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## Listening to the Experience of Living with MS: *Implications for Health Care Professionals*

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## Observations Leading to Inquiry

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- Personal:
  - Experienced poor match between the everyday needs and concerns, and focus and delivery of services
  - “Falling between the cracks”
- Professional:
  - Found limited evidence to challenge practice decisions; what was available tended to be medicalized and reductionistic, with an acute care focus



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## Objectives

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- Give voice to people aging with MS by summarizing what we have learned about their issues and concerns over the past 10 years
- Explore the practice implications of this knowledge for health care professionals

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## Focus of Research Program

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- Understanding the experiences and challenges of living with multiple sclerosis (MS),
- Documenting how health-related service needs and gaps contribute to these challenges,
- Developing and evaluating self-management interventions to minimize challenges and enhance the participation of people affected by MS.



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## Overarching Questions

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- What are the issues and concerns of people aging with MS?
- What services do they need to address these issues and concerns?
- What about carers? What are their challenges and needs?
- How can we effectively support people aging with MS and their carers?

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## Series of Related Studies

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*(combined, over 2000 participants)*

- Profile of older adults with MS (65+)
- Exploration of issues & concerns of people aging with MS (55+)
- Examination of service use and needs of people aging with MS (45+)
- Examination of falls among older adults with MS (55+)
- Evaluation of interventions for fatigue, falls prevention, carer problem-solving

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## Realities of and Hopes for Aging with MS

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## Magnification of Aging Experience

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- “...everybody has these fears about things as you grow older, but with MS I think you feel like you've been cheated out of some time. That somehow I shouldn't be going through this at 55...I should be 75 or whatever when I have to deal with going to a nursing home...so that's kind of the scary...”

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## Concerns about Aging with MS

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- “I've got friends [with MS] that can't talk, that can't get out of bed at all. They have to be in nursing homes...is this going to be me?”
  - Overall fear of the future
    - Implications of mobility loss
    - Concern about burdening family & friends
    - Worry about having to go to a nursing home
- (Finlayson, 2005)

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## Reflections on Aging with MS

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- “Decline is going to happen, you know that it is eventual. Aging shrinks the gap between where you are now and that eventual decline. Aging magnifies your concerns, because it brings them closer.”
- “I think it is just very discouraging in general to think about how little time is left...or how little useable time is left. I guess that's where the MS sort of gets in the way.”

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## Living and Aging with MS

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- Strengthens some relationships and roles but destroys others
    - Difficulty fulfilling expected roles; on-going negotiations
  - Internal conflict between being “independent” and participating with supports
- (Blank & Finlayson, 2007; Fong, Finlayson & Peacock, 2006)

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## Hope for Aging with MS

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- An older adult with MS is:
  - Vital and engaged in a range of life roles
  - Living independently in a modified and convenient home,
  - Utilizing available resources,
  - Walking, driving and traveling with the use of assistive technology,
  - Knowledgeable about MS,
  - Learning and adapting to changes in his/her life and disease.

(Finlayson, Van Denend & Shevil, 2003)

## Key Messages

- People with MS share the same concerns about aging as their peers
  - Concerns are emerging sooner
- General stereotypes about aging and disability make it difficult to prioritize participation with supports over “independence”
- Yet, vision of what is possible does exist

## Aging While Experiencing & Managing MS Symptoms

Extent that Symptoms Interfere with Daily Life Either a Little or a Lot			
	%		%
Problems with balance or mobility	90.0	Problems with sleeping	48.0
Fatigue	89.6	Pain	44.5
Weakness	88.0	Depression	41.9
Loss of coordination	79.0	Problems seeing	40.9
Spasticity	68.3	Incontinence of bowel	40.5
Incontinence of bladder	63.0	Problems speaking	33.2
Numbness, tingling	62.8	Tremors	29.8
Poor concentration, forgetfulness	60.9	Problems swallowing	28.1

N=1282, aged 45-90 years

## Experience of Mobility Loss

- “So I think my biggest fear is to become more debilitated where I won’t be able to get around even as much as I can nowadays”.
- “I think the worst part is the unpredictability of it...the fear that it could get worse at any time and not knowing, even with the progression if it's going to...if I'm ultimately going to end up in a wheelchair or, whatever. I would say that is probably the very worst part of it”.

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## Managing Mobility Loss

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- Greater mobility loss increased expressed need for choice and control
- Barriers in the physical environment increased need for planning in advance (decreased social spontaneity)
- Trying to maintain mobility had social, financial and emotional costs
- Mobility losses - facilitated advocacy, redefined roles, leads to tough decisions, requires planning for future

*(Finlayson & Van Denend, 2003)*

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## Experience of fatigue

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- “debilitating, frustrating, scary” “invisible” “overwhelming” “relentless” “mysterious” “Like walking in cement”
- “I’ve given up golfing. Using a cart just isn’t the same [as walking the course]. I just gave it up.”
- “I go out less after work now, my social network is smaller.”
- “I used to love shopping and wandering around. Now I just go for exactly what I need. Nothing else.”

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## Managing Fatigue

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- Use of strategies depends on:
  - Experience with and progression of disease
  - Variability of fatigue
  - Cognitive symptoms
  - Communication skills, and
  - Social support

*(Holberg & Finlayson, 2007)*

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## Experience of Cognitive Symptoms

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- “I’m slower to remember, slower to organize my thoughts. It’s taking me longer.”
- “I’m losing my ability to be sure of myself...I’m not trusting what I read. So I will stick it in front of my husband and say, ‘I don’t understand’, and then I will feel like a failure.”
- “It’s understanding the signals I’m getting from other people...lot of times I don’t decipher it right.”

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## Managing Cognitive Symptoms

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- Trial and error, self-taught solutions
  - Frustrating and sometimes ineffective
- Prefer environmental and personal strategies over use of social supports
  - Simplifying activities
  - Eliminating some activities, often with emotional and social costs
  - Modifying or organizing environment to reduce distractions; Using external cues

(Shevil & Finlayson, 2006)

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## Key Messages

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- MS symptoms have a profound impact on performance of and participation in everyday activities
- Solutions are often self-initiated trial and error, not based on structured problem-solving and decision making (*gap in services*)
- Successful use of strategies is highly contextualized and complex
  - Weighing symptoms, personal preferences, supports, experiences

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## Aging, MS and the Experiences and Challenges of Caregiving

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## Fear of Becoming a Burden

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- “But I think again using the word burden, my wife tells me not to use it, but I'm going to need more help than other people. I realize that the little help I get now - I'm afraid it's going to get a lot worse”.
- “I just feel more like a burden than a wife. I'm not a wife anymore”.

## Profile of Carepartners (N=302)

### Spouses

- 44 – 84 years old (average 64)
- 66% husbands
- 50% retired
- 98% live with their spouse
- 13% have their children living with them

### Children

- 20 – 65 years old (average 41)
- 70% daughters
- 66% employed FT
- 57% live with spouse
- 51% have their children living with them

(Finlayson & Cho, 2008)

## Do you ever help PWMS...

	%		%
Prepare a hot meal	71.9	Deal with health insurance claims and payments	37.4
Provide transportation	69.2	Go up and down a flight of stairs	36.1
Move around inside the house	42.7	Get in and out of bed	33.4
Get dressed	41.1	Manage his/her bladder	24.2
Coordinate medical appointments	38.7	Get in and out of the shower or tub	23.5
Manage medication	38.1	Manage his/her bowels	21.2

## Reasons Carepartners Could Not Continue

### According to PwMS

- Carepartner is burnt out from caregiving
- Care is becoming too heavy or demanding
- Other family responsibilities
- Work responsibilities

### According to Carepartner

- Deteriorating physical status of PwMS
- Deteriorating mobility and risk of falls for PwMS
- Just need more help
- My own deteriorating health

## Carepartner Challenges

- Dealing with their own health conditions at the same time they are providing care
  - Most commonly reported conditions: Arthritis, Hypertension, Hearing loss
- “I’m experiencing health conditions of my own – arthritis, hypertension, cancer”
- “I have a very bad back and I fractured my arm. I have to be careful with any lifting I do”

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## Carepartner Challenges

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- Dealing with incontinence
  - Managing the meds and aids
  - Urgency, accidents and extent of clean up
  - Emotionally laden for both the PwMS and the caregiver
- “Traveling is practically impossible because the incontinence keeps us homebound”
- “I get mad when I have to clean up after him”

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## Carepartner Challenges

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- Physical demands of caregiving
  - Helping with mobility (transfers, falls)
  - Taking on additional IADL that require physical abilities
- “If he falls I can’t get him up”
- “It can be physically challenging getting the wheelchair out of the car and helping her into the wheelchair”

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## Carepartner Challenges

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- Availability of social networks
  - Family members, friends, neighbors
  - Social supports either facilitate caregiving or have a negative impact
- “Nobody else cares”
- “[The family] need to learn to share responsibility”
- “We have no social life outside of the home”

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## Key Messages

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- Many persons aging with MS are dependent on a single carepartner
- Carepartners are an aging population themselves
- Carepartners can be required to provide a lot of care yet have limited supports and training to fulfill and maintain their role

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## Implications and Concluding Comments

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## Together Our Research Shows....

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- Aging with MS has the potential for a pervasive, negative influence on activity and participation
  - Not universal experience though
  - Varies over time
  - Many contributing factors
- Means initial assessments must be comprehensive; re-assessments regular

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## Together Our Research Shows....

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- Individuals who maintain participation are able to:
  - Identify and articulate needs,
  - Find or develop resources to address needs,
  - Problem-solve and use resources
  - Set goals to change or adapt behavior, roles, relationships and/or environment,
  - Advocate and negotiate for what is important
  - Evaluate outcomes of decisions

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## Practice Issues Identified

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- Many psychosocial & communication issues
  - Unpredictability, fear, burden
- Need for information, education and support for future planning and decision making
  - Person with MS and carepartner
- Typical 'aging' services needed sooner
- Service access – prevention & maintenance
- Activity modifications & alternatives

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## Practice Implications

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- Need to develop empirically informed disability self-management education
  - Move away from medicalized acute care model to a chronic illness management model
- Need to actively involve carepartners as clients
  - Training on AT and home modifications, lifts, transfers
  - Life course and future planning; Plan B for older caregivers
- Need to examine referral patterns and timing



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## The final word...

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- “MS is truly so unpredictable and differs greatly from person to person. There are no cookie cutter answers with MS....Make no assumptions about MS or the people with MS. Do not come to any conclusions or judgments without listening very carefully to the person with MS. If you do not listen, chances are you will be wrong, and MS will fool you. Instead, apply your knowledge of MS and experiences to what the person with MS is telling you now.”



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## Research Support

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- Thanks to key collaborators and research staff:
  - Elizabeth Peterson, Katharine Preissner, Eynat Shevil, Toni Van Denend, Chris Cho, Jennifer Garcia
- Thanks to funders:
  - National MS Society, National Institute of Disability and Rehabilitation Research, Retirement Research Foundation, UIC Campus Research Board

