

## **Epidemiology of Multiple Sclerosis in the Manawatu-Wanganui Region of New Zealand**

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**ABSTRACT** A survey carried out in the Manawatu-Wanganui area of New Zealand was designed to locate all individuals known to have Multiple Sclerosis. Of the 84 persons noted, 80 were found and interviewed to ascertain demographic, financial, psychological, social and vocational data. This article reports on findings related to epidemiology. Among other results, the findings confirm previous studies demonstrating an increased gradient from North to South. Also, it was remarkable that no persons who identified themselves as Maori were found.

### **INTRODUCTION**

The geographical variation in prevalence of diagnosed Multiple Sclerosis (Rose et al., 1976) with respect to latitude and the possible influence of genetic factors, i.e., gender just to mention one, are known to be significant in the epidemiology of Multiple Sclerosis. The situation in New Zealand has not been studied widely. The most recent information on this comes from an article by Skegg and others (1987) titled "Occurrence of Multiple Sclerosis in the North and South of New Zealand". This article reports on a prevalence study in Waikato Hospital Board area and in Otago Southland, each having a population of about 300,000 people. There is about a seven degree difference in latitude with the latter being further south. Various sources of data were used, primarily doctors treating patients and the Multiple Sclerosis Society Member list. The overall prevalence in Waikato was 23.6 per hundred thousand and in Dunedin an amazing 68.5 per hundred thousand, a substantial difference. In both areas there were nearly three times as many females as males. In commenting the authors draw attention to the fact that the genetic pool

differs slightly in the South Island in that there are fewer Maori people and there is a higher percentage of people with Scottish ancestry in the South of New Zealand.

In the early 70's, Hornabrook (1971) in the Wellington area and Cunningham (1972) in Christchurch, had published studies. It is interesting that the prevalence described by the latter lay between the two figures mentioned above and therefore adds further support to the fact that the prevalence of multiple sclerosis increases as you go further south in New Zealand.

### **THE PRESENT STUDY**

The Manawatu-Wanganui survey adds to the literature on this important topic, as the authors made every attempt to contact all the people with MS in the area, and so present the numbers as indicating a minimum prevalence of the disease. The study group are resident in the area under the jurisdiction of the Manawatu Wanganui Area Health Board, i.e., the Palmerston North, Wanganui, Manawatu, Taranaki, Rangitikei, Ruapehu and Otaki districts. The total population of the area is 216,730, which represents 6.55% of the New Zealand population. It includes the city of Palmerston North and the smaller cities of Wanganui and Levin and a number of rural towns and takes in large, rural farming areas; the population distribution between cities and towns and their surrounding rural communities could thus be seen as typical within New Zealand.

### **METHODOLOGY**

Ethical consent was obtained through the

Ethics Committees of both Palmerston North Hospital and Massey University. The following channels were used to find people in the Manawatu-Wanganui Area Health Board area with diagnosed multiple sclerosis.

1. The Manawatu Multiple Sclerosis Society - officials of the society approached members with details of the study. If they agreed to participate they were sent an information sheet, and signed consent to be interviewed, in front of a witness. They were only approached if they signed consent.
2. General Practitioners—all General Practitioners in the area were contacted and asked to co-operate by asking people with MS who were their patients if they would participate. Each person who agreed was then contacted formally in the same way as members of the MS Society had been.
3. Radio - The study was promoted twice on National Radio and people with MS who had not been contacted in the above ways, were asked to contact the researcher if they wished to participate.

The Ethics Committee of Palmerston North Hospital considered it unethical to provide the names of hospital patients.

The assurance of anonymity and the encouragement of the Multiple Sclerosis Society and General Practitioners probably helped in the almost total, positive response from those located. The authors accept, however, that there may be individuals within the defined area, perhaps isolated from society, with whom no contact was made.

### INTERVIEW PROTOCOL

The participants and their caregivers were interviewed in their homes over the period November 1989 through to April 1990. The 80 participants of the study individually answered a lengthy questionnaire during an interview that produced data on various aspects of their lives: their income and perceived financial wellbeing, the impact of their disability on their income and the social conditions in which they live, the level of their disability and the effect of their disability on their wellbeing and their quality of life, the extent to which they are served by or are in need of support, either financial, or back up services, the resources available to meet these needs, how well these needs are met.

Thirty-one caregivers identified as main caregivers of these subjects were interviewed separately and they also completed a questionnaire that covered many aspects of the role of carer to a person with multiple sclerosis.

One person, the principal investigator, interviewed all the 80 participants and the caregivers. The value of this (although it prolonged the process of data collection) was that a consistent assessment of the subjects and their situation was possible. The interviews were generally conducted over a period of several hours and the person with MS and the caregivers were, where possible, interviewed separately. The questionnaires to both parties overlapped in some areas and this proved a useful validity measure as well as a means of pointing to the different perspectives of people with MS and their caregivers.

### RESULTS

The general and demographic information about the people interviewed in this study is intrinsically of interest, has potential for comparative analyses in the future, and sets the stage for discussion.

These data include:

|                                                      |                                        |
|------------------------------------------------------|----------------------------------------|
| Number of people with multiple sclerosis Identified: | 84                                     |
| Number of subjects interviewed:                      | 80                                     |
| Prevalence per 100,000:                              | 38.75                                  |
| Median age:                                          | 50 years                               |
| Mean duration:                                       | 19 years (range 1-56 years)            |
| Mean age at first symptoms:                          | 31 years (range 15-60 years)           |
| Ratio females to males:                              | 55 f (68.8%) / 25 m (31.3%)<br>2.2 / 1 |

The authors failed to interview 4 of the people with MS whose names were received for the following reasons:

- 1 — unable to trace person
- 1 — unavailable for interview
- 2 — confused or difficulty in understanding speech, and unlikely to answer accurately.

The ages of participants varied from the twenties to over seventy years. As recalled by the participants, their age at the onset of symptoms of MS was generally much earlier.

**Age at Time of Interview**

|             |           |       |
|-------------|-----------|-------|
| 20-30 years | 2         | 2.6%  |
| 31-40 "     | 22        | 27.7% |
| 41-50 "     | 17        | 21.4% |
| 51-60 "     | 20        | 25.0% |
| 61-70 "     | 17        | 21.4% |
| 71+         | 2         | 2.6%  |
|             | <u>80</u> |       |

**Age at Onset of MS Symptoms (as recalled)**

|       |    |       |       |                 |
|-------|----|-------|-------|-----------------|
| 15-20 | 20 | 25.0% | 25%   | before 20 years |
| 21-25 | 10 | 12.5% |       |                 |
| 26-30 | 15 | 18.8% | 56.3% | before 30 years |
| 31-35 | 8  | 10.0% |       |                 |
| 36-40 | 10 | 12.5% | 78.9% | before 40 years |
| 41-45 | 6  | 7.5%  |       |                 |
| 46-50 | 4  | 5.0%  | 91.3% | before 50 years |
| 51-55 | 3  | 3.8%  |       |                 |
| 55+   | 4  | 5.0%  |       |                 |

Diagnosis was sometimes made several or many years later. The authors had no access to medical records of the participants of this study, so their earliest recollection of symptoms (as recalled) which were later, upon diagnosis, thought to be multiple sclerosis symptoms, is as accurate a date of onset as is available.

**Duration of Multiple Sclerosis**

| Years   | No. of People |
|---------|---------------|
| 1 - 5   | 14            |
| 6 - 10  | 6             |
| 11 - 15 | 15            |
| 16 - 20 | 17            |
| 21 - 25 | 5             |
| 26 - 30 | 8             |
| 31 - 35 | 9             |
| 36 - 40 | 1             |
| 41 - 45 | 2             |
| 46 - 50 | 2             |
| 51 - 56 | 1             |
|         | <u>80</u>     |

**Ethnic Origin**

All participants in the study were Caucasian. No persons with MS identified themselves as Maori. This finding calls for further research as to why only Caucasian participants were located. Could it be genetic, or were there other reasons which influenced this finding?

**Country of Birth**

|                                |           |       |
|--------------------------------|-----------|-------|
| New Zealand                    | 65        | 81.3% |
| Britain                        | 10        | 12.5% |
| Other (Netherlands, Australia) | <u>5</u>  | 6.2%  |
|                                | <u>80</u> |       |

Fourteen of the 15 people born outside New Zealand spent their first fifteen years in the countries in which they were born. One emigrated as a young child.

Forty-nine were born and have remained in the area of this study and 17 moved to this area after the age of fifteen.

**Presence of Other Chronic Illness**

The existence of other chronic illness could affect the degree of disability experienced by a person with multiple sclerosis.

18 (22.5%) had another chronic condition

|   |    |                          |
|---|----|--------------------------|
| - | 5  | arthritis                |
| - | 2  | diabetes                 |
| - | 11 | various other conditions |

Effect of other condition on this group of 18 people.

|   |   |                   |
|---|---|-------------------|
| - | 6 | no disability     |
| - | 4 | minor disability  |
| - | 8 | severe disability |

Thus 8 people already had severe disability from another condition to cope with before the impairment and disability resulting from multiple sclerosis. Three of the eight with severe disability were also affected severely by multiple sclerosis. The number of people with multiple disabilities exceeds the numbers anticipated.

The value of including these 8 people in the study outweighed the possibility of distorted information because of the participant's inability to determine the effect of MS as distinct from the other condition.

**Marital Status**

|              | Now | At Onset  |
|--------------|-----|-----------|
| Single       | 2   | 8         |
| Married      | 57  | 68        |
| Living Apart | 6   | 4         |
| Divorced     | 8   | 0         |
| Widowed      | 7   | 0         |
|              |     | <u>80</u> |

Six persons with multiple sclerosis married after the diagnosis was made. Eleven married persons lost their spouse through divorce.

Fifty-seven (71.3%) people were married. Thus 23 (28.7%) of the sample were without the support of a spouse at the time of the study. Of those divorced (8) and living apart (2) since acquiring multiple sclerosis, multiple sclerosis was not always given as the reason for

separation, although in most cases was believed to have had some bearing on it.

### Children

Seventy one (88.8%) of the sample have, or have had, children. The average number of children is 2.57 per person. Nineteen participants said that having MS had either prevented them from having children, or had limited the number of children they had (generally on their physician's advice).

### SUMMARY

The above data provide a background about the participants in this study, and permit some comparisons to be drawn in future analyses. A number of findings are of particular interest. The prevalence rate of 38.75 per one hundred thousand fits extremely well with previous New Zealand research, as would be predicted from the location of the Manawatu-Wanganui region. Remarkably, no persons who identified themselves as Maori were included as people with MS. There may be a genetic factor at work, and this would be an important consideration

for future research. It may be however, that other factors were involved. Other findings are presented which may be of value in other epidemiological research.

### NOTES

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