

THE MS CARE PARTNER

Mary Elizabeth Quig, Ph.D.

Carol Saunders, BSN, MSCN

MS Center

Neurology Center of Fairfax

Caregiving:

- **Caring for a physically-challenged loved one can be both a rewarding, as well as physically and emotionally demanding experience for the Caregiver.**

Caregiving Stress in General:

- **Caregivers have increased risk for depressive and anxiety disorders.**
- **Caregivers have smaller social networks (and describe their relationships as “less supportive” than well-matched controls.)**

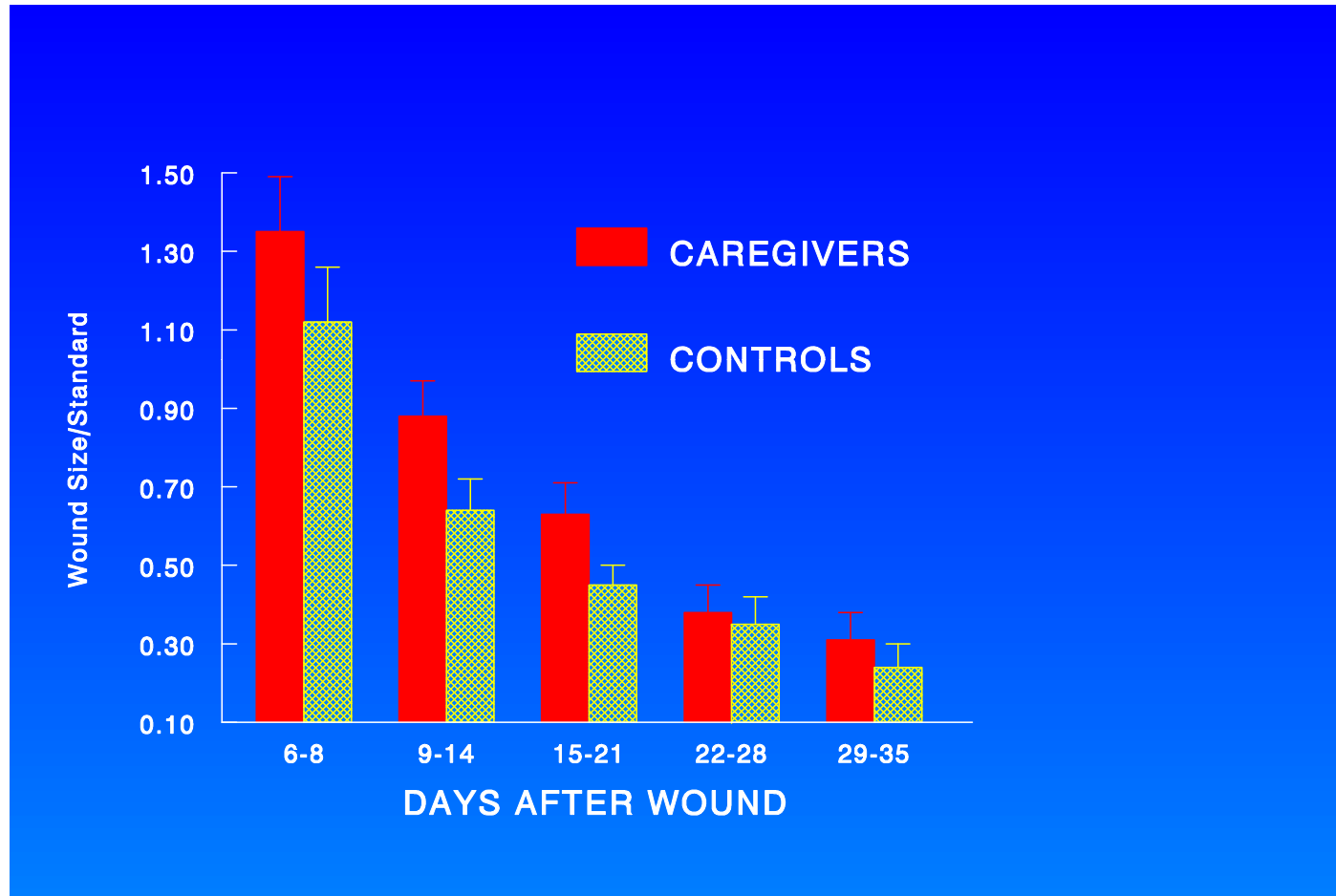
Caregiving Stress in General:

- **Chronic caregiving stress places the CarePartner at heightened risk of illness, early chronic disease onset, increased morbidity and mortality.**
- **The National Alliance for CareGiving estimates that CarePartners (age 66+) who are experiencing mental or emotional strain have a 63% higher risk of dying than people the same age who are not caregivers.**

Caregiving Stress in General:

- **Chronic, prolonged caregiving stress can negatively impact cardiovascular, immune and endocrine function in caregivers.**
- **Caregivers have increased number of respiratory tract infections, a poorer response to influenza virus and slower wound healing than well-matched noncaregivers.**

CHANGES IN WOUND SIZE OVER TIME: CAREGIVERS VS. CONTROLS



Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser.
Lancet, 1995

WARNING SIGNS OF CAREPARTNER STRESS

- **DENIAL**
- **ANGER**
- **SOCIAL WITHDRAW**
- **ANXIETY**
- **DEPRESSION**
- **EXHAUSTION**
- **SLEEPLESSNESS**
- **IRRITABILITY**
- **LACK OF CONCENTRATION**
- **HEALTH PROBLEMS**

NURSING PERSPECTIVE OF MS CAREPARTNER ISSUES

Carol Saunders, BSN, MSCN
Neurology Center of Fairfax

Newly Diagnosed With MS

- Inquire about support system
- Insist that carepartner attend information sessions

Individual MD and nurse sessions

Support groups for newly diagnosed

Teaching sessions for injectable therapies

Patient & Carepartner Sessions

- Present basic MS information – what it is – how diagnosis was made – cause – treatments – managing the disease
- Provide written information on MS
- Importance of communication between partners – verbal and non-verbal

All MS Patients & Carepartners

- Need for time *AWAY* from MS
- Need individual interests and time to pursue them
- Provide assistance to make home safe

Encourage Carepartner

- Regular health care for self a priority
- Time away from partner benefits both
- Assist schedule planning and finding help within and outside of family
- Ask what they would want for their partner if they were the one with MS

Emphasize Over and Over

- Encourage patient independence and self care
- Discuss how enabling can be harmful to patient and carepartner
- Discuss need to understand MS symptoms and their management- cognitive problems in particular

Multiple Sclerosis

- Affects the individual diagnosed with the disease
- Affects the family- spouse, children, parents, siblings
- Especially affects the carepartner

MS CAREPARTNER STRESS: A NARCOMS STUDY

Mary Elizabeth Quig, Ph.D.

MS Center
Neurology Center of Fairfax
Department of Neurology
Georgetown University Medical
Center

THE RESEARCH TEAM

MS Center, Neurology Center of Fairfax

- Mary Elizabeth Quig, PhD
- Carol Saunders, RN, BSN
- James Simsarian, MD
- Special thanks to the Fairfax MS CarePartner Support Group Members for 5+ years of clinical input and considerable wisdom.

NARCOMS TEAM

Barrow Neurological Institute, Phoenix AZ

Medical Director

Denise Campagnolo, MD

Co-Investigator

Timothy Vollmer, MD

Program Manager

Tuula Tyry, Ph.D.

Research Assistant

Nancy Silingo

Breanna Bullock, BA

Off-site:

Research Fellow

Ruth Ann Marrie, MD

Biostatistician

Gary Cutter, Ph.D.



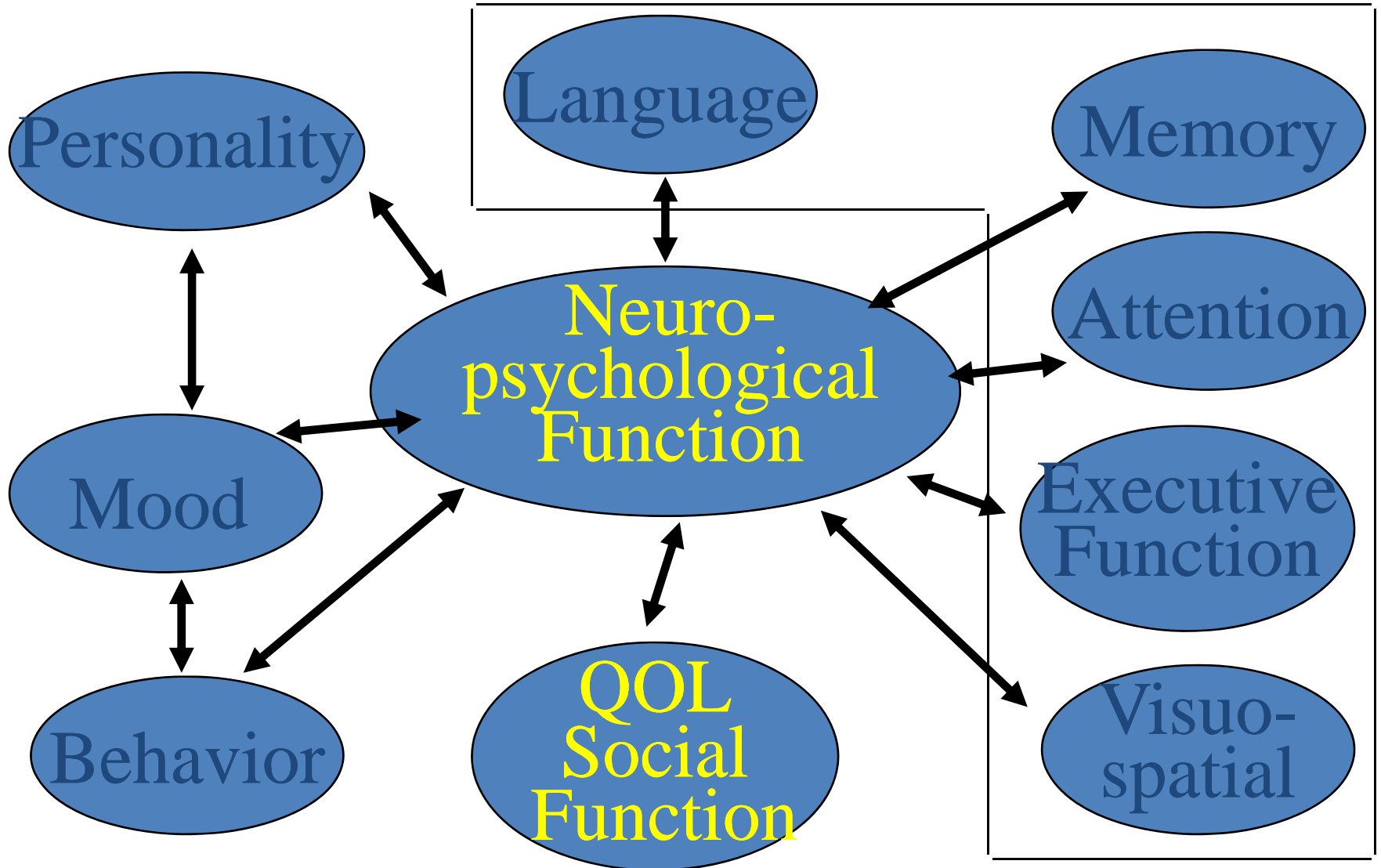
Sample of research projects completed with NARCOMS data

- Factors affecting quality of life
- Cost of illness
- Dysphagia
- Enhancement of clinical trial design
- Spasticity
- Disability levels
- Aging with MS
- Depression
- Treatment patterns
- Treatment adherence/switching behavior
- Employment status
- Fatigue
- Pain syndromes
- Access to healthcare
- Healthcare experience of minorities with MS

Neuropsychology

The study of
brain-behavior
relationships.

Spectrum of Neuropsychology



METHODS:

- Approximately 12,000 registrants in the NARCOMS database were electronically contacted. Permission for participation and referral to a secure website (separate from the NARCOMS database) to complete a specific CarePartner survey was requested.
- Electronic informed consent was collected. CarePartner responses were anonymous and confidential.

METHODS:

- Basic demographic information was collected, and the Zarit Caregiver Burden Interview was electronically administered.
- The Zarit Burden Interview has been specially designed to reflect the stresses experienced by caregivers by asking 22 questions about the impact of the patient's abilities and disabilities on their life.

ZARIT BURDEN INTERVIEW

- Caregivers are asked to respond to a series of 22 questions about the impact of the patient's disabilities on their life. For each item, caregivers are to indicate how often they felt that way - never, rarely, sometimes, quite frequently, or nearly always.

OVERALL GROUP OF MS PATIENTS

N = 1,461 MS Patients

Mean age: 50.4 years (SD 10.0 yrs;18-83)

Yrs of Education: 15.1 yrs (SD 3.1 yrs, 2-20+)

Years since Diagnosis: (9.4 yrs; 1-49)

OVERALL GROUP OF MS CAREPARTNERS

N = 1,461 MS CarePartners

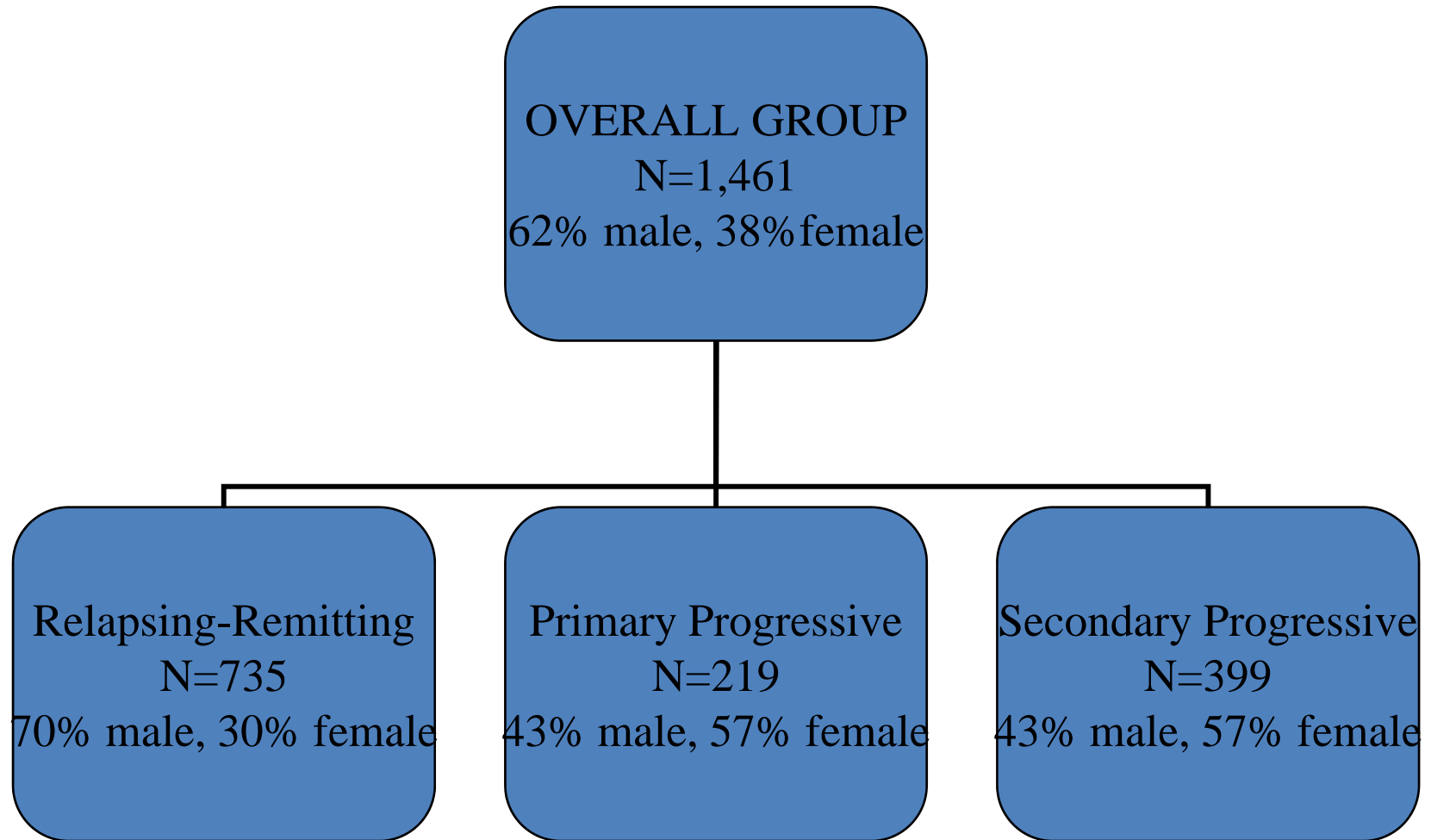
Gender: 62% male; 38% female

Mean age: 51.3 yrs (11.2 yrs; 18-84 yrs old)

Years of Education: 15.8 yrs (3.3 yrs; 2-20+)

Years of Caregiving: 11.2 yrs (9.4 yrs; 1-49)

GROUP GENDER CHARACTERISTICS



The Health of the CarePartner

- 28% of CarePartners reported high blood pressure
- 26% reported high cholesterol
- 13% reported chronic headache
- 13% reported persistent sleep disturbance and
- 17% reported Mood Disorder.
- Hypertension rates tended to be higher for CarePartners of patients with Secondary Progressive MS than for CarePartners of patients with Relapsing-Remitting MS.

The Health of the Patient:

■ Walks with a cane	28%
■ Wheelchair / Scooter	17%
■ Gait Disability	12%
■ Normal	11%
■ Mild Disability	10%
■ Bilateral Support	10%
■ Moderate Disability	9%
■ Bedridden	2%

ZARIT BURDEN INDEX

- Ranges from 0-88
 - 0-20 No Caregiver Burden
 - 21-40 Mild-Moderate Caregiver Burden
 - 41-60 Moderate-Severe Caregiver Burden
 - 61+ Very Severe Caregiver Burden
-
- Mean Total Score = 22.9 (14.3, (0-82))

ZARIT TOTAL SCORES BY MS TYPE

OVERALL GROUP
N=1,461
62% male, 38% female
Zarit Total: **22.9** (14.3)

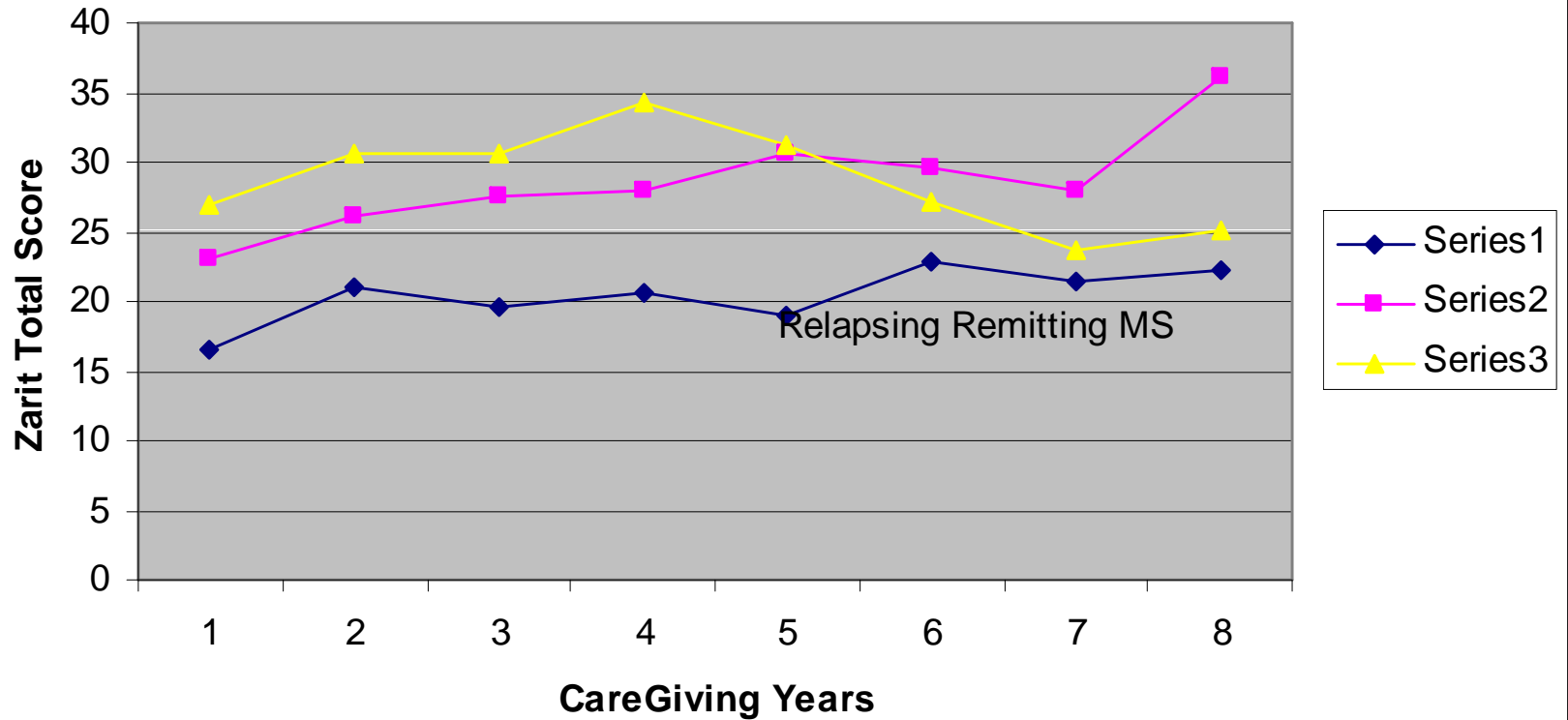
ZARIT CUT-OFF SCORES:
0-20 No Burden
21-40 Mild-Moderate Burden
41-60 Mod-Severe Burden
61+ Very Severe Burden

Relapsing-Remitting
N=735
70% male, 30% female
Zarit Total: **19.1** (12)

Primary Progressive
N=219
43% male, 53% female
Zarit Total: **26.7** (15)

Secondary Progressive
N=399
43% male, 57% female
Zarit Total: **30.4** (16)

Caregiving Years by Zarit Total



**CarePartner Stress correlates
poorly to.....**

**Disease duration
(i.e. years as a CarePartner)**

#1 STRESSOR:

- **Restricted mobility 38%**
- **Fatigue 18%**
- **Cognitive dysfunction 15%**
- **Bladder / bowel difficulties 13%**
- **Inability to use hand 4%**
- **Personality change 4%**
- **Visual disability 4%**
- **Spasticity 1%**

#2 STRESSOR:

- **Fatigue 31%**
- **Depression 23%**

- **Personality Change 15%**
- **Bladder / bowel difficulties 10%**
- **Cognitive Dysfunction 7%**
- **Spasticity 7%**
- **Visual disability 2%**

#1 STRESSOR BY MS TYPE:

PPMS: MOBILITY (56%)

BLADDER ISSUES (15%)

RRMS: MOBILITY (27%)

FATIGUE (17%), COGNITIVE (17%)

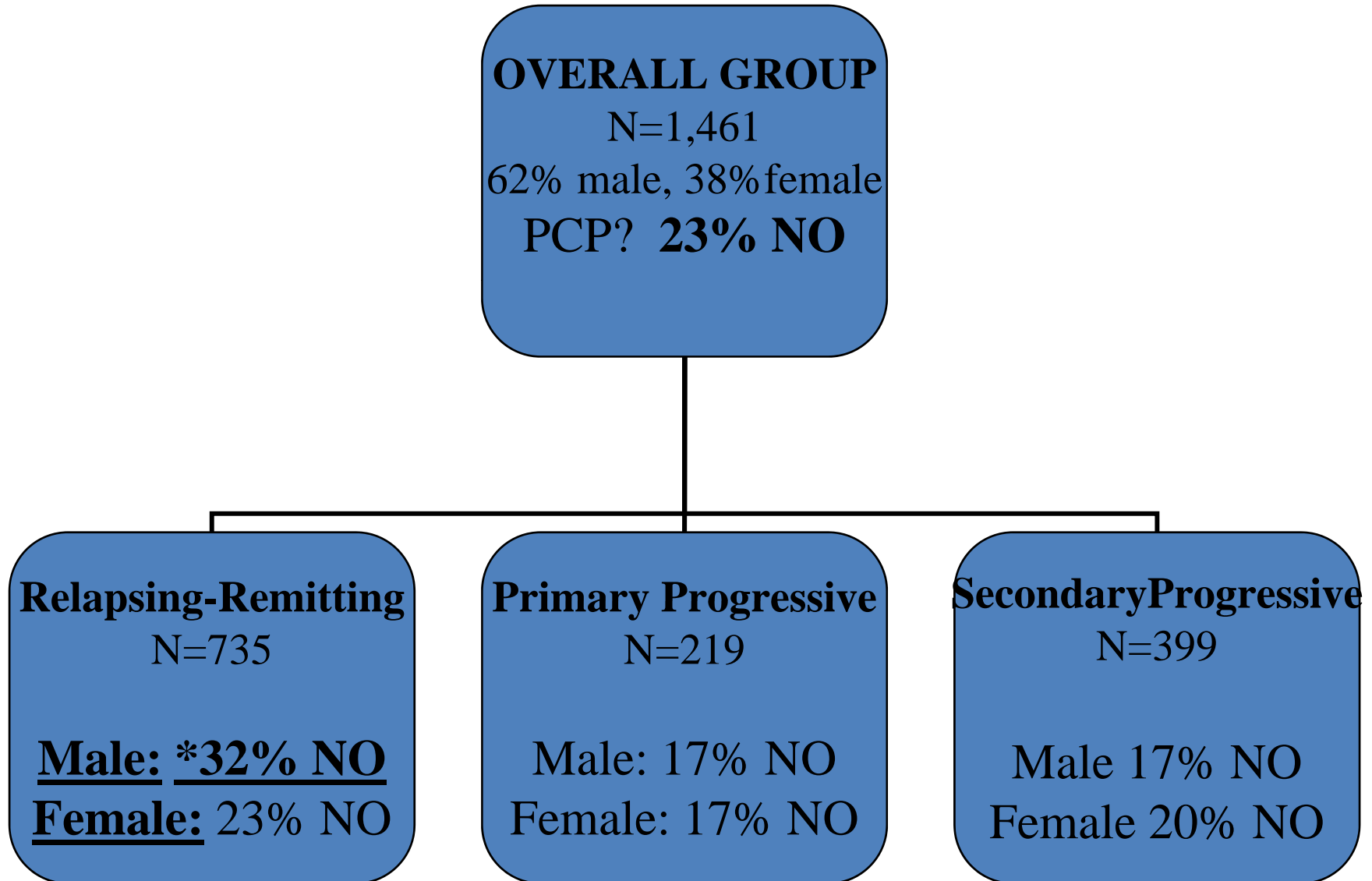
SPMS: MOBILITY (50%)

COGNITIVE DYSFUNCTION (16%)

“Is your PCP aware of your role as a CarePartner?”

- Although the literature often refers to caregivers as the “hidden patient” and stresses the importance of letting their physicians know they are caring for someone (Parks, & Novielli, 2000), 23% of the respondents indicated that their Primary Care Physician was not aware of their role as a CarePartner.

“IS YOUR PCP AWARE THAT YOU ARE A CAREPARTNER?”

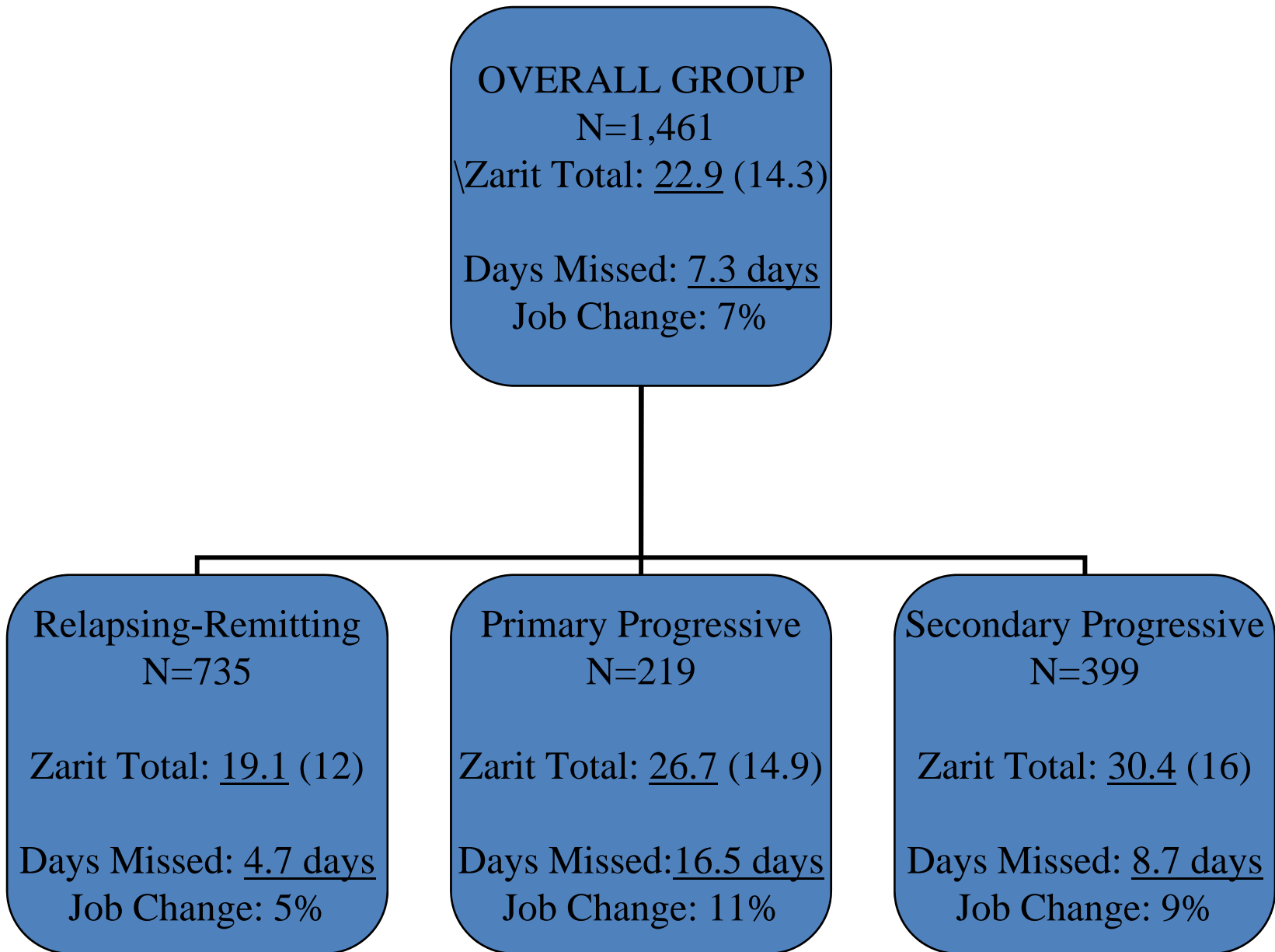


Zarit Total Score

- Higher Zarit Burden Index more likely to have sleep disturbance.
- Zarit Total Score predicts Mood Disorder for Female carepartners of PPMS and SPMS

The Impact of MS CarePartner Stress in the Workplace

- Survey findings revealed that **53%** of MS CarePartners had “missed work over the past year due to caregiving responsibilities.” This descriptive statistic is consistent with other findings in the Caregiver literature.



The Impact of MS CarePartner Stress in the Workplace

- Overall, the MS CarePartners surveyed **missed an average of 7.3 days of work** (SD=40.1 days) over the past year due to “MS caregiving responsibilities.” 7% of MS CarePartners reported having changed their employment altogether due to their “role as a caregiver.”

The Impact of MS CarePartner Stress in the Workplace

- CarePartners of patients with Primary Progressive MS missed **three times** as many days at work (16.5 days) and were **twice** as likely to change their jobs altogether due to their role as a caregiver (11%) when compared to CarePartners of patients with Relapsing-Remitting MS (4.7 days missed, 5% report employment change).

Medico-Economic Impact:

- Reliance on family support networks is a major part of national health policy, and demographic trends suggest an increased reliance on family caregivers in the future.
- It is estimated that 80% of community care is provided by family caregivers, at an approximate economic value of \$200 billion annually.

Medico-Economic Impact:

- **Studies on the economic impact of Alzheimer's disease (AD), for example, have found that the average caregiver with a full-time job misses more than three weeks of work a year, and that one fifth will quit their jobs altogether to provide full time care.**

CONCLUSIONS:

- CareGiver Burden (Zarit) did NOT increase over time. That is, years of caregiving does NOT predict increased caregiving burden/burnout in this study.
- In contrast, the health of the CarePartner DID predict increased caregiving burden/burnout.
- 32% of male RRMS carepartners have not yet told their PCP of their role as a carepartner.

FUTURE DIRECTIONS:

- Sub-groups differentially at risk:

PPMS CarePartners

Male RRMS CarePartners

As mobility becomes an issue

Need to develop a standardized paradigm for identification of these issues. There are, of course, confidentiality/privacy issues to be considered.