

Aging with Multiple Sclerosis

by Terry DiLorenzo, PhD

Considering the evidence that life expectancy of people with MS is essentially normal, and that the number of older individuals in the general population is growing, it is likely we will see increasing numbers of older individuals with MS. A recent estimate based on weighted data from the Sonya Slifka Longitudinal Multiple Sclerosis Study places the percentage of MS patients over the age of 65 at 9% (Minden et al., 2004). Despite the projected growth of this population, relatively little MS research has targeted, or even included, older individuals. In fact, in published trials of disease-modifying agents, the highest mean age of participants was 47 years (Stern, 2005). A few recent studies have examined the older MS population; however, “older” has been defined differently by different investigators. In this report we discuss research that specifically focused on the older population—the youngest age for inclusion in any study was 45 years. However, the mean ages of the samples was typically between 60 and 70 years.

DEMOGRAPHIC CHARACTERISTICS

Older individuals with MS are demographically similar to the younger MS population. In Minden and colleagues’ (2004) study, the sample of participants age 55 and above was 72% female and 92% Caucasian, and 43.9% had graduated college. While these percentages were not different from those of the under 55 group, differences did emerge, in relation to marital status (more older individuals [25%] were widowed), living arrangement (more older individuals lived alone), and employment status and average family income (as would be expected in an older sample, fewer people were working and income levels were lower).

CLINICAL CHARACTERISTICS

While most people with MS are diagnosed between the ages of 20 and 50, some are diagnosed at an older age. Consequently, the older MS population includes some people who have been living with MS for a relatively short period of time, although most have had the disease for a much longer time. The average duration of illness in older samples is typically around two decades, with recent

investigations reporting mean durations of disease ranging from 19 years (Finlayson, 2002) to 24 years (Minden et al., 2004). Despite having a longer duration of illness, older individuals are less likely than younger individuals to have a regular source of MS care (Minden et al., 2004).

Even though they tend to be more physically disabled, and are more likely to have a progressive form of MS (two-thirds are diagnosed with progressive disease), older individuals have reported levels of perceived health status equivalent to those of younger individuals (DiLorenzo, Halper & Picone, 2004; Minden et al., 2004). The most common MS symptoms reported by older individuals are similar to those reported by younger individuals, including pain (Stern et al., 2010), fatigue, problems with balance, and weakness (Finlayson, 2002). While treatments for younger and older individuals are similar, it is important to consider that older individuals are more sensitive to side effects due to a decreased ability to distribute and eliminate metabolites (Stern et al., 2010). These symptoms and many other MS symptoms can mimic, and may be exacerbated by, the physical effects of aging. Overlapping symptoms include diminished muscle strength, balance problems, weakness, fatigue, reduced sensation, visual changes, alterations in bowel/bladder function, cognitive impairment (Stern, 2005; Stern et al., 2010), osteoporosis (which may result from long-term use of corticosteroids), and sleep disturbances (Fleming & Pollak, 2005). As such, it may be difficult to determine whether presenting symptoms are due to MS or normal aging.

Notwithstanding the similarities between age-related physical changes and MS-related symptoms, comorbid conditions found in older MS patients differ from those diagnosed in the general elderly population. Older MS patients more commonly suffer from urinary tract infections, pneumonia, septicemia and cellulitis, while their non-MS peers are more like to have angina, myocardial infarction, congestive heart failure, cerebrovascular disease, diabetes, and pulmonary disease (Fleming & Blake, 1994). Nonetheless, older MS patients remain at risk for diseases of aging and must be evaluated for these (Stern et al., 2010).

Physical Functioning

Research has generally found that older individuals with MS are more physically disabled than younger individuals. While duration of disease may partially explain this finding, the association between age, duration of illness and physical functioning is not clear cut. One study found age to be associated with disability level after controlling for duration of disease (DiLorenzo et al., 2004), while another divided a sample into several duration categories and found that the largest percentage of patients in every category were moderately disabled (Minden et al., 2004). These findings indicate that there is significant individual variability in the relation between duration of illness and physical functioning. Despite this variability, older MS patients have more bladder and bowel problems (Minden et al., 2004), more frequently report loss of balance (Finlayson & Van Denend, 2003), and need more support for walking (30% are wheelchair users or are confined to bed). In one study, 52% of participants reported that balance loss interfered "a lot" with daily activities (Finlayson & Van Denend, 2003), while in another study 80% indicated that their physical health limited their daily activities and caused them to accomplish less than they wanted (Minden et al., 2004).

◆ Assistance from Others

Given these physical limitations, older individuals with MS need more assistance with daily activities. In Minden and colleagues' (2004) sample, 85% of participants reported needing help with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). Caregivers have been found to provide an average 2.75 hours of assistance per day, with more assistance given to individuals with cognitive impairment (Finlayson et al., 2009). The most common types of assistance include meal preparation, housework, shopping, transportation, bathing, dressing, household mobility and transferring (Minden, 2004; Finlayson, Garcia & Preissner, 2008).

Most of this assistance is provided by family members, particularly spouses (Finlayson & Van Denend, 2003; Minden et al., 2004; Finlayson et al., 2008), but friends have also provided physical assistance for older MS patients (Finlayson & Van Denend, 2003). Spouses of older MS patients may be a population of particular concern, given that the normal stress and burden of caregiving may be compounded by their own aging and comorbid physical conditions. Friends have also been reported to provide physical assistance for older MS patients. Interestingly, while some research has found that older MS patients are concerned about becoming a burden (Fong Finlayson & Peacock, 2006), DiLorenzo and colleagues (DiLorenzo et al., 2008) found that older individuals described their willingness to accept assistance from family and friends as having evolved with age. However, obtaining support may be difficult for individuals with considerable impairment—it has also been suggested that utilizing social support may require a level of effort that is difficult for those experiencing accelerated decline to achieve (Harrison, Blozis & Stuifbergen, 2008).

◆ Use of Assistive Devices

Older individuals have reported that their willingness to use assistive devices increased as they got older (DiLorenzo et al., in press). Older persons have also indicated that when they initially accepted assistive devices, they felt as though they were giving in, but that, with time, these devices proved to be valuable (Finlayson & Van Denend, 2003).

Assistance (both social support and assistive devices) can modify people's experiences and perceptions of their levels of mobility and independence, which, in turn, can impact their overall well-being. DiLorenzo and colleagues (DiLorenzo et al., 2008) found that participants' self-perceptions of mobility were generally more liberal than ratings on "objective" measures. Many who required substantial assistance with ambulation still felt mobile because assistance was available.

Psychological Functioning

Emotional problems, including depression, are not uncommon in MS. However, evidence indicates that older individuals experience fewer mental health problems than their younger counterparts. More younger than older individuals with MS reported emotional or mood problems, and few of the older participants indicated that such difficulties interfered with social activities (Minden et al., 2004). Individuals over the age of 65 have been found to experience more MS-related helplessness, but fewer depressive symptoms than younger individuals (Kneebone, Dunmore & Evans, 2003). In a

comparison of self-reported mental health challenges in four age categories, the two oldest groups had the lowest prevalence (above age 75, 10%; age 64–75, 14%; ages 45–54 and 55–64, 21%) (Garcia & Finlayson, 2005). One study of people 45 and above (Patten et al., 2003) reported a 15.7% prevalence rate for major depression. Depression was more common in participants with a longer duration of disease, greater mobility impairment, and cognitive difficulties. IADL limitations were positively associated with mental health symptoms in another study (Garcia & Finlayson, 2005).

While aging may serve a protective function in terms of mental health, it is important to note that many individuals with MS (of all ages) who do experience emotional problems do not receive professional assistance (Hadjimichael, 2001; Feinstein, 2002). In a study of older individuals, fewer than half (44%) who reported that depression interfered with their lives and that their mental health was fair or poor had ever seen a mental health professional. Interestingly, only 15% of those reporting mental health problems who were not receiving services felt that they needed services (Garcia & Finlayson, 2005). These results present two challenges to MS clinicians. First, we need to better assess and identify mental health problems in our older patients. This may be more difficult due to the fact that older individuals are likely to experience age-related changes that mimic the vegetative and cognitive symptoms of depression. Second, individuals who do exhibit mental health symptoms must be encouraged to seek treatment—this may be more difficult in the current elderly cohort who feel more stigma regarding mental health services.

Cognitive Functioning

As many as 65% of individuals with MS experience disease-based cognitive loss including slowed information processing, and impairments in attention/concentration, recent memory (particularly explicit and episodic), executive functioning, and planning and sequencing (DeLuca, 2006). Natural aging may also lead to impaired cognitive functioning, placing older persons with MS at greater risk for experiencing cognitive decline (Stern et al., 2010). However, recent evidence has found that older individuals with MS self-report cognitive problems less often than their younger counterparts (Minden et al., 2004). Several explanations for this seem possible. First, the existence of cognitive problems may limit awareness of such problems, leading to under-reporting. Older individuals may underestimate cognitive decline because they compare their own functioning to that of their elderly peers who are also beginning to exhibit impairment. Alternatively, it is possible that depressive symptoms are associated with self-reporting of cognitive symptoms in the “young old” as reported by Finlayson and colleagues (2009).

USE OF COMPENSATORY STRATEGIES/COPING METHODS

It seems that older individuals with MS tend to adjust or adapt to MS as they age. Despite typically being more physically disabled, older MS patients report levels of quality of life, mental health, and general health equivalent to, or better than, younger MS patients. Recent work has identified a number of strategies or responses that older individuals find helpful in dealing with MS. Identification of these strategies is important in terms of clinical implications.

Pacing/Planning

Qualitative research has found that many older individuals maximize mobility and independence by using advanced planning. For example, individuals have reported investigating the accessibility of planned destinations prior to arrival (Finlayson & Van Denend, 2003). Another study found that individuals learned to pace themselves and plan more appropriate activities to make living with MS easier (DiLorenzo et al., 2008). It may be that pacing and planning become easier as people get older and family and work related responsibilities begin to decline.

Prioritizing/Reframing

In qualitative investigations, participants reported prioritizing as a way of managing MS. Prioritizing activities was reported to allow individuals to manage mobility (Finlayson & Van Denend, 2003), while changing expectations and reframing situations by recognizing personal resources promoted participation in social activities (Fong, Finlayson & Peacock, 2006). In another study, individuals described a process of learning to appreciate the more simple or basic things in life, resulting in a greater sense of well-being (DiLorenzo et al., 2008).

Generativity

In a qualitative study, older participants with MS who reported “giving back” also reported good quality of life. Generativity, including raising good families, community involvement, and volunteering, was important to most participants (DiLorenzo et al., 2008). Given the availability of assistive devices, even the most disabled participants were able to engage in some of these activities, for example, on-line support groups or chat rooms.

DEALING WITH SPECIAL NEEDS

While the services outlined below are important to consider for any individual with MS or any frail elderly person, these are particularly important for the older individual with MS, who will have different needs than both his or her younger MS counterparts, or the general elderly population.

Home Health Care

Home care is intended to provide an individual who is living at home with individualized services that are developed collaboratively with him/her and the family to foster health and quality of life. Services provided in the home may include: health-related services (e.g., skilled nursing, medication management); social services (e.g., family and personal support/counseling, facilitating access to social and recreational activities, care management); personal care services (e.g., assistance with activities of daily living); homemaker and chore services (e.g., assistance with laundry, meal preparation); rehabilitation services (e.g., physical, occupational, speech therapies, durable medical equipment); and child care (special arrangements are generally required and availability and coverage vary from state to state). For additional information, see *Serving Individuals with Multiple Sclerosis in the Home: Guidelines and Recommendations for Home Care Providers and Personal Care Assistants*.

Assisted Living

Assisted living is an option for individuals with disabilities who desire to continue to live independently, but who may require accessibility and assistance with day to day living. Typical residents in assisted living facilities are older and are experiencing some physical and/or cognitive decline. As such, these facilities may be more acceptable to an older individual with MS than to a younger person who will be demographically quite different from most residents. However, it would be important to consider the extent of one's physical impairment and the likely course of his or her disease, given that assisted living arrangements typically cannot accommodate individuals with extensive care needs. For additional information, see *Assisted Living for Individuals with Multiple Sclerosis: Guideline & Recommendations*.

Adult Daycare

Adult daycare programs provide recreation and stimulation to participants and respite for caregivers. These programs sometimes cater to specific populations. Most "general" programs have a high percentage of elderly individuals with significant cognitive impairment, while most MS-specific programs cater to younger individuals. As such, the characteristics and preferences of the older individual with MS must be considered before choosing an adult daycare program. Both MS-specific and "general" programs do look for ways attendees can contribute to the program (e.g., teaching a skill, leading a discussion), and promote intergenerational activities and volunteer opportunities, which can enhance a sense of generativity in an older attendee. Refer to the publication *Serving Individuals with Multiple Sclerosis in Adult Day Programs: Guidelines & Recommendations* for more information.

Nursing Home Care

Typical MS residents in nursing homes are younger, more mentally alert, more physically dependent, have more symptoms of depression, and have longer lengths of stay than residents without MS. These differences are minimized with elderly individuals with MS, perhaps with the exception of level of physical dependence. However, differences between the typical frail elderly resident and a "young-old" MS resident are likely to be apparent. Factors such as staff training, recreational activities, opportunities for interactions with younger residents, etc. should be considered. See the publication *Nursing Home Care of Individuals with Multiple Sclerosis: Guidelines & Recommendations for Quality Care* for more information.

End of Life Issues/Advanced Directives

End of life issues and advanced planning should be discussed with older MS patients. Patients should be encouraged to define his/her wishes for treatment and care so that family and clinicians understand what measures to take or avoid should an individual be unable to state his or her preferences. Providers should be ready to call in other professionals with expertise in dealing with these issues. These include clergy, psychologists, social workers, and hospice professionals, among others, who are skilled at assisting the patient, his/her family and other providers deal with care plans and emotional responses.

Any discussion of end of life issues should include the topic of advanced directives. Advanced directives should be contemplated and executed in advance of an imminently terminal situation, and legally, must be completed while an individual is competent. Advanced directives include do not resuscitate orders, health care proxies, and living wills. Through these advanced directives, an individual can make known his/her wishes regarding life sustaining measures including resuscitation, artificial feeding, mechanical ventilation, etc. For more information about advanced directives, refer to the chapter on Life Planning by Laura Cooper, Esq. in *Multiple Sclerosis: A Guide for Families* (3rd ed.), edited by Rosalind Kalb, PhD (New York: Demos Medical Publishing, 2006).

UNMET NEEDS

A study of older individuals with MS identified a host of unmet needs, including physical therapy, eye doctors, health insurance, MS support groups, wellness and health promotion, transportation and neurologists. (It should be noted that most participants did have a neurologist, so this finding likely reflects a lack of satisfaction with care, rather than availability [Finlayson, 2005].) These needs are important to consider in future programming for older individuals with MS. While many of these needs might also be reported by younger individuals, we need to be aware of, and sensitive to, how older and younger individuals may differentially perceive or express these needs and how they can best be met in this population. Attempts to provide needed services must consider not only the needs of older individuals, but also service delivery options. For example, the MS Society offers a number of support groups, recreational activities, and educational programs for members. However, many are geared toward newly diagnosed individuals, or may have content more appealing to younger members. Furthermore, groups must be offered at times and locations that are convenient for older individuals. In fact, one study found people over age 65 to report no longer going to support groups, and that support groups was an unmet need in the oldest age group (65–74 years) (Finlayson, 2006).

RECOMMENDED INTERVENTIONS

- ◆ Encourage older adults to use assistive devices to augment their sense of mobility and independence. Discuss their feelings around the use of such devices, and, when possible, provide short term loans to enable them to get past the feeling of “giving up” (Finlayson & Van Denend, 2003).
- ◆ Because the older individual with MS will have needs related to both MS and aging, interdisciplinary collaborations are particularly important. In addition to physicians, care providers should include occupational therapists, social workers, and psychologists, who are familiar with these needs and who can connect clients with appropriate services.
- ◆ Provide caregiver support. Considering that much care for older MS patients is provided by spouses, who also tend to be older, it is important to monitor their health and well-being. Make appropriate referrals to allow for respite, education, and support.
- ◆ Research has identified a number of practical strategies that can be taught to older clients. These include pacing one’s self and planning appropriate activities. In addition, instilling a

sense of generativity by encouraging clients to “give back,” may promote psychological well-being. Facilitating participation in educational programs or support groups can be beneficial and accomplished by individuals with significant mobility limitations through the use of assistive technology.

- ◆ Given the prevalence of depression in both individuals with MS and elderly individuals, as well as the association between cognitive functioning and depressive symptoms, depression screening (see Mohn, Hart, Julian & Tasch, 2007 for a brief screening inventory) is recommended for all older individuals with MS.

REFERENCES

- DeLuca J. What we know about cognitive changes. In LaRocca N, Kalb R. *Multiple Sclerosis: Understanding the Cognitive Challenges*. New York: Demos Medical Publishing, 2006.
- DiLorenzo TA, Becker-Feigeles J, Halper J, Picone MA. A qualitative investigation of factors related to adaptation in older individuals with multiple sclerosis. *Disability and Rehabilitation*, 2008; 30(15):1088–1097.
- DiLorenzo TA, Halper J, Picone MA. A comparison of older and younger individuals with multiple sclerosis: A preliminary investigation. *Rehabilitation Psychology* 2004; 49:123–125.
- Feinstein A. An examination of suicidal intent in patients with multiple sclerosis. *Neurology* 2002; 59:674–678.
- Finlayson M. *Aging with Multiple Sclerosis: Unmet Needs in the Great Lakes Region*. Final report submitted to the National Multiple Sclerosis Society, 2006.
- Finlayson M. Health and social profile of older adults with MS: Findings from three studies. *International Journal of MS Care* 2002; 4:139–151.
- Finlayson M. Concerns about the future among older adults with multiple sclerosis. *American Journal of Occupational Therapy* 2004; 58:54–63.
- Finlayson M, Garcia JD, Preissner K. Development of an educational programme for caregivers of people aging with multiple sclerosis. *Occupational Therapy International* 2008; 15(1):4–17.
- Finlayson M, Sheevil, E, Cho, CC. Perceptions of cognitive symptoms among people aging with multiple sclerosis and their caregivers. *The American Journal of Occupational Therapy* 2009; 63:151–159.
- Finlayson M, Van Denend T. Experiencing the loss of mobility: Perspectives of older adults with MS. *Disability and Rehabilitation* 2003; 25:1168–1180.
- Finlayson M, Van Denend T, Hudson E. Aging with multiple sclerosis. *Journal of Neuroscience Nursing* 2004; 36:245–252.
- Fleming ST, Blake RL. Patterns of comorbidity in elderly patients with multiple sclerosis. *Journal of Clinical Epidemiology* 1994; 47:1127–1132.
- Fleming WG, Pollak CP. Sleep disorders in multiple sclerosis. *Seminars in Neurology* 2005; 25(1):64–68.

- Fong T, Finlayson M, Peacock N. The social experience of aging with a chronic illness: Perspectives of older adults with multiple sclerosis. *Disability and Rehabilitation* 2006; 28(11):695–705.
- Garcia J, Finlayson M. Mental health and mental health service use among people aged 45+ with multiple sclerosis. *Canadian Journal of Community Mental Health* 2005; 20(2):9–22.
- Hadjimichael O. Depression among registry participants. *Multiple Sclerosis Quarterly Report* 2001; 20:13–16.
- Harrison T, Blozis S, Stuifbergen A. Longitudinal predictors of attitudes toward aging among women with multiple sclerosis. *Psychology and Aging* 2008; 23(4):823–832.
- Kneebone II, Dunmore EC, Evans E. Symptoms of depression in older adults with multiple sclerosis: Comparison with a matched sample of younger adults. *Aging & Mental Health* 2003; 7:182–185.
- Minden SL, Frankel DH, Hadden LS, Srinath KP, Perloff JN. Disability in elderly people with multiple sclerosis: An analysis of baseline data from the Sonya Slifka Longitudinal Multiple Sclerosis Study. *NeuroRehabilitation* 2004; 19:55–67.
- Mohr DC, Hart SL, Julian L, Tasch ES. Screening for depression among patients with multiple sclerosis: Two questions may be enough. *Multiple Sclerosis* 2007; 13:215–219.
- Patten SB, Beck CA, Williams JVA, Barbui C, Metz LM. Major depression in multiple sclerosis; a population-based perspective. *Neurology* 2003; 61:1524–1527.
- Stern M, Sorkin L, Milton K, Sperber K. Aging with multiple sclerosis. *Physical Medicine and Rehabilitation Clinics of North America* 2005; 16:219–234.
- Stern M. Aging with multiple sclerosis. *Physical Medicine and Rehabilitation Clinics of North America* 2010; 21:403–417.

NATIONAL MS SOCIETY PUBLICATIONS

(available online at www.nationalmssociety.org/PRCPublications or by email at healthprof_info@nmss.org)

- Brandis M, Reitman NC, Gruenewald D, Del Bene Maura. *Opening Doors: The Palliative Care Continuum in Multiple Sclerosis*. 2008 (available at <http://www.nationalmssociety.org/for-professionals/healthcare-professionals/publications/clinical-bulletins/download.aspx?id=1027>).
- National Multiple Sclerosis Society. *Serving Individuals with Multiple Sclerosis in the Home: Guidelines and Recommendations for Home Care Providers and Personal Care Assistants*, 2010.
- National Multiple Sclerosis Society. *Serving Individuals with Multiple Sclerosis in Adult Day Programs: Guidelines & Recommendations*, 2010.
- National Multiple Sclerosis Society. *Assisted Living for Individuals with Multiple Sclerosis: Guidelines & Recommendations*, 2010.
- National Multiple Sclerosis Society. *Nursing Home Care of Individuals with Multiple Sclerosis: Guidelines & Recommendations for Quality Care*, 2009.