three months later, she receives a diagnosis of multiple sclerosis (MS), a disease that she has not heard about. She is slowly absorbing the implications of preparing for progressive loss of neural function, increasing disability, psychological distress, and a host of symptoms including pain and fatigue.

The diagnosis process is often confusing and stressful for individuals faced with an uncertain future (Isaksson and Ahlström 2006). MS consumer organizations exist to support individuals with MS (such as our case study) and their families throughout the disease course. However, significant barriers still exist in accessing services offered by consumer organizations. Investigating predictors of help-seeking behaviors can help to uncover barriers that when left unaddressed can increase health disparities. This investigation will examine predictors of help-seeking behavior but first will discuss the background of MS including prevalence, pathophysiology, symptom burden, disease course, treatments and financial cost to illustrate disease impact. We will also discuss how health and wellness activities such as those offered through consumer organizations can positively impact MS patients, and assess unmet needs reported by MS patients. We will profile one such consumer organization, the National MS Society. We will then describe our primary question focusing on how a model frequently used in health services research, Anderson's Behavioral Model of Health Services Use, can inform variables associated with seeking help from a consumer organization (Andersen 1995).

a. Prevalence and Demographic Characteristics

MS is a progressive neurodegenerative disease of the central nervous system (Keegan and Noseworthy 2002). Prevalence estimates range from 250,000 – 400,000 in the United States (Noonan, Kathman et al. 2002). As the National Census or other large surveys do not gather information about this clinical population, prevalence may be underestimated. Women are 2.5 times more likely than men to be diagnosed (Noonan, Kathman et al. 2002). Global prevalence is highly correlated to race and ethnic group with higher disease risk in those of Western European decent and lower risk in those of Inuit, Native American or African descent (Compston and Coles 2008).

b. Risk Factors and Pathophysiology

Vitamin D and sunlight exposure have been causally implicated in MS (Grant 2010) , though results are far from definite (Noseworthy 1999). A strong latitude gradient exists causing northern portions of the United States, including Alaska, Montana and Washington, to have a higher prevalence than the national average (Beretich and Beretich 2009). Those living in northern climates prior to 15 years of age have a higher risk of developing MS that is reduced via immigration to a southern climate (Hernán, Olek et al. 1999).

MS acts primarily through immune-mediated damage to central nervous system myelin and oligodendrocytes, axon insulating cells common to the brain (Stadelmann, Wegner et al. 2008). Myelin both surrounds and insulates neurons (Trapp and Nave 2008). Demylination and resulting axonal loss the main causes of disability in MS, along with inflammation and edema that slow or disrupt conduction of electrical signals (Stadelmann, Wegner et al. 2008). Autopsy of brain tissue of MS patients indicates correlation between damaged axons or white-matter lesions and higher disease burden (Trapp and Nave 2008). Location of lesions often determines neurological symptoms; for example, a lesion on the brain stem may result in vertigo (Keegan and Noseworthy 2002).

c. Symptoms

The widely acknowledged conceptualization of MS involves mobility limitations and an inevitable wheelchair-bound life. However, an array of "invisible symptoms" has been increasingly scrutinized as adding to overall symptom burden. Lowered mobility and these invisible symptoms are typically classified as *primary, secondary* or *tertiary* (Schapiro 1994).

Primary symptoms involve functional limitations such as visual deficits, muscle weakness, spasticity (unusual muscle tightness or stiffness), mobility limitations, loss of bladder control, ataxia (loss of muscle coordination) and numbness (Confavreux and Vukusic 2006). Pain is reported by approximately half of patients with MS at any one time and varies in intensity over the life course (O'Connor, Schwid et al. 2008). Cognitive issues exist in 45% - 65% of MS patients primarily in the areas of memory, spatial ability, processing speed and executive function (Julian 2011). A phenomenon known as Uhthoff's symptoms is experienced by 80% of MS patients and is characterized by sensitivity to increases in body temperature brought on by environmental change or exercise (Guthrie and Nelson 1995).

Secondary symptoms are thought to be caused by *primary symptoms* and include fatigue, sleep disorders, depression, muscle atrophy, and urinary tract infections (Schapiro 1994). Fatigue is one of the most common disabling symptoms of MS, affecting as many as 65% of patients on a daily basis and increasing in intensity in afternoons and evenings (Hadjimichael, Vollmer et al. 2008). Depression occurs in approximately half of all patients with MS during the life course (Arnett and Randolph 2006). Depression is also confounded by higher prevalence of sleep disorders such as insomnia and narcolepsy, broadly estimated to occur in as many as 54% of patients with MS (Brass, Duquette et al. 2010; Caminero and Bartolome 2011) as well as fatigue, leading to difficulty in diagnosing and quantifying the burden of depression (Kroencke, Lynch et al. 2000).

Tertiary symptoms are impacted by both *primary* and *secondary symptoms* and exist in larger domains of social participation, psychological issues, vocational issues and personal care (Gulick 2001; Yorkston, Johnson et al. 2005). *Tertiary symptoms* are more difficult to quantify and have received much less attention in MS research. Given that diagnosis most commonly occurs at a young age, the effect of MS on employment, social role and social participation can be drastic. Five years post diagnosis, an estimated 60% - 70% of MS patients are unemployed (Roessler, Fitzgerald et al. 2001). Diagnosis is associated with increased stress around employment as many individuals re-evaluate their working future (Edgley, Sullivan et al. 1991). Among those who do continue to work, employment is associated with lower quality of life due to increasing symptoms and stress (Johnson, Bamer et al. 2009).

d. Diagnosis and Disease Course

Diagnosis most commonly occurs between the ages of 20 and 50 through a combination of self-reported symptom history and clinical examinations (McDonald, Compston et al. 2001; Compston and Coles 2008). Diagnostic criteria developed by McDonald et al. are commonly used and have been standardized by the International Panel on Diagnosis of MS (McDonald, Compston et al. 2001). A clinical diagnosis of MS is made if an individual has reported at minimum two discrete attacks or relapses characterized by a sudden increase in symptoms and presents with objective clinical evidence of at minimum two lesions in mylinated areas of the central nervous system, such as cerebral white matter or optic nerves (Keegan and Noseworthy 2002). Clinical evidence for lesions is determined through a variety of mechanisms including MRI for visual documentation and evoked potentials in which neurological conduction is measured along a specific pathway to find clinically relevant lesions blocking conduction (Keegan and Noseworthy 2002). Visual detection through MRI of demylinating lesions and later detection of muscle atrophy is a common diagnostic technique (Keegan and Noseworthy 2002).

Predicting symptom occurrence and severity over time is difficult as the course of MS is highly variable. Cohort studies have shown that female sex, younger age at diagnosis, longer interval between first and second relapse, complete recovery from initial relapse and lower incidence of relapses in the first five years are associated with better prognosis (Confavreux, Vukusic et al. 2003; Hutchinson 2009). Worse prognosis is associated with male sex, older age at diagnosis, presence of both optic neuritis and spinal cord symptoms at diagnosis and presence of motor symptoms and signs at diagnosis (Hutchinson 2009). Research into progression of other symptoms of MS has yet to be extensively conducted.

e. MS Type

MS is categorized as one of 4 types [**Table 1**] or dichotomously as relapsing-remitting or progressive (Bamer, Cetin et al. 2007). MS type is clinically important because it can be used to project future disease severity and prognosis (Scalfari, Neuhaus et al. 2010). Despite widely recognized types, disease course is highly individualized as symptom severity and cluster differ between individuals. However, the overall trajectory is almost always marked by progression in severity and an increase in number of symptoms (Deshpande, Kremenchutzky et al. 2006).

Table 1: Multiple Sclerosis Type

MS Type	Description	% of cases	When diagnosed
1. Relapsing-Remitting	Clinically significant events with outward symptoms followed by stability or improvement.	85% of initial diagnoses	Initial
2. Primary Progressive	Escalating disease but can include temporary periods of stability or small reductions in symptoms.	8-10% of initial diagnoses	Initial
3. Progressive-Relapsing	Continuous progression of disease with clear and acute relapses followed in some cases by an initial full recovery.	~5% of initial diagnoses	Initial
4. Secondary Progressive	Continuous progression in number and severity of symptoms and occasional discrete relapses.	~50% of those diagnosed with relapsing-remitting	Secondary

The majority of patients are diagnosed with the relapsing-remitting type, characterized by periods of discrete relapses followed by stability or even improvement (Confavreux and Vukusic 2006). A relapse is defined as a clinically significant event characterized by an increase in existing symptoms such as numbness spreading up the leg or the sudden appearance of new symptoms lasting at minimum 24 hours (Rosenblum and Saffir 1998). Periods of improvement are thought to result from resolution of immune-mediated neural inflammation and edema although residual deficit may be present (Waxman 2006). The change from relapsing-remitting to secondary progressive is thought to occur when the brain is no longer able to compensate for axonal loss. Although not spontaneous, the causal mechanisms for this change are not well understood (Trapp and Nave 2008). The majority of those initially diagnosed with relapsing-remitting MS will develop the secondary progressive type within 25 years of initial diagnosis (Confavreux, Vukusic et al. 2003).

f. Treatment

Pharmacological treatments target either disease progression or symptomatology. Disease modifying agents are intended to resolve acute attacks, reduce frequency of exacerbations, address the consequences of previous relapses, and prevent progression of disability (Freedman, Patry et al. 2004). Acute relapses are treated with corticosteroids to speed recovery from effects of the attack (Keegan and Noseworthy 2002). Interferon B and Glatiramer Acetate are the two main types of immunomodulatory therapies that reduce relapses and slow progression of disability (Trapp and Nave 2008). These medications must be administered via subcutaneous injection as often as every other day, resulting in injection site reaction, pain, and increased anxiety that together can contribute to decreased adherence (Baum, O'Leary et al. 2007). Addressing psychological issues resulting from introduction of an invasive treatment process has been associated with higher adherence and better disease outcome (Freedman, Patry et al. 2004).

Symptom medications are concerned with protecting physical function and quality of life (Keegan and Noseworthy 2002). These medications commonly treat pain, spasticity, fatigue, bladder and bowel control problems, tremor, depression, and dizziness or vertigo (Kargiotis, Messinis et al. 2010).

g. Financial Cost

Patients with MS are doubly disadvantaged, facing higher probability of unemployment and higher medical costs. The annual per capita cost of an individual living with MS has been estimated to be $34,103 (Whetten-Goldstein, Sloan et al. 1998). These costs include but are not limited to durable medical equipment, such as wheelchairs and grab-bars, and medication (Whetten-Goldstein, Sloan et al. 1998). Increase in medical cost coupled with decreased employment results in high financial stress. In one study, more than a quarter of respondents with MS reported postponing necessary health care because of expense, by delaying prescriptions, skipping medication doses or splitting pills (Iezzoni and Ngo 2007).

Costs of care are also correlated to MS disease course, increasing with progression as total cost for individuals with secondary progressive requires 110% the cost for an individual with relapsing-remitting MS and is as much as 124% higher for those with primary progressive MS (McCrone 2009). Furthermore, much of the true cost of an MS diagnosis is hidden, such as lost income due to lost or reduced work and the opportunity cost of unpaid care giving by family and friends (Whetten-Goldstein, Sloan et al. 1998). In fact, more than half of MS patients need help from another person to perform personal care activities as their disease progresses (Minden, Frankel et al. 2006).

h. Assessment of Unmet Need

Economic strain and lack of access to health care can result in increased utilization of services offered by consumer organizations in addition to or as an alternative to medical care. Assessments of reported need have found broad issues across many domains (Ross, Hackbarth et al. 2008). Qualitative interviews of patients with MS and their caregivers found needs around access to medical care, information about MS and MS services, access to aids and adaptations and an underlying idea that patients with MS struggle to meet needs (Edmonds, Vivat et al. 2007). Unmet needs have also included socio-environmental support and adaptation, enhanced care provision, rehabilitation therapies and non-professional care such as supportive caregiving (Forbes, While et al. 2007; Golla, Galushko et al. 2012).

Focus groups with health professionals identified support from family and friends, health care services, managing everyday life, and maintaining biographical continuity as unmet needs for MS patients (Golla, Galushko et al. 2012). Reporting an unmet need for health and wellness services has been associated with being female, higher education, having lower income, pain, decline in physical function and being unmarried (Plow, Cho et al. 2010). Help with decreasing symptom burden and information on how to better manage of MS is a much-needed service.

i. Health and Wellness Activities

In order to mitigate symptoms, consumer organizations are increasingly focused on health and wellness programs for patients with MS. Health and wellness most often focus on reduction of pain, fatigue, depression and increasing ability to cope with disease burden, interact with the medical system, and strengthen social role (Plow, Finlayson et al. 2011; Rae-Grant, Miller et al. 2011). A subset of health and wellness interventions has focused on self-management as a way for patients with chronic conditions to have better control over symptoms.

Innovative methods to reach patients with mobility limitations have successfully used telephone or web-based programs. The impact of fatigue on MS patients has been effectively reduced in a multitude of studies ranging from a telephone-counseling motivational interviewing course (Bombardier, Cunniffe et al. 2008), a randomized clinical trial focused on health promoting behaviors (Ennis, Thain et al. 2006), and a six-week teleconference intervention (Finlayson, Preissner et al. 2011). Results have been sustained for up to 8 weeks (Ennis, Thain et al. 2006) 12 weeks (Bombardier, Cunniffe et al. 2008), and 6 months (Finlayson, Preissner et al. 2011). Reductions in pain have been seen in both self-hypnosis and progressive muscle relaxation (Jensen, Barber et al. 2009). Cognitive behavioral therapy has also been shown to be effective in reducing pain (Ehde and Jensen 2004).

Psychological issues such as depression, anxiety, stress and self-efficacy have also shown to be effectively reduced in MS patients via wellness or self-management interventions. Depression has been significantly reduced via telephone-administered psychotherapy and in-person group therapy (Tesar, Baumhackl et al. 2003; Mohr, Hart et al. 2005). Psychological issues around medication management including self-injection anxiety and phobia have also been successfully addressed with a nurse-administered program (Mohr, Cox et al. 2005).

Interventions focused on broader quality of life issues have been successful on multiple outcome measures. An intervention focused on development of knowledge and skills to increase wellness resources and self-efficacy had significant effects on employment and quality of life for up to 8 months post intervention (Stuifbergen, Becker et al. 2003). A 14-week hospital-delivered intervention with exercise and self-management components increased quality of life as well (Hartley 2009). An outpatient evening course focused on symptom management, self-efficacy and adjustment to MS diagnosis was shown to be associated with improvement on fatigue, sleep disturbance and general quality of life measures (Wassem and Dudley 2003). The next step in improving outcomes among MS patients is to ensure that patients have access to evidence-based treatments that have been found to be efficacious for their specific symptoms. Understanding characteristics of patients who have unmet needs and understanding perceived barriers is also key.

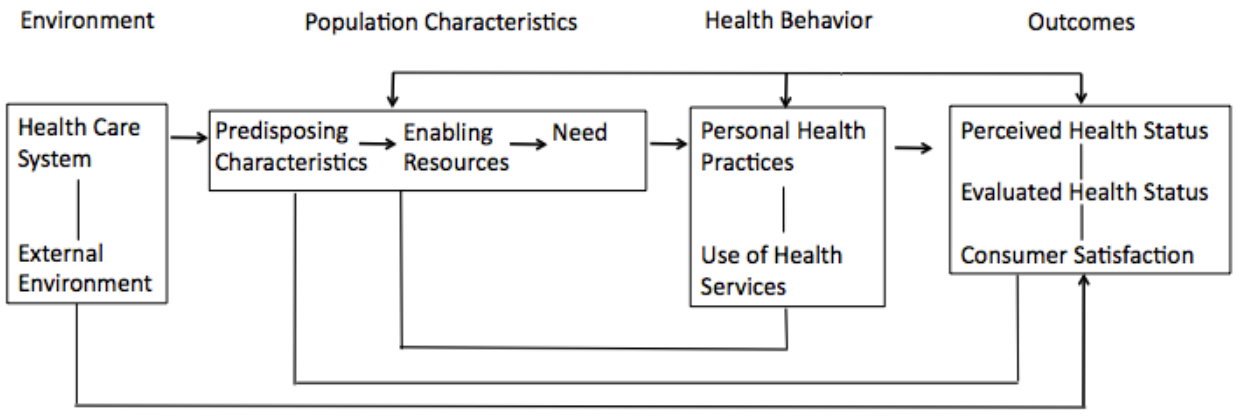
j. National Multiple Sclerosis Society

The Greater Northwest Chapter of the National MS Society serves more than 12,000 people with MS living in Alaska, Montana, as well as 26 counties in Washington State (National Multiple Sclerosis Society 2011). The National MS Society focuses on researching MS prevention, treatment and cure, connecting and providing services for people with MS, their caregivers and families, working with politicians and legislation to advocate on behalf of people with MS, inspiring people with MS, and helping to establish normalcy of everyday life. The MS Society offers a multitude of programs and services to both patients, their families and caregivers, and other organizations and individuals who work with MS patients by organizing support groups for people with MS and caregivers; providing educational sessions about specific symptoms such as fatigue; serving as a resource for navigating the medical system; and offering a small-grants program for people with MS in need of financial assistance (National Multiple Sclerosis Society 2011). Ensuring accessibility by MS patients and their caregivers is a key part of this mission.

k. Model of Help Seeking Behavior

Fostering help-seeking behavior among MS patients is an important goal. Our analysis of help seeking behavior draws from Anderson's Behavioral Model of Health Services Use [**Figure 1**] (Andersen 1995). This model allows for guidance on selection of variables by recognizing three primary categories of population characteristics that predict health service use or help-seeking behavior: *predisposing* or individual demographic characteristics such as age and sex; *enabling characteristics* including characteristics of the family, community and social environment and the ability of the individual to access those services; and *need* or indicators of health status such as functional capacity and presence of symptoms. The model hypothesizes that *predisposing characteristics* lead to *enabling resources* that in turn lead to *need*, or that individual characteristics influence community assets that lead to functional capacity. The model shown in **Figure 1** integrates broader environmental factors for an ecological approach, however our analysis is only concerned with individual predictors of help-seeking behavior.

Figure 1: Anderson's Behavioral Model of Health Services Use, (Andersen 1995)



This model has been used extensively in health services research to predict help-seeking behavior for services as diverse as antidepressant, mammography and emergency department use (Champion, Skinner et al. 1997; Fan, Shah et al. 2011; Karkare, Bhattacharjee et al. 2011).

Anderson's model has also been used previously in the MS population to predict use of occupational therapy services in Canada (Finlayson and DalMonte 2002) and to model usage of wellness or health promotion programs in the American Midwest (Plow, Cho et al. 2010). Occupational therapy use was associated with seeing a greater number of health professionals, being hospitalized in the last year, and having higher functional limitations (Finlayson and DalMonte 2002). Health and wellness service use was predicted by being female, having at least a high school education and reporting no problems with mobility or balance (Plow, Cho et al. 2010). However, these studies did not quantify secondary symptom burden in such as way to be nationally comparable or investigate known barriers such as transportation issues and low social support. Previous studies have also not investigated perceived barriers to provide a more comprehensive pathway to fully accessible programs.

Summary MS greatly impacts all facets of a patient's life. Although etiology is currently poorly understood, known risk factors such as gender, race and a latitude gradient speak to environmental factors. An array of visible mobility limitations and invisible symptoms such as increased fatigue and cognitive effects are commonly experienced. The diagnosis process is stressful, utilizing a multitude of tests. Overall financial costs for MS patients are much higher than for the population at large, a double disadvantage as employment is often reduced due to symptom burden. MS patients have many unmet needs that can partially be met through offerings of health and wellness programs from consumer organizations such as the National MS Society.

Objective of this Study The purpose of this study was to investigate differences between members of the Greater Northwest Chapter of the National MS Society who have and have not used a program or service in the last two years by building demographic profiles based on Anderson's Model of Health Services Use. We hypothesized that significant predisposing, enabling and need characteristics would all predict help-seeking behavior. A secondary purpose was to examine

differences between reported barriers among those who had and had not used services and to explain reported differences using demographic profiles.

II. Methods

a. Participants

This analysis was part of a needs assessment conducted by the Multiple Sclerosis Rehabilitation Research and Training Center, located within the Department of Rehabilitation at the University of Washington School of Medicine, in collaboration with the National MS Society, Greater Northwest Chapter. Participants were members of the National MS Society, Greater Northwest Chapter. Lists of members were generated and given to trained research assistants (RAs). Eligible participants were at least 18 years of age, had a self-reported diagnosis of MS but were asked if the diagnosis was previously confirmed by a physician, and were able to read, write, and understand English.

In order to guarantee representation from groups of patients who had not historically utilized services and not were typically vocal about needs, a purposive sampling strategy was developed using input from the MS Chapter. Targets were set within each region of Western Washington; Eastern Washington; Clark County, Washington; Alaska; and Montana. Targets were 30% male participants, 40% living in a rural area; 10% having a progressive form of MS, 10% newly diagnosed (defined as diagnosis by a physician within the last five years); and 10% under 30 years old. All targets were assessed with self-report. Urban or rural designation was later verified using the Centers for Medicare and Medicaid Services zip code designation (Centers for Medicare and Medicaid Services 2012).

b. Procedures

RAs left two voice messages on a participant's answering machine over the course of three days before marking the member as unreachable. Calls made to a number with whom a voicemail had previously been left were made during a different time of day to better reach the participant. The overall response rate of the total number of participants called was 15% (n=3,000). The survey completion rate of participants who were actually contacted (not including those for whom a

message was left) was 60% (n=734). A typical survey took between 45 and 90 minutes to complete.

b. Measures

The survey battery was developed from focus groups themes; input from MS Society board members; a template developed by the National Office of the MS Society, and validated measures. Focus group participants were recruited by referral from the MS Chapter or through contact with ElderHealth, an adult day center with locations in Seattle and Everett, WA. Focus groups were conducted for the larger needs assessment. Common themes were developed from focus groups using content analysis and were subsequently cross-referenced in the literature. Whenever possible, questions from validated surveys or previously launched surveys from national organizations were used to ask about themes raised in the focus groups. The measures used in the current study are described below.

i. Demographics and Disease Specific Measures Participants self-reported age, education, relationship status, race, ethnicity, receipt of Medicaid, duration of time with MS diagnosis (in years) and accessible transportation use. MS type was assessed with self-report of "relapsing-remitting" or "progressive type" (secondary progressive, primary progressive, or relapsing-progressive) based on the recommendations of Bamer and colleagues (Bamer, Cetin et al. 2007).

ii. National Multiple Sclerosis Society Chapter Questions National Multiple Sclerosis Society Chapter questions were developed from a previous survey written by the National office, but never deployed. These questions included the primary outcome of interest: whether participants had "attended an education or support program or advocacy event sponsored by your National MS Chapter (a live program or event) in the last two years." Those who answered "yes" were deemed "help-seekers" and those who answered "no" or "not sure" were deemed "non-help-seekers." Barriers were assessed with the questions: "What barriers have you encountered in attending an

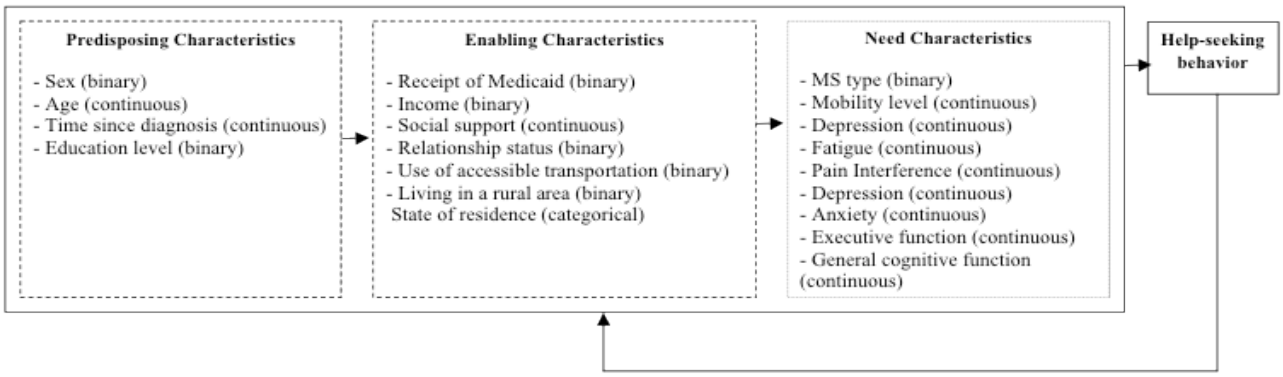
NMSS-sponsored event" and "Some people report that they don't like to attend educational programs for the following reasons. Do you share any of these?" followed by a list of possible responses.

iii. Symptom Burden Mobility was assessed using the Kurtzke Expanded Disability Status Scale (EDSS) self-administered version, a method of quantifying level of disability specific to the MS population (Bowen, Gibbons et al. 2001). Fatigue, pain interference, depression and anxiety were assessed with Patient Reported Outcomes Measurement Information System (PROMIS) (Ader 2007). The PROMIS measures were a joint effort between the National Institutes of Health and a variety of research groups to develop generalizable measures of clinical outcomes in which results are compared United States population norm of 50 and SD of 10 (Reeve, Hays et al. 2007). The measures have been shown to be reliable in populations of people with disabilities (Harniss, Amtmann et al. 2007). General cognitive function and executive cognitive function were assessed with Quality of Life Outcomes in Neurological Disorders (Neuro-QOL), also centered on the United States population mean (Miller, Nowinski et al. 2005).

iv. Social Support Perceived social support was measured with the Multidimensional Scale of Perceived Social Support (MSPSS), a 12 question measure of social support from three sources: family, friends and significant other (Zimet, Dahlem et al. 1988). Each item asked participants to rate degree of agreement on a 7-point Likert scale. Overall score was an average of individual rating items with higher scores indicating higher perceived social support. Internal consistencies are high, Cronbach's alpha of 0.85 – 0.91, and test-retest reliability of 0.72 – 0.85 (Zimet, Dahlem et al. 1988).

Anderson's Behavioral Model of Health Services Use was used to choose relevant variables as shown in **Figure 2**.

Figure 2: Variables chosen with Anderson's Model



i. Data Reduction Time since diagnosis was rounded to the nearest year and treated as a continuous indicator. Education was measured as high school education or less and greater than high school education. Income was initially measured categorically as annual household income as less than $25,000; $26-$40,000; $41-$55,000; $56-$70,000; $71-$85,000; $86-$100,000, and greater than $100,000 but collapsed into more meaningful categories of less than $25,000, $26-$40 and more than $40,000 annual household income. Relationship status was reduced to a binary variable. The categories of divorced, single never married and widowed were collapsed into "not in a relationship." Although these categories are functionally different, very small numbers of participants fell into each and results were deemed more scientifically meaningful as a binary variable. Place of residence was determined by two factors: living in an urban or rural area as found by zip code, and region of residence: Eastern Washington; Western Washington; Clark County, Washington; Alaska and Montana.

c. Analysis

Our primary outcome was whether participants had not used a program or service in the last two years, a non-help-seeker. Initial analysis comparing help-seekers and non-help-seekers was conducted using t-tests and chi square tests. Missing data was treated as missing completely at random. The outcome variable met the assumptions of a proportional odds model therefore a

logistic regression model was used to compare help-seekers to non-help-seekers. Hypothesized predictors shown in **Figure 2** were analyzed in univariate models. Odds ratios with 95% confidence intervals were calculated. The referent group was those who had sought help (used a program or service in the last two years). A second multivariate analysis was run using significant results from the first analysis to control for possible confounding from variables with similar pathways of influence.

Due to the possibility of inflated Type 1 error because of multiple comparisons, a Bonferroni adjustment was made to control overall alpha-level and significance was set at $p<0.004$ for the primary analysis of predictors of help-seeking behavior and for the question "What barriers have you encountered in attending an NMSS-sponsored event?" and at $p<0.006$ for answers to the question "Some people report that they don't like to attend educational programs for the following reasons…do you share any of these?" Analysis was conducted using STATA version 12 (Copyright 1985-2011 StataCorp LP).

III. Results

Demographic features of the 437 participants who completed the service utilization portion of the survey are shown in **Table 2**. Demographic features of the total sample are reflective of the demographic distribution of MS as discussed in the introduction with 69.3% of the sample being female, 92% reporting primary race as Caucasian, 59.6% reporting a relapsing-remitting MS sub-type, 32.3% reporting a progressive sub-type and 8.1% reporting another MS sub-type or unknown. Average age was 52.5 years (SD 12.9 years) and average time since MS diagnosis 14.6 years (SD 9.8 years). The majority of participants had at least a high school education (81.2%) and 36.6% had a college degree. Medicare recipients made up 43.2% of the sample; only 5.6% reported no insurance. Finally, 61.7%, were married, in a domestic partnership or civil union, 28.2% had a household income of $25,000 or less and 31.1% lived in a rural area according to the Centers for Medicare and Medicaid Services (2012).

Help-seekers made up 37.5% of the sample while non-help-seekers comprised 62.5% of the sample. Help-seekers were younger with an average age of 50.8 as compared to 53.5, ($p<0.05$), had been diagnosed for a shorter amount of time, ($p<0.01$), and were more educated shown by a significantly larger proportion having an education greater than high school, ($p<0.01$). Non-help-seekers did not differ from help seekers in state of residence or urban/rural residence.

Table 2: Demographics of Sample

	Total Sample	Non-help-seekers	Help-seekers	p-value
N	437	273	164	n/a
		Mean (SD)		
Age	52.5 (12.9%)	53.5 (12.4)	50.8 (13.6)	<0.05
Years since diagnosis	14.6 (9.8)	15.7 (9.9)	12.3 (9.3)	<0.01
		N (%)		
Female	303 (69.3%)	189 (69.2%)	114 (69.5%)	0.95
Caucasian	401 (92%)	249 (91.5%)	152 (92.7%)	0.57
Annual Household income				0.60
<$25,000	107 (28.2%)	68 (29.1%)	39 (26.9%)	
$26-$45,000	75 (19.8%)	49 (20.9%)	26 (17.9%)	
>$46,000	197 (51.9%)	117 (50%)	80 (55.2%)	
MS type				<0.01
Relapsing-Remitting	260 (59.5%)	160 (58.6%)	100 (61%)	
Progressive	142 (32.5%)	88 (32.2%)	54 (32.9%)	
Other/unknown	35 (8%)	25 (9.2%)	10 (8.5%)	
Geographical Region				0.09
W. Washington	221 (50.6%)	143 (52.4%)	78 (47.6%)	
E. Washington	63 (14.4%)	32 (22.7%)	31 (18.9%)	
Clark County, WA	25 (5.7%)	13 (4.8%)	12 (7.3%)	
Alaska	63 (14.6%)	38 (13.9%)	25 (15.2%)	
Montana	65 (14.9%)	47 (17.2%)	18 (11%)	
Living in Rural Area	136 (31.1%)	39 (23.8%)	97 (35.5%)	0.06
High school education or less	82 (18.8%)	63 (23.1%)	19 (11.6%)	<0.01
Employed	99 (22.9%)	55 (20.5%)	44 (26.8%)	0.13
In an intimate relationship	311 (72.2%)	195 (72.8%)	116 (71.2%)	0.72
Receipt of Medicaid	71 (16.3%)	56 (20.6%)	15 (9.2%)	<0.01

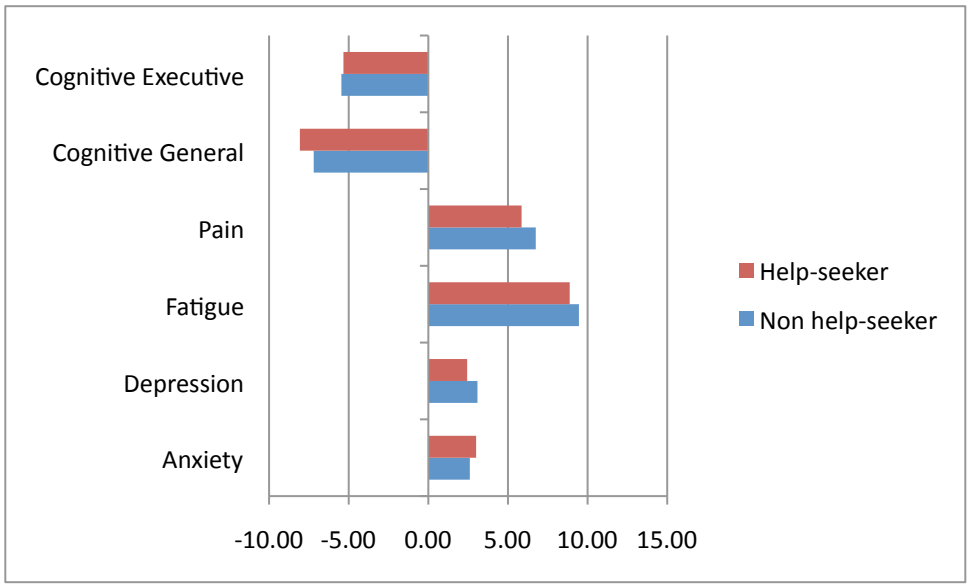
When compared on psychosocial measures and symptom burden, social support score did not differ significantly between the two groups **[Table 3].** Mean EDSS score was significantly different, ($p<0.01$). PROMIS measures of fatigue, pain interference, depression and anxiety and Neuro-QoL executive cognitive function and general cognitive function were compared graphically to the United States population norm in **Figure 3**.

Table 3: Psychosocial Indicators and Symptom Burden

	Total Sample	Non-help-seekers	Help-seekers	Difference	95% CI	p-value
N	437	273	164	n/a	n/a	n/a
MSPSS* (SD)	5.5 (1.1)	5.4 (1.2)	5.6 (1)	1.2	-0.41, 0.03	0.10
EDSS** (SD)	4.7 (3)	5.1 (3)	4.1 (2.9)	0.89	0.30, 1.47	<0.01
Fatigue	9.24	9.5	8.9	0.58	-1.22, 2.38	0.53
Pain Impact	6.41	6.7	5.9	0.89	-1.07, 2.85	0.37
Depression	2.84	3.1	2.4	0.65	-1.24, 2.54	0.50
Anxiety	2.85	2.6	3.0	0.39	-1.41, 2.20	0.67
Cognitive General	-7.53	-7.2	-8.1	0.87	-0.97, 2.71	0.35
Cognitive Executive	-5.46	-5.5	-5.3	0.13	-1.93, 1.67	0.89

*MSPSS = Multidimensional Scale of Perceived Social Support
**EDSS = Expanded Disability Status Scale

Figure 3: Symptom Burden as Compared to US Population Norm at 0



Significant differences were seen in the distribution of answers between help-seekers and non-help-seekers for barriers to participating in a National MS Society event [**Table 4-5**]. Not surprisingly, a significantly larger proportion of help-seekers reported no barriers in attending an event. Analysis was conducted using chi-square tests. Non-help-seekers endorsed the inconvenient location of the event, lack of interest in issues or topics, having MS symptoms that prevented them from leaving the house, not being informed about the event(s), not knowing they were a member of the chapter, and not knowing attendance was possible, and needing someone to

accompany the participant and provide assistance, ($p<0.01$). Participants were next asked to review a list of reasons why MS patients may not attend events. Compared to help-seekers, non-help seekers were more likely to endorse preferring not to participate with other individuals with MS, just not being ready, and preferring one-on-one interaction, ($p<0.01$).

Table 4: Participant response to "What barriers have you encountered in attending an NMSS-sponsored event?"

Type of Preference	Total Sample	Non-Help-Seekers	Help-Seekers	p-value
I had no transportation	75 (17.2%)	53 (19.4%)	22 (13.4%)	0.11
The day of the week was not convenient for me	87 (19.9%)	57 (20.9%)	30 (18.3%)	0.51
The location of the event was not convenient for me	157 (35.9%)	115 (42.1%)	42 (25.6%)	< 0.01*
The time that the event was held was not convenient for me	101 (23.1%)	63 (23.1%)	38 (23.2%)	0.98
I have not been interested in the issues or topics presented	80 (18.3%)	60 (22%)	20 (12.2%)	<0.01
My MS symptoms prevent me from leaving my home	62 (14.2%)	47 (17.2%)	15 (9.2%)	<0.05
I was not informed about these events	55 (12.6%)	46 (16.9%)	9 (5.5%)	<0.01*
I am not a member of the chapter and did not know that I could attend	28 (6.4%)	25 (9.2%)	3 (1.8%)	<0.01*
I don't have anyone to help me with childcare	11 (2.5%)	9 (3.3%)	2 (1.2%)	0.18
I would need someone to accompany me and provide assistance	63 (14.4%)	50 (18.3%)	13 (7.9%)	<0.01*
I do not have a computer and/or Internet access	25 (5.7%)	18 (6.6%)	7 (4.3%)	0.31
Assistive technology was not available for me	19 (4.4%)	14 (5.1%)	5 (3.1%)	0.30
Other	64 (14.7%)	46 (16.9%)	18 (11%)	0.09
None	132 (30.2%)	59 (21.6%)	73 (44.5%)	<0.01*

* Significant at adjusted level of p<0.004.

Table 5: Participant response to "Some people report that they don't like to attend educational programs for the following reasons. Do you share any of these?"

Type of Preference	Total Sample	Non-Help-Seekers	Help-Seekers	p-value
I prefer not to participate with other individuals with MS	45 (10.3%)	38 (13.9%)	7 (4.3%)	<0.01*
I feel more comfortable participating in programs that are more of my peer group	162 (37.2%)	97 (35.5%)	65 (39.9%)	0.36
I would like it if my partner or caregiver could attend a program designed to meet their needs specifically, conducted at the same time	177 (40.6%)	109 (39.9%)	68 (41.7%)	0.71
I find that I do not fit in with the audience	88 (20.2%)	62 (22.7%)	26 (16%)	0.09
I am just not ready	66 (15.1%)	52 (19.1%)	14 (8.6%)	<0.01*
I do not need any help	90 (20.6%)	64 (23.4%)	26 (16%)	0.06
I would prefer one-on-one interaction	137 (31.4%)	100 (36.6%)	37 (22.7%)	<0.01*
Other	109 (25%)	83 (30.4%)	26 (16%)	<0.01*
None	86 (19.7%)	45 (16.5%)	41 (25.2%)	0<.05

* Significant at adjusted level of p<0.006.

As can be seen in our univariate analysis in **Table 6**, time since diagnosis, having at most a high school education, receipt of Medicaid, use of accessible transportation, and EDSS (mobility) score were associated with help-seeking behavior after adjusting for multiple comparisons**.** Specifically, the odds of being a non-help-seeker increased by 3% (95% CI 1% - 5%) for each year post-diagnosis, ($p<0.01$). Less educated participants, those with at most a high school education were 2.29 times more likely (95% CI 1.31 – 3.99 times more likely) to be a non-help-seeker, ($p<0.01$). The odds of being a non-help-seeker were similarly elevated in those receiving Medicaid at 2.56 times more likely (95% CI 1.39 to 4.69 times), ($p<0.01$). Those who use accessible transportation as their primary form of transportation were 7.45 times as likely (95% CI 1.73 – 32.04 times as likely) to be non-help-seekers, ($p<0.01$). Finally, having higher mobility limitations was significantly associated with help-seeking behavior as the odds of being a non-help-seeker increased by 11% (95% CI 3% - 18%) per unit increase in EDSS score, ($p<0.01$).

A secondary analysis **[Table 7]** using all significant predictors in a multivariate model found that only having at most a high school education, receiving Medicaid and using accessible transportation were significantly associated with help-seeking behavior using an unadjusted significance level of $p<0.05$. Specifically, the odds of being a non-help-seeker increased 2.11 times (95% CI 1.17 – 3.77 times) for those with at most a high school education, ($p<0.01$); 2.13 times (95% CI 1.12 – 4.04 times) for those receiving Medicaid, ($p<0.05$); and 5.17 times (95% CI 1.17 – 22.9 times) for those using accessible transportation, ($p<0.05$).

Table 6: Logistic regression predicting help-seeking behavior

	Odds Ratio	95% Conf. Interval		p-value
Predisposing Characteristics				
Sex	0.97	0.65,	1.50	0.95
Age	1.01	1.00,	1.03	0.04
Time since diagnosis	1.03	1.01,	1.05	<0.01*
At most high school education	2.29	1.31,	3.99	<0.01*
Enabling Resources				
Receiving Medicaid	2.56	1.39,	4.69	<0.01*
Annual Household income				
<$25,000	1.74	1.18,	2.58	<0.05
$26-$45,000	1.08	0.58,	2.00	0.81
>$46,000	0.84	0.52,	1.36	0.48
MSPSS[a]	0.969	0.77 -	1.22	0.79
In a relationship	1.08	0.70,	1.67	0.72
Use accessible transportation	7.45	1.73,	32.04	<0.01*
Living in a rural area	1.77	1.14,	2.73	0.01
Region				
Western Washington	1.83	1.39,	2.42	<0.01
Eastern Washington	0.56	0.32,	0.99	0.05
Clark County, WA	0.59	0.26,	1.36	0.22
Montana	0.83	0.47,	1.47	0.52
Alaska	1.42	0.77,	2.62	0.26
Need				
Progressive MS	0.88	0.57,	1.32	0.54
EDSS[b]	1.11	1.03,	1.18	<0.01*
Fatigue	1.01	0.99,	1.03	0.53
Pain Interference	1.01	0.99,	1.03	0.37
Depression	1.01	0.99,	1.03	0.50
Anxiety	1.00	0.98,	1.03	0.67
Executive Cognitive Function	0.99	0.98,	1.02	0.89
General Cognitive Function	1.01	0.99,	1.03	0.35

[a] MSPSS = Multidimensional Scale of Perceived Social Support.

[b] EDSS = Expanded Disability Status Scale.

* Significant at p<0.004.

Table 7: Final logistic regression model predicting help-seeking behavior

	Odds Ratio	95% Conf. Interval	p-value
At most High School Education	2.11	1.17, 3.77	p<0.01
Time since diagnosis	1.02	1.00, 1.05	0.056
Receiving Medicaid	2.13	1.12, 4.04	p<0.05
Accessible Transportation	5.17	1.17, 22.9	p<0.05
EDSS [a]	1.03	0.95, 1.11	0.45

[a] EDSS = Expanded Disability Status Scale.

IV. Discussion

a. Help-seeking behavior

Our key results showed that help seeking behavior is predicted by both social determinants of health and physical barriers to accessing services. Specifically, having at most a high school education, receiving Medicaid, and using accessible transportation were significantly associated with not seeking help. Time since diagnosis approached but failed to attain significance and having lower mobility was not significant in our final model through possible confounding with accessible transportation.

An association between low health service utilization and low education has been found in various other populations of people with disabilities and chronic conditions (Plow, Cho et al. 2010; Lehnert, Heider et al. 2011). The pathway from education to help seeking behavior has several plausible explanations. First, higher levels of education lead to better ability to effectively find and use information in the environment (Embrey 2005). Managing MS is partially accomplished through identification of resources in the community. Education is therefore associated with higher levels of help-seeking behavior from consumer organizations.

Second, low education is associated with low self-efficacy, which according to Bandura's social cognitive theory refers to an individual's belief that one can master specific challenges as well as encompassing broader themes such as self-esteem and being in control of future events (Bandura 1997). Self-efficacy in this population refers to confidence in ability to manage MS symptoms and reduce MS symptom interference with daily life (Fraser and Polito 2007). This construct is especially important in managing a chronic disease such as MS that requires daily monitoring of symptoms. Self-efficacy is also challenged or reduced by the unpredictable nature of MS that may undermine feelings of control over future events (Macleod and Macleod 1998). As a predictor of help-seeking behavior, self-efficacy may lead to the belief that one can find benefit in

health and wellness programs offered by consumer organizations and effectively use the skills gained to better manage MS. Those with higher self-efficacy would therefore be more likely to use programs through consumer organizations. Third, higher education may lead to better referral networks through access to similarly educated peers (Robins, Elliott et al. 2001). Access to these networks leads to knowledge that consumer organizations can positively influence health status and therefore would increase utilization of these services. Therefore, low education may inhibit help-seeking behavior by reducing access to information, lowering self-efficacy, and lowering access to peer networks.

Receipt of Medicaid, another social determinant of health, was associated with help-seeking behavior. Previous studies have used lack of insurance and specifically receipt of Medicaid as a proxy for low income or socio-economic status (Foraker, Rose et al. 2010). Although the validity to this approach is unknown, Medicaid is provided to recipients below the Federal poverty level (Rosenbaum 2002). As our income questions lacked precision at the low income levels, asking solely if a participant had an annual household income below $25,000, receipt of Medicaid may be both a reasonable estimation of low income and a better indicator of low socio-economic status than our measure of income alone.

MS is a very economically taxing disease, leading to high medical costs, low rates of employment and therefore lower earning potential. This characteristic of the disease puts increased economic pressure on low-income groups. Low income MS patients have been shown to be less able to access both medical and community-based resources (Judicibus and McCabe 2007). The relationship between low levels of help-seeking and low-income follows many of the same pathways as from education to help-seeking, partially due to an association between education and income. Low-income MS patients may be less able to find resources in the environment, have lower MS self-efficacy, and have low access to social networks that would create awareness of programs and services. Furthermore, low-income MS patients may be less likely to physically access health

services due to lower material resources, such as access to automobile transportation, less access to public transportation routes and lessoned free time to spend seeking help.

These differences in help-seeking behavior can cause low-income MS patients to be vulnerable to low quality of life and have high prevalence of psychiatric disorders, furthering health disparities based on income (de Judicibus and McCabe 2005; McCabew and De Judicibus 2005). This increased vulnerability further stigmatizes those most in need of services offered through a consumer organization and may also result in reduced help-seeking behavior due to feelings of stigmatization.

There was a trend towards significance for time since diagnosis. MS patients diagnosed for longer periods of time may have become more knowledgeable about managing disease and less reliant on or interested in programs from consumer-based organizations. This association has been not been studied extensively in the MS population but has demonstrated in other chronic disease population as in inflammatory bowel disease in which health services utilization was less likely when a patient had been diagnosed for more than 15 years (Longobardi, Jacobs et al. 2004). Lower reliance is reflected in lower rates of help-seeking behavior among those diagnosed for longer periods of time.

Among pre-determined disease characteristics, mobility as measured with the EDSS retained significance to be included in the final model, but failed to attain significance once included. It is clear that for patients with MS mobility limitations serve as a great functional barrier to seeking help, coupled with the difficulty in accessing transportation (Finlayson and DalMonte 2002). This relationship is conceptually clear as those with lower mobility have increased difficulty physically accessing services in disparate locations. Mobility is one of the most visible symptoms of MS and one of the most difficult to intervene upon through the services of a consumer organization. MS patients with mobility limitations may not see the benefit of seeking help.

Accessible transportation's inclusion in our final model points toward broad structural challenges impacting MS patients. Environmental adaptation has been found to be an unmet need and significant barrier to accessing services and high quality of life (Forbes, While et al. 2007). This illustrates the importance of the social environment in creating access or barriers to help-seeking. Environmental adaptation as both a need and barrier becomes increasingly important with disease progression (Golla, Galushko et al. 2012). Transportation as a barrier stems from broad structural challenges in navigating a world built for able-bodied individuals as an MS patient. This form of transportation is clearly not an acceptable substitute for driving oneself or accessing transportation through a friend or family member. This barrier has broader policy implications beyond the scope of this analysis.

Only one individual (predisposing) characteristic and two community (enabling) characteristics retained significance in the final multivariate model: education, receipt of Medicaid and use of accessible transportation. Individual-level demographic features, such as being male have been shown to be predictive in previous research (Plow, Cho et al. 2010). Our study may have lacked sufficient power to detect a sex difference or may have been biased in such a way as to not be able to find a sex difference due to a low number of male participants despite our attempt to oversample by male sex.

The lack of inclusion of disease profile characteristics, other than mobility, as significant in our model, may indicate that MS patients may not see the value in attending programs and services to address secondary conditions such as pain and depression. Programs to address these disease symptoms do exist as demonstrated by the discussion of health and wellness activities, however there is often disconnect between conducting research and disseminating results to consumer organizations and consumers themselves. Academic institutions should prioritize both dissemination of successful health and wellness interventions to the broader community and work

toward translating those same successful health and wellness activities into successful and sustainable community-level programs. Consumers should be made aware of how health and wellness services can help reduce MS symptoms and be able to easily access these services.

b. Known Barriers

To further our understanding of help-seeking behavior, we also investigated differences in barriers between help-seekers and non-help-seekers. Those who had not sought help endorsed event location, not being informed about events and not knowing about being ability to attend at significantly higher rates. These barriers speak to accessibility and communication issues on the part of consumer organizations. Creating options for service utilization by those with transportation issues is very important. Investing in methods of reaching out to patients with MS in their own homes is another method of reducing barriers for those with transportation issues. However, offering programs and services through available technology may create more barriers for low-income individuals or those living in rural areas without Internet access. Offering a variety of program formats would be the most equitable method of increasing accessibility.

Unfortunately, not being interested in issues or topics presented was also more frequently endorsed by those who did not exhibit help-seeking behavior. This finding is understandable given the vast number of programs and services offered and vast differences in individual preference. Increased data collection when an individual first contacts the consumer organization could help tailor programs and services to particular interest groups to address disinterestedness and increase help-seeking behavior.

Interestingly, citing a need for a caregiver to accompany the participant and provide assistance was also endorsed more frequently by non-help-seekers than help-seekers. Need for caregiving and care assistance is commonly acknowledged by patients with MS, and is an understandable barrier to help-seeking behavior (Forbes, While et al. 2007; Golla, Galushko et al.

2012). For MS patients with advanced disease, reliance on a caregiver or caregiving services is crucial to maintaining quality of life. There is a general need for caretaking services in the MS population among those lacking the support of a spouse, close family member or close friend(s). Information on available caregiving services should be provided by consumer organizations as should individualized counseling as to how to access caregiving or other organizations that may be able to offer such services.

c. Limitations

This study had several limitations. Most importantly, the study population was drawn from members of the National MS Society, Greater Northwest Chapter. This population may be categorically different from the population of patients with MS in the Pacific Northwest at large. Furthermore, participants were limited to residents of Washington, Montana and Alaska who may not be representative of patients with MS in the United States. However, barriers in these states are most likely found throughout the United States MS population.

The majority of participants were contacted during working hours, though effort was made to call participants after 5pm. This may have led to a bias toward those who either work at home or have a more progressed disease and are therefore no longer working. Setting a target of 10% of patients under 30 years of age may have helped to reduce this bias and our finding of a 27% employment rate is consistent with previous cross-sectional studies of employment in patients with MS (Johnson, Bamer et al. 2009). However, these studies may have been biased in a similar manner. As the study was conducted via telephone, individuals with severely progressed MS unable to speak and unable to speak through an available caregiver were not included in the sample.

There were also limitations in survey questions. Our primary limitation was that our analysis was unable to determine if patients with MS were unable to access services or not

interested in doing so. Data interpretation is also therefore limited. The primary investigative question asked whether the survey participant had participated in a program or service in the past two years, not specifically a health or wellness program. Although health and wellness programs make up the majority of services offered by the MS Society, there are also services that do not fall into this category. Specific information on type of program or service utilized was not gathered. However, as this study was only investigating general barriers to help-seeking behavior this limitation is acceptable. Furthermore, two years may be too long a period to find significant differences between those who do and do not seek help. An individual who has gone to an event once in two years is most likely categorically different from one who is a frequent and repeated help-seeker, a distinction not captured in this study. Although the primary question of interest was designed to ask about participation in any activity including phone consultations and activities done over the Internet, participants may have misunderstood the question leading to interpretation of service utilization as solely an in-person activity. This may have biased the results toward the null.

The survey also only captured information as to whether a participant had relapsing-remitting or progressive MS as opposed to differentiating between the four identified types. Although previous research indicates that having a diagnosis of relapsing-remitting or progressive MS type is easier for a participant to understand and usually results in more accurate information, combining the three progressive categories also limits finer understanding of the differing barriers among MS types and may limit generalizability of this study. Furthermore, this survey took place over a vast geographic area including the very rural states of Alaska and Montana. Some participants may not have been able to physically travel to their local MS Chapter to seek help due to distance rather than any intrinsic differences in demographic profile. Attempts to control for this were made through analysis of help seeking behavior based on location of residence, determined by both rural zip code designation and state of residence but may not have been specific enough to

detect differences in distance to consumer organization. Furthermore, as we used a univariate model in our primary analysis, we were unable to discover interaction between terms.

d. Future Research

Future research could help to understand why particular barriers impact particular groups of patients with MS. This avenue of inquiry could help to create more cost-effective services utilizing technological intervention to better address those unable to seek help from consumer organizations in-person. Technological intervention would be well served to focus on increasing equitable distribution of information through teleconference, videoconference, and other forms of digital communication. However, rigorous program evaluation must be conducted as to the efficacy of these interventions to build an evidence base, as should tracking of income as a possible barrier to accessing these services. Gathering information on distance traveled to health and wellness activities could better inform future avenues of research as could future studies looking at type of caregiver as associated with use of health and wellness activities.

Accessible transportation is highly valued, but as cities face budget cuts nation-wide this service is at risk of further minimization. Efficiency studies need to be conducted as to how this service can be better accessed by the most vulnerable, namely very low-income MS patients and MS patients with higher mobility limitations. Accessible transportation has the potential to greatly increase help-seeking behavior, but is currently underused.

Greater collaboration between consumer organizations and academic institutions should also be a component of future research. The partnership between the Department of Rehabilitation Medicine, University of Washington School of Medicine and the National MS Society has allowed for a fruitful academic and practical understanding of both the type of person who seeks help and the barriers faced by those unable to use services. Specifically, categorization of the frequency of usage of health and wellness services and programs for a finer understanding of how potential barriers can impact help-seeking behavior could help to reduce health disparities in MS. Finally, future

needs assessments conducted by consumer organizations or in conjunction with academic institutions should focus on studies of efficient health promotion and self-management strategies that could potentially be replicated by other consumer-based organizations.

V. Conclusions

We found that social determinants of health and physical barriers were predictive of not seeking help. Creating options for participation for patients with MS who have lower income, those with lower education levels and those with mobility limitations should be a primary goal. Reaching out to these groups who are less able to seek help will reduce health disparities and increase the health status of people with MS overall. Furthermore, adults with MS may not be aware that the MS Society provides programs that address secondary conditions such as anxiety and fatigue. Evidence-based programs that address secondary conditions should be highlighted through informational outreach.

Creating participation options for those facing significant environmental barriers is necessary to offer equitable services. Options should focus on methods of reducing transportation barriers such as programs and services offered in a range of locations and through a range of technology. Low-income individuals could be specifically identified through when MS patients initially contact consumer organizations or through outreach to physicians and neurologists who serve Medicaid recipients. Providing a diversity of services and communicating the benefits of these services to this diverse group of patients in necessary to increase help-seeking behavior.

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