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[www.va.gov/ms](http://www.va.gov/ms)

# MS Research and Caregiving

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# MSCoE - Background

- MS Centers of Excellence (MSCoE): Funded by the VA in January 2003 to address health needs of veterans with MS at a national level.
- MSCoE-East: Baltimore & Washington, DC
- MSCoE –West: Portland & Seattle
- MS research is part of the mission of MSCoE, along with:
  - Clinical Care
  - Education
  - Informatics

# VA Research

- **MSCOE Research Goal**: To improve health care for Veterans with MS.
- VA ranks as one of the leaders in health research.
- Interdisciplinary professionals: several different health care disciplines
- For example: physicians, psychologists, nurses, social workers, occupational therapists, physical therapists, public health professionals, graduate students, medical students, etc.
- Each discipline gives a different perspective to enrich research.

## MSCoE - Research Focus

- Studies that address special health care needs of Veterans with MS
- Not typical in the “non-Veteran” population of MS
  - Much higher proportion of males w/MS
  - More disabled
  - Higher % of progressive forms of MS
  - Patterns, correlations, and/or how effective an intervention or medication may help a problem or symptom in MS.

# Research Methods

- Starts with A THEORY of why something happens
- This theory helps
  - Organize the information about the problem/issue/medication
  - Explain past findings (if any)
  - Predicts or validates new or current use

## Types of Research Studies

- Pre-clinical & clinical trials: Clinical trial of a new medication or intervention, or new use or “off-label” use of existing medication or intervention. Often several phases/stages of research before FDA-approved.
- Pilot studies: Involves a smaller number of people. May help decide if it makes sense to do a larger study in the future.
- Multi-site studies: Involves more than one site, e.g., may be many VA sites and/or VA in collaboration with non-VA site.
- Health services research: Improves quality of patient services.
- Economics research: Improves costs of care for MS.
- Secondary data analysis: Obtain data from existing databases to answer a question.

# MSCoE - Types of Research We Do

- Pilot Studies/Small clinical trials: Randomize into intervention / control group, e.g.,
  - Ritalin Study: off-label use of Ritalin to decrease fatigue.
  - Ginkgo biloba Study: off-label use of Ginkgo biloba to improve memory.
  - DMT Adherence Study: Counseling intervention & home telehealth monitoring for MS medication adherence
  - MS Fit Study: Counseling intervention & home telehealth monitoring for exercise adherence to decrease fatigue

# MSCoE - Types of Research We Do

- Health Services Research: MS Specialty Care Study (improve access to MS appointments)
- Economics research: Improve costs of care for MS.
- Secondary data analysis: Answer a question from existing databases, e.g., MS National Data Repository, Gulf War and MS Study.

## MSCOE –Studies Completed (in Data Analysis)

- Specialty Care: Examining MS-specific care appointments and cost.
- Home Telehealth: An intervention to improve access to MS care and quality of care for using a home telehealth monitor. Study will help inform national home telehealth programs & future implementation.
  - MS Symptoms Monitoring Questions
  - DMT Adherence (health behavior change)
  - MS Fit Study – monitor adherence to exercise goals
- Gulf War study with MSCoE–East – Using VA and other DOD databases. Study is a result of concern for US veterans deployed to the 1990-1991 Gulf War (GW) may be at increased risk in developing neurologic disease. Potentially controversial.

# MS Research

## How do I participate?

- You might receive a letter announcing a MS study
- You might see flyers or posters about a study
- You might be approached in MS clinic
- Check VA MSCoE website: [www.va.gov/ms](http://www.va.gov/ms)
- Check non-VA MS organizations' websites:  
[www.nationalmssociety.org/](http://www.nationalmssociety.org/)  
[www.mscares.org/cmssc](http://www.mscares.org/cmssc)  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

# MS Research Regulations

- Commitment to research ethics
- Privacy/Confidentiality of participants
- IRB/R&D regulations and approvals
  - Review & approve each study
  - Research has to be scientifically valid
  - Risks are minimized
  - Potential benefit to participants/Veterans
  - Potential contribution to society/Veterans

# Participating in MS Research

## Questions to Ask

The VA is required to describe in detail the study on the consent form.

Ask yourself:

- Why is the research being done?
- Why do they think this treatment might be effective?
- What kind of tests will be done?
- What are the risks?
- How do the risks compare to the risks of standard treatments?
- How much time is involved (hours, number of visits, days of the week, # months)?
- Will it cost me anything?
- How will my privacy be maintained?

## Participating in MS Research

- You have the right to withdraw from the study at any time.
- Ask questions if you don't understand something!
- Try to read the consent form in advance of the appointment.
- Ask the research coordinator to review the consent form with you before signing.

# MSCOE – Publications

- Published in MS Professional journals.
- Published in Patient centered journal articles.
- Published in MSCoE website articles:

<http://www.va.gov/ms/>

- Presentations at national conferences to share knowledge with other MS professionals.
- Published in VA newsletters, video teleconferences, telephone conference calls.
- Published on websites of MS organizations.
- PubMed: To look up publications/abstracts  
<http://www.ncbi.nlm.nih.gov/pubmed/>

# Caregivers at a Glance

- 54 Million adults in the US provide unpaid care to an adult family member or friend
- The average unpaid family caregiver is 60 years old
- 24% caregivers live with or close to the person they are caring for and 58% are more than 20 minutes away.
- The average caregiving load of direct services is 18 hrs/wk. For those who need assistance with two or more activities of daily living: 40 hrs/wk.
- Over 75% have worked while caregiving, nearly half are employed at full-time jobs (48%).
- Caregiving goes on for a long time—an average of 8 years

From website: [www.caregiver.va.gov/index.asp](http://www.caregiver.va.gov/index.asp), 3/14/11. Data from National Alliance for Caregiving and American Association of Retired Person Survey, 2009.

# Impact on Caregiver Health

- As Caregivers, you are at higher risk of having unmet health needs.
- One-fourth of you report health problems as a result of care giving activities.
- You report higher levels of symptoms of depression and mental health problems than do your non-Caregiver peers (20% to 50% report depressive disorders or symptoms).
- Two-thirds of you report a high burden of care: you need help finding care for yourselves, to balance work and family responsibilities and to manage emotional and physical stress.

[http://www.caregiving.org/data/2010\\_Caregivers\\_of\\_Veterans\\_FULLREPORT\\_WEB\\_FINAL.pdf](http://www.caregiving.org/data/2010_Caregivers_of_Veterans_FULLREPORT_WEB_FINAL.pdf)

# Caregiver Demographics National Vs. Veteran Statistics

	Caregivers of Veterans (n = 462)	Caregivers of Adults Nationally (n = 1,307)
Female caregiver	96%	65%
Spousal caregiver	70%	6%
Caregiver lives with care recipient	80%	23%
Primary caregiver	82%	53%
Caregiving for 10 years or more	30%	15%

Source: Caregivers of Veterans – Serving the Homefront. [www.caregiving.org](http://www.caregiving.org)

# Caregiver Demographics National Vs. Veteran Statistics

	Caregivers of Veterans (n = 462)	Caregivers of Adults Nationally (n = 1,307)
High Emotional Stress (4+ on 5-point scale)	68%	31%
High Physical Strain (4+ on 5-point scale)	40%	14%
Stopped working or took early retirement (among those who worked while caregiving)	47%	9%
High Financial Hardship (4+ on 5-point scale)	50%	13%

Source: Caregivers of Veterans – Serving the Homefront. [www.caregiving.org](http://www.caregiving.org)

## MSCOE Study: “Individuals with Multiple Sclerosis: Implications for Adherence to Disease-Modifying Therapies.”

- DMT Study with Veterans & their Caregivers
- Alicia Sloan, Study Coordinator
- Goal of study: Better understand relationship between Caregivers and Veteran’s adherence to Disease modifying Therapies (DMTs = ABCR MS medications).
  - Participants: 54 veterans with MS who identified a caregiver.
  - 85% male Veterans.
  - Over 80% caregivers are spouses.
  - Veterans 85% adherence to prescribed DMTs.
  - “Quality of Relationships Inventory” – To what degree is caregiver willing to listen, provide advice, help with a problem.
- **Conclusion:** The supportive qualities of caregiver was important for DMT adherence. Caregiver are important for medication adherence.

**Source:** Siegel, S.D., Turner, A.P., & Haselkorn, J.K. (2008). *Adherence to disease modifying therapies in multiple sclerosis: Does caregiver social support matter?* *Rehabilitation Psychology*, 53, 73-79. Seattle VA funded study, Career Development Award, Aaron Turner, PhD.

## MS Center of Excellence – Caregiver Research “Perceived Social Support & Depression among Veterans with MS”

- DMT Study with Veterans & their Caregivers
- Alicia Sloan, Study Coordinator
- 451 Veterans with MS
- Veteran’s perceived social support and the degree of Veteran experiencing depression.
- The greater global perceived social support, the less depression.
- Global social support (from MSSS Scale): How often someone is available to provide certain perceived social support? 4 aspects of support: tangible, emotion/information, affection & positive interaction.
- **Conclusion:** The greater perceived emotional/informational support, the more positive social interactions. Greater affectionate support was related to less depression in Veterans with MS.

Source: Bambara, J.K., Turner, A.P., Williams, R.M., Haselkorn, J.K. (early online, 2010). Perceived social support and depression among veterans with multiple sclerosis. Disability and Rehabilitation. Seattle VA funded study, Career Development Award, Aaron Turner, PhD.

## We Learn from You!

- Bottom Line: We learn from Caregivers and the Veterans with MS!
- You teach us valuable information to help improve MS care for all caregivers and people with MS.
- Thank you!