

A Needs Assessment Survey of MS Patients and Care Partners

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Introduction

Little is known about the changing needs of MS patients and their care partners. To better understand the informational, educational, programmatic and service needs of MS patients and their care partners, a needs assessment survey was developed.

Methodology

Using the Multiple Sclerosis Association of America (MSAA) client database, the survey was sent by mail to 2,058 MS patients and care partners, of which 762 completed and returned the survey (37% response rate).

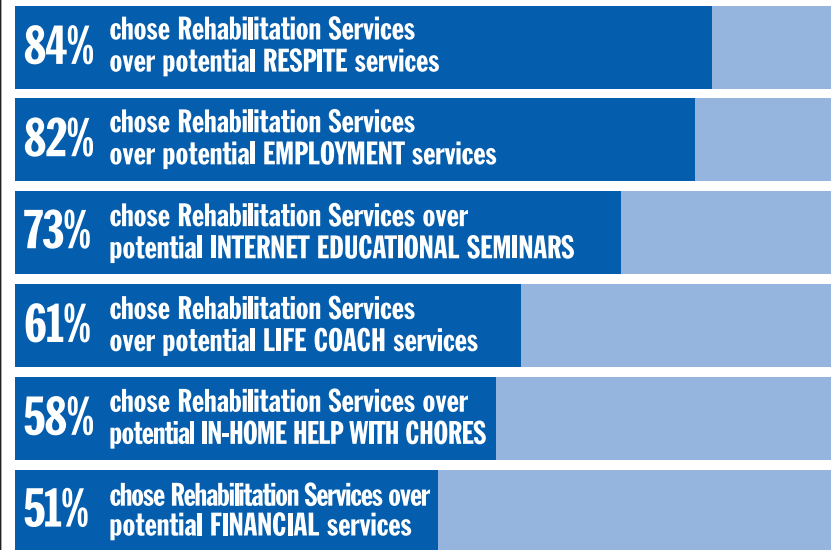
Participants

Participants were overwhelmingly female (78%), their MS diagnosis (52% RRMS; 21% SPMS; 10% PPMS; 5% PRMS; 12% don't know), their annual income (42% less than \$25,000; 41% \$40,000 or more; 15% more than \$70,000), and age (52% over 50 years old) varied.

The respondents were highly symptomatic, with more than 50% being at least moderately affected **in the past week** in 13 of 16 symptom categories. Only 18% reported no problems with walking, and 22% use a wheelchair or scooter most or all of the time. Other demographic information includes:

- 86% Caucasian; 6% African-American; 3% American Indian/Alaskan; 2% Hispanic/Latino
- 70% are receiving disability, retired or unemployed
- 70% have some college education; 42% have an Associate's Degree or higher

The majority of survey participants cited a **greater need for rehabilitation services** (information, education, programs, and services) as **compared to other potential programs and services** that could be offered. Shown below are the percentage of participants who chose Rehabilitation Services over each of these other options.



Results

Overall, the research suggests that medical information, rehabilitation and therapeutic services, as well as attaining life skills are important, and unmet, needs for MS patients.

In particular, participants expressed a great need for information, education, programs and services related to rehabilitation and alternative/complementary therapies.

Limitations of Research

- Findings may reflect needs that are particular to MSAA clients
- Care partners' low response rate (only 7% of respondents) made the findings relating to care partners inconclusive

Informational and Educational Needs

Participants were asked how often they needed information and education over the past year in 16 areas. Information on new medications, treatment and research was the greatest perceived need (84%). Other areas of informational and educational need included: information about exercise (77%); fatigue management/conservation (74%); better problem solving and coping (74%); and complementary or alternative therapies (72%).

Need for Programs and Services

From a list of 13 program areas currently provided by the MSAA, respondents were asked to identify the three most important programs and services. Publications and brochures were rated first, with educational awareness events following. Programs which combine social activities with therapeutic benefits, such as water exercise and Tai Chi classes, were rated third most important.

Participants were also asked to choose among six potential programs and services using a forced choice technique. Rehabilitation services (i.e. occupational or physical therapy, nutrition assistance and psychotherapy) were needed most compared to any of the other five potential program offerings. Services that provide skills, encouragement and support to help one manage one's life were identified as needed most when compared to all other potential programs except rehabilitation services. The need for both of these programs surpassed the need for assistance in meeting essential financial obligations.

The information presented in this section has been reformatted from the original content appearing on the poster described on page 35.

For more information about this study, please contact Amanda Montague at amontague@msaa.com or at (800) 532-7667, ext. 155.