Optimizing Multiple Sclerosis Health Care:

Health care priorities of Americans with MS

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Background

This presentation describes a patient-based, participatory action research project aimed at identifying the MS care priorities of Americans with MS.

This research, funded through a **Health Care Delivery and Policy Research grant from the National Multiple Sclerosis Society (NMSS)** addresses the exclusion of MS consumers from the design and delivery of MS health care, and the limited current understanding of the health care priorities and preferences of MS health care consumers.

Objectives

The objectives in this research included:

(1) to identify the priorities and preferences of MS care consumers,

(2) to provide MS health care providers with information that will promote the design and development of individualized care models that capitalize on patient priorities and preferences, and

(3) to increase consumer participation in order to promote positive health outcomes and optimize MS care.

Methods

This is a multi-stage research project, incorporating:

- A comprehensive literature review,
- Clinical survey,
- National focus groups with NMSS members, and
- Large national survey of adults with MS, conducted in cooperation with the NMSS and the NARCOMS patient registry.

Demographics- On-Line Survey

- N = 1,274
- Age: M=53.36, SD=11.33, Range= 18-87
- 84.1% females
- 63.7% married, 12.8% single, 11.6% divorced
- 91.6% Caucasian. 3.3% African Americans, 2.0% Latinos/Hispanics
- 14.4% High school graduate, 15.2% 2-year college, 29.8% 4-year college, 30.6% post-graduate
- 29.4% full-time employed, 10.2% part-time employed, 29.8% permanent disability, 17.6% retired.

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Demographics

Household income	n	%
< $15,000	79	6.5
$15,001 - $25,000	113	9.3
$25,001 - $35,000	118	9.7
$35,001 - $45,000	106	8.7
$45,001 - $55,000	109	8.9
$55,001 - $65,000	95	7.8
$65,001 - $75,000	86	7.1
$75,001 - $85,000	86	7.1
$85,001 - $100,000	126	10.3
> $100,000	300	24.6

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Demographics

- 20.4% urban area, 56.6% suburban, 23.0% rural

- There are significant chi-square correlations between community types (i.e., urban, suburban, rural areas) and household incomes, education levels, employment status.
  - Suburban residents had higher levels of income, education and full-time employment.

Overall MS conditions

- 63.1% RRMS
- 15.8% Secondary progressive MS
- 9% Primary progressive

- Age at diagnosis: M = 39.61, SD = 10.84
- Age first symptoms: M = 33.65, SD = 11.04

“Health care provider most responsible for your MS treatment and follow-up”

- A neurologist: 88.2%
- A general practice doctor: 3%
- A nurse practitioner: 2.6%
- (No significant difference: urban, suburban, rural)

“Are there enough MS health care services in your area?”

- For all participants, 49.8% Yes *vs.* 50.2% No
- Significantly related to living areas:

	Yes	**No**
Urban	61.5%	38.5%
Suburban	51.9%	48.1%
Rural	34.7%	65.3%

“How often do do you see your main MS provider for regular follow-up appointments?”

Once a year	Twice a year	More than twice a year
18.1%	51.9%	21.2%

- This schedule is About right: 85.7%; Not often enough: 11.9%
- Significantly related to living areas:

Schedule is…	About right	Not often enough	Too often
Urban	86.6%	10.5%	2.9%
Suburban	84.7%	10.0%	2.7%
Rural	81.8%	16.7%	1.5%

“How many minutes do you spend in your regular appointments with your main MS health care provider?”

- 75%: 30 minutes or less; Mode: 16-20 minutes (24%)

2. “Is this amount of time…?”

About right: 76.5% Not enough: 19.9%

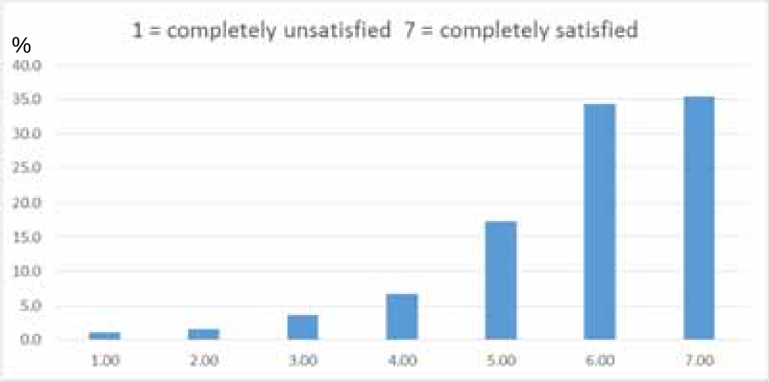
	About right	Not enough	More than enough
Urban	79.0%	17.2%	3.8%
Suburban	78.6%	17.7%	3.7%
Rural	69.3%	27.4%	3.3%

“Your ability to afford MS health care?”

- 36.0% No concerns at all
- 42.2% Worry some
- 14.3% Worry a lot
- 7.5% Worry constantly
- Significantly related to living areas:

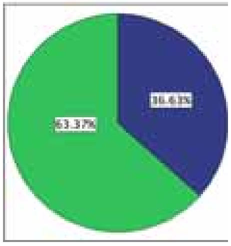
	No concerns at all	Worry some	Worry a lot	Worry constantly
Urban	31.5%	42.7%	14.9%	10.8%
Suburban	37.7%	44.4%	12.9%	5.0%
Rural	35.5%	36.2%	17.4%	10.9%

Overall, how satisfied are you with your MS health care in general (including all your MS health care professionals, specialists, and therapists)?



Evaluating Health Care

- In the last 12 months, did your primary MS health care provider give you a chance to evaluate the quality of your health care?

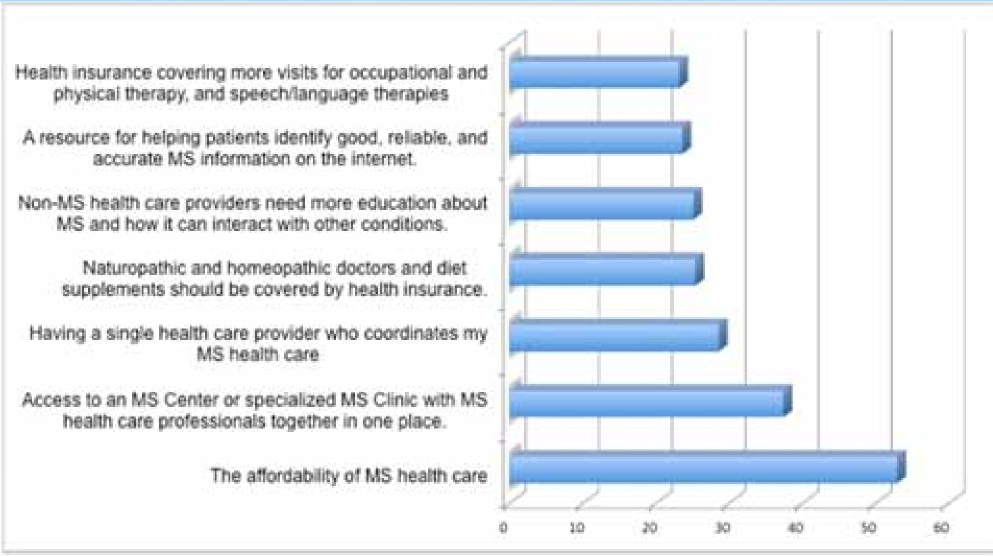


- **Yes: 36.6%; No: 63.4**
- How important is it to you that your provider give you an opportunity to evaluate the quality of the care you receive?
- **Important to Very important: 64%**

MS Health Care Priorities

- Presented 12 Health Care Priorities identified in National Focus Groups
  - Asked to rate from 1 (“Not a priority”) to 4 (“Top priority”)
- Two items significantly different for those with family incomes under $15,000:
  - Better access to MS care on weekends and after hours.
  - Transportation for health care

Rated Top Priorities by over 20%



Health Care Expectations and Experience

- Developed a multidimensional scale evaluating elements of interactions with Main MS Care Provider:
  - Accessibility and Health Communication;
  - Medical Tests;
  - MS Treatments and Medications;
  - Electronic Health Communication/Technology;
  - Cultural Competence/Communication;
  - Complementary and Alternative Therapies
- Participants rated Importance and Frequency of event

Accessibility and Health Communication