Welcome!
South Central Chapter
Annual Meeting & Research Update
December 2, 2015
Annual Meeting & Research Update

• Society Impact
Annual Meeting & Research Update

- Board of Trustees, Finance Committee
  - Financial Report
Annual Meeting & Research Update

• Board of Trustees, Governance Committee
  – 2016 Board of Trustees
  – Recognize outgoing trustees
Research Update

Meet Alexa Stuifbergen, PhD, RN, FAAN
Dean & Professor
The University of Texas at Austin
School of Nursing
Successful Strategies you can use for Managing the Challenges of MS

Findings from 25 years of research
Collaborators

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Financial Support

• The University of Texas at Austin
• National MS Society
• Rehabilitation Nursing Foundation
• Donors

• National Institutes of Health
  – National Institute of Child Health and Human Development
  – National Institute of Nursing Research
  – National Center for Medical Rehabilitation Research
  – Office of Research on Women’s Health
Most Importantly.....

• More than 1,500 persons with MS who shared their time and participated in our studies...
Overview

- Findings from early studies
- Wellness intervention studies
- Longitudinal Study
- Cognitive Rehabilitation Study
25 Years of Systematic Study

• Learned from research of others
• Learned from my own data
• Most of all - learned from my research participants and persons with MS
Times have Changed.....

1989 - 2014
1989

- MRI – relatively new
- Time to diagnosis
- No disease modifying medications
- Limited symptom management
- “Take it easy and rest”
2015

- Rapid diagnosis
- Disease and symptom management meds
- Recognition of the role of self-care and health behaviors
Contrasting Perspectives

Glass half-empty
(due to losses)
or
Glass half-full
(due to potential)
Focus on the strengths and positive resources that people use in their everyday lives in the community to maintain and enhance their quality of life.
Overall Research Question:

- Does the practice of health promoting behaviors make a difference in quality of life for persons with MS?
What Is Health Promotion?

• Ongoing lifestyle activities to maximize health including:
  – Physical activity
  – Healthy eating practices
  – Managing stress
  – Seeking social support
  – Adequate rest and sleep
So – Translated.....

- If you use ‘strategies’ including increasing your exercise, getting adequate sleep and rest, eating healthy and managing stress - will it improve your quality of life while living with MS?
Early Findings

- Interested in health promotion behaviors
- Viewed health positively
- Need to adapt health behaviors to context of living with MS
- Barriers are important
Health Promotion Behaviors

• Useful to manage disease-related symptoms
• Resulted in ‘feeling better’ and ‘having more energy’
• Significantly lower in physical activity behaviors
1996 – Survey Study

- Study packets sent to a sample of 936 persons on the mailing list of the Southeast Texas Chapter of the National MS Society (66 counties)

- **834 surveys (89%) were returned**
• **Participant characteristics**
  – Average age of 48 (range 18-95 years)
  – 80% of respondents were female
  – 70% were married
  – 39% were employed full or part-time
  – 93% completed 12 years or more of school
  – Had MS for an average of 11 years (range 6 months to 50 years)
A Few Key Findings….

- Factors most strongly related to more positive perceptions of quality of life were:
  - Greater Social Support – feeling connected and supported by others
  - Fewer barriers to taking care of one’s health
  - Greater confidence in the ability to practice wellness behaviors
  - More frequent health promoting behaviors
  - Less severe functional limitations related to MS
Importantly….

• Health promoting behaviors mediated the impact of MS-related functional limitations on quality of life
Promoting Wellness for Women with MS

1996-2000
Intervention Development

- Intervention based on theory and data from earlier studies
- Later adapted for men with MS and women with fibromyalgia, cancer survivors and women with HIV
Goals of Wellness Intervention

- Engage participants in assessing their present health behaviors
- Assist in setting meaningful goals for change
- Address barriers, resources and skills necessary to change
Randomized Controlled Trial of Intervention

- Phase I - educational and skill building lifestyle change program
  - 8 group sessions over an 8 week period
  - Sessions co-led by nurse and a woman with MS
- Phase II - supportive phone follow-up
  - Bi-monthly phone calls from intervention facilitator for 3 months
  - Goal setting by participants and monitoring of goal achievement
Topics of Intervention Classes

• Maximizing health while living with MS
• Lifestyle adjustment
• Physical Activity (2)
• Healthy eating
• Stress management
• Relationships, intimacy & sexuality
• Women’s health issues
Study Measures completed at:

- Baseline (prior to study)
- Two months (end of class sessions)
- Five months (end of phone follow-up)
- Eight months (end of study)
Study Participants (N=113)

- Range in age from 21 to 70 years
- Community-residing women with physician diagnosed multiple sclerosis in Austin and Houston
- Majority were white, married, well-educated, and not employed full time
- Average length of time diagnosed with MS was 10.76 years
Changes in Self-Efficacy for Health Behaviors

![Graph showing changes in self-efficacy for health behaviors over time (T1 to T4). The graph compares two groups: Control and RX. The RX group shows an upward trend, while the Control group remains relatively stable.](image-url)
Changes in Health Behaviors

![Graph showing changes in health behaviors over time for Control and RX groups.]

- **Control** line shows a slight increase over time.
- **RX** line starts relatively high and maintains a steady increase over time.

**Axes:**
- Y-axis: Values range from 130 to 160.
- X-axis: Time points labeled as T1, T2, T3, T4.

**Legend:**
- Red line: Control
- Green line: RX
Changes in Mental Health Scores

![Graph showing changes in mental health scores over time for Control and Rx groups.](image)
Overall....

• Significant improvements in self-efficacy scores, health behaviors and selected dimensions of quality of life (pain and mental health scores, employment status)
Why is an intervention to increase health behaviors important for persons with MS?
Findings from Longitudinal Study Re Progression of Functional Limitations

![Graph showing the progression of functional limitations over time for High HP (red line) and Low HP (green line). The graph displays data at six time points: Time 1, Time 2, Time 3, Time 4, Time 5, and Time 6.]
Longitudinal Study

- Started in 1999 as follow up to 1996 survey
- 621 (82%) of those eligible and reachable entered the study
- Annual mailings - >80% of those eligible have responded to annual questionnaires
Current Study Enrollment

• Year 19
• 388 participants (as of 8/2014)
  – Houston and Austin metropolitan areas
  – Rural counties primarily in the Panhandle of Texas
• 87% female
• 71% married
• 26.5 years diagnosed with MS (range 17-56 years)
• 17% employed full or part time
• 30% ”retired due to disability”
Effects of Exercise on the Progression of Functional Limitations

- 611 persons with MS over a 7 year time period
- Change in functional limitations was slow but significant and in a direction that indicates increasing limitations
- Participation in exercise at Time 1 was related to the trajectory of functional limitations over time (-.34)
Increasing exercise scores over time corresponded with decreasing rates of change in functional limitations ($r = -0.25$).

- Functional limitations at Time 1 were not related to the rate of exercise behaviors.
- Consistent with research documenting short-term benefits of exercise.

(Stuifbergen, Blozis, Harrison & Becker “Exercise, Functional Limitations and Quality of Life: A Longitudinal Study of Persons with Multiple Sclerosis”. Archives of Physical Medicine & Rehab, July, 2006)
Longitudinal Study of Depressive Symptoms

• No significant differences in depressive symptoms between men and women at the beginning of the longitudinal study or over time
• Depressive symptoms related to functional limitations at all time points
• Depressive symptoms change little over time for the group
• Depression scores increase in years when there are sharp increases in functional limitations
Cognitive Concerns

- Most participants in the longitudinal study had significant concerns about their memory.
  - 65% thought something was wrong with their memory
  - 61% thought their memory was going downhill,
  - 62% were embarrassed about their memory
Cognitive Concerns

- Participants reported frequent memory mistakes and very limited use of internal strategies or external aids to memory.
- Depressive symptoms, functional limitations, memory contentment scores, and gender accounted for 61% of the variance in scores on the Quality of Life Index.
Cognitive Problems in MS

- Thought to occur in 40-75% of those with MS
- Numerous studies have demonstrated deficits in tasks assessing:
  - Recent memory
  - Attention
  - Information processing (including processing speed)
  - Executive functions (including verbal learning)
  - Visuospatial abilities
• Cognitive deficits may occur at any point in the disease and are only weakly associated with physical impairment.
• No approved medications for cognitive impairment in MS and almost no clinical trials to determine treatment efficacy.
Cognitive Rehab Intervention (2009-2011)

- Developed using data and strategies from earlier wellness studies
- What ‘worked’ and what participants found helpful
- 61 participants who were experiencing cognitive difficulties in Houston and Austin
- Randomized controlled trial of 8 week intervention
MAPSS-MS Intervention

- Memory, Attention and Problem Solving Skills for Persons with MS
- Purpose is to help the individual acquire the highest level of cognitive functioning and functional independence through:
  1. Teaching the use of compensatory skills
  2. Retraining skills (home-based computer training)
  3. Environmental/lifestyle support for cognitive functioning including wellness strategies that may impact cognition
MAPSS-MS Intervention

• Classes – Compensatory strategies for memory, attention and problem solving skills
• Lifestyle factors that affect cognitive performance (physical activity, stress management, depression, sleep/rest)
• Computer practice 45 minutes three times per week
• Measures at baseline, immediately after 8 week intervention and 3 months after intervention

• Neuropsychological tests and measures of use of compensatory strategies
Cognitive Strategies

- Time 1
- Time 2
- Time 3

Treatment

Control
Verbal Memory

![Graph showing the comparison of Verbal Memory over Time 1, Time 2, and Time 3 between Treatment and Control groups. The graph indicates an upward trend in Verbal Memory for both groups, with the Treatment group showing a more pronounced increase.]
Outcomes – Pilot Study

- Significant improvement in use of cognitive strategies
- Significant improvement in verbal memory performance
- Significant improvement in performance on measure of complex scanning and visual tracking
Multi-Site Trial of MAPSS-MS

- Ongoing in Houston, San Antonio and Dallas/Fort Worth
- Will recruit 180 participants over 3 years
- Study participation lasts for 8 months and includes testing at 4 time points
- Randomized to treatment or comparison
- Funded by the National Institutes of Health
MAPSS-MS
MEMORY, ATTENTION, & PROBLEM SOLVING SKILLS for PERSONS with MS
THE UNIVERSITY OF TEXAS AT AUSTIN SCHOOL OF NURSING
Final Thoughts
• Low cost health promotion and wellness interventions may hold substantial promise as a complementary strategy for decreasing the burden of functional limitations and cognitive symptoms among persons with MS.
• Improving health behaviors - especially exercise, diet and stress management - reduces the accumulation of functional limitations and reduces risk for many other chronic disease (e.g. cardiovascular disease or cancer)

• Major way to reduce risk is a healthy lifestyle
Diet and MS

• Maintain a healthy weight – especially over time
• Limit sugar and highly processed foods – especially those high in sodium
• Increase fruits and vegetables
• Choose lean sources of protein and healthy fats
• Consume adequate fiber, fluids and calcium
• Role of Vitamin D is unclear
Physical Activity and MS

- Exercise training is effective for improving mobility, quality of life, fatigue and depression
- Aerobics, strength and flexibility are all important
- Lifestyle physical activity – everyone can do something (roller skating???)
- Avoid overheating
For help with Tailored exercise programs:

www.nchpad.org

• National Center for Health and Physical Activity in Disability
Key Question:

• Does the practice of health promoting behaviors make a difference in quality of life for persons with MS?
Evidence Suggests:

- Decreased accumulation of functional limitations over time
- More likely to remain employed
- Improves some symptoms
- Improved mental health
- Important for management of cognitive symptoms
And.... In multiple studies

- Consistent and strong relationship with perceived quality of life
Annual Meeting & Research Update

• Questions Submitted in Advance

  – Does your research show any difference or trends in cognitive function between those individuals that have been taking immunomodulating MS medications since diagnosis vs those that didn't/haven't/or because those meds were not invented yet?

  – I know that people suffering from MS are often able to "manage" their symptoms with exercise and/or yoga through moving the body mindfully. Can you tell me which form of movement (yoga or exercise) is more beneficial and why??
Thank you for joining us today for the South Central Chapter Annual Meeting & Research Update

If you would like more information on multiple sclerosis and how you can make a positive, life-changing impact, please visit us online at www.nationalMSsociety.org or call us at 1-800-344-4867.