

**Title:** Updated Prevalence Estimates of Multiple Sclerosis in Texas, 1998-2003

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**Abbreviations used:**

MS	multiple sclerosis
DSHS	Department of State Health Services
ICD	International Classification of Disease
ATSDR	Agency for Toxic Substances and Disease Registry
NHIS	National Health Information Survey

**SUMMARY**

The Texas Department of State Health Services extended a prevalence study of multiple sclerosis (MS) in a 19-county area in north Texas to include three additional years of data and included a new geographic area with a predominantly Hispanic population (El Paso County). Patients diagnosed with MS by a neurologist, who resided in the study areas, and who had an office visit between 1998 and 2003 were included in the study.

The six-year MS prevalence estimate for the north Texas counties was 71.5/100,000 and for El Paso County was 49.4/100,000. In both areas, prevalence estimates were higher for females, age groups 40 to 49 and 50 to 59, and for non-Hispanic whites. These estimates provide valuable information about the epidemiology of MS in Texas and allow for a comparison with national estimates. The results also provide much needed prevalence data for the Hispanic population.

## **INTRODUCTION**

Multiple sclerosis (MS) is an autoimmune disease that develops when the body's T-lymphocytes attack the myelin sheath surrounding the nerve fibers of the central nervous system. It is one of the most common diseases of the central nervous system, currently affecting an estimated 250,000 to 350,000 people in the United States (1). Multiple sclerosis is not usually a fatal disease, but disability and decreased quality of life are common. MS may be diagnosed in adolescence but typically occurs between the ages of 20 and 50 years, differentially affecting Caucasians and women (2, 3).

Multiple sclerosis has not been a priority health condition for most public health agencies, resulting in a paucity of basic epidemiologic information (such as ethnic group-specific prevalence data) concerning this disease. This lack of epidemiologic information has precluded timely and appropriate responses to local communities concerned about potential associations between environmental exposures and MS.

In 2000, the Texas Department of State Health Services (DSHS) conducted a pilot surveillance project of multiple sclerosis (MS) in a 19-county area centered around Lubbock, Texas (4). This 19-county study area offered a unique opportunity to conduct a pilot surveillance project because of the relatively isolated geographic location, a defined number of neurologists, and the race/ethnicity distribution of the population (4). The goal of this study was to determine sex-, age-, race-, and ethnic-specific MS prevalence estimates for the 19-county study area. This study was conducted because public health officials could not adequately address concerns raised in several Texas communities about the number of individuals with MS due to the lack of current prevalence estimates for the disease (5).

To obtain current MS prevalence estimates, DSHS staff reviewed medical records from neurology offices that had the following International Classification of Disease, 9<sup>th</sup> Revision (ICD-9) codes or corresponding conditions: MS (340), other demyelinating diseases (341.8, .9), transverse myelitis (323.9), and optic neuritis (377.3). ICD-9 codes for conditions similar to MS, or symptomatic for MS, were also included to ensure an accurate case count. Records were considered for inclusion in the case count if they resided in the 19-county study area and had an office visit between January 1, 1998 and December 31, 2000. Residence was determined by the address indicated on the patient's medical record. A three-year time period was selected to allow for sufficient time for patients to have visited their physician. Data related to the diagnosis of MS was abstracted from the medical record using a standardized form. This information was then evaluated by a board certified neurologist (R.S.) for case confirmation using a strict case definition for MS that included use of the Poser criteria (6).

The overall prevalence estimate for the 19-county study area was 42.8/100,000. Prevalence estimates were higher for females, age groups 40 to 49 and 50 to 59, and for non-Hispanic whites (4). Although the results from this study provided much needed current MS prevalence estimates for Texas, a limitation of the pilot surveillance project was that the three-year time period (1998-2000) may have been insufficient to capture all of the individuals with a mild or stable form of MS and who may not have been seen by a neurologist during the study period. A second limitation was the use of a very strict case definition that may have excluded true cases of MS because inadequate information was available in medical charts to allow for a definitive confirmation of MS based on the Poser criteria.

The goals of the current study were to: 1) extend the surveillance time period to include three additional years of MS surveillance data; 2) abridge the case definition to include all medical records with a MS diagnosis; and 3) to include an additional study area with a predominantly Hispanic population (El Paso County, in west Texas). This project was approved by the Texas Department of State Health Services' Institutional Review Board.

## **METHODS**

Two geographic areas were included in this study: 1) the original study area that included 19 counties surrounding Lubbock; and, 2) El Paso County, in west Texas (Figure 1). Medical records from neurologists' offices and clinics within the study areas with an International Classification of Disease, 9<sup>th</sup> Revision (ICD-9) code of 340 for multiple sclerosis were the main data source for case ascertainment. Individuals who resided in either the 19-county Lubbock study area or El Paso County, who had an office visit between January 1, 1998 and December 31, 2003, and who had an MS diagnosis were included, irrespective of age, sex, or race/ethnicity.

Demographic variables collected from the medical record for each case included sex, race/ethnicity, and information on the treating physician. Identifying variables including name, address, and date of birth were also collected to avoid duplication in case counts.

Crude and age-adjusted MS prevalence estimates, as well as age-, sex-, and race/ethnicity-specific prevalence, were calculated for each of the two study locations. The number of MS cases was used as the numerator value and the US Census 2000

population estimates were used as the denominator. Prevalence estimates and their corresponding 95% confidence limits were calculated using SAS, version 9.1, and R, version 2.2.1. Ninety-five percent confidence intervals were calculated using a Poisson distribution.

## **RESULTS**

In the 19-county north Texas study area, 6 private neurologists' offices, 1 university medical centers, and 1 private hospital provide neurological services and care. All participated in the study although the private hospital was unable to identify individuals with MS who were seen between 2000 and 2003. In El Paso County, 11 private neurologist's offices and 1 university medical center provide neurological services and care. All but one private office participated in this study.

A total of 687 medical records with an ICD-9 diagnostic code corresponding to MS (340) were screened for study eligibility. Forty-seven cases (6.8%) were found to be duplicates and were removed from the total case count. Six hundred and forty records met the criteria for the study (n=304 in the 19-county north Texas study area and n=336 in El Paso County).

Table 1 presents the overall MS prevalence estimates and specific estimates for sex, age, and race/ethnicity for both study areas. The overall crude prevalence estimate for the 19-county north Texas study area for 1998 to 2003 was 71.5/100,000 (95% CI 63.5 – 79.6) and the age-adjusted prevalence was 77.8/100,000 (95% CI 69.3 – 87.1). The female to male ratio was 4:1. The prevalence of MS increased steadily with age, peaked in the 50 to 59 age group at 183.5 (95% CI 144.3 – 230.0), and then declined

dramatically in the population over 60 years of age. Non-Hispanic whites had the highest prevalence at 68.8 (95% CI 58.6 – 79.1), followed by non-Hispanic Blacks and Hispanics. Information on race and ethnicity was missing for 32% (n=98) of the MS cases in the 19-county north Texas study area.

The overall crude and age-adjusted prevalence estimates for El Paso County from 1998 to 2003 were 49.4/100,000 (95% CI 44.2 – 54.7) and 54.0/100,000 (95% CI 48.3 – 60.1), respectively (Table 1). Although the sex-, age-, and race/ethnicity-specific prevalence estimates were lower than those in the 19-county study area, the El Paso County prevalence estimates showed a similar pattern: the female to male ratio was 3.5:1; the prevalence of MS increased steadily with age, peaked in the 50 to 59 age group at 139.4 (95% CI 111.3 – 172.4), and then declined to a low of 4.4 (95% CI 0.5 – 15.9) in the 70 and older age group. Non-Hispanic whites had the highest prevalence at 65.1 (95% CI 51.4 – 79.2), followed by non-Hispanic Blacks and Hispanics. Information on race and ethnicity was missing for 57% (n=191) of the MS cases in El Paso County.

## **DISCUSSION**

The prevalence estimates developed from this study provide much needed geographic- and ethnicity-specific data for MS in Texas. The overall crude prevalence for the 19-county north Texas study area ( 77.5/100,000) and for El Paso County (49.4/100,000) are lower than the reported national MS prevalence from the National Health Interview Survey (NHIS) (85/100,000) and estimates provided by the National MS Society (135/100,000) (7, 8) The sex-specific estimates for the 19-county north Texas study area are higher for women than those reported for the south using NHIS data (114/100,000 vs. 91/100,000 respectively) and lower for males (28.5/100,000 vs.

36/100,000) (7). The differences could be due to a number of factors including the possibility of an actual geographic gradient (9, 10), a difference in case definition, an under-ascertainment of MS cases in the Texas study areas, or a combination of these factors.

The age distribution pattern for age-specific prevalence for both Texas study areas is similar to that reported using NHIS data (7). The highest prevalence estimates were reported for 40 to 49 and 50 to 59 age groups and the lowest prevalence estimates in the <30 and over 70 age groups. The female to male ratio in both study areas, however, was approximately double that of previous national studies (3, 7, 9). This difference in the sex-specific prevalence estimates could be the result of under-ascertainment of male cases, or an actual difference in the prevalence estimates between Texas and national estimates.

The lack of information on race and ethnicity for a substantial portion of cases for both Texas study areas (32% to 57%) precludes any definitive estimates of race- and ethnic-specific prevalence. The estimates calculated from this study can only be viewed as the lower bound for the true prevalence estimates. More emphasis on obtaining race and ethnicity will be crucial for future studies and alternative methods for obtaining this information will need to be explored. The results for El Paso County demonstrate the need for greater emphasis on race and ethnicity. According to the US Census, approximately 78% of the population is Hispanic. We were unable to assign race and ethnicity for 191 MS cases in El Paso County. If 78% of the 191 cases were actually Hispanic, this could raise the current prevalence estimate for Hispanics in El Paso County from 10.9 to 61 cases per 100,000 population, nearly identical as the non-Hispanic

whites. There is currently no published national Hispanic data which would allow us to compare the Texas data. This underscores the need for good national prevalence estimates for specific race and ethnicities.

One of the major challenges in conducting disease surveillance is enlisting the cooperation of all medical entities. In this study, one private hospital in Lubbock and one neurologist in El Paso did not fully participate in the study. Although we cannot quantify the impact of underascertainment on the prevalence estimates, we can assume the reported estimates are lower than the true prevalence in the study areas. The difficulties in conducting surveillance on a disease such as MS are compounded because physicians, clinics, and hospitals are not used to participating in chronic disease surveillance (with the exception of cancer registries) and it is a difficult task to educate the entities as to the need for such surveillance, as their focus is typically on diagnosis and treatment, not prevention. State and local health departments rarely have laws and regulations which address specific diseases such as MS, even though most states can conduct special investigations as warranted.

The MS prevalence estimates presented are under-estimates since we did not have the participation of all neurologists in the study areas and we did not attempt to ascertain individuals with MS through secondary data sources such as local MS Societies, death certificates, etc. These data sources were found not to be informative in our initial pilot study, or we were not allowed to contact them by the IRB (11).

This study has a number of strengths including the geographic location of the study areas. Both of the study areas are fairly isolated from any other major cities which may have drawn MS cases out of the study areas for diagnosis and treatment. Because of

the distances involved in traveling to see a neurologist outside each of the study areas, there was essentially a circumscribed population in each of these locations.

Also, for the first time in the United States, MS surveillance was conducted in a predominantly Hispanic population. Although there were a substantial number of Hispanic cases, we were challenged with the large number of cases for which there was no identified race/ethnicity. The overall prevalence for El Paso County (49/100,000) may be a more accurate indication of the true Hispanic prevalence given that approximately 78% of the population is Hispanic according to the 2000 U.S. Census.

The greatest strength of this study is that it provides timely MS prevalence estimates for Texas that include sex-, age-, and race/ethnicity-specific estimates. These estimates were based on a physician diagnosis for MS and were developed for a six-year period which also helped to ensure that even milder cases of MS were captured in the estimates. The prevalence estimates provide valuable information about the epidemiology of MS in Texas and allow for a comparison with national estimates. This study also provides much needed prevalence data for the Hispanic population.

These results underscore the need for additional epidemiologic information regarding the distribution of MS in the other areas of Texas and the United States, as well as information on the underlying etiology of the disease. Perhaps the most critical need is a nationally coordinated effort that would provide national surveillance guidelines and standards for MS and other neurological diseases. There are still many basic questions that need to be addressed including: 1) appropriate case definition, 2) cost effectiveness of traditional surveillance methods, and 3) the need for ongoing versus periodic surveillance. The nationally-coordinated efforts could be sponsored by either national

disease organizations or by a federal public health agency. The coordinating body could also serve as a repository for best practices, surveillance data, technical support for entities conducting surveillance, and could assist in educating health care providers on the importance of surveillance. As with other diseases and conditions such as cancer and birth defects, it will take a national effort to prioritize surveillance for MS and other neurological conditions. A nationally-coordinated effort could help ensure maximum benefit from limited funding for surveillance, research, prevention, and education.

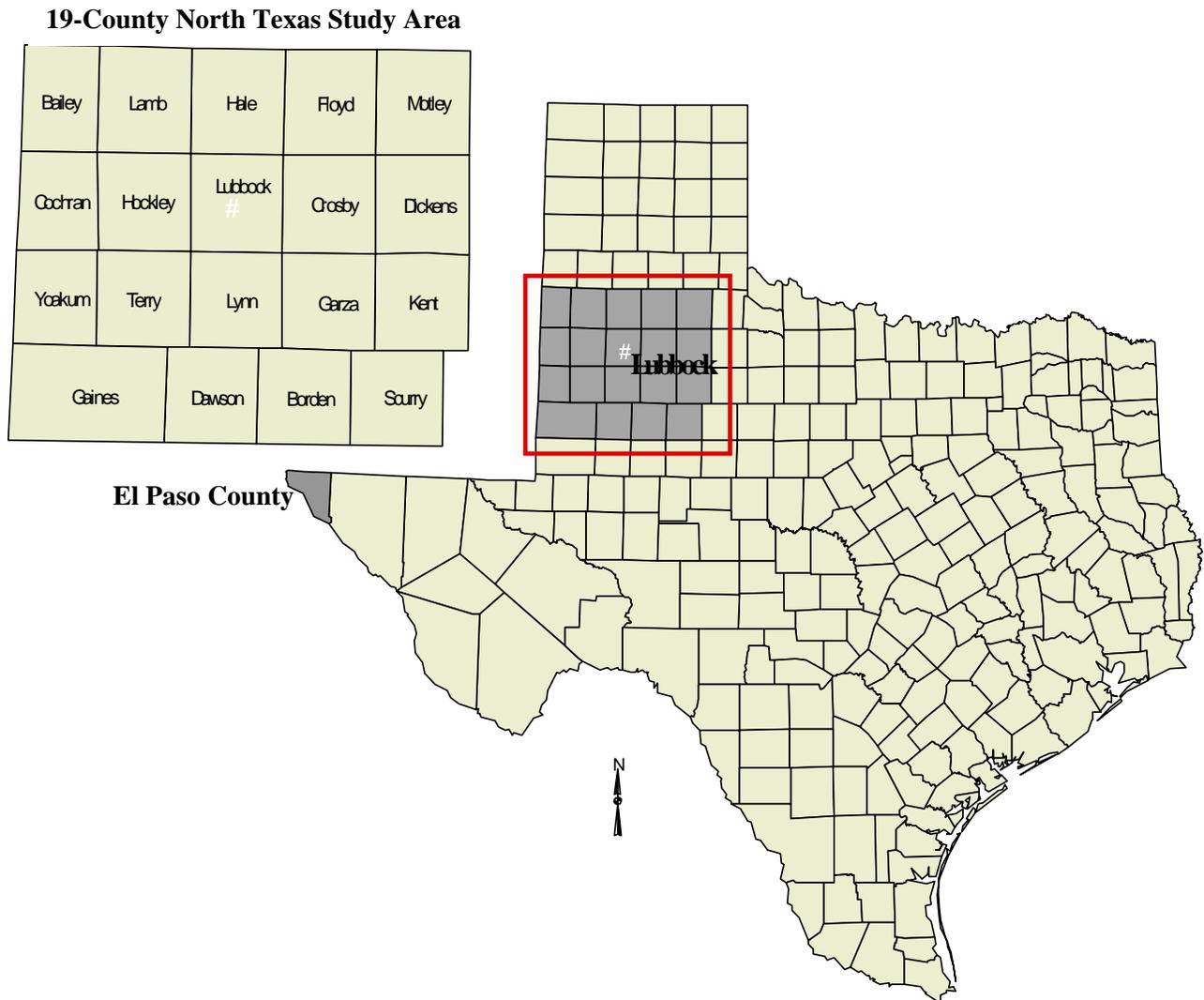
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**Figure 1.** Map of Study Areas.



**Table 1.** Number of MS cases and prevalence estimates for two Texas study areas: 19-county North Texas study area and El Paso County, 1998-2003.

	19-County North Texas study area			El Paso County		
	Number of Cases	Prevalence per 100,000 <sup>1</sup> (95% CI)		Number of Cases	Prevalence per 100,000 <sup>1</sup> (95% CI)	
<b>Overall crude prevalence</b>	304	71.5	( 63.5 – 79.6)	336	49.4	( 44.2 – 54.7)
<b>Age-adjusted prevalence<sup>2</sup></b>	304	77.8	( 69.3 – 87.1)	336	54.0	( 48.3 – 60.1)
<b>Sex</b>						
Women	244	113.9	( 99.6 – 128.2)	266	75.6	( 66.5 – 84.6)
Men	60	28.5	( 21.7 – 36.7)	70	21.4	( 16.7 – 27.0)
<b>Age (years)</b>						
<30	33	16.4	( 11.3 – 23.0)	47	13.8	( 10.2 – 18.4)
30–39	60	104.7	( 79.9 – 134.8)	88	88.8	( 71.2 – 109.3)
40–49	95	166.0	(134.3 – 202.9)	96	105.1	( 85.1 – 128.3)
50–59	75	183.5	(144.3 – 230.0)	85	139.4	(111.3 – 172.4)
60–69	28	91.3	( 60.7 – 131.9)	17	39.8	( 23.2 – 63.7)
≥70	12	32.1	( 16.6 – 56.0)	2	4.4	( 0.5 – 15.9)
Unknown	1	----		1	----	
<b>Race/Ethnicity<sup>3</sup></b>						
Hispanic	22	15.4	( 9.7 – 23.4)	58	10.9	( 8.3 – 14.1)
Non-Hispanic White	172	68.8	( 58.6 – 79.1)	77	65.1	( 51.4 – 81.3)
Non-Hispanic Black	12	44.2	( 22.8 – 77.1)	8	40.2	( 17.4 – 79.2)
Unknown	98	----		191	----	
Other				2	----	

<sup>1</sup> Prevalence = cases/100,000 population. Except where indicated, all values are crude prevalence estimates. 95% confidence intervals were calculated using a Poisson distribution.

<sup>2</sup> Age-adjusted to the 2000 U.S. Census population

<sup>3</sup> Race/Ethnicity was determined by information available on the medical records. This information was missing for 32% (n=98) of the MS cases in the 19-county north Texas study area and 57% (n=191) of the MS cases in El Paso County.