

AMYOTROPHIC LATERAL SCLEROSIS PATIENTS' SELF-REPORTED SATISFACTION WITH ASSISTIVE TECHNOLOGY

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ABSTRACT: *Introduction:* Assistive devices are prescribed for amyotrophic lateral sclerosis (ALS) patients with motor deficits, but little is known about their perceived benefit. Therefore, we assessed ALS patients' satisfaction with commonly prescribed devices. *Methods:* A telephone survey of 63 ALS patients from a single multidisciplinary clinic was conducted to assess the frequency of use, perceived usefulness, and satisfaction with 33 assistive devices. *Results:* Of those assistive technologies used 'often or always' by $\geq 20\%$ of respondents, arm rails by the toilet, elevated toilet seat, shower seat, shower bars, and slip-on shoes were ranked very highly for both usefulness and satisfaction. The ankle brace for ambulation, transfer board, speaker phone, and electronic seating controls were also ranked highly. The button hook, dressing stick, and long-handled reaching tool received low ratings for both usefulness and satisfaction. *Conclusions:* ALS patients reported high usefulness and satisfaction levels with all bathroom adaptive devices and certain low-technology devices.

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Amyotrophic lateral sclerosis (ALS) is a degenerative disorder of motor neurons that results in progressive muscle weakness. As a result of this weakness, ALS patients have physical impairments that affect their activities of daily living (ADL). Clinical management recommendations for ALS patients with physical impairments include medical provider assessment and prescription of assistive devices to improve their function, maintain independence, and decrease fatigue.^{1–4} Although there has been some assessment of patient satisfaction with wheelchairs,⁵ there is little information about the reported usefulness of, and satisfaction with, commonly prescribed assistive devices. Understanding the usefulness of current assistive devices from the patient's point of view may aid in clinical practice and in the development of future assistive technology. The purpose of this study was to determine the reported usefulness of and satisfaction with current assistive devices among patients with ALS.

METHODS

ALS patients followed in the University of Michigan multidisciplinary ALS clinic from March 2008

Abbreviations: ADL, activities of daily living; ALS, amyotrophic lateral sclerosis; ALS-FRS-R, Amyotrophic Lateral Sclerosis Functional Rating Scale—Revised; IQR, interquartile range; PDA, personal digital assistant

Key words: activities of daily living, amyotrophic lateral sclerosis, assistive technology, rehabilitation, survey

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to July 2009 were identified ($n = 96$). A telephone survey was administered, and responses were recorded anonymously. Proxy responses were not used, but information was sometimes conveyed to and from the patient by a caregiver. The survey instrument addressed four general topic areas: (1) demographics; (2) caregivers and dwelling; (3) functional impairments; and (4) assistive devices. Each of these four sections is described in what follows.

Demographic information included age, gender, race and ethnicity, and economic status. Data from the U.S. Census Bureau, 2006–2008 American Community Survey 3-Year Estimates for the State of Michigan were used for income status comparison.⁶ Census data frequencies were rounded to the nearest whole integer; income data were collapsed to two categories: $\leq \$49,999$ and $\geq \$50,000$ for comparison to our survey income categories. The numbers and type of people who served as caregivers for each survey respondent were collected. A single item assessed dwelling type and included single-family home, multifamily or group home, apartment-style residence, assisted living facility, or other. Functional status was measured by the ALS Functional Rating Scale—Revised (ALS-FRS-R).⁷ Finally, respondents were asked about their frequency of use, perceived usefulness, and satisfaction with several different types of assistive devices (listed in Tables 1 and 2). Frequency of use was recorded on a 5-point scale from “never” to “always” (see tables). Device usefulness and satisfaction were each recorded on a 10-point scale where 1 = “not at all” and 10 = “extremely well/satisfied.” The 10-point scale was employed in an attempt to capture a greater range of device usefulness and satisfaction responses. The types of assistive devices investigated in this study were divided into six different categories of ADL: mobility; communication; eating; dressing; bathing/toileting; and using environmental controls. Additionally, the respondent rated the importance of independence with each ADL domain on a scale of 1 to 10, and higher scores indicated greater importance.

Frequencies and percentages or medians and interquartile ranges (IQRs) were calculated as appropriate using S-Plus, version 7.0 for Windows. For results recorded on a scale of 1–10, the

Table 1. Mobility, communication, and eating assistive device use and satisfaction.

ADL and assistive device	Frequency, <i>n</i> (%)			Median (IQR)	
	Never	Rarely/ sometimes	Often/ always	How well does the device work?	How satisfied are you with the device?
Mobility					
Cane	28 (44%)	24 (38%)	11 (18%)	5 (4–8)	5 (5–8)
Walker	32 (51%)	18 (29%)	13 (20%)	7 (5–9)	5 (5–8)
Non-motorized wheelchair	50 (79%)	10 (16%)	3 (5%)	5 (2–7)	5 (4–5)
Motorized scooter at home or store*	53 (85%)	6 (10%)	3 (5%)	9 (6–10)	8 (5–10)
Motorized wheelchair	36 (57%)	10 (16%)	17 (27%)	7 (5–8)	5 (5–9)
Ankle brace	29 (46%)	14 (22%)	20 (32%)	9 (5–10)	8 (5–10)
Sliding or transfer board	26 (38%)	10 (16%)	29 (46%)	9 (8–10)	8 (5–10)
In-home hydraulic lift*	56 (90%)	2 (4%)	4 (7%)	7 (5–10)	7 (6–9)
Communication					
Write on paper	20 (32%)	23 (37%)	20 (31%)	5 (4–7)	5 (3–10)
Portable erase board	49 (78%)	11 (17%)	3 (5%)	5 (4–7)	5 (3–5)
Letter, word, or picture board	60 (95%)	1 (2%)	2 (3%)	8 (7–9)	10 (8–10)
Laptop computer	16 (25%)	26 (41%)	21 (34%)	7 (5–10)	5 (5–10)
PDA or Palm Pilot	34 (54%)	15 (24%)	14 (22%)	7 (5–10)	6 (5–10)
Electronic speaking device*	54 (87%)	8 (13%)	None	5 (4–7)	5 (2–6)
Eating					
Modified eating utensils	38 (60%)	12 (19%)	13 (21%)	5 (5–8)	5 (5–8)
Wrist braces	37 (59%)	9 (14%)	17 (27%)	5 (5–8)	5 (5–7)
Mobile arm supports	50 (79%)	6 (10%)	7 (11%)	5 (2–8)	5 (5–5)

ADL, activities of daily living; PDA, personal digital assistant.
**n* = 62.

median scores were classified on a 5-point descriptive scale: 1 or 2 = “very low”; 3 or 4 = “low”; 5 or 6 = “medium”; 7 or 8 = “high”; and 9 or 10 = “very high.” The same 5-point scale (very low, low, medium, high, or very high) was then used to describe device usefulness and satisfaction results in text

while median and IQR data are in Tables 1 and 2. We defined device usage as “high-frequency use” if the device was used “often” or “always” by at least 20% of the ALS subjects surveyed. This study was approved by the institutional review board of the University of Michigan Medical School.

Table 2. Dressing, bathroom, and environmental control assistive device use and satisfaction.

ADL and assistive device	Frequency, <i>n</i> (%)			Median (IQR)	
	Never	Rarely/ sometimes	Often/ always	How well does the device work?	How satisfied are you with the device?
Dressing					
Zipper pull	50 (79%)	7 (12%)	6 (10%)	5 (4–5)	5 (3–5)
Button hook	57 (90%)	5 (8%)	1 (2%)	4 (2–5)	4 (1–5)
Dressing stick with hook	51 (81%)	8 (13%)	4 (6%)	4 (3–5)	4 (2–5)
Sock aid	51 (81%)	8 (13%)	4 (6%)	5 (5–5)	5 (4–5)
Slip-on shoes or shoes without laces	22 (35%)	6 (10%)	35 (55%)	10 (9–10)	10 (5–10)
Bathroom function					
Arm rails by the toilet	26 (41%)	12 (19%)	25 (40%)	10 (5–10)	10 (5–10)
Elevated toilet seat, riser, commode	33 (52%)	5 (8%)	25 (40%)	10 (8–10)	10 (8–10)
Shower seat or chair	31 (49%)	2 (3%)	30 (48%)	10 (9–10)	10 (10–10)
Shower bars	29 (46%)	7 (11%)	27 (43%)	10 (9–10)	10 (8–10)
Environmental control					
Large push-button telephone	58 (92%)	2 (3%)	3 (5%)	8 (6–8)	5 (5–8)
Speaker phone	28 (44%)	19 (30%)	16 (26%)	8 (7–10)	8 (5–10)
Large button remote control for television, light, etc.	50 (79%)	11 (18%)	2 (3%)	7 (5–8)	7 (5–8)
Sound or voice activated control	59 (94%)	3 (5%)	1 (1%)	8 (8–10)	8 (5–10)
Long-handled reaching tool	51 (81%)	10 (16%)	2 (3%)	2 (1–5)	1 (1–4)
Electronic bed control	47 (75%)	6 (10%)	10 (15%)	8 (5–10)	9 (5–10)
Electric seating controls for recliner or wheelchair	38 (60%)	7 (12%)	18 (29%)	8 (5–9)	8 (5–9)

ADL, activities of daily living.
**n* = 62.

RESULTS

Of the 96 ALS patients identified, 65 (68%) were reachable by phone and completed the survey. Of the 65 surveyed, 2 were proxy responses and were removed from further analysis to yield a final sample of 63 ALS subjects. The median age was 62 years (IQR 52–72 years); 37 (59%) were male, and 52 (83%) reported limb-onset symptoms. The median duration between the diagnosis and survey was 26 months (17–50 months), and the median ALS-FRS-R score was 25 (18–33).

The majority of respondents self-identified as Caucasian (71%) and non-Hispanic (87%), whereas the remainder identified as African American (2%), multiracial (6%), or other (8%). Only 3% indicated Hispanic ethnicity. In terms of economic status, 40% reported an income of \leq \$49,999, and 36% reported \geq \$50,000. These sample data are similar to U.S. Census statistics that show half the population of Michigan has an income of \leq \$49,999 and half \geq \$50,000.

The majority of respondents indicated that they live in a single-family home or apartment (85%); 5 (8%) reported living in a facility that provides assistance, and the remaining 6% reported living in a multifamily, group home, or other. Most respondents ($n = 52$, or 83%) reported having a caregiver. Of those with a caregiver, a majority (79%) had one ($n = 24$) or two ($n = 17$) caregivers, whereas 21% reported three or more caregivers. Family members were most frequently cited (93%), but caregivers also included friends (37%), employees (38%), and respite-care workers (10%).

Frequency of use, usefulness of, and satisfaction with assistive technology devices are shown in Tables 1 and 2. Sixteen of the 33 devices surveyed were designated as having “high-frequency use” with devices used “often or always” by 20–55% of respondents, including: walker, motorized wheelchair, ankle brace for ambulation, sliding transfer board, writing on paper to communicate, laptop computer, personal digital assistant (PDA), modified eating utensils, wrist braces, slip-on shoes, arm rails by the toilet, elevated toilet seat, shower seat, shower bars, speaker phone, and electric seating controls for a recliner or wheelchair.

Among those devices with high-frequency use, the ankle brace, transfer board, all bathroom devices, slip-on shoes, speaker phone, and electronic seating controls received a high or very high median rating for both how well the device worked and satisfaction with the device. Walkers, motorized wheelchairs, PDAs, and laptop computers all received high median ratings for how well each worked, but the satisfaction scores were lower for each device. Only a small number of ALS patients reported using motorized scooters; letter, word, or

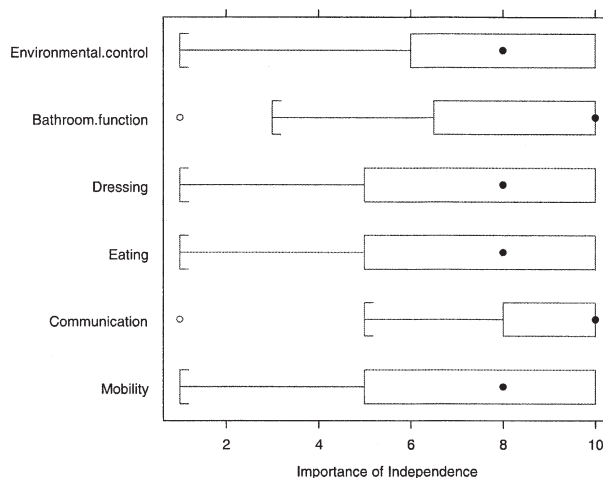


FIGURE 1. ALS patients' self-reported importance of independence for each ADL category. Importance was rated on a 10-point scale from 'not at all important' to 'extremely important.' The boxplots demonstrate the median value (filled circles), with the first and third quartiles outlined by the box, and individual outliers shown as open circles. The boxplot whiskers extend to the extreme values of the data or a distance 1.5 times the intra-quartile distance from the center, whichever is less.

picture boards; electronic bed controls; and sound- or voice-activated environmental controls. All four devices, however, were rated as very high, both for how well the device worked and satisfaction (Tables 1 and 2).

In contrast, the button hook, dressing stick with hook, and long-handled reaching tool (Table 2) all received low or very low median ratings for usefulness and satisfaction.

Finally, patients with ALS were asked to rate the importance of each functional ability domain to their own independence. Although all six domains received universally high ratings, two domains—communication and bathroom function—received a median score of 10 on the 10-point scale (Fig. 1).

DISCUSSION

This cross-sectional telephone survey of a cohort of ALS patients from a single multidisciplinary clinic has shown that bathroom adaptive devices were uniformly the most frequently used and received the highest reported usefulness and satisfaction scores. Additionally, of those assistive technologies used often or always by \geq 20% of respondents, the ankle brace, transfer board, slip-on shoes, speaker phone, and electronic seating controls were highly ranked for both usefulness and satisfaction. Although motorized wheelchairs were used frequently by $>$ 25% of respondents, overall satisfaction with these devices was only moderate.

This study is one of the first to describe in detail ALS patients' self-reports of assistive technologies. We examined not only the frequency of

device use but also patient-centered indicators of usefulness and satisfaction. Other researchers have queried patients about satisfaction with a specific technology, such as wheelchairs.⁵ Trails et al. found that ALS patients who used a motorized wheelchair reported significantly higher satisfaction with their activity level than manual wheelchair users, but no significant differences were found with respect to comfort, ease of maneuvering, or portability. Our data are similar to those of Trails et al. in that our respondents reported a relatively high median score for how well a motorized wheelchair worked, but satisfaction with both non-motorized and motorized wheelchairs was only moderate. Although motorized wheelchairs offer desirable functions, including independent mobility and tilt/recline features, their large size and reduced portability may decrease overall satisfaction.⁵ Improved motorized wheelchair functions that optimize comfort and portability while allowing users to maintain control of the chair may increase ALS subject satisfaction with this expensive medical equipment.

Interestingly, we found that low-technology assistive devices, such as ankle braces for ambulation, transfer boards, slip-on shoes, and speaker phones, were used frequently and rated quite highly in usefulness and overall satisfaction. All four of these devices can be easily prescribed or recommended to the patient and, in some cases, provided during the multidisciplinary clinic visit. Not all low-technology assistive devices, however, were rated as highly. Although dressing sticks, button hooks, and long-handled reaching tools may assist some subjects with weakened upper limb function, these three devices received lower usefulness and satisfaction scores. Efforts to use these devices to perform tasks with an already weakened upper extremity may be more cumbersome and may worsen fatigue.

Although used by a minority of respondents, we found it of interest that motorized scooters; letter, word, or picture boards for communication; and sound- or voice-activated environmental controls were very highly rated for both usefulness and satisfaction. We were also surprised to find a high frequency of laptop computers and PDAs being used for communication. Although these two devices were rated highly for how well the devices worked, overall satisfaction was only moderate. The discrepancy between usefulness and satisfaction ratings for portable electronic devices is unclear. It may be that ALS patients find that these devices function well and provide convenience along with many communication formats such as e-mail, instant messaging, and electronic social networks. However, satisfaction may be decreased if the individual has limited ability to interface with

the device due to limb weakness. Further investigation into ALS patient use of these two common devices may lead to improved satisfaction and expanded use of portable electronic devices for communication. Although electronic speaking devices were used by only 13% ($n = 8$) of ALS respondents, these devices received the same rating (medium) as did writing on paper for both usefulness and satisfaction in communication. Our findings suggest further investigation is needed to improve ALS patient satisfaction with the current electronic speaking devices.

Across the board, ALS subjects rated independent function with activities of daily living quite high. The current sample of patients rated independent function with communication and bathroom activities most highly. Therefore, medical providers should pay particular attention to optimizing assistive technology for both communication and bathroom activities.

Limitations. Not all possible assistive technologies were assessed in this survey. Still, the variety of devices surveyed was quite broad in terms of complexity of device technology, and we looked at devices across different activities of daily living. Given that ALS patients were surveyed from a single academic clinic, the results may not apply to all ALS patients. Furthermore, the ALS patients who participate at our multidisciplinary clinic may have a higher socioeconomic status and therefore have greater access to assistive technology. However, this seems unlikely, because our respondents were relatively representative of the income status of the population in the state of Michigan. Although we were able to survey 68% of our clinic population, it is unknown whether the remaining individuals, who were unavailable for the phone survey, would have reported similar responses. Last, given the cross-sectional design of our survey and the changing needs of ALS patients, our study cannot correlate change in ALS patient function, as assessed by the ALS-FRS-R, with assistive device usefulness and satisfaction. Further research studies that include a longitudinal study design, following ALS patients over the disease course, would be useful to correlate change in function and assistive device satisfaction.

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