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Use of cognitive aids and other assistive technology by individuals with multiple sclerosis

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Abstract

Purpose. To investigate the use of assistive technology (AT), unmet needs for AT, and examine correlates of use of memory aids and cognitive strategies among individuals with multiple sclerosis (MS).

Method. A cross-sectional study of 1,063 community dwelling adults with MS in Washington State. A self-report survey assessed use of AT as well as depression, fatigue, mobility, and other demographic and disease related variables.

Results. Some 70% of respondents reported using memory strategies and 50.7% reported using electronic memory aids. The strongest correlate of use of electronic memory aids was endorsement of difficulties thinking (OR: 2.09, $p < 0.001$) though younger age, higher education, and report of higher fatigue were also significant. Fatigue (OR: 1.27, $p < 0.001$) and depression (OR: 0.89, $p < 0.001$) were highly associated with use of memory strategies. Subjects who were older, unemployed, more depressed, and have more mobility disability were less likely to use memory strategies.

Conculsions. Use of AT for memory is widespread and further research should be conducted on efficacy of AT. Many individuals who might be presumed to need AT for memory most (older, less educated, more disability) are least likely to report use. Healthcare providers are urged to ask about memory AT and make appropriate referrals.

Keywords: *Assistive technology, adaptive technology, assistive devices, memory aids, memory strategies, multiple sclerosis, compensation*

Introduction

Multiple sclerosis (MS) is a neurological disease with several chronic and progressive courses and is most commonly diagnosed between the ages of 20 and 50. It is one of the most frequent causes of disability in young and middle-aged adults. MS does not normally decrease overall life expectancy so individuals with MS may live with the illness for many years [1,2].

Individuals with MS may experience a wide range of functional limitations associated with fatigue, pain, depression, bowel and bladder dysfunction, cognitive deficits, weakness, spasticity, ataxia, vision impairments, as well as limitations in mobility, dexterity, exertion, and communication [3–5]. The severity of the disease and symptoms vary among individuals, however, many individuals with MS experience more severe disabilities as the disease progresses.

The functional limitations associated with MS may lead to decreased participation in life domains including personal care, household management, employment, leisure and recreation, and relationships [6]. Individuals with MS may experience a gradual decline in the performance of activities of daily living (ADL), including both personal ADL, such as self-care tasks, and instrumental ADL, such as household management [7,8]. They are employed at rates lower than would be anticipated, with unemployment rates as high as 70–80% five years after diagnosis [9,10]. Neuropsychological deficits [11] and fatigue [9] are strongly associated with unemployment. Individuals with MS may additionally experience significant changes in roles within their family and community, reduced ability to cope with daily challenges, and diminished quality of life [12].

Many strategies have been recommended to compensate for the functional limitations associated

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with MS. One class of strategies is assistive technology (AT). AT has been defined in United States Public Law 100–407 as, '... any item, piece of equipment, or product system whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities' [13]. The law also references the services necessary to select, implement, and maintain AT. Some AT suggested as potentially useful for people with MS include mobility aids, screen enlargement software for vision impairment, memory aids such as personal digital assistants (PDAs), devices for use in self-care tasks, modified computer hardware or software, augmentative and alternative communication devices, and vehicle modifications [3,14–16]. Cognitive aids have been used to assist in monitoring medication, remembering daily routine or appointments, recalling addresses or telephone numbers, and navigating in the community.

The major focus of research on AT use by individuals with MS has been on mobility aids and includes descriptive articles and literature reviews [17,18], a case study [19], small studies investigating the perspectives of individuals with MS regarding mobility aids [20,21], and a large longitudinal survey including the use of mobility aids [22]. The existing literature investigating other types of AT includes several descriptive articles speculating about the potential applications of AT in MS [3,15,23–25], small studies evaluating specific high-tech strategies [24–26] and one empirical study surveying a population about a wide range of AT [27]. Finlayson et al. (2001) investigated the use of AT in a population of individuals with MS, including mobility aids, bathroom modifications, aids for self-care, orthotics, vehicle modifications, visual aids, and communication aids. They found a high rate of use of mobility aids and bathroom modifications, while the use of other AT was less prevalent. In their study, they did not ask participants about use of modified computer access, or cognitive aids.

Although use of cognitive aids to assist in performance of daily activities has been reported most frequently in individuals with traumatic brain injury [28–32], some preliminary evidence exists for use of cognitive aid for individuals with MS [29]. Further research is needed on the use of AT including cognitive aids in MS for several reasons. First, cognitive changes pose significant barriers for people with MS [33,34]. Second, individuals living with MS are involved in relatively complex medical decision making and are required to adhere to multifaceted medication and/or treatment regimes. It has been well established that cognitive functioning is important in treatment adherence [35–37] and in medical decision-making [38–44].

We have evidence from our qualitative work [6,45] and clinical work that people with MS use a variety of cognitive aids ranging from low tech aids such as 'yellow stickies' inserted into the environment as prompts, day timers, and memory books to high tech electronic devices such as digital audio memory key fobs on which they can record the location of their car after parking or text paging from calendars with reminders, or PDA or smart phones with calendars, alarms, and integrated task lists. We also know of individuals with MS who e-mail themselves reminders and/or use elaborate organisational schemes they have designed in Microsoft Outlook®, Microsoft Office® and other applications. Others have told us they use GPS to compensate for difficulties in navigation.

Studying effectiveness of cognitive strategies adopted by people with MS may lead to the development of effective cognitive strategies that compensate for the cognitive decline. To assess the prevalence of the use of cognitive aids and cognitive strategies by people living with MS we included questions in a large survey about the major categories of AT, including computer access and memory aids by people with MS. The study had three primary objectives:

(1) To investigate the use of AT, including memory aids, cognitive strategies and computer access among individuals of MS;
(2) To examine the reported unmet needs for AT;
(3) To examine the correlates of use of memory aids and cognitive strategies.

Methods

Participants

Research participants were recruited through the Greater Washington chapter of the USA National Multiple Sclerosis Society (NMSS), which serves 23 counties in Washington State. Letters of invitation were sent to 7,806 persons from the NMSS mailing list, which included only individuals who self-identified with the NMSS as having MS. Of the 1,477 to respond, 1,362 were eligible for and indicated interest in participation. Eligible individuals were required to report having a definitive diagnosis of MS and be at least 18 years of age. Eligible individuals were mailed a self-report survey, and reminder letters were sent to all non-responders between 3–6 weeks after the survey was mailed. A subset of individuals also received a reminder phone call but this procedure was dropped once recruitment goals were met. Some 1,077 individuals returned surveys and individuals with missing data were called up to four times to collect data via phone. Surveys from 1,063 individuals were considered mostly complete and included in the analysis. To better assess the degree to which the sample of respondants was representative of the larger population, a second anonymous one-page survey of demographics was sent to individuals on the NMSS mailing list to examine potential recruitment bias and reasons for non-response to the initial solicitation. Additional information on non-responders was not available as letters of invitation were sent by the NMSS and study investigators did not have access to the mailing list. Responses from 1,046 individuals indicate that many individuals on the mailing list did not have MS despite the NMSS classification as such (13%) or did not remember the initial survey invitation (34%). Study participants were slightly younger, more educated, and those with MS had mean disease duration shorter than respondents of the anonymous questionnaire. All research participants were consented prior to participation and all study procedures were approved by the human subjects division of the University of Washington.

Measures

A survey was mailed to each participant containing a variety of questions on demographics, psychosocial, and functional or disease specific characteristics.

Demographics and disease-specific measures. Questions about ethnicity, education, employment, gender, age, marital status, disease duration, and mobility were included in the questionnaire. Mobility was assessed using the self-administered version of the EDSS [46]. Mobility scores were categorized into three groups: Minimal (0–4.0), intermediate (4.5–6.5), and advanced (7.0–10.0). Minimal indicated that individuals were able to walk without aid or rest for more than 500 meters. Individuals classified as intermediate were limited by their disability in daily activities, and individuals in the advanced category were restricted to wheelchairs. MS subtype was assessed in this sample using an instrument containing graphic images with associated text [47]. This allowed for classification of individuals into the four MS subtypes: Relapsing remitting, secondary progressive, primary progressive and progressive relapsing. Although individuals were asked to determine which of the four subtypes of MS best fits them, for the purposes of analysis, the recommendations of Bamer et al. (2007) were accepted and responses were collapsed into 'relapsing remitting' and 'progressive types' [47].

Assistive technology. Use and availability of assistive technology were assessed using a series of 11 questions written by the authors. Types of assistive technology surveyed included: Walking aids, mobility aids, vehicle modifications for driving, vehicle modifications for loading, home modifications, bathrooms aids, aids for cooking or eating, aids for communication, aids for computer, electronic memory aids, and memory strategies. One or more examples of each type of aid were provided for clarification and are listed in Table II. In response to each question, participants were asked to indicate if they never use, sometimes use, use always/most of the time, or if the technology was needed but not available to them.

Fatigue. The Modified Fatigue Impact Scale (MFIS) was used to measure overall fatigue levels for each individual [48]. This scale uses a subset of 21 items from the Fatigue Impact Scale [49]. Individuals answered each question on a 5–point Likert scale ranging from 0 (never) to 4 (almost always), and an overall score was generated by summing answers to all items. Individual scores were divided by 8 to create a scale ranging from one to 10.5 for purposes of regression analysis. The MFIS is an appropriate measure for assessing fatigue in individuals with MS when limited time is available [48,50].

Depression. Depressive symptoms were measured using a short form of the Centre for Epidemiologic Studies Depression Scale (CES–D). This is a 10–item, self–rating scale developed to screen for depressive symptoms and with summary score shown to have adequate reliability and validity [51–53]. Overall scores were generated by summing the 10 items and scores were later divided by three to create a scale ranging from 1–10 for ease of interpretation in the regression analysis.

Pain. In order to assess pain levels, individuals were asked to rate their average pain intensity over the past week on a numerical rating scale from 0–10. This scale is part of the Brief Pain Inventory (BPI) developed by Von Korff et al. [54] and has been widely used in research on people with many kinds of disabilities including MS and has been recommended for measuring pain in clinical trials [55].

Cognitive function. Difficulties with cognitive function were assessed by asking individuals to indicate on a 5-point Likert scale how much of a problem the symptom 'problems thinking' was for them. Individuals who reported that difficulty with thinking was at least *a little bit* of a problem for them were categorized as having difficulties for purposes of the analysis. This item was part of a larger scale developed by the authors which asked about the severity of 16 different MS-specific symptoms.

Analysis

Descriptive statistics were generated to characterize the study sample and their use of AT. Logistic regression modeling was used to identify factors that were significantly associated with the use of electronic memory aids and memory strategies. Disease duration, education level, household income, employment status, problems thinking, fatigue, pain, depression, disability level (EDSS), and use of mobility aids were all candidates for the multivariate models. Age and gender were also included in the models regardless of significance. Age and disease duration were included as continuous variables and gender as categorical with males as the reference group. Education was coded into five categories with the reference group as vocational training or some college education for the analysis. Individuals were defined as being employed if they reported 20 or more hours of paid employment. Pain and depression were included as continuous variables on a scale from 0–10, and fatigue as a continuous variable on a scale from 0–10.5. Disability (EDSS) was categorized into low, intermediate, and advanced with low as the reference category. Difficulty thinking was coded into two categories with no difficulties as the reference group. All variables significant at the 0.05 level according to a two-sided Wald test were considered to be associated with memory aid or memory strategy use. Prevalence odds-ratios with 95% confidence intervals were calculated for all significant variables. The model fit was tenable. Statistical analyses were completed using Stata 9.0© [56].

Results

Population and use of assistive technology

As can be seen in Table I, individuals in this study had a mean age of 51 years, were primarily women (81%), caucasian (97%), and had a mean disease duration of 14 years. The majority (69%) were married or living with a significant other, about half (46%) had completed undergraduate or graduate degrees, and approximately one third (35%) were employed at 20 hours or more per week.

In our survey of AT use (Table II) we found that 70.2% of respondents used memory strategies sometimes or always, the higest percentage of use of any type of AT. The second most frequently used category was walking aids (50.7%) followed by electronic memory aids (41.6%). Mobility aids (37%), home modifications (38%), and bathroom aids (37%) were also used by a significant number of individuals while vehicle aids, cooking aids, computer access aids, and communication aids were used by a smaller portion of individuals. Responses to the questions about unmet need for AT suggested that there was little perceived unmet need for AT in this sample. The most frequent types of AT reported as needed but unavailable were vehicle modifications for loading (4.6%) and computer access aids (4.0%).

Table I. Demographic and disease characteristics of a community sample of individuals with multiple sclerosis ($n = 1{,}063$).

Variable	*n* (%) mean ± SD
Age	50.9 ± 11.7
Duration of disease	13.7 ± 10.2
Sex	
Women	865 (81.4)
Men	198 (18.6)
Race[a]	
Caucasian	1,034 (97.4)
Native American or Alaska Native	31 (2.9)
Asian	10 (0.9)
African-American	20 (1.9)
Education Completed (n =3,391)	
<High School	18 (1.7)
High School/GED	137 (12.9)
Vocational/Some college	411 (38.7)
Bachelors Degree	308 (29.0)
Professional/Graduate	189 (17.8)
Employment Status[a]	
Employed 20 + hrs/wk	372 (35.0)
Employed < 20 hrs/wk	59 (5.6)
Unemployed	371 (34.9)
Retired	337 (31.7)
Homemaker	125 (11.8)
Student	26 (2.5)
Married	
Married/Live with significant other	734 (69.1)
Separated/Divorced	197 (18.6)
Never married	93 (8.8)
Widowed	38 (3.6)
Course of disease	
Relapsing remitting	599 (57.5)
Secondary progressive	209 (20.1)
Primary progressive	142 (13.6)
Progressive relapsing	91 (8.7)
Level of disability (EDSS)	
0–4.0	324 (30.7)
4.5–6.5	520 (49.2)
7.0–10.0	212 (20.1)

[a] Numbers may sum to more than 100% as individuals were allowed to choose multiple answers.

Correlates of use of memory aids and memory strategies

Variables found to be significantly associated with memory aids use included age, education, fatigue, and difficulties thinking (Table III). Endorsement of any difficulties thinking was found to be the most influential with odds of memory aids use twice (OR: 2.09, $p < 0.001$) that of those without difficulties thinking. Individuals with lower age, higher

Table II. Use of AT by individuals with multiple sclerosis.

	Never use *n* (%)	Sometimes use *n* (%)	Use always or most of the time *n* (%)	Needed but not available *n* (%)
Walking aids (e.g., canes, crutches, walker)	519 (48.8)	285 (26.8)	254 (23.9)	2 (0.2)
Mobility aids (e.g., scooter, wheelchair)	668 (62.8)	221 (20.8)	161 (15.2)	11 (1.0)
Vehicle modifications for driving (e.g., hand controls)	969 (91.2)	8 (0.8)	45 (4.2)	30 (2.8)
Vehicle modifications for loading (e.g., ramp, lift)	881 (82.9)	32 (3.0)	94 (8.8)	49 (4.6)
Home modifications (e.g., ramp, wider doorways, grab bars)	654 (61.5)	124 (11.7)	251 (23.6)	32 (3.0)
Bathroom aids (e.g., raised toilet seat, shower chair)	667 (62.8)	115 (10.8)	62 (24.7)	17 (1.6)
Cooking or eating aids (e.g., large handled utensils)	866 (81.5)	103 (9.7)	67 (6.3)	24 (2.3)
Communication aids (e.g., voice amplifier or ACD)	1,007 (94.7)	17 (1.6)	17 (1.6)	17 (1.6)
Computer access aids (e.g., voice recognition, special mouse, screen enlargement)	916 (86.2)	58 (5.5)	44 (4.1)	42 (4.0)
Electronic memory aids (e.g., computer, Palm or Pocket PC, cell phone)	581 (54.7)	218 (20.5)	224 (21.1)	35 (3.3)
Memory strategies (e.g., daily planner)	296 (27.9)	286 (26.9)	460 (43.3)	18 (1.7)

ACD = Augmentative communication device.

Table III. Correlates of memory strategy and aid use by individuals with multiple sclerosis.

	Memory strategies				Memory aids ^{f}			
Characteristic	OR	95% CI	*p*	z	OR	95% CI	*p*	z
Gender	2.02	1.41–2.91	< 0.001	3.8	1.04	0.73–1.45	*NS*	*0.2*
Age^{a}	0.91	0.84–0.97	0.007	2.69	0.86	0.81–0.91	< 0.001	− 4.94
Education^{b}	1.51	1.29–1.76	< 0.001	5.13	1.28	1.11–1.46	< 0.001	3.54
Employment (20 + hrs/week)	0.65	0.46–0.94	0.02	− 2.28	–	–	–	–
Fatigue^{c}	1.27	1.14–1.41	< 0.001	4.28	1.12	1.05–1.20	0.001	3.23
Difficulties thinking	2.61	1.77–3.85	< 0.001	4.84	2.09	1.41–3.12	< 0.001	3.64
EDSS^{d}								
Intermediate (4.5–6.5)	0.99	0.66–1.48	*NS*	*− 0.04*	–	–	–	–
Advanced (7.0–9.5)	0.45	0.27–0.75	0.002	− 3.11	–	–	–	–
Depression^{e}	0.89	0.82–0.98	0.016	− 2.41	–	–	–	–

^{a}OR for each 5-year increase in age; ^{b}The five categories are shown in Table I. Reference group is vocational/some college; ^{c}On a scale from 0–10.5; ^{d}Expanded Disability Status Scale (EDSS). Reference group is 0–4.0; ^{e}On a scale from 0–10; ^{f}Employment, EDSS, and depression were not significantly associated with memory aid use.

education, and higher fatigue were also more likely to endorse use of memory aids. Similarly, variables associated with the use of memory strategies included gender, age, education, employment, fatigue, difficulties thinking, disease severity, and depression. Fatigue (OR: 1.27, $p < 0.001$) and depression (OR: 0.89, $p < 0.001$) were found to be most highly associated with the use of memory strategies. The odds ratios presented are associated with only a one out of 10 unit increase in these traits. Overall, age, employment, and higher levels of disability and depression were all associated with decreased odds of using memory strategies. Being female, of higher education, having higher fatigue, and endorsing difficulties thinking were associated with increased odds of using memory strategies.

Conclusions

The frequency of use of mobility devices and home modifications in our study was similar to those of Finlayson et al. [27]. Of the two categories of technology that could be used to address cognitive problems, three quarters of the respondents reported that they used memory strategies and almost half used electronic memory aids 'sometimes or most of the time'. Although study participants who reported difficulties thinking were more than twice as likely to use memory strategies, participants who did not report cognitive problems also reported using memory strategies. A previous study that investigated the use of memory strategies by older adults in the context of treatment adherence reported that memory strategies were used often or always by more than 50% of the study participants [57]. The current results are consistent with other studies of community dwelling older adults that suggested those who reported that they would use electronic memory aids and memory strategies had higher levels of education. However, in our study individuals with higher levels of disability were less likely to use memory strategies whereas older community dwelling adults and with more health problems were more likely to wish to use memory devices [58].

Younger participants were more likely to use memory aids, as well as memory strategies. We hypothesize that older participants may have had less exposure to technology during their earlier years and as a result may be less likely to use memory aids that require some level of technology savvy, however it is less clear why younger people also reported using more memory strategies. One possible explanation is that younger people lead busier lives and have to juggle more responsibilities, and therefore need to remember more tasks. People with higher fatigue levels were also more likely to use memory strategies and memory aids. It may be that these individuals compensate for their low levels of energy by using cognitive aids.

Only a small proportion of respondents reported that they used a computer access aid. Based on our qualitative research [6,45] we hypothesize that some of the computer access aids may have also served as memory aids, thus increasing the number of respondents who reported use of memory aids.

Because of the apparent widespread use of memory aids and strategies, the potential of memory aids to serve as compensatory tools for cognitive changes, and the crucial role cognitive changes play in reducing participation in employment and other key life areas, it seems prudent for healthcare providers to ask about use of memory aids or strategies. Some of the very individuals who may benefit (e.g., people who are older, with lower educational level, and with higher disability) are least likely to report using memory aids or strategies. Also, for people who are most likely to use memory aids or strategies (e.g., individuals with fatigue, higher education, and difficulties thinking) it is important to inquire about the adequacy of the compensatory strategies they are employing. The results of our regression analysis suggest that this is especially important in those who are less likely to use memory aids or strategies. This group includes people who are older, less educated, have higher disability, and report more depressive symptoms. Our results also suggests that while use of aids is higher in individuals with fatigue, and those with difficulties thinking, these individuals are likely to need more compensatory strategies and providers should inquire about their aid use and ensure the appropriateness of any aids or strategies used. Because the state of technology is changing rapidly, individuals who have cognitive deficits and are not currently adequately compensating should be referred for assessment for both low and high tech compensatory strategies.

One limitation of this study is related to the sample. First, the sample was derived from one state and may represent georgraphical bias. Second, the response rate was low so the estimates of technology use may be inaccurate. However, the demographics and other characteristics of our sample appear highly similar to the Sonya Slifka study sample, a national sample thought to be highly representative of the large US MS population [59]. Also, as a cross-sectional study design, regression results can only be interpreted as associations and the direction of relationships is unknown.

We could find no research on the use of memory strategies and devices in the general population and for comparison groups we relied on research with people who are aging. Since people with MS represent a broad range of ages, we cannot know whether their uses of memory strategies and devices are unique. Because our inquiry about the uses of assistive technology was part of a larger survey, we were limited in the degree of specificity we could achieve in our question. Therefore, we may have not provided enough detail for people to respond accurately and/or with depth.

It is likely that with the proliferation of smart phone technology, internet-based calendars which may be linked to mobile phones, and other technology, the use of memory aids in the general population is rising. Although we lack of knowledge of the use of memory aids among the general population, surveys of community-dwelling older adults suggest that they are interested in using technology as a memory aid [58]. Published listerature on memory strategies used by older adults supports our findings. Several studies noted that older adults adopted a number of cognitive strategies for enhancing prospective memory, such as strategies for remembering to take medications [37,57,60,61]. Because of the association of self-described difficulties thinking and use of memory aids, we recommend that further research is warranted to more thoroughly understand the use of memory aids by people with MS.

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