

# WHAT ARE THE EDUCATIONAL NEEDS OF PEOPLE WITH MULTIPLE SCLEROSIS SHORTLY AFTER DIAGNOSIS?

Catherine Jacobs<sup>1</sup>, Audrey Osinski<sup>1</sup>, Kaye Gooch<sup>2</sup>, Prudence Plummer<sup>1</sup>

<sup>1</sup>University of North Carolina at Chapel Hill, Chapel Hill, NC ; <sup>2</sup>National MS Society, Greater Carolinas Chapter, Raleigh, NC

## INTRODUCTION

- Individuals with Multiple Sclerosis (MS) desire more information than they receive, especially at the time of diagnosis
- Although resources are available, there are several limitations:
  - Too many sources of information
  - Uncertainty about the type of questions to ask of health care professionals
  - Inability to find answers to specific questions
  - Lack of awareness of available resources
  - Generalized information

## OBJECTIVE

The purpose of this study was to assess the educational needs of people with MS soon after diagnosis

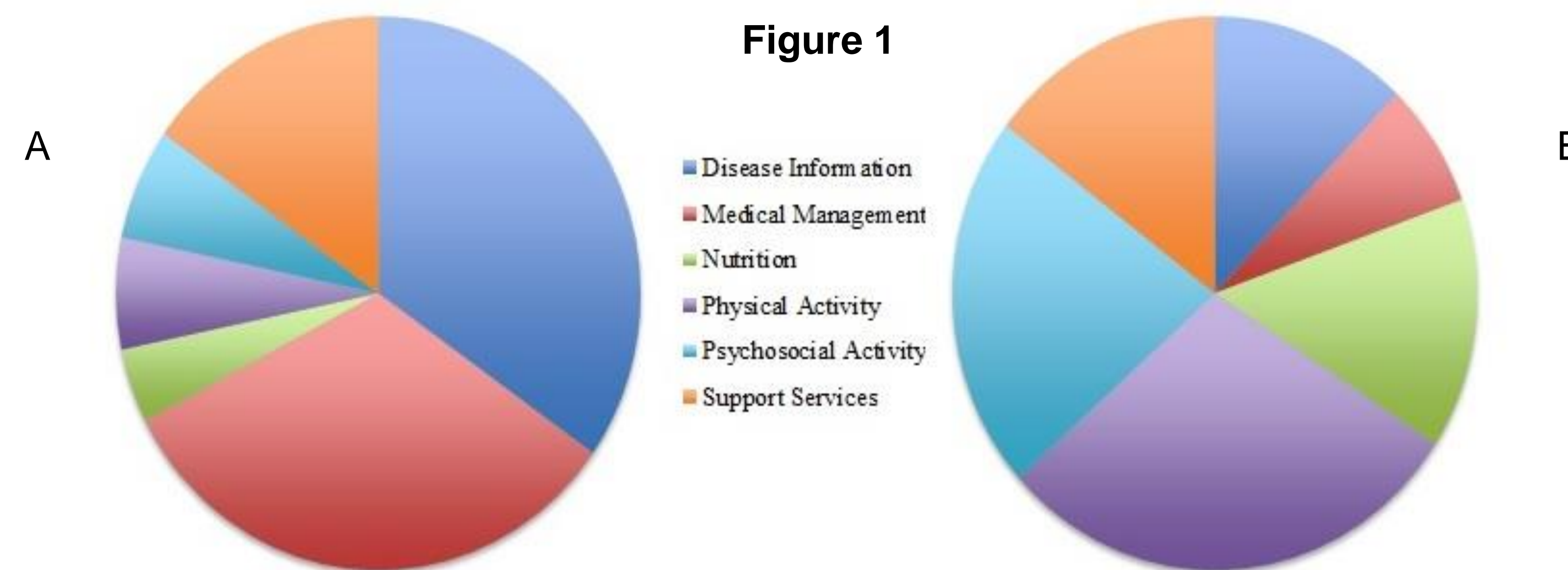
## METHODS

- An 8-question survey was distributed in paper or electronic copy through the Greater Carolinas Chapter of the National MS Society, physical therapists, and self-help group leaders to people living in North Carolina, South Carolina, and New York
- Survey questions asked about:
  - Time since diagnosis
  - Information considered valuable received at time of diagnosis
  - Information that would have been helpful at diagnosis
  - Level of physical activity
  - Interest in wellness information
  - Specific areas of interest regarding health and wellness
- Survey responses from North Carolina (n=21) are presented here
- 12 individuals had MS longer than 10 years and 4 had MS less than 2 years

## RESULTS

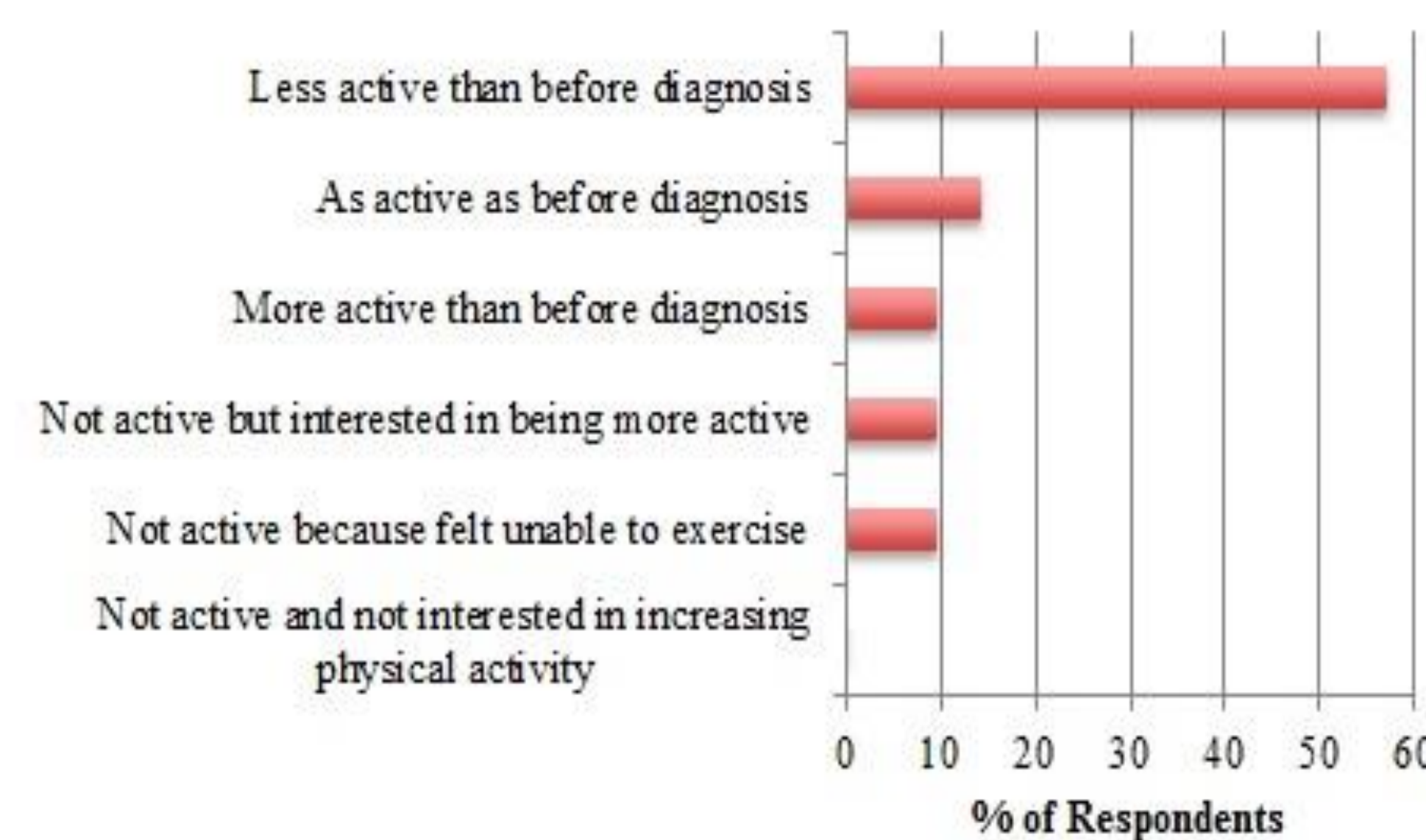
### Valued Information at Diagnosis

Figure 1 illustrates the distribution of responses for each information category for (A) information that was received and considered valuable at diagnosis and (B) information that was not received but would have been valuable



### Current Physical Activity

Figure 2. Current Activity Level



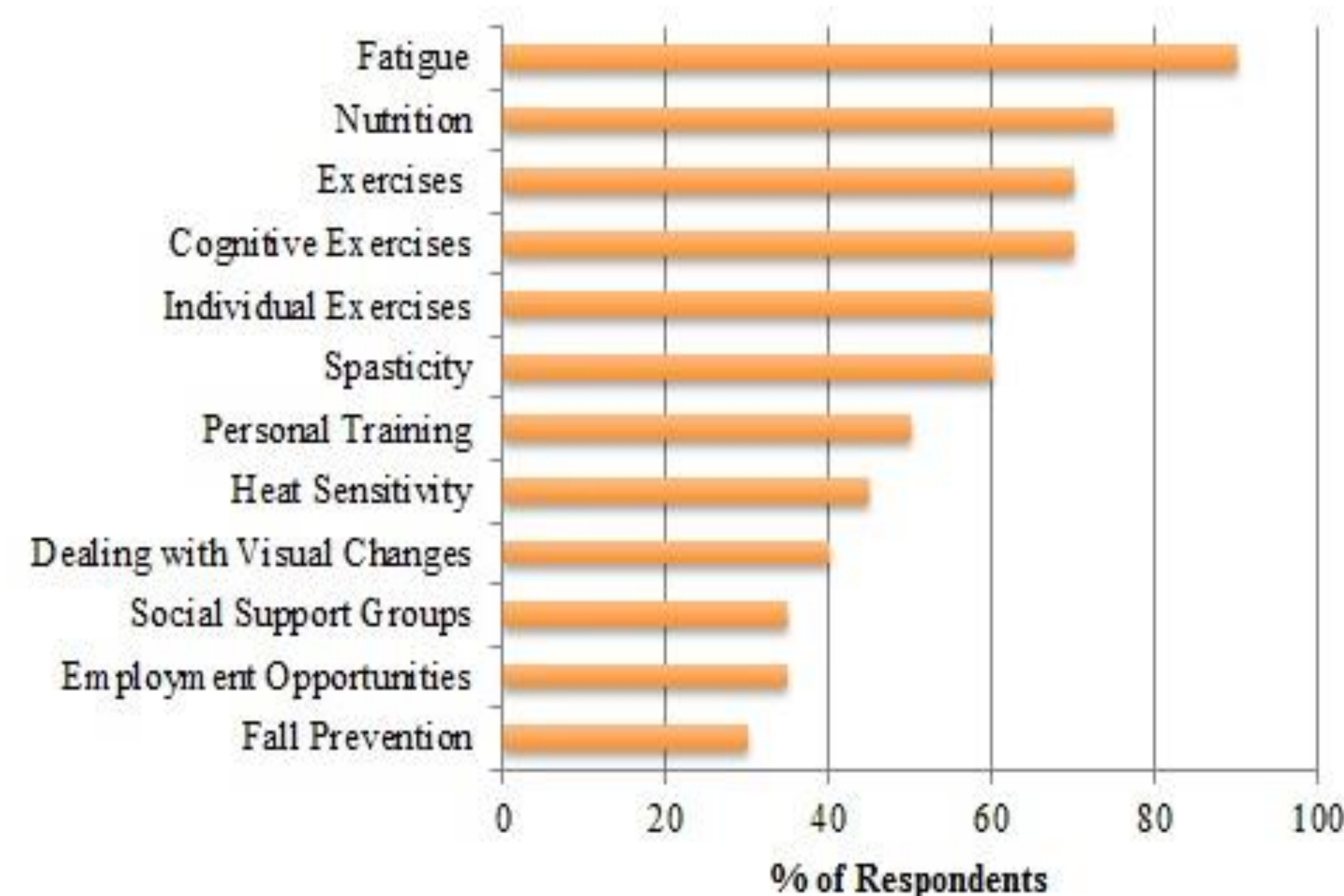
Types of activities reported by the participants:

- Walking
- Physical therapy exercises
- Stretching
- Playing with children
- House and yard work
- Group exercise classes at the gym
- Individual workouts at gym
- Water aerobics
- Running

### Interest in Wellness Program

Of the 21 respondents, 18 were very interested / interested in attending a wellness event; 2 were unsure

Figure 3. Wellness topics of interest to the respondents



Topics that were of less interest to the respondents ( $\leq 25\%$ ) response rate were:

- Medical information
- Balance and walking evaluation
- Adaptive devices
- Group exercise
- Support groups for family members
- Medication management
- Competitive sports
- Wheelchair mobility

Lack of interest in these topics may reflect the health and activity level of the respondents

## SUMMARY

People with MS, regardless of the duration of the disease, are interested in learning about wellness related topics, especially topics related to physical activity

## FUTURE DEVELOPMENT

- This information has informed the design of a pilot wellness program that was recently conducted for 14 individuals with MS, as well as 3 family members and over 10 community members. Topics included integrative health coaching, individualized exercise (addressing fatigue, spasticity, and balance), cognitive exercises, Tai Chi, yoga, and nutrition
- Participants at the wellness program identified additional interest in communicating invisible symptoms with family members, isometric exercises, instructed exercise sessions, and connecting with community exercise groups
- Family members of those with MS as well individuals with other neurological diagnoses are also interested in an organized wellness event



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