

Rural Health Care Needs and Utilization Survey

National MS Society, South Central

Survey Description

A telephone survey of people with MS who live in all rural counties of the South Central Region (SCR) was conducted by a professional research firm, Galloway Research Service of San Antonio, TX. The survey took place between December 19, 2011 and January 17, 2012. All five states in the Region were represented in the survey, and the percentage of survey responses from each state was closely proportionate to the rural MS population of that state.

Definition of “Rural”

For purposes of this survey, rural counties are those that lie outside an MSA (Metropolitan Statistical Area) and have a total county population of less than 50,000. This definition is consistent with the CDC (Centers for Disease Control) definition of a rural county.

Survey Methodology

The total number of National MS Society registered clients in the rural counties of the South Central Region is approximately 4,300. Of this total, valid phone numbers were identified for approximately 3,500 clients. Interviewers made up to ten attempts to reach each of these 3,500 clients by telephone, and were successful in reaching 899 clients and completing interviews with them. Each interview lasted approximately fifteen minutes. Standardized questions were used in the interview. The interview included both closed-ended and open-ended questions, and probing follow-up questions were used as needed for clarification. All interviews were conducted by professional interviewers, and all interviewers followed a standard interview protocol.

The survey methodology meets appropriate statistical requirements for sampling, and the responses collected may be viewed as accurately representing the views and behaviors of rural MS patients.

Objectives of the Survey

The objectives of the survey were to:

- Assess accessibility to MS specialty care and utilization of ancillary healthcare services (such as ophthalmology and urology) related to MS symptoms among people with MS in rural areas across the South Central Region (AR, LA, NM, OK, TX).
- Identify patient needs for specialized care and the barriers patients face in receiving that care.

- Determine the frequency of MS disease types and medication use among rural patients with MS.
- Build a contact database of physicians and therapists treating people with MS in rural counties.

Summary of Findings

Initial significant findings include:

1. 40% of people with MS are not taking one of the approved treatments for MS.
2. 18% of respondents do not have a doctor whom they regard as their “MS doctor.”
3. Of these 18%, who do not have a doctor whom they regard as their “MS doctor,”
 - a. 59% have not seen a neurologist within the past two years
 - b. 38% have not seen a neurologist within the past six years.
4. 17% of respondents are unsure of what type of MS they have.
5. 36% of respondents feel that they face significant barriers to accessing specialized care for their MS.
6. 26% of respondents feel that they face significant barriers to accessing care for MS-related symptoms (such as ophthalmology, urology, rehabilitation and mental health services).

Contact Database of Rural Healthcare Providers

One of the objectives of the survey was to create a contact database of healthcare providers who currently treat people with MS in the rural counties of the region. Complete contact information has been collected for approximately 1,500 rural healthcare providers including the following:

264 Neurologists.

675 Primary Care Physicians.

44 Mental Health Counselors.

150 Urologists.

228 Ophthalmologists.

127 Physical Rehabilitation Therapists.

Next Steps

Society staff will use these survey results in FY12-13 to strategically reach out to rural healthcare providers and to develop strategies to eliminate or minimize barriers to access healthcare that is needed by people with MS who live in rural areas.

- All healthcare providers identified through the survey will receive contact from the Society and will receive basic information and support for treating people with MS.
- High priorities for personalized outreach include:

- Rural healthcare providers who treat relatively large numbers of people with MS
- Rural healthcare providers who are the only source of care in an area of the Region
- Rural healthcare providers who meet a specific need identified by relatively large numbers of people with MS
- Rural healthcare providers who are strategically located to facilitate development of a region-wide network of MS care providers.
- The Region will work to establish a network of MS care providers that offers a point of entry into the network that is no more than a two-hour drive from any physical location within the Region. A point of entry may be an MS specialist, but in many cases, will be a general neurologist who is not an MS specialist. The network will facilitate professional relationships among the members, and these relationships will expedite needed referrals from the non-specialists to the specialists and the comprehensive MS care centers. When appropriate, care will continue to be provided by the local neurologist, with consultation or other support provided by an MS specialist and/or the Society. In some cases, members of the network will become Partners in MS Care. In other cases, members will not have the expertise, training, or knowledge to become a Partner in MS Care, but will be an important link between people in rural areas and the MS care that they need.

To establish the network, it will be necessary to identify network points of entry in approximately 30-35 strategically located communities within the Region. The Society is currently engaged with MS Clinics and/or MS Specialists in approximately 15 communities, so engagements are needed in 15-20 additional communities. Many of these new engagements will be with rural neurologists who are not MS specialists, but who, with the Society's support and facilitation, will establish a referral/consultative relationship with MS specialists.

A detailed summary of survey findings is provided in Appendix A, attached.

A list of survey questions is provided in Appendix B, attached.

Appendix A: Detailed Summary of Survey Findings

- Across the South Central Region 18% of rural MS patients do not have a physician who they regard as their MS doctor. The number of patients without a physician whom they perceive as their MS doctor is highest in Arkansas (24%) and New Mexico (26%).
- In every state, 93% or more of patients who do see a physician whom they regard as their MS doctor report that their MS doctor is a neurologist, and 82% say they have seen their MS doctor within the past six months.
- Overall, nine of ten rural patients (89%) say they have a primary care physician whom they see for routine medical care, and 81% of them have seen this primary care physician in the past six months. Arkansas has significantly more rural patients who say it has been more than a year since they've been to their primary care doctor (11% vs. 6% overall). Of those rural patients who have a primary care physician, 80% say they see a general or family practice physician, 14% see an internist, and 3% see a neurologist or some other specialty. While 3% of rural patients overall, said they see a physician assistant or nurse practitioner for routine care, New Mexico patients are significantly more likely (8%) to depend on PAs and NPs for their routine medical care.
- Almost all (98%) of rural patients who do not have a doctor whom they regard as their MS doctor say that they have seen a neurologist at least one time in the past. Of these, however, 59% said that the last visit they made to a neurologist was three or more years ago.
- More than one-third (36%) of rural MS patients in the South Central Region face barriers in getting all the MS specialty care they want or need. The most significant categories of barriers were:
 1. Travel Distance to MS Specialist (too far away, 2 hour drive one way, they are only in the big cities, 140 miles away) 57%
 2. Cost Issues (don't have insurance, insurance won't cover all my expenses, cost for the back and forth travel high, have to see a doctor within network, doctor won't accept insurance, etc.) 31%
 3. Transportation Issues (my son has to take off work and take me, problems finding someone to take me, bus does not go to doctor's office, don't drive) 17%
 4. Difficulty finding Experienced Doctor (knowledge of MS is not good, can't find the right doctor, few specialists in my area, local doctors don't know anything about MS) 15%
 5. Poor Experience with Doctor (I was not happy with the other one, the neurologist I saw was terrible, doctor doesn't know anything, doctor was not helping me, couldn't understand doctor) 12%

6. Accessibility or Schedule Issues (can't reach by phone, hard to get an appointment, appointments set too far away when I need someone right away, nurses don't return calls, wait for months to see one, they're booked for a year, if you are too progressed they don't want to see you again) 11%

- 40% of the rural patients surveyed say they do not take any of the disease modifying agents for MS. Of those who take a disease modifying agent, 21% take Copaxone and 15% take Avonex. The other drugs named in the survey are taken by 7% or fewer of rural patients.
- When asked what other healthcare services they required for conditions related to their MS, 38% of rural patients say they need help for eye and vision problems; 27% named urology services; 21% required physical therapy; and 7% said they needed counseling or mental health services.
- More than one-fourth (26%) of rural patients who required ancillary services (such as ophthalmology and urology) say they face barriers getting the help they need. The most common barriers they face are similar to the barriers patients face in getting MS specialty care. The most significant categories of barriers were:
 1. Insurance/Cost Issues (lack of money/insurance, main issue is money, treatments are so expensive and I have to make choices, can't afford deductible) 53%
 2. Travel Distance (the distance it takes to get to doctors, have to drive 140 miles, it is so far away) 27%
 3. Transportation Issues (transportation is the main issue, no public transportation, I have to get someone to take me) 18%
 4. Lack of needed Services or Facilities in the Area (no aqua or physical therapy facilities, no access to care where I live, lack of MS related services in my area, no support groups in area) 10%

Appendix B: Survey Questionnaire

The questionnaire included 18 questions, but not each question was applicable to each respondent.

The questions were as follows:

- Which of the following best describes your MS? (The types of MS were listed).
- Is there a physician who you see specifically for your MS, who you regard as your MS Specialist? (For purposes of the survey, “MS Specialist” does not necessarily describe a physician that the MS Society regards as a MS Specialist, based on experience, expertise, knowledge and patient volume. This question was based on the respondent’s perception of a “specialist”).
- Which of the following describes the medical specialty of the doctor you see specifically for MS care? (Neurology and primary care specialties were listed).
- What is your physician’s name, location, etc.?
- When was the last time you visited the doctor who sees you specifically for MS?
- Do you have a main physician who you see for routine medical care?
- What is your physician’s name, location, etc.?
- When was the last time you visited your main doctor for routine care?
- Which of the following describes the medical specialty of the main doctor you see for routine care? (Neurology and primary care specialties were listed).
- Have you ever seen a neurologist about your MS? (Not applicable to all interviews).
- When was the last time you saw a neurologist about your MS? (Not applicable to all interviews).
- Do you feel like there are barriers or issues that prevent or hinder you from getting all the MS care you want or need from doctors who are MS specialists?
- Please tell me what are the issues you face in getting the MS care you want or need from MS specialists?
- Please tell me which, if any, of the following MS medications you are currently taking? (8 MS disease-modifying drugs were listed).
- Which of the following other health care services do you require for conditions related to your MS? (Typical ancillary services were listed).
- What are the names, locations, etc. of these providers?
- Are there barriers that prevent or hinder you from getting healthcare services you want or need for conditions related to your MS?
- Please tell me what barriers you face in getting healthcare services you want or need for conditions related to your MS.

National MS Society, South Central
MS-CARE-LINK

A System of Relationships between the South Central Region of the National MS Society
And Health Professionals who Treat People with Multiple Sclerosis

Background

Most MS specialists in the National MS Society's South Central Region are concentrated in large urban medical centers and are located far away from many of the people who need their care. In the smaller cities and the rural areas of the Region, access to care by MS specialists is quite limited, and access to care by health professionals who are knowledgeable of MS, although not MS specialists, varies widely from place to place.

The South Central Region has established relationships with MS specialists and other health professionals in many parts of the Region, and these relationships are a source of support, in the form of information and resources, for health professionals. Equally important are the relationships between MS specialists and other health professionals who treat people with MS; these relationships support patient care through consultation and facilitate patient referrals when specialized care is needed. All of these relationships enhance the quality and the accessibility of healthcare for people with MS; however, relationships such as these have not yet been established in every part of the Region.

In early 2012, the South Central Region conducted a consumer survey, of people with MS who live in the rural counties of the Region, to assess healthcare needs and utilization. The survey indicated a number of barriers that these consumers face when attempting to access the healthcare that they need, and the South Central Region is currently working to identify strategies to address the barriers. Another important result of the survey was the creation of a contact database of approximately 1500 rural healthcare providers who currently treat people with MS, including 264 neurologists, 675 primary care physicians, 44 mental health counselors, 150 urologists, 228 ophthalmologists, and 127 physical rehabilitation therapists. The database provides a means of initiating relationships with health professionals who treat people with MS in rural areas of the Region, which is a critical component of implementing MS-CARE-LINK.

MS-CARE-LINK

MS-CARE-LINK will establish relationships with health professionals who treat people with MS in every part of the Region. A goal of MS-CARE-LINK is to establish relationships between the South Central Region and health professionals, in strategically selected locations, so that no person with MS is more than a 2-hour drive away from one of these health professionals. Some of the professionals will be MS specialists, and when appropriate, will be designated as Partners in MS Care. Others will not have the experience and expertise necessary to be designated as Partners in MS Care but will be important links between people with MS and the healthcare that they need. MS-CARE-LINK will use the relationships between the South Central Region and health professionals as the vehicle for delivering information and resources to healthcare providers who treat people with MS. These relationships, and the relationships between health professionals, will enhance healthcare in every part of the Region and will facilitate access to care that is not available in the community where a person with MS lives.

Achieving MS-CARE-LINK's goal of establishing a professional relationship within two hours of everyone in the Region will require that the South Central Region form relationships with health professionals in approximately 15-20 communities where relationships do not currently exist. This work is a major focus of the South Central Region for 2012 and 2013. For more information, contact Ray Owens at ray.owens@nmss.org .