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Research Paper

Predictors of institutionalization for people with multiple sclerosis

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Abstract

Background: Multiple Sclerosis (MS) is a chronic, progressive disease of the central nervous system with a high prevalence in Canada. While the disease course is highly variable, a significant portion of people with MS may spend more than 10 years living with severe disability, and many of those will eventually require full time institutional care. Despite the high personal and economic cost of this care, little is known about predictors of institutionalization.

Objective: The objective of this study was to identify predictors of institutionalization.

Methods: Longitudinal data from a university MS clinic database were extracted to explore nursing home placement over time of an urban subgroup. Cox regression analysis was performed with age of MS onset and sex, as well as baseline information obtained at the first MS clinic assessment: MS course, Kurtzke Expanded Disability Status Scale score, and functional system scores.

Results: Older age of onset ($p = .019$) and higher baseline scores in specific functional systems (cerebellar, bowel/bladder, brainstem, and cerebral/mental) were significant ($p = .000$, $p = .000$, $p = .001$, $p = .000$ respectively) predictors of nursing home placement.

Conclusions: Patients with older age of MS onset and those with baseline impairment in specific functional systems (cerebellar, bowel/bladder, brainstem, and cerebral/mental) may be at higher risk for future institutionalization and should be assessed with particular care to determine potential avenues of support to minimize this.

Keywords: Multiple sclerosis; Institutionalization; Nursing facilities; Prognosis

Multiple sclerosis (MS) is a chronic degenerative, inflammatory disease of the central nervous system with onset of first symptoms typically in early adulthood. MS survival rates may be increasing, leaving persons with MS living well into older age,[1–3] often with significant disability. There is considerable variability in the literature on disability outcomes, with median time to needing a cane between 15 and 32 years after disease onset.[4] A relapsing-remitting MS (RRMS) course at onset is most common, offering a more favorable initial prognosis compared to the 10% presenting with a primary progressive MS (PPMS) course at onset. However, 50% of those with RRMS convert to a secondary progressive MS (SPMS) course an average of 15 years after first MS symptoms.[5] Progress has been made in the treatment of RRMS, although the impact on long term disability outcomes remains a subject of controversy and no effective treatments are yet available for progressive forms of the disease.[6] More information is needed on predicting and planning the care needs of the aging MS population.

It has been estimated that over 93,500 people in Canada are living with MS.[7] There is considerable geographic variation in prevalence rates across the country.[8] Saskatoon, within the province of Saskatchewan, has been reported by Hader & Yee to have a particularly high prevalence rate of 293.8 per 100,000 with a yearly incidence of about 9.5/100,000 per year.[9] This high prevalence, coupled with the

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natural features of the disease predict the need for high levels of personal and nursing support related to MS care. Unfortunately, despite the progressive and variable nature of the disease course, there is little literature exploring risk factors for institutionalization specific to MS. Data from the US National Multiple Sclerosis Society (cited by Buchanan, Wang & Ju, 2002) suggested that 20–25% of people with MS eventually end up in long term care, and that the risk might be particularly high in those with bowel dysfunction, poorer health and greater functional decline, as well as in those with greater caregiver burden.[10] Studies based on other populations have found that bowel system dysfunction[11,12] and cerebellar and cortical system atrophy[13] may be increased in institutionalized individuals. A review of general community-based studies[14] suggests that age, low self-rated health, functional and cognitive impairment, dementia, prior nursing home placement, and high number of prescriptions are risk factors for nursing home placement.

Institutionalization is likely to depend not only on individual needs, but also on the availability and proximity of resources. Saskatchewan is a province large in geography but small in population, which results in people being dispersed over large distances, often removed from the major sources of formal support. This might be expected to result in higher institutionalization rates in general (and for MS patients in particular), and indeed, Saskatchewan was reported to have the second highest ratio of long-term care beds per population in Canada in 2008 at 112.8 beds per 1000 population aged 75+.[15]

Another factor potentially contributing to institutionalization is insufficient planning for future care needs. Putnam & Tang suggested that most people with MS are not adequately informed about the availability of services for possible future needs, and frequently do not plan adequately for long term care.[16] Even if sufficient alternate community-based supports are available, a lack of readiness to discuss services or knowledge about services could lead to early caregiver burnout and precipitous institutionalization.

The Multiple Sclerosis Society of Canada states that individuals themselves generally “prefer to live in the comfort of their own homes.”[17] In spite of that, little information is available concerning the prevalence of institutionalization or predictors for institutionalization in general or specific to the Canadian MS population. Institutionalization removes people from their familiar environment and family supports, and may decrease their overall autonomy and quality of life. Social isolation within the nursing home is a particular issue for those with MS as they are usually younger and more mentally alert than the general, usually elderly population.[18] Health may also be adversely impacted by institutionalization, as home-based care (compared to institutional care) has been associated with improvements in various health dimensions.[19] Lastly, institutionalization is very costly to the health care system, with hospitals and other institutions taking up the largest portion of the nation’s expenditures.[20]

For all of these reasons, it is essential to improve the understanding of the prevalence of and contributors to institutionalization. While the natural history of MS and risk factors for disease progression in treated and untreated populations have been evaluated,[6] these studies generally focus on mobility (i.e., needing a cane to walk), relapse rates, imaging or more recently, quality of life outcomes. Predictors related to institutionalization outcomes identified at clinical assessments might help focus resources optimally to minimize or delay institutionalization. The objective of this study was to identify predictors of institutionalization, using the longitudinal data from a well-established longitudinal MS clinical database maintained at the University of Saskatchewan. We chose to focus on the functional system sub-scores of the EDSS as these sub-scores provide a graded rating of impairment and related function.

Methods

The clinical database was initially established as a registry by one of the authors (WH) in 1969 at which time records of patients with MS were extensively searched. Sources included the Saskatoon MS clinic (located in one of the acute care hospitals in Saskatoon), other physicians, nursing homes or home care, and the three city hospitals. Patients were also identified through contact with the MS society and through other provincial records.[9] This database was updated every five years under the guidance of WH until 1990 as well as in 1986, 1996 and 2003. Clinical cases coming through the MS clinic at any time or through any of the three Saskatoon hospitals between 2001 and 2005 were added or had their information updated. Yearly phone calls ascertained residence type and living status. The entire group was most recently updated in December 2011 and the records of patients living in Saskatoon at the last contact were additionally updated in summer 2012. Publicly published obituaries were regularly searched by the clinic administrator to update the registry when directly obtained data were missing. The Saskatoon MS Clinic registry as of August 30, 2012 included 1217 patients, of whom 150 had been followed since 1977.[21]

Standard diagnostic information in the MS registry included clinically-definite, probable, and suspected MS; sex; place of birth; date of birth; place of onset of MS; age at diagnosis of MS; ethnic origin; family history; and date of death. Most records also included disability levels according to Expanded Disability Status Scale (EDSS) scores, functional system subscales,[22] and course of MS (relapsing-remitting, secondary progressive, and primary progressive) at assessment times. The MS Clinic registry had additional information available including marital status, education, religion, physical comorbidities, measures of mental health, specific symptoms such as bladder