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**MULTIPLE SCLEROSIS PILOT SURVEILLANCE
19 TEXAS COUNTIES**

SUBMITTED BY:

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ABSTRACT

In response to community concerns about multiple sclerosis (MS) in Texas, the Agency for Toxic Substances and Disease Registry (ATSDR) provided funding to the Texas Department of Health (TDH) to conduct a pilot surveillance project for MS in a 19-county area of North Texas. The principal goals were (1) to determine the sex-, age-, race- and ethnic-specific prevalence estimates for MS in Texas and (2) to reanalyze the Mesita Elementary School cohort cluster investigation in El Paso, Texas using Texas-specific prevalence estimates.

The primary data source for case ascertainment was medical records from the offices of private neurologists practicing in the 19-county study area and the Texas Tech University Medical Center. Death certificates were used as a secondary source of case ascertainment. Records of patients who resided in the 19-county study area at any time between January 1, 1998 and December 31, 2000 and who had a documented office visit to a neurologist during that time period were considered eligible for inclusion in the study. Demographic and diagnostic information was abstracted from the medical records by project staff. The project neurologist using the Poser criteria for MS confirmed case status. Definite and probable MS cases were used as the numerator and the year 2000 census counts were used as the denominator in the calculation of prevalence estimates.

The results of this project represent the first Texas-specific population-based MS prevalence estimates, including the first MS prevalence estimates for Hispanics and Blacks in Texas. The prevalence estimate for the 19-county study area of 42.8/100,000 (n=182 “definite” and “probable” MS cases) is half that reported for the entire United States in the NHIS data of 85/100,000. The prevalence estimate for non-Hispanic whites is the highest for any of the race/ethnic groups at 56.0/100,000 (95% CI 47.1 – 66.1) followed by non-Hispanic Blacks at 22.1/100,000 (95% CI 8.1 – 48.1), and Hispanics at 11.2/100,000 (95% CI 6.4 – 18.2). The proportion of MS cases among Blacks and non-Hispanic whites for Texas is similar to that reported nationally with the prevalence among whites approximately twice that of Blacks. However, the actual prevalence estimates for both non-Hispanic whites and Blacks in Texas are approximately half that reported nationally. There are no estimates for Hispanics included in the NHIS data that would allow comparison of the Texas data. The lack of information on Hispanic prevalence represents an important data gap.

The findings from the El Paso MS cluster investigation were also re-evaluated. Using the prevalence estimates from the 19-county pilot project, the revised standardized morbidity ratio (SMR) for the Mesita cohort is 8.2 (95% CI 4.5 – 13.8). The SMR for females is 7.1 (95% CI 3.4 – 13.1) and for males the SMR is 13.3 (95% CI 3.6 – 34.1). The original risk estimate that used the 1989-1994 National Institute of Health Survey data was 1.93 (95% CI = 1.06 - 3.24).

The results from this project 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. As is illustrated by the revised risk estimate for the El Paso Mesita Elementary cohort, the results of this pilot surveillance project also highlight the need for timely and region-specific prevalence estimates for evaluating MS cluster concerns.

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 the most common demyelinating disorder of the brain and spinal cord. The clinical course of MS may vary from an aggressive form that can cause death within months of diagnosis to an asymptomatic condition that is recognized incidentally at autopsy. Most commonly, the clinical course involves a series of remissions and relapses that may become progressively more severe over time. Multiple sclerosis is not usually a fatal disease, but severe disability and decreased quality of life are common. Multiple sclerosis may be diagnosed in adolescence, but it typically occurs between the ages of 30 and 50 years and differentially affects women and Caucasians (1,2).

Multiple sclerosis has not been a priority health condition for most public health agencies. There is a lack of basic epidemiologic data concerning the disease, particularly current background prevalence estimates for many geographic regions and ethnic groups in the United States. Over the past several years, several communities around the country located near hazardous waste sites have expressed concern about elevated numbers of MS cases. Investigating local community concerns regarding the potential association between environmental exposure from hazardous waste sites and MS is difficult due to the lack of registries for this condition; the lack of standard clinical and surveillance definitions; the lack of timely age-, sex-, race- and ethnic-specific background prevalence estimates; and the apparent difference in regional prevalence across the United States. The Agency for Toxic Substances and Disease Registry (ATSDR) partnered with the Jackson County Health Department in Missouri, the Ohio Department of Health, and the Texas Department of Health to determine MS prevalence in three geographic areas. This report presents the findings of the Texas Department of Health. The results from the Missouri and Ohio study sites are presented in separate reports.

The Texas Department of Health first become involved with multiple sclerosis and environmental concerns in Texas when a citizen requested an investigation of a possible cluster of MS among people who spent their childhoods in an El Paso neighborhood and who attended the same elementary school (Mesita Elementary) in the late 1940s through 1970. The results of the investigation, published in 2002, showed a crude prevalence estimate for the Mesita study cohort of 360/100,000. The standardized morbidity ratio (SMR) calculated for the Mesita study cohort was 1.93 (95% CI = 1.06 - 3.24), indicating a statistically significant two-fold increased risk of MS. The SMR was calculated using data from the 1989-1994 National Institute of Health Survey (NHIS). (3)

National prevalence estimates vary widely and are dependent on the methodology and population sample used for the estimate. Baum and Rothschild reported a prevalence of 57.8 per 100,000 population based on a 1976 survey of physicians and hospitals by the National Institute of Neurological Disorders and Stroke (NINDS) (4). Anderson et al. (5) attempted to adjust the 1976 NINDS survey data to reflect changes in the U.S. population and improved diagnostic techniques. Anderson's reported adjusted prevalence estimate was 95 per 100,000 people. The National Health Interview Survey (NHIS) for 1989 through 1996, a national probability sample based on self-reported cases, provided a prevalence estimate of 87 per 100,000 people in the

civilian non-institutionalized population (6). Prevalence estimates for specific locales published since 1970 range from 22 to 160 per 100,000. The highest reported prevalence for a specific geographic area is from a 1985 Minnesota study using the centralized diagnostic index at the Mayo Clinic (7).

To examine the effect of using different published U.S. prevalence estimates for MS on the risk estimate calculated for the El Paso cohort, risk estimates were calculated using the information on age-specific MS prevalence estimates from Baum and Rothschild (4), Wynn et al. (7), and the 1989-1994 NHIS survey (6). The standardized mortality ratios calculated using the three different published estimates ranged from 1.05 (95% CI 0.57 – 1.76) to 2.80 (95% CI =1.52 - 4.66). Depending on the baseline prevalence used in the El Paso study, the resulting SMRs ranged from essentially no elevated risk to an almost three-fold risk. When attempting to apportion limited public health resources to investigate potential public health concerns such as disease clusters; it is essential to understand the basic epidemiology of the disease under investigation and to have appropriate baseline population estimates for the disease to use as a comparison.

The primary limitation noted for the El Paso investigation was the lack of appropriate MS comparison prevalence estimates for Texas or for the southwest region of the United States. Although an excess of MS was evident in the Mesita cohort, the lack of appropriate comparison prevalence estimates precluded an assessment of the true impact of the disease in the cohort. Two of the recommendations from the El Paso investigation were to: (1) develop current MS prevalence estimates for Texas and (2) re-analyze the El Paso MS cluster data when Texas prevalence estimates become available.

The Agency for Toxic Substances and Disease Registry provided funding to TDH to develop a pilot MS surveillance project in 19 counties centered on the City of Lubbock, Texas. This 19-county study area offered a unique opportunity to conduct a pilot surveillance project because of the relatively isolated geographic location, the limited number of neurologists, and the race/ethnicity distribution of the population. The Texas Tech University Medical System is one of the major health care providers for the 19 counties and the majority of north and west Texas. In addition to Texas Tech, neurological services were also provided by eight private practice neurologists based in Lubbock during the study period, all of whom agreed to participate in surveillance activities.

The principal goal for this study was to determine MS prevalence estimates for the 19-county study area using neurologists' medical records as the primary data source. Sex-, age-, race-, and ethnic-specific prevalence estimates were also calculated. In addition, data were gathered from death certificates for the 19 county study area.

STUDY OBJECTIVES

The objectives of the study were to:

1. Identify and solicit support and participation of stakeholders in the study area, including neurologists and other members of the medical and public health community.
2. Identify prevalent cases of MS for the years 1998 – 2000.
3. Evaluate the completeness of case ascertainment from neurology practices by comparing with cases that were identified from other sources.
4. Calculate prevalence estimates by sex, age group, and race/ethnicity.
5. Conduct a re-analysis of the El Paso MS cluster using the new prevalence estimates.

METHODS

Study Area

Nineteen counties in north Texas were included in this surveillance project (see Figure 1). These counties are Bailey, Borden, Cochran, Crosby, Dawson, Dickens, Floyd, Gaines, Garza, Hale, Hockley, Kent, Lamb, Lubbock, Lynn, Motley, Scurry, Terry, and Yoakum. The City of Lubbock, located in Lubbock County, is the only metropolitan area in the 19-county area.

Case Ascertainment

The primary data source for case ascertainment was medical records from the offices of private neurologists practicing in the 19-county study area and the Texas Tech University Medical Center. All the neurologists were located in the City of Lubbock in Lubbock County.

Additional data sources such death certificates and hospital discharge data were also explored to ensure complete case ascertainment. Death certificates were available and were used as a secondary source of case ascertainment. Electronic hospital discharge records with identifying information were not available for the study time period. Other potential sources of cases may also have included nursing facilities and primary care physicians, particularly in the rural part of the study area. However, these data sources were not able to be accessed for this project.

Neurologists were asked to supply medical records coded to the following International Classification of Disease, 9th Revision (ICD-9) codes:

- 323.9 Unspecified cause of encephalitis
- 334.3 Other cerebellar ataxia
- 334.9 Spinocerebellar disease, unspecified
- 336.9 Unspecified disease of spinal cord
- 340 Multiple Sclerosis
- 341.9 Demyelinating disease of central nervous system, unspecified

- 344 Other paralytic syndromes
- 377.3 Optic neuritis

Records of patients who resided in the 19-county study area at any time between January 1, 1998 and December 31, 2000 and who had a documented office visit to a neurologist during that time period were considered eligible for inclusion in the study. Residence was determined by the address or addresses listed in the patient's medical record.

A standard abstracting form (Appendix A) was used by abstractors who were trained and supervised by the principal investigator and the project neurologist. Clinical examination and attack histories were collected, as well as laboratory and magnetic resonance imaging (MRI) results. Descriptive variables collected included sex, race/ethnicity, age, family history of MS, country/state of birth, treating physician's diagnosis, criteria used to determine diagnosis, date of diagnosis, and date of symptom onset. Identifying information was recorded on the abstract form to ensure accurate counts of cases and avoid duplicate counting from other sources. Individual identifiers were removed prior to review by the project neurologist and for the final analysis.

Case Definition

To be included as a case in this surveillance project, the following criteria had to be met for the time period January 1, 1998 and December 31, 2000:

1. residence in the 19-county study area at any time.
2. documented office visit with a neurologist.
3. multiple sclerosis status (definite and probable) confirmed by the project neurologist using the Poser criteria. (8)

Case Confirmation

All potential MS cases identified were verified by a single reviewing neurologist using the abstracted information from the medical records. No identifying information was provided in the abstract material reviewed and rated by the neurologist. Each case was rated according to two sets of criteria, the Poser criteria of 1983 and the McDonald criteria of 2001 (8, 9).

Appendix B contains a listing of the Poser and McDonald criteria. An additional category of APresumptive MS@ was created to enumerate individuals for which there is strong clinical or historical evidence of MS, but insufficient supporting diagnostic records which would allow categorization based on criteria. Presumptive MS cases were not included in the final prevalence estimates.

Data Management and Quality Control

Records were abstracted from the Texas Tech University Medical Center and from private neurology practices by project staff. Data from the abstract forms were entered into an

electronic database by project staff. Study participants who had records abstracted from more than one neurologist were identified and all pertinent information combined into one record. All identifying information from each abstract was removed from the database for the final analysis. Access to the paper and electronic records were limited to project staff.

Quality assurance and control measures included the initial training of project abstractors prior to the start of abstracting and periodic reviews of abstracting elements with the abstractors during the course of the project. In addition, each abstract was reviewed for accuracy by a second abstractor in the field and by the principal investigator prior to review and rating by the project neurologist. Primary data elements from all abstracts were visually checked for accuracy by the principal investigator after data entry.

Data Analysis

Period prevalence ratios and 95% confidence intervals were calculated for the study area based on race/ethnicity, sex, age group, and residence. Definite and probable MS cases ascertained from the surveillance activities were used as the numerator and the year 2000 census counts for the study areas were used as the denominator. (12) Period prevalence was chosen over point prevalence or incidence because of difficulties associated with MS diagnosis. Period prevalence provides a snapshot of existing cases and newly diagnosed cases within the study period. A re-computation of the standardized morbidity ratio for the El Paso cluster investigation was also computed using results from this study.

Protection of Human Subjects

The Investigational Review Boards of the U.S. Centers Disease Control and Prevention and the Texas Department of Health approved the protocol for this study. The TDH Institutional Review Board did not allow direct patient contact, so there was no formal involvement of MS advocacy groups or contact with individuals with MS in the study area.

In accordance with the Privacy Act of 1974 (5 U.S.C. Section 552a-e) and the Texas Health and Safety Code (Chapter 161), all completed abstract forms and other identifying information were kept secure and access was limited to authorized personnel. The findings of the study are presented in aggregate form to avoid disclosing the identity of any study participant.

RESULTS

The Texas Tech University Medical System and eight private neurologists provided neurologic specialty services and care for the 19-county Texas study area during the study period (1998 to 2000). During the pilot surveillance project one private practice neurologist office closed, but this neurologist's patients were dispersed to other health care providers in the area. Records were reviewed from the Texas Tech University Medical System, the remaining seven private practice neurologists and from the physician who retired.

A total of 480 medical records were screened for study eligibility. Thirty-four records (7%) were found to be duplicates (an individual had seen two or more physicians). Two hundred and

forty-seven records met the criteria for the study: eligible ICD code, residence in study area, and a documented physician visit during the study time period. Of the 247 records that met the study criteria, 224 were submitted to the consulting neurologist for review. The 23 records that were not submitted for review were those records for which abstractors were not able to find any indication that MS had ever been considered as a diagnosis or records for which there was little or no medical information included in the chart. For those records, an abbreviated abstract form that collected demographic data was completed.

Table 1 contains a summary of the diagnostic categories, for both Poser and McDonald, assigned to each medical record abstract by the consulting neurologist. According to the 1983 Poser criteria, 182 abstracted records were classified as Definite or Probable MS by the reviewing neurologist. Using the McDonald 2001 criteria, 177 abstracts were classified as Definite MS. One hundred sixty-eight abstracts were classified as Definite MS under both the Poser and McDonald criteria. Table 2 contains a comparison of the number of cases classified under each of the two sets of criteria.

Medical records coded for multiple sclerosis (ICD-9 340) accounted for 98% (n=221) of all abstracts that were classified as Definite and Probable MS under the Poser criteria and Definite MS under the McDonald criteria. One case was identified under ICD-9 377.3 (optic neuritis) and two cases under ICD-9 341.9 (demyelinating disease of central nervous system, unspecified).

Table 3 is a comparison of potential sources for identifying cases of MS. Fourteen death certificates were identified through a vital record search that listed multiple sclerosis as either the immediate, underlying, or contributing cause of death. Five decedents were identified through medical record abstraction as well as vital records review. One decedent, however, had not visited a neurologist during the study time period. Nine other individuals were not identified through the Texas Tech system or private neurologists' offices. Seven of the nine individuals identified exclusively through vital records died in 1998 or 1999. Four of the five individuals identified both through medical abstraction and through vital statistics died in 2000. Medical record abstraction did not begin until 2001.

The distribution of cases by sex, age, race/ethnicity, and residence is presented in Table 4. The overall prevalence for the 19-county study area, based on the Poser criteria, is 42.8/100,000 (95% CI 36.8 – 49.5). The prevalence estimate for females is 68.6/100,000 (95% CI 58.0 – 80.6) and for males is 16.6/100,000 (95% CI 11.6 – 23.1). The two age groups with the highest prevalence were the 40 to 49 year old age group (103.1/100,000; 95% CI 78.5 – 132.9) and the 50 to 59 year old age group (119.9/100,000; 95% CI 88.7 – 158.5).

Information on race and ethnicity was missing in 30% (n=55) of the medical records of the MS cases. Race/ethnicity information was supplemented using information from public records and vital statistics data. Individuals for whom no additional information could be located are listed under the “unknown” category. The prevalence estimate for non-Hispanic whites is the highest for any of the race/ethnic groups at 56.0/100,000 (95% CI 47.1 – 66.1), followed by non-Hispanic Blacks at 22.1/100,000 (95% CI 8.1 – 48.1), and Hispanics 11.2/100,000 (95% CI 6.4 – 18.2).

El Paso Cluster Investigation

Findings from the El Paso MS cluster investigation were also re-evaluated using the age- and sex-specific prevalence estimates from the 19-county pilot project (Table 5). The revised standardized morbidity ratio for Mesita cohort is 3.91 (95% CI 2.24 – 6.35). The SMR for females is 3.12 (95% CI 1.56 – 5.58) and for males the SMR is 8.93 (95% CI 8.89 – 20.84).

In the original El Paso cluster investigation, SMRs were calculated using three different reference populations because no Texas-specific data was available. The SMRs ranged from 1.05 (95% CI= 0.57 - 1.76), indicating essentially no excess of MS among the cohort members to 2.80 (95% CI =1.52 - 4.66) indicating an almost three-fold excess. In the final analysis the decision was made to use the latest NHIS data survey data as a comparison primarily because it represented the most current data and had estimates for the southern portion of the United States. The resulting SMR was 1.93 (95% CI = 1.06 - 3.24) indicating a statistically significant two-fold increased risk of MS. Using the Texas-specific data, the final risk estimate is a four-fold increased risk of MS, doubling the original risk estimate from the first study.

DISCUSSION

The results of this project support a regional difference in the prevalence of MS across the United States with the Texas prevalence of 42.8/100,000 approximately half that reported for the entire United States in the NHIS survey data of 85/100,000. (6) Comparing sex-specific prevalence estimates from the study area with the NHIS data for the nation and southern region of the United States, the Texas prevalence estimates for both males and females (16.6/100,000 for males and 68.6/100,000 for females) are substantially less than those reported for the nation of 48/100,000 for males and 123/100,000 for females and those reported for the Southern region of 36/100,000 for males and 91/100,000 for females. The female to male prevalence ratio from the Lubbock area is substantially higher at approximately 4 to 1 than that typically reported nationally of 2 to 1 and that reported for the southern region of the United States in the NHIS survey of approximately 2.5 to 1. This difference in the sex-specific prevalences could be the result of underascertainment of male cases, underdiagnosis of the disease in males in the Lubbock area, or an actual difference in the prevalences.

The pattern of the overall age distribution for age-specific prevalence in the 19-county study area, however, is similar to that reported in the NHIS data. The highest prevalences were reported for 40 to 49 and 50 to 59 age groups and the lowest prevalences in the <30 and over 70 age groups. The Texas data, however, indicate a considerably lower prevalence in each of the age groups.

Race and ethnicity proved to be the most challenging variable to collect. Thirty percent of the medical records reviewed had no information on race or ethnicity. Additional information was retrieved from other sources, but there was no objective criteria applied from any source of information as to how race and ethnicity were determined. Even with supplemental information, we still were not able to classify 10% (n=20) of the cases as to their race and ethnicity. Due to

the varying definitions used to classify ethnicity among the sources that listed ethnicity, the estimates provided for Hispanics should be considered approximate.

Based on the available information, the relative proportion of MS cases among Blacks and non-Hispanic whites for Texas is similar to that reported nationally with the prevalence among non-Hispanic whites approximately twice that of Blacks. However, the actual prevalence estimates for both non-Hispanic whites and Blacks in Texas are approximately half that reported nationally: 48/100,000 versus 22/100,000 for Blacks and 96/100,000 versus 56/100,000 for whites. There are no estimates for Hispanics included in the NHIS data that would allow comparison of the Texas data with national data.

The lack of information on Hispanic prevalence, not only in the NHIS, but also in the published scientific literature represents an important data gap. One Mexican study published in 2000 indicated an MS prevalence for Mexico of 1.5/100,000; approximately 10% of that reported for Hispanics in the Texas study (11.2 /100,000). (10) There are also indications in the Mexican literature that MS is on the rise in Mexico. (11) Although the results from this study are an important contribution, additional work in Hispanic populations is needed to understand the basic epidemiology of MS in Hispanics and the underlying etiology of the disease. Additional work is also needed to clarify issues related to how ethnicity is defined and reported.

The prevalence estimate reported for Lubbock County, the only county with a major metropolitan area, the City of Lubbock, is twice that of the other 18 rural counties. This could represent the effect of differential migration of people diagnosed with MS to Lubbock to be closer to specialty neurology care or an under ascertainment of cases, particularly less severe cases of MS in the rural counties.

This project has generated the first Texas-specific population-based MS prevalence estimates, including the first MS prevalence estimates for Hispanics and Blacks in Texas. While prevalence estimates cannot inform us regarding the trend in newly diagnosed cases of MS, they are useful to provide a snapshot of the burden of disease in a geographic area. In addition, the prevalence estimates help us understand how the El Paso cohort and the 19-county study area compare with the rest of the United States. This can provide important clues for additional studies. The results apparently support a regional difference across the United States in disease prevalence. These study results also 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. As is illustrated by the revised risk estimate for the El Paso Mesita Elementary cohort, the results also highlight the need for timely and region-specific prevalence estimates for evaluating MS cluster concerns.

STRENGTHS AND LIMITATIONS

This project has several strengths. First, it provided the first population-based MS prevalence estimates for Texas and allowed the re-analysis of the El Paso cluster using comparison data that is region-specific, timely, and used a standardized case definition.

Second, the geographic location of the 19-county study area and the cooperation of the local neurology community were critical to the success of the surveillance efforts. Due to the distances involved in using a neurologist located outside the study area, there was essentially a circumscribed population in the study area. This coupled with the cooperation of all of the practicing neurologists and the Texas Tech Medical system increases our confidence that the case ascertainment efforts and subsequent counts are as complete as surveillance allows. One neurologist did retire from practice at the start of the study period, but those patients were seen at other area practices.

The primary limitation of this study was the lack of case information from other sources, specifically family and general practitioners in the 19-county area who may have provided care to individuals with less progressive forms of MS. In future surveillance efforts, actively surveying family and general practitioners in the study area will help to fill that gap. There is also concern about individuals who may not have had access to the medical system, lack sufficient insurance resources to pursue a diagnosis, those who chose to manage their MS with alternative therapies, and those who have a mild or remitting form of the disease and required no care during the study period. Active participation of the local MS community, including the ability of TDH to collect limited case information from individuals who volunteer to participate, would also help to fill this data gap in future efforts. These are important limitations that may account for the low prevalence of MS in this study area. Without additional surveillance efforts and the involvement of both the medical community and MS community, these limitations will not be able to be adequately addressed in the future.

Other limitations identified during this project are those common to many surveillance systems, particularly those systems that rely on medical records for demographic and diagnostic information. First, the lack of race and ethnicity recorded in the medical records used for this surveillance and the lack of objective criteria in the classification of cases for which there was race and ethnicity recorded limits the utility of the race and ethnic-specific prevalence estimates. Second, for some MS cases, there was not sufficient diagnostic information recorded in the medical record that would allow disease confirmation and case status assignment by the consulting neurologist. This resulted in an undercount of cases for the area. Although the undercount is most likely minimal, this is a limitation that can be addressed in subsequent surveillance efforts. Finally, additional attention needs to be focused on retrieving medical records of individuals who die during the surveillance time period.

CONCLUSIONS

1. Texas has one of the lowest reported MS prevalences in the United States.
2. The results of this pilot project support an apparent regional difference in MS prevalence across the United States.

3. The overall age distribution for age-specific prevalences in the 19-county study area is similar to that reported in the NHIS data, although the Texas data indicate a substantially lower prevalence in each of the age groups.
4. The difference in the sex-specific prevalences in Texas is higher than reported in the national studies: four-fold versus two-fold.
5. There are no published national prevalence estimates for Hispanics that will allow comparison with the pilot data.
6. Re-analysis of the El Paso MS cluster using Texas-specific data resulted in an SMR for the Mesita cohort of 3.91 (95% CI 2.24 – 6.35). This is substantially higher than the initial calculation of 1.93 (95% CI 1.06 - 3.24) using national data. This also underscores the necessity of appropriate comparison data in the evaluation of purported clusters.
7. There is substantial work to be done on the basic epidemiology of MS in Texas, regionally, and nationally.

RECOMMENDATIONS

1. Continue surveillance in the 19-county North Texas study area. This will provide more stable prevalence estimates and allow us to begin to examine disease prevalence trends in the area.
2. Include a survey of family and general practitioners in future surveillance efforts in the 19-county North Texas study area assess the percentage of MS patients who do not use a neurologist for disease management, but may instead rely on a family doctor.
3. Allow local MS organizations or individuals with MS to play an active role in the surveillance efforts.
4. Continue efforts to obtain hospital discharge data that contains identifying information. Hospital discharge data as a source for case ascertainment should be evaluated for the 19-county study area.
5. Expand MS surveillance to other areas of Texas. The results of the Lubbock surveillance should be replicated in other locales to confirm the prevalence estimates. Additional surveillance sites should include larger Hispanic and African-American populations.
6. Continue efforts to evaluate and refine surveillance methods for more cost-effective surveillance and for a model to be used in other geographic locations.
7. Develop permanent surveillance sites in key regional locations in Texas and throughout the United States.

8. Make MS a reportable disease condition.
9. Target neurologists for educational efforts related to surveillance. Emphasis should be placed on the need for surveillance data, basic surveillance methods, and ensuring basic demographic elements such as race and ethnicity are contained in the medical record.
10. Initiate etiologic studies to determine risk factors for MS and to help understand the regional differences in the disease.
11. Survey the El Paso cohort at regular intervals to determine any change in MS prevalence.
12. Develop new methods to involve surveillance sources and incentives for participation. This could include the development of continuing medical education courses for participating clinicians.

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TABLES

Table 1. Outcome of reviewed medical records according to MS diagnostic criteria.

Poser 1983 criteria¹	Number of reviewed records
Definite	170
Probable	12
Possible	2
Presumptive ²	7
Not MS	33
McDonald 2001 criteria³	
Definite	177
Possible	25
Presumptive ²	1
Not MS	21
Total records reviewed	224

¹ Poser CM, Paty DW, Scheinberg L, et al. New diagnostic criteria for multiple sclerosis: guidelines for research protocols. *Ann Neurol* 1983;13:227-231.

² Presumptive category is for those records with strong indications of MS, but insufficient medical record history available to confirm diagnosis. This category was not used in the final case counts.

³ McDonald WI, Compston A, Edan G, et al. Recommended diagnostic criteria for multiple sclerosis: guidelines from the International Panel on the Diagnosis of Multiple Sclerosis. *Ann Neurol* 2001;50:121-7.

Table 2. Comparison of case classification based on the Poser and McDonald diagnostic criteria.

POSER CRITERIA	MCDONALD CRITERIA				
	Definite	Possible	Presumptive	Not MS	Not Reviewed
Definite	168	2	0	0	0
Probable	6	5	0	1	0
Possible	0	2	0	0	0
Presumptive	0	6	1	0	0
Not MS	3	10	0	20	0
Not Reviewed	0	0	0	0	23

Table 3. Sources for cases.¹

Source	MS Cases
Neurologist offices	224 ²
General practitioner or other physician	N/A
MS patient advocacy group	N/A
Death certificates	9 ³
Hospital discharge data	N/A
Self-identified	N/A
Other	N/A
Total	233

¹ For cases identified through both neurologist office records and another source(s), the case is counted only under the neurologist offices category.

² Includes four cases identified both through death certificates and medical record review.

³ Death certificates listed multiple sclerosis as either the immediate, underlying, or contributing cause of death. Medical records for these patients were not abstracted or reviewed.

Table 4. Descriptive characteristics of cases and respective strata-specific prevalence. 19-county study area, Texas: 1998 – 2000.

	MS cases ¹	Population	Strata-specific prevalence per 100,000 population (95% CI) ³
Overall Prevalence			
19 Counties	182	424,916	42.8 (36.8 – 49.5)
Sex			
Female	147	214,235	68.6 (58.0 – 80.6)
Male	35	210,681	16.6 (11.6 – 23.1)
Age			
< 30	19	201,420	9.4 (5.7 – 14.7)
30-39	33	57,282	57.6 (39.7 – 80.9)
40-49	59	57,239	103.1 (78.5 – 132.9)
50-59	49	40,869	119.9 (88.7 – 158.5)
60-69	17	30,676	55.4 (32.3 – 88.7)
70 +	4	37,430	10.7 (2.9 – 27.4)
Unknown	1	---	-----
Race/ethnicity²			
Hispanic	16	142,448	11.2 (6.4 – 18.2)
Non-Hispanic White	140	249,882	56.0 (47.1 – 66.1)
Non-Hispanic Black	6	27,173	22.1 (8.1 – 48.1)
Unknown	20	---	---
Residence³			
Lubbock County	132	242,628	54.4 (45.5 – 64.5)
18 Rural Counties	50	182,288	27.4 (20.4 – 36.2)

¹ Cases include those with Definite or Probable diagnosis according to the Poser 1983 criteria.

² Race/Ethnicity determined by information available on the medical records and public and vital records.

³ Prevalence = cases/100,000 population. Fisher's Exact 95% Confidence Intervals

Table 5. Standardized morbidity ratio for Mesita Elementary School cohort, El Paso, Texas.

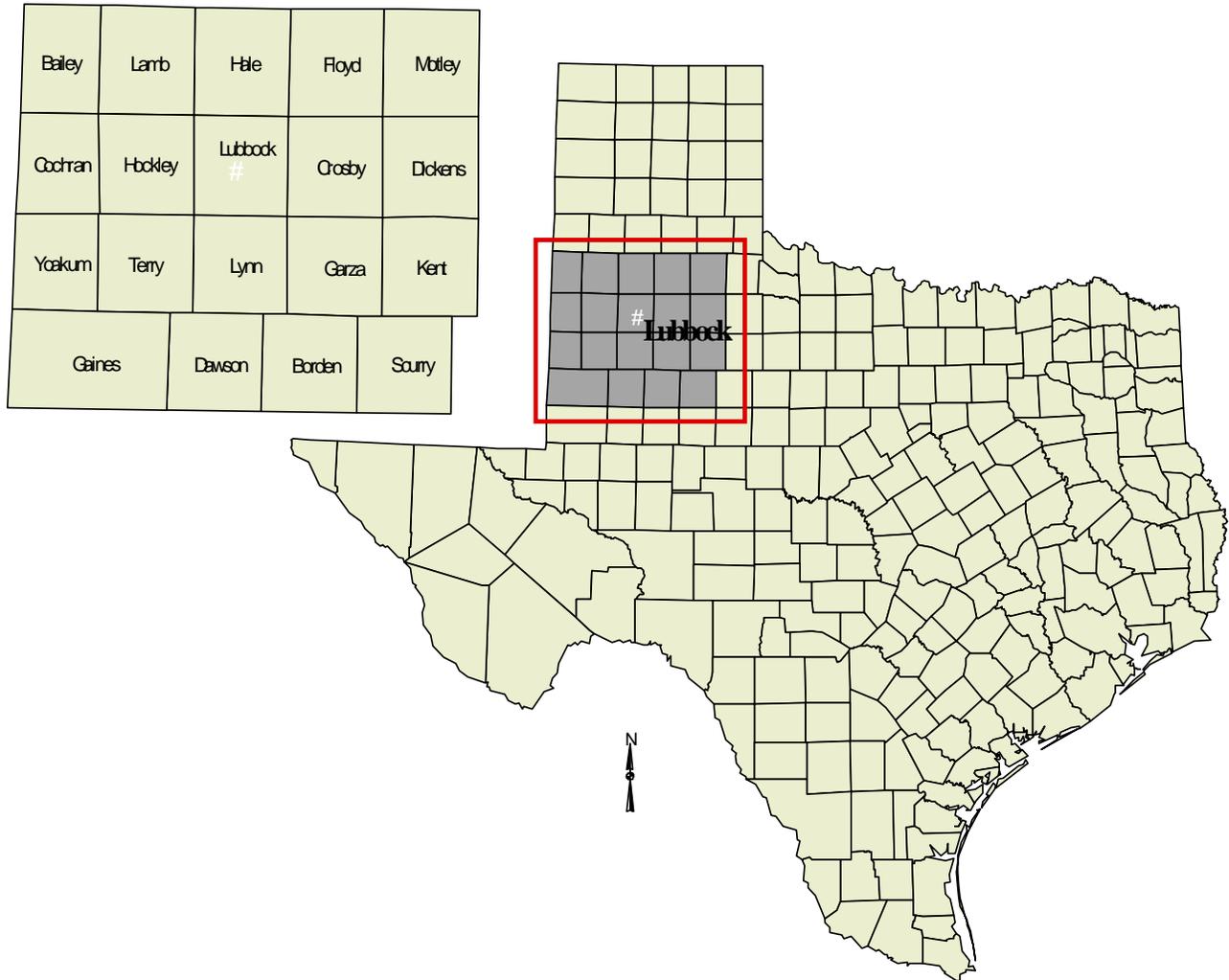
	Expected Cases¹	Observed Cases	SMR	95% CI²
Female	3.53	11	3.12	1.56 – 5.58
Male	0.56	5	8.93	2.89 – 20.84
Total	4.09	16	3.91	2.24 – 6.35

¹ Expected cases based on observed prevalence in 19-county Lubbock, Texas study area.

² The SMRs were tested for significant deviation from 1.00 by using Fisher's exact test and exact confidence intervals for the Poisson variate.

FIGURES

Figure 1. Map of 19-County Study Area.



APPENDIX A
MEDICAL ABSTRACTION FORM

I. Record Abstraction Criteria

Did the patient visit the physician between 1/1/1998 and 12/31/1998? Y ___ N ___
Did the patient visit the physician between 1/1/1999 and 12/31/2000? Y ___ N ___
Did the patient visit the physician between 1/1/2001 and 12/31/2001? Y ___ N ___
Patient's Zip code(s) during period of study: _____

II. Patient Identification

Facility/Clinic Containing Records: _____
Medical Record Number: _____
Social Security Number: _____ - _____ - _____

PATIENT'S NAME		
Last _____		
First _____		M.I. _____
Maiden _____		
DATE OF BIRTH ____/____/____ (mm/dd/yyyy)	SEX M ___ F ___ (check one)	RACE/ETHNICITY Black (non-Hispanic) ___ White (non-Hispanic) ___ Hispanic ___ Asian, Pacific Islander ___ Native/Alaskan American ___ Other (please specify) _____
CURRENT ADDRESS (Most Recent)		
Street _____		

City _____		State _____
Zip Code _____		County _____
Country of Current Residence _____		
Country of Birth _____		

ABTRACTOR'S NAME _____ **DATE** _____
SIGNATURE _____

III. Diagnosis/Physician History

DATE OF SYMPTOM ONSET	DATE OF MS DIAGNOSIS	FAMILY HISTORY OF MS (Relation – age of MS onset)
____/____/____ (mm/dd/yyyy)	____/____/____ (mm/dd/yyyy)	1) _____ 2) _____ 3) _____

<u>NEUROLOGIST'S DIAGNOSIS</u>		
Definite MS _____ Probable MS _____ Possible MS _____ Other _____		
ICD CODE(s) 1) _____ 2) _____ 3) _____ 4) _____		
INITIAL REFERRING PHYSICIAN: _____ ADDRESS: _____ _____ PHONE NO.s (____) _____ (____) _____		
DIAGNOSING NEUROLOGIST: _____ ADDRESS: _____ _____ PHONE NO.s (____) _____ (____) _____		
TREATING PHYSICIAN: _____ ADDRESS: _____ _____ PHONE NO.s (____) _____ (____) _____		
TREATING PHYSICIAN: _____ ADDRESS: _____ _____ PHONE NO.s (____) _____ (____) _____		

V. Clinical Exam and Attack History

1st Attack:

Date: _____

Area of the body affected by the attack: _____

Signs/Symptoms: _____

2nd Attack:

Date: _____

Time between 1st and 2nd Attacks: _____

Area of the body affected by the attack: _____

Signs/Symptoms: _____

3rd Attack:

Date: _____

Time between 2nd and 3rd Attacks: _____

Area of the body affected by the attack: _____

Signs/Symptoms: _____

ADDITIONAL COMMENTS: _____

Any change of diagnosis?:

VI. MS DIAGNOSIS (After Evaluation by Reviewing Neurologist)

Poser Criteria	2001 Criteria
Definite __	Definite __
Probable ___	Probable ___
Presumptive __	Presumptive __
Possible __	Not MS __
Not MS __	
REVIEWING NEUROLOGIST'S NAME _____	DATE _____
SIGNATURE _____	

APPENDIX B
DIAGNOSTIC CRITERIA

I. POSER CRITERIA ⁸

- **Clinically definite MS**
 - 2 attacks and clinical evidence of 2 separate lesions
 - 2 attacks, clinical evidence of one and paraclinical evidence of another separate lesion
- **Laboratory supported Definite MS**
 - 2 attacks, either clinical or paraclinical evidence of 1 lesion, and cerebrospinal fluid (CSF) immunological abnormalities
 - 1 attack, clinical evidence of 2 separate lesions & CSF abnormalities
 - 1 attack, clinical evidence of 1 and paraclinical evidence of another separate lesion, and CSF abnormalities
- **Clinically probable MS**
 - 2 attacks and clinical evidence of 1 lesion
 - 1 attack and clinical evidence of 2 separate lesions
 - 1 attack, clinical evidence of 1 lesion, and paraclinical evidence of another separate lesion
- **Laboratory supported probable MS**
 - 2 attacks and CSF abnormalities

II. MCDONALD CRITERIA⁹

Clinical Presentation	Additional Data Needed
<ul style="list-style-type: none"> • 2 or more attacks (relapses) • 2 or more objective clinical lesions 	None; clinical evidence will suffice (additional evidence desirable but must be consistent with MS)
<ul style="list-style-type: none"> • 2 or more attacks • 1 objective clinical lesion 	Dissemination in space, demonstrated by: <ul style="list-style-type: none"> • MRI • or a positive CSF and 2 or more MRI lesions consistent with MS • or further clinical attack involving different site
<ul style="list-style-type: none"> • 1 attack • 2 or more objective clinical lesions 	Dissemination in time, demonstrated by: <ul style="list-style-type: none"> • MRI or second clinical attack
<ul style="list-style-type: none"> • 1 attack • 1 objective clinical lesion (monosymptomatic presentation) 	Dissemination in space by demonstrated by MRI or positive CSF and 2 or more MRI lesions consistent with MS <i>and</i> Dissemination in time demonstrated by MRI or second clinical attack
Insidious neurological progression suggestive of MS (primary progressive MS)	Positive CSF <i>and</i> Dissemination in space demonstrated by: <ul style="list-style-type: none"> • MRI evidence of 9 or more T2 brain lesions • or 2 or more spinal cord lesions • or 4-8 brain and 1 spinal cord lesion • or positive VEP with 4-8 MRI lesions • or positive VEP with <4 brain lesions plus 1 spinal cord lesion <i>and</i> Dissemination in time demonstrated by: <ul style="list-style-type: none"> • MRI or continued progression for 1 year

MS = all criteria are fulfilled.

Possible MS = the criteria are not completely met.

Not MS = the criteria are fully explored and not met.