

Living With Multiple Sclerosis in New South Wales, Australia, at the Beginning of the 21st Century: Impact of Mobility Disability

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*This article is the initial report on the Multiple Sclerosis (MS) Society of New South Wales (NSW) Client Census Database study, a telephone-based cohort study of registered clients of the society in 2001. The final database sample comprised 2618 respondents with a diagnosis of MS from the registered client database, representing 73% of this target client population and an estimated 70% of all people with MS in NSW, Australia. The mean age was 49 years, and mean time since diagnosis was 11 years, with 36% diagnosed in the past 5 years. Approximately three-quarters (74%) were women. The mobility disability profile of the sample covered the entire spectrum, with half reporting being able to walk without a mobility aid and only 17% being confined to a wheelchair. The average age of respondents confined to a wheelchair was 56 years. Most respondents reported other MS symptoms they felt were disabling, such as fatigue and abnormal sensory symptoms. Most were living with a partner or spouse but were less likely to be living with children in the family home than the general NSW population. Only 5% were living in supported accommodations. Only a third of respondents were employed, with greater levels of disability leading to greater levels of unemployment—full-time employment being more adversely affected than part time and men being more disadvantaged than women with MS compared with their general NSW population counterparts. Essential medical care and personal support needs were mostly well met but less reliably so for the most severely disabled respondents and those living farther from major cities. The most frequently reported unmet needs were for breaks from home and employment support. Less than half of the sample reported being on immunotherapy. Those who were on immunotherapy were more likely to be women, employed part time, and experiencing only mild or moderate mobility disability. *Int J MS Care*. 2006;8:19–30.*

The life of people living with multiple sclerosis (MS) in Australia has mainly been described and defined in the scientific literature by a series of large epidemiological studies. These valuable surveys, conducted over many decades, explored a wide range of MS characteristics, including its incidence, prevalence, and distribution across Australia, with particular emphasis on the lateral gradient of the preva-

lence^{1–5}; genetic and environmental determinants of MS⁶; diagnostic categorization, sex ratio, duration of disease, clinical course (type categories), age at onset in relation to clinical course, and disability profile (focusing on level of mobility) distributions⁷; genetic and migration population characteristics^{8,9}; and education level as a risk factor for MS.¹⁰ Recently, several Australian studies explored the apparent worldwide trend of increasing prevalence of MS^{5,11} and the influence of ultraviolet radiation on the regional variation of MS in Australia.^{12,13} Although conducted in Australia, many of these studies have contributed to understanding of MS epidemiology in general. However, only one small population survey has

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been published to date that has examined aspects of living with MS in Australia solely from the perspective of the person with the disease. The study, commissioned by the MS Society of New South Wales (NSW) in 1991, documented the self-reported demographic details, symptoms, and unmet support needs of people with MS in NSW.¹⁴

Parallel to the development of large epidemiological studies over the past two decades, large national electronic databases have been established worldwide to more efficiently register, document, and research various aspects of MS. In Australia, two large national databases have been developed. The Australian National Registry of MS Families (NRMSF) enables more powerful explorations into the genetic etiology of MS,¹⁵ and the Australian Multiple Sclerosis Longitudinal Study (AMSLS) enables more efficient recruitment of representative subjects for larger-scale clinical studies.¹⁶ While the AMSLS was being developed in 2001 on a national level, the MS Society of NSW was conducting a comprehensive census-type investigation in the state of NSW using the burgeoning database technologies to expand on the limited work published earlier,¹⁴ focusing on self-reported experiences of people living with MS in Australia. By the end of 2001, the MS Society had succeeded in establishing a large electronic cohort database of self-reported demographic details, symptoms, met and unmet support needs, and other clinical data, including immunotherapy attitudes and use.

This article reports the methodology of the 2001 MS Society of NSW Client Census Database. Also discussed are the main results for self-reported level of mobility disability and the impact of level of this form of disability on living arrangements, employment status, service and support needs, and immunotherapy knowledge and use.

Methods

Database Questionnaire

A database file was developed in Microsoft Access with a detailed questionnaire for telephone interviewers to use. A similar paper-and-pencil questionnaire was designed and mailed to respondents who were unable to complete the interview via telephone. The questionnaire collected information on demographics, level of mobility disability, other MS symptoms, living arrangements, employment, met and unmet service and support needs, contact with the MS Society of NSW, and immunotherapy knowledge and use. Demographic information included age, sex, suburb of residence, country of birth, language spoken at home (respondent and parents), employment status, private health insurance coverage, pension status, and home environment. Spousal relationships were inferred from reported living arrangements.

Disability and symptom information included year diagnosed, disease steps (DSs),¹⁷ other MS symptoms, and health

professionals seen. The DS scale categorizes disability levels similarly to the popular physician-encoded disability rating scale, the Kurtzke Expanded Disability Status Scale (EDSS),¹⁸ predominantly in terms of level of mobility (Table 1). It correlates strongly ($r = 0.96$) with EDSS. However, DS is not dependent on physician assessment. Studies have shown that, although physicians and people with MS often disagree on many aspects of disability, they tend to agree on broad categorical measures of physical disability,^{17,19} such as those described in the DS scale. Therefore, our data should be broadly comparable with other studies that have used the EDSS.

Another benefit of the DS scale is that it allows for inclusion of other symptoms that may be significantly disabling to a person with MS regardless of mobility level. Because of this, the client census section relating to disability level included an open-ended question regarding any other significant symptoms for further clarification.

Respondents were also given the Sick Role Tendency (SRT) questionnaire.^{20,21} SRT is an individual's inclination to adopt the sick role. The questionnaire comprised a simple three-item scale to measure this tendency.

Living arrangements and employment mirrored information obtained via the Australian Bureau of Statistics whenever possible, to enable direct comparison between MS Society of NSW Client Census Database data and the general NSW population statistics. Respondents were asked specifically whether the following support needs were being met, partially met, or unmet: household tasks, transportation, recreation, short breaks (away from home), support from other people with MS, health and medical services, employment, financial support, personal care, occasional longer breaks, and support from family. Several questions related to amount of contact with the MS Society of NSW for services and support, covering topics such as contact in the past year, satisfaction with the MS Society if seen in the past year, how to improve service satisfaction, use of the MS information line, attendance at information sessions for those newly diagnosed or teleconference sessions, and contact with any other MS Society services.

The immunotherapy section included awareness of MS immunotherapy agents (Avonex, Betaseron, Copaxone, and Rebif) currently available to eligible people with MS in Australia at a heavily subsidized rate on the Pharmaceutical Benefits Scheme.²² For the purposes of this study, respondents were classified as theoretically eligible to access these subsidized MS immunotherapies if the respondents fell within the self-reported DS categories of normal, mild mobility disability, moderate mobility disability, and early cane (DS 0–3), because the federal criteria require the person with MS to be ambulant for a short distance without mobility support. We recognize that this oversimplified definition of eligibility

Table 1. Disease-step categories used in MS Society of New South Wales Client Census Database Study questionnaire

Disease step	Category (level of disability)	Comparable EDSS score	Description
0	Normal	0 or 1	I have mild MS symptoms that do not limit my activity or lifestyle.
1	Mild	2 or 3	I have mild MS symptoms such as sensory problems, mild incoordination or weakness, and fatigue but no visible problems with my walking.
2	Moderate	4 or 5	My main problem from MS is trouble walking, but I do not use any type of aid to help me walk.
3	Early cane	6	I can walk 25 feet without a cane or some other form of support, such as a splint, brace, or crutch, but I use this occasionally for longer distances.
4	Late cane	6	To be able to walk 25 feet, I must use a cane or some other form of support on one side, such as holding onto furniture or touching the wall. I may use a scooter or wheelchair for longer distances.
5	Bilateral support	6.5	To walk 25 feet, I must use two canes, a walker, or two crutches. I may use a scooter or wheelchair for longer distances.
6	Wheelchair	7–9.5	My only form of mobility is a wheelchair.
U	Unclassifiable		Intended for use for people with MS who did not fit other categories but were nevertheless disabled by problems with symptoms such as “significant cognitive or visual impairment, overwhelming fatigue, or significant bowel or bladder impairment in an otherwise minimally impaired patient.” Category not used directly in census survey but used indirectly via follow-up question on disabling MS symptoms. When participants felt they did not fit any other category, question was left blank (n = 2).*

EDSS = Kurtzke Expanded Disability Status Scale; MS = multiple sclerosis
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probably overestimated the number of respondents who would meet the federal criteria in reality, because the federal criteria also require that the person must have the relapsing-remitting type of MS. On the basis of epidemiological studies, we estimate that 75% of our sample would be expected to have relapsing-remitting MS. However, we also coded whether the patient’s neurologist had recommended that he or she go on immunotherapy, with the assumption that the neurologist would not recommend immunotherapy for people with other types of MS.

Thus, the final status of respondents in relation to their immunotherapy use was grouped around the concepts of whether they were theoretically eligible, had been recommended to go on immunotherapy, were currently on immunotherapy, were previously on immunotherapy, and were aware of the immunotherapy drugs. Other questions covered source of knowledge of immunotherapy; contact with the MS Society about immunotherapy; how the medication was chosen; time on the medication; reasons for not going on immunotherapy, not starting immunotherapy if recommended, and changing medication once started; type of injection

training received; injection method; and any apparent side effects. Only immunotherapy status is reported herein.

Pilot Trial

A pilot study was undertaken to test the questionnaire and database. Eleven clients with MS volunteered to participate in the trial after being approached by their MS Society outreach worker; however, only nine of these clients could be contacted at the time of the trial. Each client willing to participate in the trial was sent an introductory letter and a page with options for the call (eg, preferred time of day). After the interview, the outreach worker contacted the client and completed a Client Evaluation of Pilot Telephone Interview form.

Two interviewers were trained for the trial. At the end of the trial, they completed an Evaluation of the Pilot Trial form. The interviewers then became part of the general pool of interviewers.

Several amendments were made to the study methodology and database after the trial, including refinement of the database operation to amend the introduction letter so that clients could request times they preferred not to be called rather than

times they preferred to be called. The met and unmet needs section of the questionnaire and questions in the DS section were modified for clarification.

Interviewer Training

Fifteen interviewers who normally worked as telemarketers for the MS Society's fund-raising department were comprehensively trained for this study and completed a confidentiality agreement before making their first call. Nine interviewers were trained by both the principal researcher and the senior clinical psychologist of the MS Society, and six more were trained by the experienced interviewer manager as the study progressed.

MS Society of NSW Client Census Database Sample

The target population for the database sample comprised all people who were registered with the MS Society of NSW during the study period. Registration with the MS Society is free and requires that the applicant have a confirmed diagnosis of MS or one of a few other "allied neurological conditions" as determined by a state-registered neurologist. Only 1% of people on the MS Society's registered client listing had an allied neurological condition at the time of the census, and their responses were not included in the final analysis.

Of the 3599 clients registered with the MS Society during the study, almost all (3485, 97%) had given permission to be contacted by the society. Of these, 77 (2%) were no longer living in the state (22 had moved, 55 were deceased). The remaining 3408 eligible clients were sent introductory letters relating to the census study (see below). Of these, 22% were lost to the sample due to unavailability (uncontactable or unresponsive, 13%) or refusal to participate when contacted (9%).

By the end of the data collection period, 2641 interviews had been completed by telephone, where either the client (2525) or a caregiver (116, or 4% of those returned) had been interviewed. Ten additional respondents participated in a postal version of the questionnaire at their own request (18 were sent out, 10 were returned). At this point, a total of 2651 completed questionnaires were entered into the client census database, comprising 74% of the total client database, including the few clients with a diagnosis other than MS. Finally, the 1% of registered clients without MS were excluded from the sample, leaving a comprehensive data set of 2618 people with a diagnosis of MS, representing 73% of the total MS Society of NSW registered client database.

Data Collection Procedure

Data collection for the study started in August 2001 using the MS Society of NSW registered client listing, with updates entered every fortnight for those registering for the first time (last updated November 2001). An introductory letter was

sent to each client explaining the purpose and nature of the study; a page of contact options was included in the mailing, and respondents were asked to nominate periods during which they preferred to be called. Completed letters received back were entered into the database.

Attempts to contact clients to complete the survey commenced shortly after data entry. After each call, interviewers completed a shift form, detailing the time and outcome of each call (using both predetermined codes and detailed notes). Calls were checked every 2 or 3 days by a researcher for missing or inaccurate data and for notes or requests for clinical follow-up. If respondents requested that a staff member of the MS Society contact them for support, information, or counseling, a request-for-follow-up form was completed and distributed to a researcher for referral to the appropriate clinical staff member. Telephone interviews ceased in December, and all responses to interviews were acquired by January 2002.

Results

Representativeness of Sample

Of the eligible clients, 78% of women, 75% of men, 78% of rural, and 71% of metropolitan clients participated in the study, thus representing major demographic subgroups. This high capture rate allows for generalization to all people with MS in NSW.

Demographics

The mean age of the sample was 49 years, confirming MS as a disease predominantly of middle-aged adults. Age was normally distributed (median, 49 years; 25th percentile, 40

Table 2. Demographics of MS Society of New South Wales (NSW) Client Census Database study sample

Variable	Sample data
N	2618
Age, y (mean [SD])	49 (13)
Time since diagnosis, y (mean [SD])	11 (9)
Women:men	3:1
English speaking, %	
Respondent	95
Parents	88
Born in Australia, Oceania, or Antarctica, %	80
Family from northern Europe, %	90
Area of residence, %	
Major city	70
Inner regional NSW	22
Outer regional NSW	8
Remote or very remote NSW	<1

SD = standard deviation

years; 50th percentile, 40 years; 75th percentile, 57 years) and matched that found in the larger epidemiological NSW study of 2003.¹¹ The mean time since diagnosis was 11 years, indicating that most of our clients have lived for many years with this disease and know its impact on their lives (Table 2). On the other hand, 36% of our sample reported being diagnosed within the past 5 years. This sizable subgroup presents a unique challenge to support organizations such as the MS Society, because preliminary analysis shows that they are more likely than people diagnosed longer to have minimal or no disability ($P < .000$), to have children living with them in addition to a partner or spouse ($P < .000$), and to be trying to sustain full-time employment ($P < .000$). They also tend to seek different support services. For instance, they are more likely to seek information on immunotherapy than support from physical and occupational therapists.

Our sample contained the expected predominance of women (75%) over men (25%), similar to that reported in several other studies.^{4,5,8} Consistent with previous epidemiological reports,⁴ most of our database sample comprised English-speaking whites who were born in Australia or its immediate regions (Oceania or Antarctica) into predominantly English-speaking families of northern European origin (Table 2). Most of the sample reported living in areas classified as a major city of the state, when using the Australian Bureau of Statistics (ABS) Remoteness Structure.^{23,24} According to ABS criteria, a fifth of the sample reported living in areas classified as inner regional NSW. Only a few reported living in outer regional NSW, and rarely did anyone report living in remote or very remote NSW. The proportion of people living in major cities was similar in the sample (70%) and the general population (71%).

Level of Mobility Disability and Other MS Symptoms

The MS Society of NSW Client Census Database sample covered the entire spectrum of mobility disability levels (Table 3). Note that half of the sample reported being able to walk without an aid (ie, DS 0–2), confirming that most people with MS are not greatly disabled in regard to their mobility.

Significantly more women than men reported having only mild disability (29 vs 21%; $\chi^2 = 14.8$, $P = .000$). Interestingly, a similarly significant sex difference was found for those reporting being normal (11 vs 6%; $\chi^2 = 13.5$, $P = .000$).

Equal proportions of respondents reported categories within the more impaired spectrum of disability. The greatest level of disability (DS 6) was reported by only 17% of the sample. A significantly higher proportion of men than women reported being confined to a wheelchair (23 vs 15%, $\chi^2 = 19.7$, $P = .000$). Respondents were distributed uniformly across the DS scale (ie, compared with the bimodal distributions usually

found with EDSS). However, one clear peak of high frequency occurred at DS 1 (mild disability), and another possible smaller frequency peak occurred at DS 6 (severe disability) (Table 3).

More women than men reported normal and only mild disability ($\chi^2 = 13.56$, $P = .000$), whereas more men than women reported being confined to a wheelchair ($\chi^2 = 19.74$, $P = .000$). Preliminary analysis of the interaction between disability level and age indicated that those classifying themselves as normal tended to be younger (mean age 42 ± 11 [SD] years) than those confined to a wheelchair (mean age 56 ± 13 years). Age tended to increase incrementally (but not always significantly) for each step between these extremes (between DS 0 and 1, $P = .098$; DS 1 and 2, $P = .000$; DS 2 and 3, $P = .000$; DS 3 and 4, $P = .154$; DS 4 and 5, $P = .000$; DS 5 and 6, $P = .326$). Interestingly, no statistical difference in age was found between people confined to a wheelchair and those using bilateral support (mean age 57 years; $P = .38$).

Almost all respondents reported at least one other symptom of MS that they considered disabling (Table 4). Some of the categories, such as weak legs, overlap with DS categories but are reported to reflect the language respondents used to describe these other symptoms). The most commonly reported symptom was fatigue. The most frequently reported other symptoms were abnormal sensory symptoms, temperature intolerance, cognitive difficulties, visual problems, and mood problems. More than half of the 10 most frequently reported other symptoms were subjective and would be difficult or time-consuming to assess and verify objectively (eg, by specialist health professionals).

Preliminary analysis showed that the types of other symptoms reported varied according to level of mobility disability. Those with mild disability were more likely to report abnormal sensory symptoms (Cramer's $V = 0.18$, $P = .000$), fatigue (Cramer's $V = 0.18$, $P = .000$), visual problems (Cramer's $V = 0.09$, $P = .002$), or cognitive problems (Cramer's $V = 0.15$, $P = .000$). Those with moderate disability were more likely to

Table 3. Age of MS Society of New South Wales Client Census Database study sample, by level of disability

Level of disability (disease step)	Respondents (%)	Mean age (SD)
Normal (0)	10	42 (11)
Mild (1)	27	43 (10)
Moderate (2)	12	47 (11)
Early cane (3)	15	52 (12)
Late cane (4)	12	53 (11)
Bilateral support (5)	7	57 (13)
Wheelchair (6)	17	56 (13)

Details may not sum to total because of rounding.

Table 4. Self-reported symptoms in MS Society of New South Wales Client Census Database study

Symptom	Frequency (%)
Fatigue	87
Abnormal sensory symptoms	72
Weak legs	71
Temperature intolerance	68
Cognitive problems	58
Memory problems	51
Visual problems	49
Mood problems	46
Weak arms	44
Numbness	41
Pins and needles	40
Concentration	40
Balance problems	35
Speech problems	27
Depression	26
Incontinence or bladder problems	25
Pain, including headache	24
Frustration	21
Lack of coordination	18
Muscle stiffness	14

report pyramidal symptoms (problems with voluntary and discrete movements) (Cramer's $V = 0.27, P = .000$), mood problems (Cramer's $V = 0.17, P = .000$), balance problems (Cramer's $V = 0.24, P = .000$), temperature intolerance (Cramer's $V = 0.17, P = .000$), visual problems (Cramer's $V = 0.09, P = 0.002$), incontinence (Cramer's $V = 0.31, P = .000$), and problems with coordination (Cramer's $V = 0.30, P = .000$). Those with severe disability were more likely to report weakness in legs (Cramer's $V = 0.43, P = .000$), weak-

ness in arms (Cramer's $V = 0.27, P = .000$), speech problems (Cramer's $V = 0.19, P = .000$), and incontinence (Cramer's $V = 0.31, P = .000$).

Living Arrangements

The MS Society of NSW Client Census Database sample covered the entire spectrum of living arrangements. The largest proportion of the sample lived with children and a partner or spouse (Table 5) and were an average of 44 ± 9 (SD) years old. The next most common living arrangement was with just a partner or spouse (31%; age 54 ± 12 years).

The clearest relationship between disability and living arrangement was discovered for the few respondents who reported living in a hostel or nursing home, 85% of whom reported being confined to a wheelchair. Few respondents with lesser mobility reported living in this arrangement. Similarly, disability level seemed to be a significant factor for the respondents who reported living with friends (2% of total sample). Half of the respondents who were living with friends (mean age 43 ± 13 years) had only mild disability. Even so, a few individuals with more severe disability were also living with friends (eg, the 5% of this small subgroup who were confined to a wheelchair).

Most respondents living with children and a partner/spouse or just a partner/spouse reported not needing mobility aids (ie, DS 0–2, 63 and 45%, respectively). However, a significant proportion living in both of these living arrangements also reported more severe disability, such as the subgroup of 15% of respondents who were confined to a wheelchair and living with just a partner or spouse. Those living with other family members reported disability levels ranging from normal to severe. Respondents living alone also reported wide-ranging disability levels, mostly from mild disability to being confined to a wheelchair.

Table 5. Living arrangement, by level of disability, in MS Society of New South Wales Client Census Database study

Level of disability (disease step)	Living arrangement* (%)						
	Lives alone (13)	Partner or spouse (31)	Children and partner/spouse (35)	Other family member (13)	Friend (2)	Hostel or nursing home (5)	Someone else (1)
Normal (0)	4	9	14	10	2	0	10
Mild (1)	17	25	36	26	54	1	14
Moderate (2)	14	11	13	11	12	1	14
Early cane (3)	19	18	12	15	10	2	14
Late cane (4)	16	13	10	13	10	4	10
Bilateral support (5)	11	8	5	8	7	8	10
Wheelchair (6)	17	15	10	18	5	85	29
Total	100	100	100	100	100	100	100

*Numbers in parentheses are percentage of sample living in that situation. Details may not sum to total because of rounding.

The average age of respondents confined to a wheelchair was only 56 years. About one-fourth (24%) of this subgroup was already living in hostels or nursing homes at the time of the study. Our MS Society clinical records indicate that a further 65% of these severely disabled individuals were classified by experienced MS Society staff as being at risk of needing emergency supported accommodation such as a hostel or nursing home.

Employment

About one-third of the sample reported being employed (Table 6): 17% full time and 15% part time. One-fifth of those employed full time reported no disability, and half reported only mild disability. Similarly, 19% of those employed part time reported no disability, and 44% reported only mild disability. However, a somewhat greater proportion of those working part time than those working full time reported using any form of mobility aid.

Sex also played a role in level of employment. Men were more likely than women to be employed full time (25 vs 15%; $\chi^2 = 30.7, P = .000$), and women were more likely than men to be employed part time (18 vs 8%; $\chi^2 = 36.1, P = .000$) (Table 7).

Service and Support Needs

The service and support needs of people with MS were explored in some detail in the census study, but only the broad findings are reported here. Many of the finer details are primarily relevant to health and community MS support providers operating within NSW.

Most (78%) of the respondents reported seeing their general practitioner about their MS, and 72% had seen their neurologist in the past 2 years. Other specialists seen included MS Society outreach workers (15%) and MS Society-based or other physiotherapists (12%), occupational therapists (4%), nurses (4%), psychologists (2%), and neuropsychologists (1%).

In addition to contact with health professionals or MS Society services, various general service and support needs were identified as being either at least partially met or unmet. Essential health and personal care needs were generally well met. That is, access to general health and medical services was an unmet need in only 2% of the sample and partially met in only 6%, whereas personal care was an unmet need in only 1% and partially met in 3%.

Preliminary analysis of the role of mobility disability level showed that respondents in the late cane and wheelchair categories were more likely than others to report that their medical and health service needs were unmet or only partially met (20 and 25%, respectively; Cramer's $V = 0.14, P = .000$). Similarly, respondents in the late cane, bilateral support, and wheelchair categories were more likely than others to report that their personal care needs were unmet or only partially met (20, 19, and 31%, respectively; Cramer's $V = 0.15, P = .000$).

Living away from a major city was also influential. Unmet or partially unmet needs in these essential health and personal care domains were most frequently reported by respondents living farther from major cities: 15% of those living in remote or very remote NSW and 15% in outer regional NSW, compared to only 9% in inner regional NSW and 88% living in major cities ($\chi^2 = 12.45, P = .006$).

The most frequently unmet need was occasional longer breaks from home, reported by 20% of respondents; 9% reported this need as partially met. Respondents in the bilateral support or wheelchair categories were more likely to report these needs being unmet (10%) or only partially met (23%) (Cramer's $V = 0.14, P = .000$). Frequent short breaks from home was also identified as an unmet (18%) or partially unmet (10%) need. Respondents in the late cane or wheelchair categories were again more likely to report these needs as being unmet or only partially met (15 and 22%, respectively; Cramer's $V = 0.15, P = .000$).

Employment support was reported as an unmet need by 19% of respondents, and 4% reported this as a partially met need. Respondents in the wheelchair category were more likely to report their employment needs as being unmet or only partially met (20% combined; Cramer's $V = 0.17, P = .000$).

Table 6. Employment status, by level of disability, in MS Society of New South Wales Client Census Database study

Level of disability (disease step)	Employment status (%)			
	Full time	Part time	Unemployed	Not in labor force
Normal (0)	20	19	12	5
Mild (1)	51	44	23	16
Moderate (2)	14	13	27	11
Early cane (3)	10	10	21	17
Late cane (4)	4	6	4	16
Bilateral support (5)	1	4	4	10
Wheelchair (6)	1	3	8	25
Total	17	15	2	63

Table 7. Influence of sex on employment of people with MS, in MS Society of New South Wales Client Census Database Study versus state

Sex	Employment status (%)					
	Full time		Part time		Total	
	MS	State	MS	State	MS	State
Male	25	48	8	12	33	62
Female	15	25	18	22	34	48
Total	17	36	16	17	33	53

Immunotherapy

Most (92%) respondents were aware of the availability of partial treatment of immunotherapy for MS (Table 8).²⁵ Forty-three percent reported that they had found out about immunotherapy from their neurologist and 34% via communications associated with the MS Society of NSW. The few (8%) respondents who were unaware of the immunotherapies were more likely to be men ($\chi^2 = 6.04, P = .014$), older (mean age 60 years for men vs 49 years for women; $t = 11.6, P = .000$), diagnosed for longer (mean time since diagnosis 20 vs 17 years, $z = 7.77, P = .000$), and confined to a wheelchair (52%; Cramer's $V = 0.26, P = .000$). Only a third of this unaware group said they would like to know about the immunotherapies.

Although most of the census sample knew about immunotherapy, only 41% reported actually being on immunotherapy at the time of the study (Table 8). Preliminary analyses showed that those currently on immunotherapy had a wide range of mobility disability levels but were slightly more likely to have mild or moderate disability (Table 9), be women ($\chi^2 = 6.96, P = .008$), and be employed part time (Cramer's $V = 0.082, P = .036$).

The 17% of our sample who were classified as eligible (by our criteria) but were not recommended to go on immunotherapy by their neurologist probably included respondents who did not have relapsing-remitting MS and therefore did not actually meet the formal federal criteria to be eligible to access immunotherapy drugs at the subsidized

Table 8. Immunotherapy status of MS Society of New South Wales Client Census Database study sample

Immunotherapy status	Eligible	Not eligible
On immunotherapy	32	9
Previously on but not now	4	5
Never on		
Not recommended	17	16
Recommended	7	2
Not aware	3	5

rate. Of the remaining eligible respondents who were not on immunotherapy at the time of the study, 4% were previously on but not on now and 7% were never on but had been recommended to go on by their neurologist. For the latter group, preliminary analysis suggested that the reason for

not starting immunotherapy was either a poor understanding of the basic mechanism of action of the drugs (eg, "not bad enough yet" to need immunotherapy) or psychological (eg, fear of side effects or fear of needles).

Nine percent of the respondents were theoretically not eligible according to their level of disability but nevertheless reported being on immunotherapy at the time of the study (Table 8). This subgroup included respondents in the wheelchair and bilateral support categories. A further few were also not eligible, had never been on immunotherapy, but had nevertheless been recommended to go on immunotherapy by their neurologist. Sixteen percent of the study sample were not eligible and, appropriately, had not been recommended to go on immunotherapy by their neurologist. Altogether, 9% of the total respondents had previously been on immunotherapy but were not on now. Respondents who gave reasons for discontinuing therapy felt it was not doing them any good, had become depressed, or said their neurologist had recommended that they discontinue.

Discussion

The final client census database sample was highly representative of the target population. Epidemiological studies in the early 1980s indicated that the prevalence of MS in NSW was 36.5 in 100,000 people.⁴ A report in 2003, however, put this figure at 59.1 in 100,000,¹¹ which would make the total number of people with MS in NSW approximately 3770. During this study, 3599 people were registered with the MS Society of NSW. Thus, our study captured 73% of the total number of people with MS registered with the MS Society and an estimated 70% of all people with MS in NSW—an unusually high capture rate for a study of this kind. The study was also characterized by representative samples of both men and women and of people based in rural and metropolitan areas.

The main demographic variables in our study were similar to those collected via the large international study samples in the European Database for Multiple Sclerosis (EDMUS; $N = 15,000$) and the Consortium of Multiple Sclerosis Centers' North American Research Committee on Multiple Sclerosis (NARCOMS; $N = 18,000$).¹⁵ Our sample was most similar,

Table 9. Respondents on immunotherapy, by level of disability, in MS Society of New South Wales Client Census Database study

Level of disability (disease step)	On immunotherapy (%)
Normal (0)	43
Mild (1)	52
Moderate (2)	55
Early cane (3)	51
Late cane (4)	44
Bilateral support (5)	28
Wheelchair (6)	5

however, to the Sonya Slifka Longitudinal MS Study sample,²⁶ in which 77% were women (vs 75% in our study), 92% were white (vs 90%), average age was 50 years (vs 49 years), average time since diagnosis was 12 years (vs 11 years), and 57% of the sample was unemployed at the time of recruitment (vs 66%).

The study sample covered the entire spectrum of mobility disability. The frequency peaks that appeared at DS 1 (mild disability) and DS 6 (severe disability) were slightly higher than those reported by Hohol et al.¹⁷ and may be the result of methodological differences (self-reported vs physician-based classification) or of real differences in the samples.

Comparison of the sample disease profile with that of a larger epidemiological study by Hammond et al.⁷ also indicated some interesting but minor differences. These investigators subclassified their sample into mild (fully ambulatory), moderate, and severe disability groups based on EDSS (categories 0–3, 4–6, and 7–9, respectively). For their three-city group, 56% had mild disability, 21% had moderate disability, and 23% had severe disability. The corresponding distribution within our NSW client census sample (DS 0–1, 2–5, and 6) was 37, 46, and 17%, suggesting a greater concentration in moderately disabled people with MS. That our sample contained fewer than expected mildly disabled people is consistent with our clinical impression that many newly diagnosed individuals delay registering with the MS Society until they have mobility symptoms that interfere with their lifestyle. On the other hand, only 17% of the MS Society census sample reported that their only form of mobility is a wheelchair, which is lower than reported in the larger epidemiological series.⁷ Therefore, the MS Society of NSW not only represents an estimated 94% of the total MS population in NSW, but its registered client database represents the entire spectrum of disability fairly equitably and is not dominated by people with severe disability.

Most respondents in the sample also reported other MS symptoms they considered disabling, such as fatigue, abnormal sensory symptoms, heat intolerance, cognition problems, and mood problems. Interestingly, more than half of the most

frequently reported other disabling MS symptoms were subjective in nature. These symptoms are more difficult to confirm objectively and are therefore more at risk of being dismissed as insignificant by other people.

Analysis of living arrangements showed that, although the largest proportion (35%) of the sample lived with children and a partner or spouse, this arrangement was much less frequent in the MS Society sample than in the general population (49%). The next most common arrangement was living with just a partner or spouse (31%), which, conversely, was much more frequent than in the general state population (18%). When combining the data for those living with a spouse with and without children, the MS population was similar to the general state population (68 vs 67%). Thus, people with MS were found to be just as likely, overall, to be living with a spouse or partner but were more likely to be living without children in the family home than their state counterparts. The MS population was also more likely than the general population to be living alone (13 vs 8%) or living with another family member (eg, a child or parents, 12 vs 2%) than in other arrangements, such as living with friends. Although only 5% of respondents were living in a hostel or nursing home, this occurred at a much higher rate than in the general state population (0.0007%), and most of these respondents were <65 years old. Mobility disability level seemed to determine whether respondents lived in hostel and nursing home environments, in that most of the people living in this arrangement were severely disabled.

However, when looking at the accommodation needs of MS patients confined to a wheelchair as a specific subgroup of interest, their needs were not being adequately met within the state at the time of the study, particularly in terms of age-appropriate accommodation options. One-fourth of this subgroup was already living in supported accommodations designed for the elderly despite their average age of only 56 years. These people have the greatest difficulty finding appropriate supported accommodations when their in-home support services become inadequate to meet their care needs.

The current Commonwealth-State Disability Agreement policy on younger people with disabilities explicitly discourages people younger than 70 years from being considered for accommodation in residential aged-care facilities for various reasons.²⁷ Nonetheless, almost no alternative supported accommodation facilities are available for younger adults with this level of disability. Consequently, this policy, along with inadequate state and federal funding for accommodations for young people with disabilities in general, keeps many at-risk people (65%) within this very disabled subgroup from obtaining the supported accommodation and care they need, leaving many in strained living conditions with poor quality of life.

On the other hand, level of disability did not seem to influence other forms of living arrangements. The whole area of living arrangements for people with MS in Australia, and the role of factors other than level of mobility disability, is complex and needs to be investigated further.

MS clearly affects employment status, with only a third of the sample reporting being employed in any capacity. The proportion of people working full time with MS (17%) was half that of the expected proportion in the general NSW population (36%). However, the proportions working part time were comparable (16 vs 17%, respectively). Greater disability led to less employment, although among respondents using any form of mobility aid, part-time employment was somewhat more frequent than full-time employment. Therefore, MS disability appears to be disproportionately adversely affecting full-time employment compared with part-time employment. Also, when general comparative state statistics were considered, men appeared to be more disadvantaged than women with MS for both part-time and full-time employment.

Certain aspects of the influence of disability and age on employment of people with MS in Australia have been reported previously. In their 1981-based epidemiological study, Hammond et al.¹⁰ showed a significant association between level of disability and the probability of not being employed after adjusting for age. Furthermore, trade and farm workers were less likely to be in paid employment than professional or clerical workers as their level of disability increased. Black et al.,¹⁴ in their earlier survey of the views and opinions of people with MS in NSW, reported similarly high levels of “perceived threat to continued employment” among trade and process workers and argued that the manual labor demanded in these jobs seemed to be a significant factor. However, administrative workers reported only slightly lower levels of perceived threat in their sample.

Many international studies have explored the influence of other factors, eg, age, level of education, sex, duration of disease, age at diagnosis, and cognitive ability on employment in MS.^{28–30} The influence of these potential variables needs to be explored further within our census sample to determine how they may be relevant to employment of people with MS in Australia.

Respondents sought support and services for the management of their MS most frequently from their general practitioner and neurologist but also from various other health professionals, many of whom were employed by the MS Society. These essential medical professionals must keep up with new treatment advances in MS so that the benefits may be passed on without delay to their patients. The independently run state MS Societies around Australia can play a valuable support role in this challenging endeavor by sustaining robust,

open partnerships with key medical professionals in their regions and helping to disseminate relevant new MS treatment and management initiatives obtained from their interdisciplinary professional networks and close links with international MS research teams.

The essential medical care and personal support needs of respondents were mostly well met but not completely, particularly not for the most disabled people or for those living farther from major cities. The most frequently reported unmet need was for occasional longer breaks from home, followed by frequent short breaks from home and employment support. The MS Society must continue to play a strong advocacy role in ensuring that these needs are met more consistently

Finally, although the discovery that most responders were aware of the availability of immunotherapy for MS was encouraging, fewer than half (41%) of the respondents reported actually being on immunotherapy at the time of the census, and some (9%) of these were actually too disabled to meet the official federal criteria for eligibility. Sixty-four percent of the sample did meet the study’s disability-based criteria to be eligible to take immunotherapy, but only half of these (32% of the total) reported actually being on immunotherapy. Half of those who were eligible but not on immunotherapy (ie, 17% of the total sample) had not been recommended to go on immunotherapy by their neurologist, but the remaining 14% remained potential beneficiaries. This was of particular concern because the cost of immunotherapy is heavily subsidized in Australia and therefore should be affordable to all. Hence, factors other than cost were probably the reasons for eligible respondents not being on immunotherapy.

The process of getting onto immunotherapy in Australia is more complex than it may initially appear. People with MS must first be aware enough of the availability of the immunotherapies to approach their neurologist about the issue. They must then be eligible according to federal criteria. Next, the immunotherapy must be recommended and prescribed by the patient’s neurologist. Several factors (eg, poor liver function, bad side effects, desperation for relief from MS) might influence the neurologist’s recommendations for otherwise eligible people with MS, although, to our knowledge, no studies have been published on this topic. Assuming that the person with MS is both eligible and has been recommended for immunotherapy, he or she then needs to make his or her own decision about whether to start immunotherapy and, if so decided, which of the products available in Australia should be taken. Poor initial awareness, poor understanding of the method of action of immunotherapy, and adverse psychological factors seem to play key roles in decisions surrounding its uptake. Respondents on immunotherapy were

most likely to have mild or moderate disability, to be women, and to be working part time.

The respondents who were on immunotherapy despite not meeting the study's eligibility criteria may have once met federal mobility eligibility criteria, but the fact that they no longer met criteria had not yet come to the attention of the prescribing neurologist. Also, they may have obtained prescriptions for immunotherapy despite not meeting federal criteria. With a condition such as MS, in which mobility levels can fluctuate from month to month, this finding may not be surprising. However, it may also reflect the pressure on neurologists to use the only partial treatment available for their patients, regardless of whether they meet the formal federal criteria.

Potential limitations of this study relate mainly to the influence of variations in the telephone interviewers' approaches to conducting interviews. After the census data collection, eight interviewers completed a questionnaire to give their feedback on the methodology of the study and suggestions for improvement. Interviewers completed between 1 and 401 interviews each (mean 158, median 108). The most experienced interviewer assisted in cleaning the data and was personally interviewed by the principal researcher to capture qualitative information on possible interviewer bias and general methods.

The interviewers' approach to conducting their interviews was semistructured—they adapted their questioning style according to the respondent, not necessarily asking questions in the order in which they appeared in the database. As a result, the level of prompting for symptoms and practitioners seen about the client's MS in particular varied among interviewers. Within weeks of study commencement, interviewers found that respondents were underreporting other symptoms that seemed obvious (eg, speech difficulties). Therefore, although the researchers would have preferred a non-prompting approach to questioning, they were allowed to use prompts for the presence or absence of other physical or sensory symptoms (eg, pins and needles), fatigue, speech problems, temperature intolerance, visual difficulties, weakness in arms or legs, and concentration, memory, or mood problems (eg, depression). This technique enabled more accurate reporting of symptoms but may have introduced some systematic variability into the data as a result of each interviewer's style or level of prompting.

At the end of the feedback and review process, the interviewers were evaluated by both the most experienced interviewer and the principal researcher as having a good understanding of the questions overall and a good capacity to keep to the questionnaire format. A few sections of the questionnaire had initially caused either the interviewer or the respondent some mild confusion. This was noted specifically for the

sections on SRT and unmet needs. However, the problems were resolved early in the initial implementation phase of the study.

Conclusions

The MS Society of NSW 2001 Client Census Database study succeeded in establishing a comprehensive and highly representative cohort database of demographic and clinical data on the self-reported experiences of people living with MS in NSW, Australia, and the impact of mobility disability, in particular, for the purposes of supporting service planning, service quality improvement, and research. The study also successfully gathered valuable data on immunotherapy attitudes and use for the specific purposes of improving education and support services in this vital area of MS treatment.

The preliminary findings of this study clarify the broad impact of MS, and in particular the impact of mobility disability, on the lives of people living with MS in NSW, Australia, at the beginning of the 21st century. The study's findings have enabled the MS Society to better target its policies on service provision and to identify areas where more advocacy activity may be required. Further analysis of these data is under way. However, some areas of particular interest require more detailed investigation, such as identification of the factors influencing living arrangements, employment rates, and the uptake of immunotherapy. □

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