

Multiple sclerosis and mobility-related assistive technology: Systematic review of literature

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Abstract—Multiple sclerosis (MS) causes a wide variety of neurological defi cits, with ambulatory im pairment the most obvious cause of d isability. Within 10 to 15 years of di sease onset, 80% of persons with MS experience gai t problems due to muscle weakness or spasticity, fatigue, and loss of balan ce. To facilitate mobility, persons with MS frequently use mobility assistive technology (MAT), such as canes, crutches, walkers, wheelchairs, and scooters. W e systematically reviewed the published literature on MAT use among persons with MS. We used elec tronic reference lists such as Ovid MEDLINE and PubMed to search the literature. We located 50 articles that met the initial criteria of providing good evidence of the types of MAT devices and their benefits for in dividuals with MS. A limited number of articles with higher levels of evidence was found regarding benefits of MAT use specifically for persons with MS. Evidence-based literature provides the basis for the strongest met hod of measu rable clinical performance; therefore, having a strong research study design is vital to the justification of MA T p rescription and reim bursement decisio ns. However, a paucity of studies with higher levels of evidencebased practice exists.

Key words: assistive technology, cane, level of evidence, mobility, mul tiple sclero sis, qu ality of li fe, reh abilitation, scooter, walker, wheelchair.

INTRODUCTION

Multiple sclerosis (MS), a neurodegenerative disorder of the central nervous system, curre ntly af fects approximately 40 0,000 U.S. residents, with 20 0 ne wly diagnosed individuals each week [1–2]. MS causes a wide variet y of n eurological deficits, with ambu latory impairment as the most obvious cause of disability [3–4]. Within 10 to 15 years of disease onset, 80 percent of persons with MS experience gait problems due to muscle weakness or spasticity, fatigue, and balance impairments [5–7]. To facilitate mobility, persons with MS frequently employ mobility assi stive technology (MAT), such as canes, crutches, walkers, wheelchairs, and scooters.

Matching the most appropriate MAT to the needs of a person with MS is vital to his or her daily mobility. Mobility impairments frequently restrict participation in work, family, social, vocational, and leisure activities [8]. Furthermore, p ersons with MS often exp erience difficulties

DOI:10.1682/JRRD.2009.07.0096

Abbreviations: AFO = ank le-foot orth osis; AT = assistive technology; ATP = AT professional; FES = functional electrical stimulation; H FAO = hi p flex ion assist orth osis; LOE = level of evidence; MAT = mobility AT; MS = multiple sclerosis; P APAW = power -assist pu shrim-activated wheelchair; PHAATE = Policy, Human, Activity, Assistance, T echnology, and Environment (model); QOL = quality of life; RET = rehabilitation engineering technologist; SCI = spinal cord injury. *Address all correspondence to Rory A. Cooper, PhD; VAPHS, Human Engineering Resear ch Laboratories, 71 80 H ighland Dr, Bldg 4, 2nd Floor , 151 R1-HD, Pittsburgh, PA 15206; 412-954-5287; fax: 412-954-5340. Email: rcooper@pitt.edu

adapting to the changing and progressive nature of mobility loss, frequently marked by exacerbations and remissions [9]. These difficulties can compound relatively high levels of emotional distress, which can exacerbate efforts to accommodate mobility with MAT [10]. A 2008 survey of persons with MS found that 37 percent were too embarrassed to use MAT, while 36 percent reported that they do not use their MAT as much as they should [11].

In addition to standard MAT, new and emerging technologies are un dergoing development that could accommodate mobility needs for persons with MS. More studies are exploring the consequences and patterns of MAT use among persons with MS. Ho wever, no recent review has examined the growing scientific evidencebased literature about MAT use in MS. We aimed to systematically review the published literature concerning MAT use among persons with MS.

METHODS

We searched the literature using the electronic reference lists Ovid MEDLINE[®] (1950–2008), CINAHL[®] (Cumulative Index to Nursing and Allied Health Literature) (1982–2008), Pu bMed (1966–20 06), and Scop us (1985–20 08). The searches used the following keywords: fall s, mobility, multiple sclerosis, cane, walker, wheelchair, assistive technology, and psychological problems. We considered on ly publications concerning persons with MS with impaired mobility and published in a peer-reviewed journal. After reviewing potential articles, we located 50 that met the initial criteria of providing good evidence of the types of MAT devices and their benefits for persons with MS (details of these studies are presented in the **Appendix**, available online only).

The articles reviewed in our lite rature review were evaluated and included ac cording to their levels of evi dence (LOEs) and significance, as proposed by Sackett et al. [12]. Their approach is based on evidence-based medicine, which they defined as "a practice of integrating individual clinical expertise with the best available external clinical evidence from syst ematic research" [12]. To make the process of evaluating published research more efficient, S ackett et al. outlined LOEs and stratified them in order from strongest to weakest:

• I: Evidence is obtained from meta-analysis of multiple, well-designed, controlled studies.

- II: Evidence is obtained from at least one welldesigned experimental study.
- III: Evidence is obtained from well-designed, quasiexperimental studies such as nonrandomized, controlled single-group, pre-post, cohort, time, or matched-case control series.
- IV: Evidence is obtained from well-designed, no nexperimental studies such as comparative and correlational descriptive and case studies.
- V: Evidence is obtained from case reports and clinical examples.

PATTERNS OF MOBILITY IMPAIRMENTS

Multiple Sclerosis and Risk of Falling

Persons with MS are partic ularly predisposed to various impairments, including fa tigue and falls due to brain and spinal cord involvement [13–14]. In an observational survey stu dy of 1,0 89 person s with MS aged 45 to 90 years, Finlayson et al. reported that 52.2 percent of participants had experienced a fall in the past 6 months. Factors associated with an incr eased risk of falling included being male, having a fear of falling, a deteriorating MS status, balance problems or mob ility limitations, and poor concentration [13]. In addition, another survey study found that the absence of weight-bearing activities, unsteady gait, and use of a cane contributed to the multifactorial nature of falls among persons with MS [14]. Common sequelae of abrasions, lacerations, co mprofalls include fractures. mised mobility, loss of confidence in performing tasks, and fear of falling [13]. Therefore, assessment of dif ferent aspects of MS-related motor impairments and the accurate determination of factors contributing to falls are necessary for disease management and therapy and for the development of fall prevention programs [14].

Multiple Sclerosis and Mobility Through Ambulation

Understanding the experiences of mobility loss from the perspective of persons with MS may provide insight into the development of p rograms, services, and adv ocacy efforts that support people with MS as they age [15– 16]. These dev elopment efforts must cons ider se veral symptoms of MS that influence ambulation: loss of balance, weakness, fatigue, cogn itive impairment, fear of falling, spasticity, tremor, and visual impairment [17–18]. In addition, resistance to using appropriate MAT must also be addressed.

A 2000 literature review conducted by Noseworthy et al. found that even th ough MS causes a wide variety of neurological deficits, ambulatory impairment is the most common form of resulting disab ility [5]. Within 15 years of onset, 50 percent of persons with MS will require assistance with walking. Therefore, most persons with MS will require some type of mobility assistance within the course of their disease progression [5]. A survey study conducted in 2 001 with 220 participants with MS fou nd similar results to the Noseworthy et al. study, finding that the probability of participants walking 10 to 20 m without assistance 15 years after diagnosis was 60.3 percent, while the probability of managing to walk a few steps without using a manual wheelchair as a bac kup was as high as 75.0 percent [19]. The researchers also found that the existence of motor symptoms and advanced age at disorder onset indicated more unfavorable outcomes, but these factors were associated with the progressive course of MS. Baum and Rothschild in 1983 conducted an observational study with 1,145 persons with MS and found that approximately 51 percent of particip ants reported they needed help with personal mobility both indoors and outdoors [6]. Among study participants, 4 percent reported using crutches, 12 percent walkers, and 40 percent wheelchairs at 13 years after diagnosis [6]. A recent survey-based study conducted with 906 persons with MS also concluded that factors such as being seen by an occupational therapist and the type of MS were the strongest predictors of assi stive technology (AT) acquisition [20].

CURRENT ASSISTIVE TECHNOLOGY AND SERVICE DELIVERY

Mobility Assistive Technology

When gait difficulties do not respond to therapeutic interventions, MA T devices may be useful too ls to enhance m obility [1 7]. Mos t persons with MS have mobility restrictions that require MAT devices [9,20–21]. A study with 101 persons with MS indicated that their expectancy of becoming MAT us ers was as follows : 22.5 percent reported that the expect ted to be wheel - chair-dependent in the short-term (2 years), 38.7 percent in the mid-term (10 years), and 54.0 percent in the long-term (>10 years) [22]. Provision of MAT for persons with MS can potentially diminish activity limitations and participation restrictions , preve nt or redu ce fa tigue by energy conservation and, ultimately, improve quality of

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life (QOL). MAT includes any device used to maintain or improve mobility [15,23–24]. MAT is also designed to improve functioning, enable successful living at home and in the community, and enhance independence [25].

Therefore, a variety of assistive de vices have be en used by persons with MS:

- 1. Ankle-foot orthoses (AFOs) have been an effective solution for compensating weakness, restoring energy, and helping to control unstable knee and ankle musculature. AFOs are also used for foot drop, a condition in which the individual cannot clear his or her toes in the swing-through phase of mobility, which af fects normal gait [26]. AFOs can be made from composite materials or plastics with two different mechanisms: rigid or articulated. Recently, carbon-fiber AFOs have become popular among persons with MS. They generally come in two styles: (1) an anterior shell with a medial or lateral upright component that creates knee stabilization, preventing knee e xtension, and that reduces foot drop and (2) a po sterior shell that compensates for ankle dorsiflexor weakness while returning energy by providing a sprin g effect during toe push off, consequently helping with toe clearance during the swing part of gait. Negative factors associated with AFOs are limited ankle and knee mobility during kneeling, running, or stooping.
- 2. Functional electrical sti mulation (FES), which has been used for treatment of muscles deprived of ne rvous control, provides muscle contraction and functional movement [26]. For persons with MS, FES has been a useful tool for foot drop, balance, and walking training during rehabilitation treatment ; advanced technology has enabled a new system unit with wireless communication. How ever, the decision between an AFO and/or different models of FES is ultimately clinical and needs to be made by the potential user, physical therapist, and physician together.
- 3. Hip flex ion ass ist orth oses (HF AOs) are a nother option for persons with MS who do not ef fectively ambulate despite the use of an AF O or FES. The HFAO is indicated for persons with unilateral lower-limb weakness in the hip and knee flexors along with the ankle and dorsiflexor muscles [26].
- 4. Canes assist ambulation by maintaining the even distribution of weight on the hips that is characteristic of a normal gait. Canes are also beneficial when walking is only mildly unstable, reducing walking ef fort and risk of falls when compared with AFO s and HFAOs [26].

Several types of canes are available, including singlelegged canes an d "quad" canes, which hav e a bro ad base of support and can remain u pright independently so they do not become a tripping hazard.

- 5. Crutches are also used to aid with ambulation by helping with balance, widening the base of support, and decreasing weight bearing on a sing le lower limb. Crutches provide mo re balance than canes du ring walking and are indicated for people who need bilateral support and have good upper-limb control [26].
- 6. Walkers and/or wheel ed walkers (rollators) are indicated for persons with mode rate deficits and provide increased stability as a result of the walker 's lar ger footprint compared with a cane or crutches. In a ddition, they can be purchased with wheels, brakes, and modified hand grips to aid in function and safe use [26]. Further, to assist with fatigue, some walkers are equipped w ith s eats for short re st periods during ambulation.
- 7. Manual whe elchairs provide a more stable wheeled option while still providing some level of physical activity [26]. In a ddition, manual wheelchairs can be used part-time or as a primary exclusive mobility option for persons who are experiencing balance difficulties and frequent falls.
- 8. Power-assist pushrim-activated wheelchairs (PAPAWs) are manual w heelchairs with a forc e/moment-sensing pushrim, which provides assistance with wheel-chair propulsion while requiring less p hysical strain. For people with MS, PAPAWs may prove to be a good compromise between the fatigue caused by propelling among manual wheelchair users and the lack of exercise among power wheelchair users [26].
- 9. Scooters are a pop ular mod e of po wered mo bility among persons with MS. Some users prefer a scooter to a manual wheelchair, since upper limb fatigue is not an issu e. However, scoo ters are often less desirable than power wheelchairs because of their lack of stability during turns and limited seating system options to accommodate users with specific seating needs, as seen in progressive disorders such as MS [26 −27]. Scooters are available in two types: three- and four wheeled. The four-wheeled scooters typically of fer more device stability than the three-wheeled scooters, but as a result, they are difficult to maneuver and heavier and thus more difficult to transport.
- 10. Power wheelchairs shou ld n ot only be considered a mobility option for advanced stages but should also be

recommended as a MA T option to address fatigue, a hallmark symptom of MS [14,25,28–29]. In contrast to scooters, power wheelchairs permit power seating system up grades that may be indicated as the client progresses and are con figured in d ifferent typ es of driving base design s. Th ree main power wheelchair base options are available: rear-wheel, mid-wheel, and front-wheel drives [25].

Among the various MA T opt ions, manual wheelchairs (60%) have been reported as the most common MAT used by persons with MS, followed by canes and crutches (44%), walkers (3 9%), and po wer wheelchairs (8%) [20]. In an observational study, Baum and Rothschild have also shown that a greater number of persons use w heelchairs (40%) than walkers/canes (12%), leg braces (6%), and crutches (4%) [6]. In a recent retrospective study, manual whe elchairs (33%) were again the most prescribed devices, followed by power wheelchairs (13%), walkers (6%), braces (6%), and c anes (2%) [30]. The use of wheelchairs has been positively correlated to the duration of the dis ease, age, and awareness of the diagnosis [6,30].

Characteristics of ambulatory persons with MS w ho transitioned to a wheeled mobility device were compared with those of person s with sp inal cord injury (SCI) and investigated by Ambrosio et al. in a retrospective study [31]. Participants with MS were not able to ambulate at functional speeds and had sedentary activity levels. Fur ther, the quality of wheeled mobili ty devices recom mended to persons with MS was in ferior to that of devices issued to persons with SCI. In a nother surveybased study by Perks et al., 59 percent of wheelchair users stated that they did not fe el their whee lchairs met their mobilit y needs and therefore they had dif ficulty navigating within dif ferent environments [32]. In addition, a 2002 literature review study by Fay and Boninger investigated the e fficacy of manual wheelchair propulsion in full-time manual wheelchair users with MS [33]. Results showed that persons with MS were unable to maintain a functional speed of wheelchair propulsion when compared with a control group of persons with SCI and a group of persons with no disability. Kinetic analyses revealed that with propulsive stroke of the manual wheelchairs, persons with MS ap plied a for ce in the opposite dire ction of forward propulsion, esse ntially working against themselves every time they pushed their chairs, leading to incre ased energy expenditure during wheelchair propulsion. This higher energy expenditure is

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a significant problem for thesis population, for whom fatigue is a major limiting factor [33]. Thus, prescription of a powered mobility device, such as a scooter or power wheelchair, would be more a ppropriate than a manual wheelchair, depending on many factors such as clien t diagnosis, comorbid conditions, living environment, and use of trans portation. Users of MA T devices frequently view mobility devices as a symbol of loss of function or greater disability. Despite this fact, transition from manual to pow er wheelchairs has been reported to enhance users' occupational performance, with increased feelings of competence, adaptability, and self-esteem [34].

Given the scarce research on AT for persons with MS and its importance on their activities of daily living, healthcare professionals and researchers have had to refer to work done on other populations with disabilities, such as SCI or cere bral palsy [33]. Persons who cannot walk and rely primarily on a combination of manual and power wheelchairs are more likely to be active in the community than those with these disabilities but who can walk and, therefore, use an ambulation aid and manual wheelchair combined [35]. Power wheelchairs allowed persons with MS to minimize the ef fort needed to ambula te or propel a manual wheelcha ir, resulting in conserved energy for use with other activities [35–36]. Having an appropriate mobility device can significantly influence how a person with a disability perceives life [34].

Power wheelc hairs with dif ferent sea ting systems, such as tilt-in-space and rec line, help persons with MS rest comfortably in their chairs during the day without needing to return to bed or tr ansfer to a static chair [36]. In a descriptive study, Dewey et al. concluded that people with severe MS symptoms pre ferred to be out of bed as much as possible, and thus, the prescription of tilt-inspace options should be highly considered by clinicians and consumers looking for power wheelchairs despite their cost [36]. A prospective study conducted by Ding et al. examined the use of tilt-in-space and recline among nondisabled person s, and their results showed that the most favorable angles with maximum pressure reduction were 45° of tilt and 120° of recline [37]. In addition, the authors also reported that a combination of tilt and backrest recline achieved greater pressure reduction than tilt alone. Therefore, power -seat functions positively af fect users' QOL because they allow users to remain in their chairs longer, decrease the ris k of pressure sores, conserve energy, access a variety of environments, and par ticipate in more activities dur ing t he day [38]. In

addition, tilt-in-space dec reases the user's risk of pressure sores, especially in a dvanced cases of MS in which the person has decreased pr essure-relief ability [35–36]. The use of power-seat functions proves to be essential in helping p ower wheel chair users b e more comfortab le, with less need for transfers throughout the day, especially among persons with progressive diagnoses [29].

Caution should be taken in the prescription of MAT devices, especially for persons with MS; if the prescription does not meet the user 's needs, the MAT prescribed might not be used and instead abandoned. A retrospective study conducted by Verza et al. in 2006 found that AT devices were abandoned because of worsening in phys ical status (3 6.4%), followed by nonacceptance of the device by the u ser (30.3%), inappropriateness (24.2%), and insufficient/lack of info rmation and training (9.0%) [30]. A reason for this devi ce abandonment could be a change in medical condition; in addition, functional ability is a strong factor in fluencing aband onment of A T [25]. Unlike with other diagnoses, MAT for people with MS may not be a long-term solution because of the progressive nature of the disorder . MAT abandonment is costly in both financial terms and outcomes achievement, regardless of whether the abandoned equipment is high or low technology [25]. Device ab andonment could be reduced if c onsumers were actively involved from the start of the MA T service-delive ry proc ess. A better understanding of how and why persons decide to accept or reject different types of MAT is critical to improving these persons' QOL [25].

Mobility Assistive Technology Use and Service Delivery

In advanced stages of MS, s everal interventions can provide assistance with independence to the in dividual, such as (1) provision, education, and instruction in use of assistive devices (walking aids, po wer/manual wheel chairs, and car adaptations); (2) education and instruction about compensatory strategies to accomplish an activity (safe transfers); and (3) environmental modifications (ramps, lifts, w ider doors, level access showers, bath aids, and environmental control systems) [9,20].

MAT must serve as an interface between the person with a disability and the activity the person chooses to perform and must promote re integration into community life [39]. Services models are used as guidelines to provide a comprehensive conceptual model representing factors to be considered in the design of an AT device or the development of a service-delivery program that not only

meets us er needs but also is in accordance with policy regulations [39]. Therefore, researchers have been developing a comprehensive model of service delivery that includes those factors and improves not only service delivery but also policy regulations.

Researchers from the Un iversity of Pittsburgh recently developed a new service d elivery model called the Policy, Human, Activity, Assistance, Technology, and Environment (PHAATE) model. This model incorporates policy, human, activity, assistance, technology, and environment into service delivery of A T [39]. The PHAATE model was develop ed to crea te a comprehensive model representing factors that shou ld be considered in the design of AT devices or in the actual development of a service-delivery program. When prescribing AT, clinicians must prioritize each individual's medical benefit and consider the reimbursement policy to avoid denial of reimbursement due to lack of well-documented letters of medical necessity. However, the policy should not influence or dictate the final clinical recommendation for the most appropriate MAT device. The environment and context sh ould be consid ered during the service-delivery process, because people perform activities in a variety of environments [39]. One problem of AT provision lies in the paucity of AT outcome studies, partially due to inadequate funding support for research studies or lack of understanding of the need for specialized clinical expertise, especially among insurers and nonrehabilitation medical professionals [39].

Studies investigating service-delivery models in countries such as Ireland and Canada showed that the develop ment of a client-focused, social, and partic ipatory AT service-delivery model achieves the best results for people with disabilities and their caregivers [40]. Another observational study was conducted in 2005 by Ripat and Booth to identify key characteristics of the AT service-delivery model preferred by the various Canadian stakeholders [41]. When prescribing AT, clinicians should focus on persons' medical necessity and their specific needs during the decision-making process as well as when choosing appropriate AT devices. Based on these study results, recommendations for service delivery were proposed for future use in other AT clinics. These study results may help in the develop ment of funding guidelines, the support of the importance of AT in enabling meaningful activities, and the examination of current service delivery in different contexts. Participation of the end user needs to be considered throughout the entire AT process. The evaluation process should address the user's skill, goals, abilities, supports, resources, and context [40–41].

AT is, therefore, best deliv ered with a te am approach, including AT professionals (ATPs) and rehabilitation engineering technologists (RETs) working in cooperation with qualified physicians, all focused on the needs of the end users. For this reason, the Rehabilitation Engineering and Assistive Technology Society of North America provides the ATP and RET credentials to identify knowledgeable clinicians, suppliers, and engineers [42]. These efforts and research studies on how to improve AT service deliv ery may decrease AT abandonment and consequently increase users' satisfaction, community participation, and QOL.

New and Emerging Mobility Assistive Technologies

In a 2007 prospective research study, Sawatzsky et al. investigated the use of the Segway [®] Personal Transporter device (Segway Inc; Be dford, New Hampshire), another powered mobility device for persons with limited ambulatory ability, such as people with MS or lower-limb amputations [43]. Segway devices are described as "the first selfbalancing, electric-powered transportation devices." The rider stands on a small platform supported 20 cm of f the ground by two parallel wheels and holds onto the handlebars. A twist grip on the left bar is used to steer the device. When the rider moves forward, the Segway moves for ward; when the rider leans back, it moves back or stops. The Seg way is marketed as a revolutionary device that requires no special skills and that "virtually anyone can use." In this particular study, the authors found that the Segway was a useful device for a wide range of disabilities (e.g., MS, SCI, amputation) and it may also increase personal mobility for some people with functional limitations. Therefore, it would enable people with functional limita tions to become more involved in meaningful activities and, hence, increase their QOL [43].

For persons with difficulty operating a mobility device because of dec reased physical strength or environ mental accessibility barriers, a new concept has been developed to accommodate those issues: the Independence iBOT 30 00 mobility system (Independence T echnology, Johnson & Johnson; New Bruns wick, New Jersey) [44]. The iBOT was recently developed with the purpose of overcoming many of the limit ations of currently avail able mobility devices [44]. The iBOT has a computer system designed to provide a d ynamic ba lance reaction in the for e-aft direction and has five different operating functions: (1) standard (similar to a traditional power wheelchair), (2) four-wheel

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(four-wheel drive for outdoor mobility including curb climbing), (3) balance (two-wheel drive, dynamically balanced on two wheels for mobility at the elevated height of a standing person), (4) stair-climbing (rotation of the wheel clusters to allow "stepping up" one stair at a time), a nd (5) remote (nonoccupied mobility device) [44]. Even though the iBOT is a g ood mobility option for p ersons with ambulatory impairment, it is an expensive device with fu nding u navailable by Medicare; h ence, it is no longer available on the market.

Another op tion in po wer wh eelchairs de signed for indoor an d o utdoor use an d stair climbing is ca lled the TopChair (Hm c2développement; Toulouse-Montrabé, France) [45]. This power wheelchair comprises combined wheels and a caterpillar track. The TopChair was test ed in F rance amo ng 25 person s with SCI, and results showed that a ll participants were able to succ essfully operate the power wheelchair indoors and outdoors. Due to its electromechanic property and caterpillar tracks, the TopChair is a little bulkier and heavier than other power wheelchairs with similar func tions. However, no studies have evaluated the benefits of the T opChair among persons with MS.

Even though new technologies have been developed recently to enhance mobility and community partici pation, a clinician must consider many factors when trying to match a person with an assistive device [30]. Using an assistive device for mobility could vary in two ways: fulltime use or part-time use, depending on level of disability and functional characteristics [30]. Evaluating and understanding the pros an d cons of each device, eith er with a new design and features or with a device already on the market, are vital when MA Ts are pre scribed. The suc cessful use of each MAT will be based on the interaction of knowledge of the disorder stage by the rehabilitation professional and willingness of the person wi th MS to accept and use what is suggested.

PSYCHOSOCIAL FACTORS AND MOBILITY ASSISTIVE TECHNOLOGY USE

Psychological Aspects of Multiple Sclerosis

Emotional d istress is high er am ong pe rsons with MS than with other chronic illnesses and is three times more common in persons with MS than in the general population [10]. Contributing factors to high emotional distress rates in persons with MS include the uncertainty and unpredictabil-

ity of symptoms and disability over time. Results from secondary analyses of a survey-based study by Gulick suggested that the presence of emotional and financial support together with coping strategies explain how persons with MS can enhance their performance in everyday activities, including personal care, mobility, recreation, sociali zing, and intimacy, despite the presence of emotional distress arising from this disabling chronic disorder [10]. Support groups are options for persons with MS who are eithe recently diagnosed or having problems dealing with or adjusting to their diagnosis of MS. These groups are designed to take people from the initial emotional response of acknowledging their diagnoses to a different view of how to cope with and practically manage their symptoms [46]. The parti cipation of care pa rtners becomes particularly important at these times, main ly because they will t hen learn from other families how to best support their loved ones with MS [47]. The psychological aspects of MS have been reported not only among adults but also a mong children. Interestingly, the psychosocial difficulties seen among children and adolescents with MS have the same manifestations as adults [48]. These manifestations affect the persons' self-image, role functioning, mood, and cognition not only in school but also at work, in their interper sonal relation ships, and during treatment compliance. Among old er adults, fear of the future is the major concern, which enhances the fear of experiencing future losses of mobility and independence, becoming a burden on caregivers and, ultimately, moving into a nursing home [49].

Another important factor in the psychological aspect of persons with MS is the use of an AT device, especially for mobility, which has a great influence on the activities of daily living and independence of persons with MS. Inabilfficulty going out in the community ity to go out or di increases frustration a nd depende nce on others, c onsequently in creasing the probability of depression. A 2001 survey-based study by Buning et al. investigated the impact of tran sition from manual to power wheelchairs an d its influence on the persons' o ccupational performance and psychosocial coping with regard to this transition [34]. The authors fo und that chan ging from a manual to a power wheelchair increased participants' occupational performance in daily life; moreover, their satisfaction with using a power wheelchair increased their competence, adaptability, and self-esteem [34]. Even though the study population was small (n = 8), these results suggest that the use of power wheelchairs may positively influence not only peop le with chronic disabilities, such as SCI and traumatic brain injury,

but also people with progressive conditions, such as MS and muscular dystrophy. Despite how persons with MS think of their disability while using MA T devices such as power wheelchairs, these devices can cont ribute to their resilience during mobility-related activities of daily living by restoring their ability to perform acti ons, tasks, and projects, which support occupational and role performance [34].

In addition to finding the best option when prescrib ing AT devices, rehabilitation professionals must equally emphasize the influence of a good interaction between persons with MS and their family [25-46,48-50]. Having a family member with MS may affect the overall family dynamics, whether the person is a child or an adult [48]. Poor communication between persons with MS and their family may je opardize the decision to a cquire an appropriate AT device. In cases in which only family members are available to de cide on an AT device, their decision could have detrimental effects on the psychosocial w ellbeing of person s with MS if they feel that they do not have control ov er or input into the kin d of equipment obtained [50]. Persons with MS and their family should discuss and agree on the risks and benefits of the AT to be used to maintain a suppor tive environment with good adaptation to the new device [51]. An open relationship between person s with MS, th eir family members, and rehabilitation professionals involved in prescribing an AT device will result in better outcomes [34,50].

Pain is a n important factor influencing psychosocial functioning. In a stud y conducted among veterans with MS, increased fatigue, poor general he alth, and greater depression symptom severity were s ignificantly as sociated with higher levels of pain. Therefore, pain should be treated aggressively to mini mize functional impairment [51]. Also, preventing pain due to extended seating in wheeled mobility devices should be addressed.

Mobility Impairment and Quality of Life

A surv ey-based stu dy conducted with 412 persons with MS showed that more than 50 percent of persons with long-standing MS req uired assistance b oth in and out of their homes [14]. In ad dition, factors increasing the percentage of people who needed assistance included longer MS duration, diagnosis at a nolder a ge, and the in dividual's ackno wledgment of the d iagnosis [6,9]. Red uced mobility has been associated with built environmental barriers, difficulty in completion of daily activities, restricted participation in life task s [15–16], and p erceived reduced QOL and community participation [23,52]. In 2002, a literature review study by Fay and Boninger found that QOL

was closely correlated with mobility [33]. A 2007 retrospective study among 196 persons with MS showed that persons with decreased physical activity also had red uced QOL. The same study concluded that barriers in the built environment influenced p hysical activity levels and com munity participation [47]. An accessible environment not only p romotes high levels of physical activity but also results in increased community participation, particularly among persons with MS.

Significantly decreased mobility and self-reported QOL in the MS pop ulation have been highlighted as important intervention needs [6,24,47]. Over time, persons with MS experience reductions in health status and physical function [53]. In addition, persons with chronic progressive MS experience more activity limitations than do persons with relapsing-remitting and benign types of MS. Fatigue, weakness, balance impairments, spasticity, tremors, and speech and swallow ing problems are the most troublesome MS symptoms that impact the activity performance of persons with MS [53–54]. Hence, the resulting impaired ambulation is an important contributor to disability and decreased QOL in persons with MS [23,55].

CONCLUSIONS

Beside the ph ysical, p sychological, and eco nomic impact of MS on patients and family members, this disorder causes a wide variety of neurological deficits, of which ambulatory impairment is the first symptom and the most common form of disability [4]. Common symptoms of MS include fatigue, weakness, spasticity, ataxia, somatosensory symptoms su ch as visual impairment, and other impair ments of cranial nerves and brain stem structures [19].

The typ e, sev erity, and frequency of sy mptoms determine MS progression and the potential need for MA T devices. The unpredictable nature of MS is a constant challenge for not only persons with MS but also their family and friends. The possi bility of l osing the abi lity t o walk increases the stress and psychological aspects of being diagnosed with MS. Therefore, relying on an assistive device for mobility becomes very important to all persons with MS.

One of the biggest challenges for rehabilitation professionals and persons with MS is finding a mobility device that mee ts the us ers' ne eds and maint ains or increases community participation [52]. Being able to remain active in the community and also keep their jobs are some of the biggest challenges for persons with MS. Independence is just one of the important fact ors that must be considered when MAT is being prescrib ed. Other factors that require consideration are degree of fati gue, activities that the person with MS wants to do, context in which the device will be used, how the device will be funded, and user acceptance of the device. Man y MAT options are available on the market. The options vary from AFOs, canes, and walkers to power wheelchairs with many different functions. It is important to note that pursuing MAT devices is a process that involves the person with MS and his or her rehabilitation professional team a nd family members. T o be successful, the MAT device must improve the overall QOL of the person with MS.

Throughout our literature review, we observed that a limited number of articles with higher LOEs were found regarding the benefits of M AT use specifically for persons with MS. The re is a paucity in studies with higher LOE-based practice, and most of the articles found were LOE IV (n = 32) and V (n = 15), followed by III (n = 2)and II (n = 1). Evidence-based practice is the strongest method of measurable clinical performance; there fore, having a stron g study design is the best way to justify prescription and reimbursement decisions. Future quantitative studies should be conducted to provide a better understanding of the b enefits of appropriate M AT for persons with MS. In addition, assessing the QOL of potential users before and after MAT acquisition might be another way to understand and enhance the benefits of MAT for persons with MS.

ACKNOWLEDGMENTS

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Financial Disclosures: The authors have declared that no competing interests exist.

Funding/Support: This material was based on work supported by the Massachusetts General Hospital National Multiple Sclerosis Society (contract No. HC 0079T) and is the result of work supported with resources and the use of facilities at the Human Engineering Research Laboratories, Department of Veterans Affairs Pittsburgh Healthcare System.

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REFERENCES

- Ramsaransing G S, D e K eyser J. Be nign course in multiple sclerosis: A review. Acta Neurol Scand. 2006;113(6):359–69.
 [PMID: 16674602] DOI:10.1111/j.1600-0404.2006.00637.x
- 2. National Mu Itiple Sclerosis Soci ety. F AQs ab out MS [Internet]. New Y ork (NY): Nat ional Mul tiple Sclero sis Society; 2008 [cited 2010 Mar 5]. Available from: <u>http://www.nationalmssociety.org/about-multiple-sclerosis/</u> what-we-know-about-ms/FAQs-about-MS/index.aspx/.
- Pediatric MS. Pediatric MS & acquired demyelinating conditions [Internet]. Buffalo (NY): Jacobs Neurological Institute of the University of Buffalo; 2008 [cited 2008 Jun 20]. Available from: <u>http://www.pedsms.org/adc.html</u>/.
- Whetten-Goldstein K, Sloan FA, Goldstein LB, Kulas ED. A comprehensive assessment of the cost of multiple sclerosis in the United States. Mult Scler. 1998;4(5):419–25.
 [PMID: 9839302]
- Noseworthy JH, Lucchinetti C, Rodri guez M, W einshenker BG. Multiple sclerosis. N Engl J Med. 2000;343(13):938–52.
 [PMID: 11006371] DOI:10.1056/NEJM200009283431307
- 6. Baum HM, Rothschild BB. Multiple sclerosis and mobility restriction. Arch Phys Med Rehabil. 1983;64(12):591–96. [PMID: 6661022]
- Pittock SJ, Mayr WT , McClel land RL, Jo rgensen NW, Weigand SD, Noseworthy JH, Weinshenker BG, Rodriguez M. Change in MS-related disability in a population-based cohort: A 10-year follow-up study. Neurology. 2004;62(1): 51–59. [PMID: 14718697]
- 8. Assistive Technology Act of 1998, 105 U.S.C. Sect. 508 (1998).
- Cattaneo D, De Nuzzo C, Fascia T, Macalli M, Pisoni I, Cardini R. Risks of falls in subjects with multiple sclerosis. Arch Phys Med Rehabil. 2002;83(6):864–7. [PMID: 12048669]
- Gulick EE. Emotional distress and activities of daily living functioning in persons with multiple sclero sis. Nurs Res. 2001;50(3):147–54. [PMID: 11393636] DOI:10.1097/00006199-200105000-00004
- Harris Interactive. Key fin dings from two new multiple sclerosis surveys [Internet]. New York (NY): National MS Society and Acorda Therap eutics; 2 008 [cit ed 200 8 Mar 30]. A vailable from : <u>http://www.nationalmssociety.org/ news/news-detail/download.aspx?id=1018/</u>.
- Sackett DL, S traus SE, Richardson WS, Rosenber g W, Haynes RB. Evidence -based medicine : How to practic e and teach EBM, 2nd ed. Edinburgh (UK): Churchill-Livingstone, 2000.
- Finlayson ML, Peterson EW, Cho CC. Risk factors for falling among people aged 45 to 90 years with mul tiple sclerosis. Arch Phys Med Rehabil. 2006;87(9):1274–79.

[PMID: 16935067] DOI:10.1016/j.apmr.2006.06.002

- Gulick EE, Yam M, Touw MM. Work performance by persons with multiple sclerosis: Conditions that im pede or enable the performance of work. Int J Nurs Stud. 1989; 26(4):301–11. [PMID: 2613450] DOI:10.1016/0020-7489(89)90017-5
- Blake DJ, Bodine C. An overview of assistive technology for p ersons wi th mu ltiple s clerosis. J Rehabil Res Dev. 2002;39(2):299–312. [PMID: 12051472]
- 16. Finlayson M, V an D enend T. Ex periencing t he lo ss o f mobility: Perspectives o f o lder adult s with MS. D isabil Rehabil. 2003;25(20):1168–80. [PMID: 14534060] DOI:10.1080/09638280310001596180
- Peterson EW, Cho CC, Finlayson ML. Fear of falling and associated activity curtailment among middle aged and older adults with multiple sclerosis. Mult Scler. 2007;13(9): 1168–75. [PMID: 17881391] DOI:10.1177/1352458507079260
- Klewer J, Pöhlau D, Nippert I, Haas J, Kugler J. Problems reported by elderly patients with multiple sclerosis. J Neurosci Nurs. 2001;33(3):167–71. [PMID: 11413662]
- Myhr KM, Riise T, Vedeler C, Nortvedt MW, Grønning M, Midgard R, Nyland HI. D isability and prognosis in multiple sclerosis: Demographic and clinical variables important for the ability to walk and aw arding of disability pension. Mult Scler. 2001;7(1):59–65. [PMID: 11321195]
- Finlayson M, G uglielmello L, L iefer K. D escribing an d predicting the possession of assi stive devices among persons with multiple sclerosis. Am J Occup Ther. 2001;55(5): 545–51. [PMID: 14601815]
- 21. Miller A, Coyle PK. Clinical features of multiple sclerosis. Continuum. 2004;10:38–73.
- 22. Janssens AC, De Boer JB, Van Doorn PA, Van der Ploeg HM, Van der Meché FG, Passchier J, Hintzen RQ. Expectations of wheelchair -dependency in recently diagnos ed patients with mu ltiple sc lerosis and their partners. Eu r J Neurol. 2003;10(3):287–93. [PMID: 12752403] DOI:10.1046/j.1468-1331.2003.00583.x
- Aronson K J. Quality of life among persons w ith multiple sclerosis and their caregivers. Neurology. 1997;48(1):74–80.
 [PMID: 9008497]
- 24. Lankhorst GJ, Jelles F, Smits RC, Polman CH, Kuik DJ, Pfennings LE, Cohen L, V an der Plo eg H M, K etelaer P, Vleugels L. Quality of life in multiple sclerosis: The Disability and Impact Profile (DIP). J Neurol. 1996;243(6):469–74. [PMID: 8803821] DOI:10.1007/BF00900502
- 25. Scherer MJ. Outcomes of assistive technology use on quality of life. Disabil Rehabil. 1996;18(9):439–48.
 [PMID: 8877302]
 DOI:10.3109/09638289609165907

- 26. Sutliff MH. T eam fo cus: Phy sical t herapist. In t J M ulti Scler Care. 2008;10(4):127–32.
- Kraskowsky LH, Finlayson M. Factors af fecting older adults' use of adaptive equipment: Review of the literature. Am J Occup Ther. 2001;55(3):303–10. [PMID: 11723971]
- Freeman JA. Improving mobility and functional independence in persons with multiple sclerosis. J Neurol. 2 001; 248(4):255–59. [PMID: 11374088] DOI:10.1007/s004150170198
- 29. Lacoste M, W eiss-Lambrou R, Allard M, Dansereau J. Powered tilt/recline systems: Why and how are they used? Assist Technol. 2003;15(1):56–68. [PMID: 14760982]
- 30. Verza R, Carvalho ML, Ba ttaglia MA, Uccelli MM. An interdisciplinary approach to evaluating the need for as sistive technology redu ces eq uipment abandonment. Mult Scler. 2006;12(1):88–93. [PMID: 16459724] DOI:10.1191/1352458506ms12330a
- 31. Ambrosio F, Boninger ML, Fitzgerald SG, Hubbard SL, Schwid SR, Cooper RA. Comparison of mobility device delivery within Dep artment of V eterans Affairs for individuals with multiple sclerosis versus spinal cord in jury. J Rehabi l Res Dev. 2007;44(5):693–701. [PMID: 17943681] DOI:10.1682/JRRD.2006.02.0016
- Perks BA, Mackintosh R, Stewart CP, Bardsley GI. A survey of marginal wheelchair users. J Rehabil Res Dev. 1994; 31(4):297–302. [PMID: 7869277]
- 33. Fay BT, Bo ninger ML. The science b ehind m obility devices for i ndividuals with multiple sclero sis. Med Eng Phys. 2002;24(6):375–83. [PMID: 12135646] DOI:10.1016/S1350-4533(02)00037-1
- 34. Buning ME, Angelo JA, Schmeler MR. Occupational performance and the transition to powered mobility: A pilot study. Am J Occup Ther. 2001;55(3):339–44. [PMID: 11723976]
- 35. Ambrosio F, Boninger ML, Fitzgerald S, Liu B, Mapa M, Collins DM. Mobility dev ice as a determinant of social participation in persons with multiple sclerosis. Proceedings of the RESNA 26th International Annual Conference. 2003. Atlanta, Georgia. Arlington (VA): RESNA; 2004.
- 36. Dewey A, Rice-Oxley M, Dean T. A qualitative study comparing the experiences of tilt-in-space wheelchair use a nd conventional wheelchair use by clients severely disabled with multiple sclerosis. Br J Occup Ther. 2004;67(2):65–74.
- 37. Ding D, Co oper RA, Co oper R, Kell eher A. Monitoring seat feature usage among wheelchair users. In: Engineering in Medicine and Biology Society, 2007. 29th Annual International Conference of the IEEE. 2007 Aug 22–26. L yon, France. Los Alamitos (CA): IEEE; 2007; p. 4364–67.
- Devitt R, Chau B, Jutai JW. The effect of wheelchair use on quality of life of persons with multiple sclerosis. Occup T her Health Care. 2003;17:63–79. DOI:10.1300/J003v17n03_05

SOUZA et al. MS and mobility-related assistive technology

- Cooper RA, Ohnabe H, Hob son DA. An introduction to rehabilitation engineering. Boca Raton (FL): T aylor & Francis; 2007. p. 444.
- 40. Craddock G, McCormack L. Delivering an AT service: A client-focused, social and pa rticipatory service d elivery model in assistive technology in Ireland. Disabil R ehabil. 2002;24(1–3):160–70. [PMID: 11827150] DOI:10.1080/09638280110063869
- 41. Ripat J, Boot h A. Character istics of assi stive tech nology service deliv ery m odels: Stakeholder perspectives and preferences. Disabil Rehabil. 2005;27(24):1461–70.
 [PMID: 16421071] DOI:10.1080/09638280500264535
- Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) [Internet]. [cited 2008 Jul 10]. Arlington (VA): RESNA. Available from: <u>http://www.resna.org/</u>.
- 43. Sawatzky B, D enison I, Langrish S, Richardson S, Hiller K, Slobogean B. The Segway Personal T ransporter as an alternative mobility device for peopl e with disabilities: A pilot study. Arch Phys Med Rehabil. 2007;88(11):1423–28. [PMID: 17964882]
 DOI:10.1016/j.apmr.2007.08.005
- 44. Uustal H, Minkel JL. Study of the In dependence IBO T 3000 Mobi lity Syst em: An in novative pow er mob ility device, during use in community environments. Arch Phys Med Rehabil. 2004;85(12):2002–10. [PMID: 15605340] DOI:10.1016/j.apmr.2004.04.044
- 45. Laffont I, G uillon B, Fermani an C, Poui llot S, Ev en-Schneider A, Boyer F, Ruquet M, Aegerter P, Dizen O, Lofaso F. Evaluation of a stair-climbing power wheelchair in 25 peo ple with tet raplegia. Arch Phys Med Rehabil. 2008;89(10):1958–64. [PMID: 18929024] DOI:10.1016/j.apmr.2008.03.008
- 46. Simsarian J, Sanders C. An evol ving approach to pati ent support programs for MS. MS Exchange. 2008;12(2):1–2.
- 47. Doerksen SE, Motl RW, McAuley E. Environment correlates of physical activity in multiple sclerosis: A cross-sectional

study. Int J Behav Nutr Phys Act. 2007;4:49. [PMID: 17922918] DOI:10.1186/1479-5868-4-49

- MacAllister WS, Boyd JR, Holland NJ, Milazzo MC, Krupp LB; International Pediatric MS Study Group. The psychosocial consequences of pediatric multiple sclerosis. Neurology. 2007;68(16 Suppl 2):S66–69. [PMID: 17438240]
- Finlayson M. Concern s about the future among ol der adults with multiple sclerosis. Am J Occup Ther. 2004;58(1):54–63.
 [PMID: 14763636]
- Boss TM, Fi nlayson M. Resp onses to t he acquisition and use of p ower mobility by in dividuals who have multiple sclerosis and their families. Am J Occup Ther. 2006;60(3): 348–58. [PMID: 16776403]
- Osborne TL, Turner AP, Williams RM, Bowen JD, Hatzakis M, Rodrigu ez A, Haselkorn JK. Correl ates of pain interference in multiple sclerosis. Rehabil Psychol. 2006; 51(2):166–74. DOI:10.1037/0090-5550.51.2.166
- Scherer MJ, Glueckauf R. Assessing the benefits of assistive technologies for activities and participation. Rehabil Psychol. 2005;50(2):132–41. DOI:10.1037/0090-5550.50.2.132
- Finlayson M, Impey, MW, Nicolle C, Edwards J. Self-care, productivity and leisure limitations of people with multiple sclerosis. Can J Occup Ther. 1998;65(5);299–308.
- 54. Solari A, Ferrari G, Radice D. A longitudinal survey of self-assessed health trends in a community cohort of people with multiple sclerosis and their significant others. J Neurol Sci. 2006;243(1–2):13–20. [PMID: 16380136] DOI:10.1016/j.jns.2005.11.005
- 55. Månsson E, Lexell J. Performance of activities of daily living in multiple sclerosis. Disabil Rehabil. 2004;26(10):576–85.
 [PMID: 15204511] DOI:10.1080/09638280410001684587

Submitted for pu blication July 10, 2009. Acce pted in revised form January 20, 2010.