MS NURSING: ADVOCACY AND ADHERENCE

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OBJECTIVES

Discuss advocacy in the realm of chronic illness

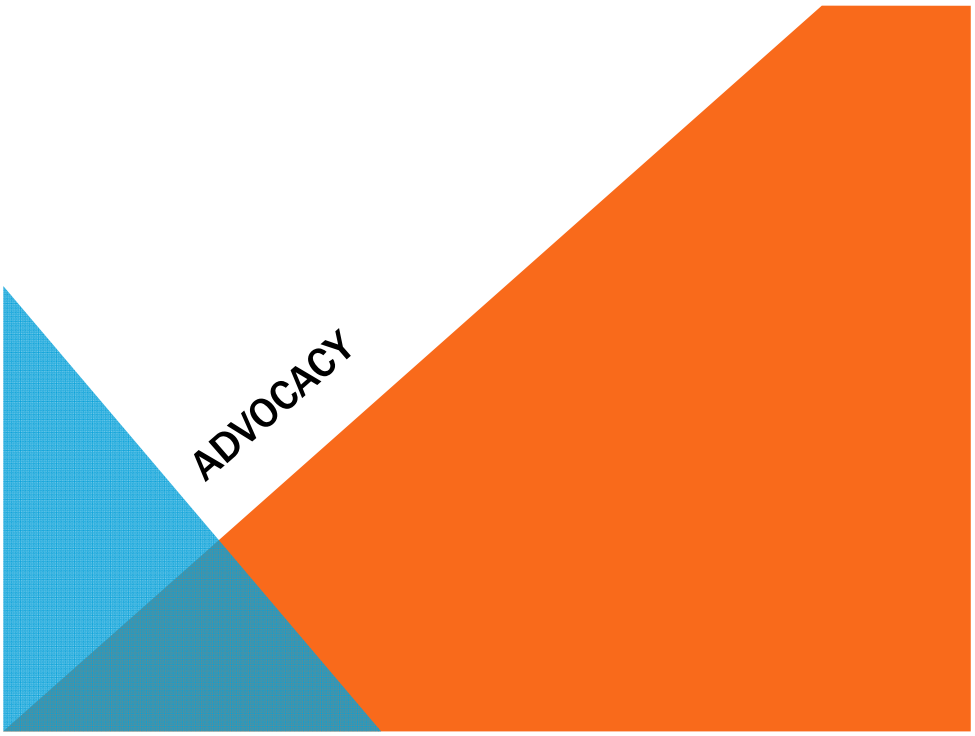
Define the importance of primary and specialist care in MS

Discuss the role of the MS Nurse in DMT selection, symptom management, and prescription of durable medical equipment (DME)

Discuss methods to ensure income security

Discuss adherence to complex treatment protocols in MS, including challenges of reimbursement, patient choice, barriers to adherence

Define the nursing role in alternative and complementary therapies (CAM)



ADVOCACY IN MS

What is it?

"Standing up for our patients"[1] in order to:

-Ensure appropriate interventions are received

-Direct patients to appropriate care to improve outcomes, and help them navigate the healthcare system[2]

-Ensure patients are accessing evidence-based sources of information

-Improve the care of people living with MS (PLMS)

-Ultimately to teach patients to be their own advocates, by improving self-efficacy

1. Smrtka, J., et. al. (2010). *The dynamic role of the multiple sclerosis nurse: challenges, expanding role, future directions.* Retrieved from http://www.iomsn.org. 2. Costello, K., Halper, J., Morgante, L, & Namey, M. *Case management in multiple sclerosis: a stage-by-stage guide to MS care for nurse case managers.* Retrieved from http://www.iomsn.org

ADVOCACY IN MS

How do MS nurses advocate for patients?

-Establish relationship with needed resources

Collaboration among nurses and other HCPs

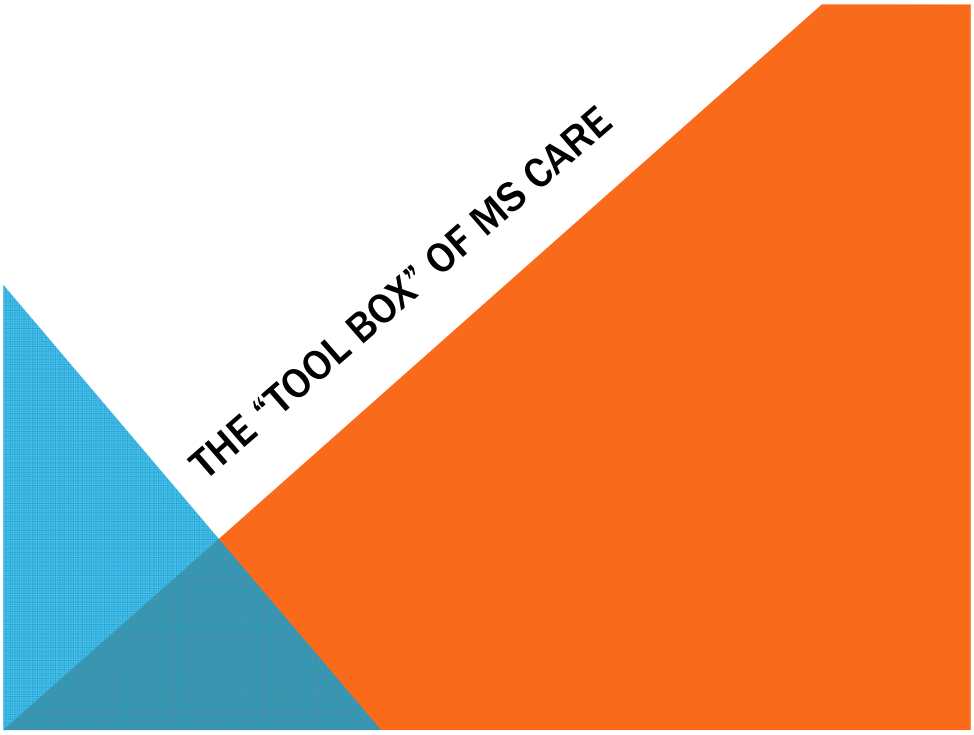
Identify/familiarize oneself with community resources

NMSS, MSAA, MSF; community transportation; home health and respite services; exercise programs

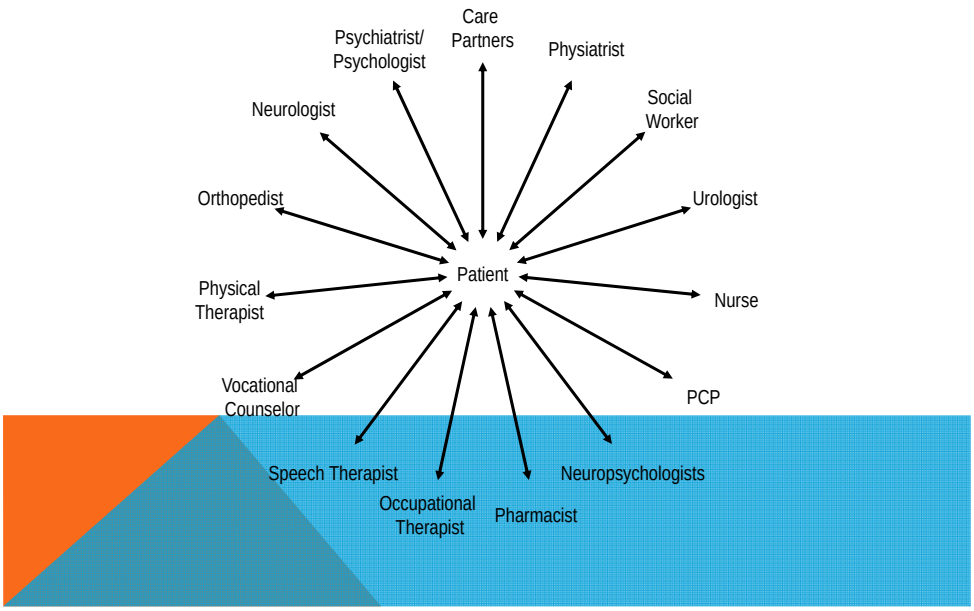
-Be a voice for patients and for MS Nursing

-Educate patients about disease process, importance of getting needs addressed at HCP visits, current insurance processes/hindrances

Harris, C., & Halper, J. *Multiple sclerosis: best practices in nurse care. Disease management, pharmacologic treatment, nursing research, 4th ed.* Retrieved from http://www.iomsn.org.



“IT TAKES A VILLAGE”



WHY IS PRIMARY CARE IMPORTANT?

- **The most common comorbidities among people with MS are:**
  - High Cholesterol
  - Hypertension
  - Arthritis
  - Irritable Bowel Syndrome
  - Lung Disease
- **These conditions can add to decreased functionality, quality of life, increased costs of medical care**

North American Research Committee on MS (NARCOMS)

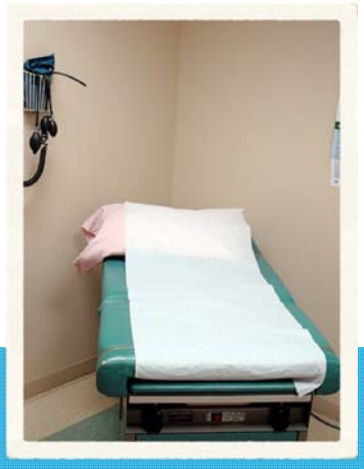
WHY IS PRIMARY CARE IMPORTANT?

- Comorbidities delay the time to MS diagnosis[1]
- Comorbidities are associated with increased disability at time of diagnosis
- Vascular comorbidities (high cholesterol, hypertension, diabetes, heart disease, and peripheral vascular disease) are associated with increased disability progression[2]
- They aren't good for the nervous system, either!

1. Marrie, R., et. al. (2009). Comorbidity delays diagnosis and increases disability at diagnosis in MS. *Neurology, 72*(2): 117-24. 2. Marrie, R., et. al. (2010). Vascular comorbidity is associated with more rapid disability progression in multiple sclerosis. *Neurology, 74*(13): 1041-1047.

BARRIERS TO RECEIVING PRIMARY CARE…

- Offices are not easily accessible
- PCPs may not be knowledgeable about MS
- Mobility/functional limitations
- PCPs defer to neurologist, leaving person living with MS feeling frustrated with medical system



WHY CAN'T AN MS PROVIDER BE A PRIMARY CARE PROVIDER?

- Because we don't know how!
- In a small study, ~25% of MS patients considered their neurologist to be their PCP
- MS care providers may make recommendations for preventive screenings, but are unlikely to manage primary care needs according to the most up to date guidelines

WHAT SPECIALISTS SHOULD BE TEAM MEMBERS?

Rehabilitation Specialists: Physical, Occupational, Speech Therapists

Behavioral Specialists: Psychiatrists, Psychologists/LMHCs, Neuropsychologists

Social Workers

Urologists

Physical Medicine and Rehabilitation physicians

OB-GYN

Orthopedist

Pharmacist

ROLE IN DISEASE MANAGEMENT

ROLE OF MS NURSE IN MS TREATMENT

DMT Selection

Symptom Management

Durable Medical Equipment

DMT SELECTION

Familiarity of therapeutic agents used to modify disease, treat relapses, and treat symptoms is a "Knowledge-based Competency" in MS.

Most important role of MS Nurse in DMT selection is EDUCATION:

Teach:

Efficacy, mechanism of action, route of administration, safety, & monitoring parameters of DMTs appropriate for each patient; provide resources for learning more information about DMTs

Formulate a Plan:

Narrow down DMT choices based on disease state, patient preferences, medical comorbidities, patient responsibility, financial/insurance issues, social support. Schedule follow-up appointment to make decision and initiate treatment

Monitor:

After a DMT is chosen, schedule regular follow-up to assess adherence, side effects, and provide new safety information; if patient is on an injectable drug, regularly assess injection sites and technique

Harris, C., & Halper, J. *Multiple sclerosis: best practices in nurse care. Disease management, pharmacologic treatment, nursing research, 4th ed.* Retrieved from http://www.iomsn.org.

SYMPTOM MANAGEMENT

Performing a comprehensive assessment of the person living with MS is a domain of MS nursing, this includes assessment of functionality and symptoms

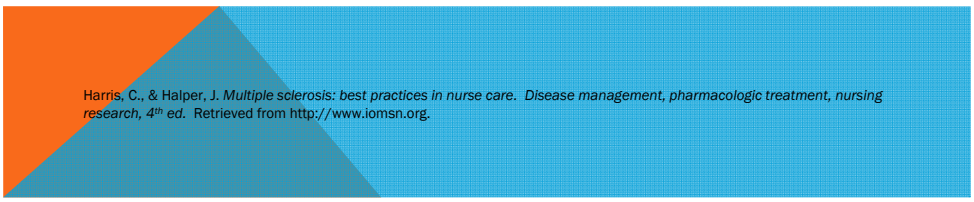
Nurses are often the first point of contact when a person has a new or worsening symptom

Effective management of symptoms improves quality of life

SYMPTOM MANAGEMENT

Assessment:

- Identify possible cause of new symptom
  - Psychosocial or physical issues, underlying medical conditions, new medications, relapse
- Offer treatment for new symptom
  - Pharmacologic (titrate doses of medication for tolerability)
  - Non-pharmacologic (PT/OT/ST, counseling, DME, behavioral changes)
- Schedule follow-up to assess efficacy of intervention



Harris, C., & Halper, J. *Multiple sclerosis: best practices in nurse care. Disease management, pharmacologic treatment, nursing research, 4th ed.* Retrieved from http://www.iomsn.org.

DME SELECTION

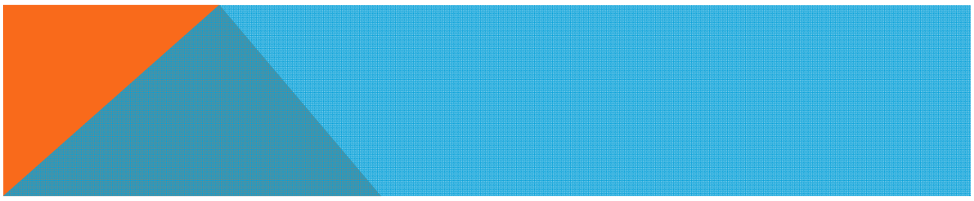
Durable Medical Equipment: mobility aids, including powered mobility devices (PMDs); braces; home-based hospital equipment (bed, potty chair, Hoyer lift)

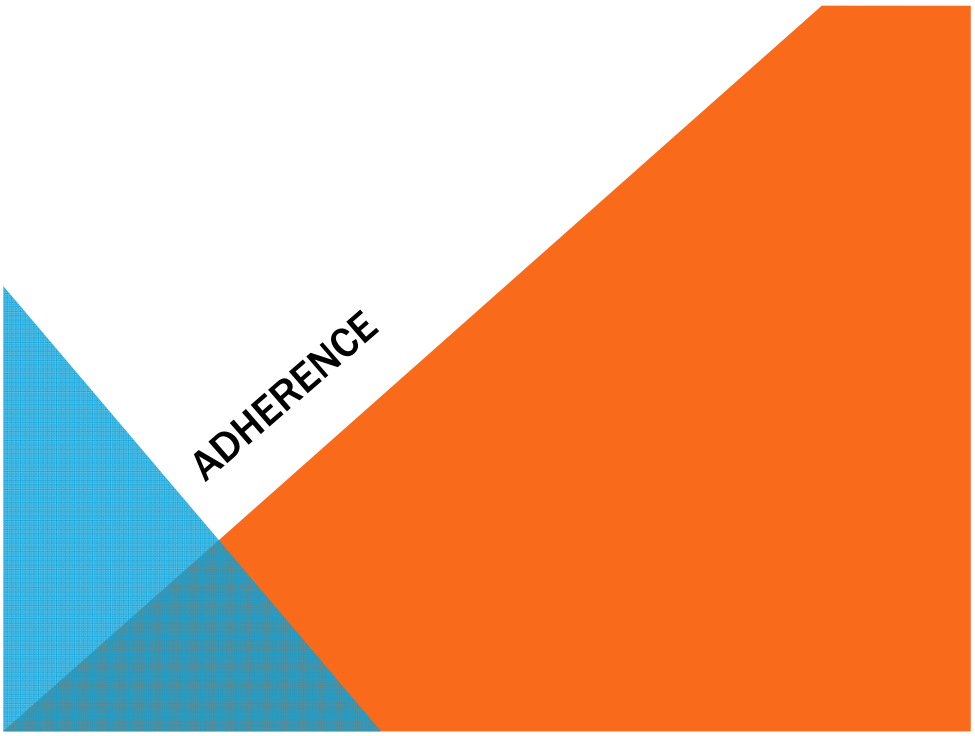
Often seen as negative discussion by the patient/caregiver as it indicates "the next phase" or loss of independence

Major goal of MS Nurse in DMT selection is REFRAMING, or changing the meaning of something.

Appropriate use of DME, for most patients, means an increase in independence, functionality, quality of life, and safety

PT/OT referral with DME selection is important to safely incorporate equipment





ADHERENCE V. COMPLIANCE[1]

Adherence: Faithful attachment; devotion; the process of sticking to something, of sticking together; collaborative[2]

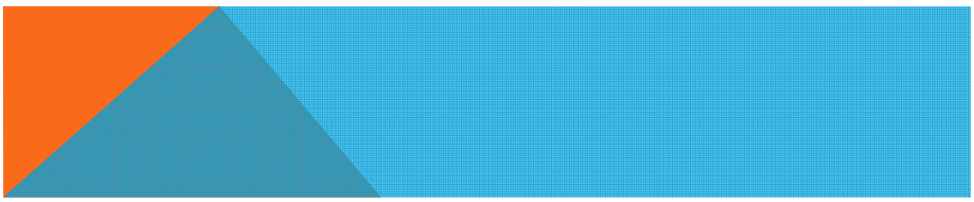
- Implies belief in a process, "it takes a village"

Compliance: The act of yielding to a wish, request, or demand; acquiescence

- Lonely

1. http://www.thefreedictionary.com. 2. Namey, M. (2007). Promoting adherence to complex protocols. In J. Halper (Ed.), *Advanced concepts in multiple sclerosis nursing care* (2nd ed., pp. 91-100). New York: Demos Medical Publishing.

"DRUGS DON'T WORK IN PATIENTS WHO DON'T TAKE THEM."
C. EVERETT KOOP



ADHERENCE IN MS

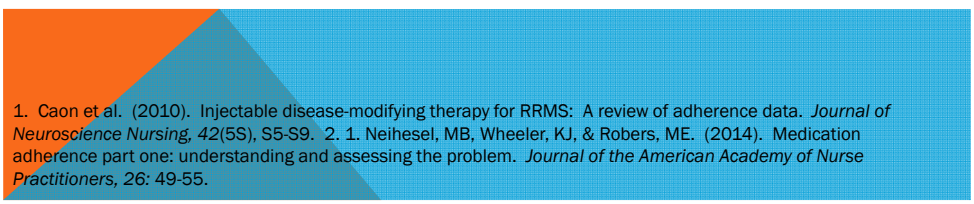
Research is aplenty, but limited by
- Inconsistency of methodology
- Lack of generalizability because of study population

Strict adherence to DMT results in optimal functional, cognitive, and quality of life prospects[1]

Measured by discontinuation rates, proportion of days covered, and medication possession ratios

Lower adherence rates = more inpatient visits and higher MS related medical costs

In general, adherence rates are lowest in psychiatric disorders, when there are cognitive issues, and comorbidities[2]



1. Caon et al. (2010). Injectable disease-modifying therapy for RRMS: A review of adherence data. *Journal of Neuroscience Nursing, 42*(5S), S5-S9. 2. 1. Neihesel, MB, Wheeler, KJ, & Robers, ME. (2014). Medication adherence part one: understanding and assessing the problem. *Journal of the American Academy of Nurse Practitioners, 26:* 49-55.

REVIEW OF ADHERENCE DATA

Approximately 60-76% adhere to interferon beta or glatiramer acetate for 2-5 years[1]

Retrospective review of pharmacy database revealed 80% compliance with interferon beta-1a (both administration types), interferon beta-1b, and glatiramer acetate[2]

Discontinuation of treatment usually occurs during the first 2 years of treatment[3]

Global Adherence Project (n=2646, 179 sites, 22 countries) reported 25.3% nonadherence rate after 6 months[4]

1. Costello et al. (2008). Recognizing nonadherence in patients with MS and maintaining treatment adherence in the long term. *Medscape Journal of Medicine, 10*(9), 225. 2. Reynolds et al. (2010). Persistence and adherence to disease modifying drugs among patients with MS. *Current Medical Research and Opinion,* 26(3), 663-674. 3. Rio et al. (2005). Factors related with treatment adherence to interferon beta and glatiramer acetate therapy in MS. *Multiple Sclerosis, 11*(3), 306-309. 4. Devonshire et al. (2006). The Global Adherence Project – A multicentre observational stuy on adherence to disease-modifying therapies in patients suffering from RRMS. *Multiple Sclerosis, 12*(Suppl.), S82.

FACTORS AFFECTING ADHERENCE

Drug-related Factors

- Side Effects/Adverse Events
- Cost
- Education

Patient-related Factors

- Psychosocial
- Physical
- System Access

SIDE EFFECTS/ADVERSE EVENTS

Adverse events account for 14-51% of treatment discontinuations among the injectable DMTs[1]

Injection site reactions[2], flu-like symptoms of interferons, "Copaxone (glatiramer acetate) flush"

Patients fear side effects/AEs (blood count/liver abnormalities, hair thinning, cardiac concerns, infections, GI issues, flushing)

Oral DMTs and natalizumab require more lab monitoring, more frequent office visits, and more specialty care

1. Costello et al. (2008). Recognizing nonadherence in patients with MS and maintaining treatment adherence in the long term. *Medscape Journal of Medicine, 10*(9), 225. 2. Caon et al. (2010). Injectable disease-modifying therapy for RRMS: A review of adherence data. *Journal of Neuroscience Nursing, 42*(5S), S5-S9. 3. Saunders, C. (2010). Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *Journal of Neuroscience Nursing, 42*(5S), S10-S18.

COST

Economic feasibility[1,2]

- Is the patient insured?
- What is the burden of medication cost?
  - Increased drug copayments associated with decreased adherence[3]
  - Coinsurance v copayment
- Cost of office visit copays
  - Frequency of appointments increased with newer DMTs
- Cost of laboratory and ancillary testing
  - More testing required with newer DMTs

1. Saunders, C. (2010). Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *Journal of Neuroscience Nursing, 42*(5S), S10-S18. 2. Dor et al. (2010). Cost sharing, benefit design, and adherence: the case of MS. *Advances in Health Economics and Health Services Research, 22*, 175-193. 3. Lafata et al. (2003). Measuing adherence and persistence to disease-modfiying agents among patients with RRMS. *Journal of the American Pharmacists Association, 48*(6), 752-757.

EDUCATION

Understanding of disease

- Periods of relapse and remission with paroxysmal symptoms
- Uncertainty and unpredictability
- Low health literacy[6]

(Un)Realistic expectations of DMTs[1]

- Perceived lack of efficacy was cause of suspended therapy in 29%[2] of interferon patients
- "I failed" or "My drug failed"
- Perceived benefit of medication at baseline and confidence that DMT will positively affect course of MS predicted adherence at 6 months[3]

No or minimal symptoms = no disease?

- Patients with stable disease demonstrate poorer adherence and more missed appointments[4]
- Meds no longer needed once symptoms resolve[5]

1. Caon et al. (2010). Injectable disease-modifying therapy for RRMS: A review of adherence data. *Journal of Neuroscience Nursing, 42*(5S), S5-S9. 2. Portaccio et al. (2008). Long-term adherence to interferon beta therapy in RRMS. *European Neurology, 59*(3-4), 131-135. 3. Turner et al. (2007). Predicting ongoing adherence to disease modifying therapies in MS: Utility of the health beliefs model. *Multiple Sclerosis, 13*, 1146-1152. 4. Hancock et al. (2011). Exacerbation history is associated with medication and appointment adherence in MS. *Journal of Behavioral Medicine, 34*(5), 330-338. 5. 1. Neihesel, MB, Wheeler, KJ, & Robers, ME. (2014). Medication adherence part one: understanding and assessing the problem. *Journal of the American Academy of Nurse Practitioners, 26:* 49-55. 6. 1. Neihesel, MB, Wheeler, KJ, & Robers, ME. (2014). Medication adherence part two: predictors of nonadherence and adherence. *Journal of the American Academy of Nurse Practitioners, 26:* 225-232.

PSYCHOSOCIAL FACTORS

Self-efficacy[1]

- Ability to organize/implement a course of action; ability to initiate coping mechanisms for an unfavorable task, persist in the behavior, and set goals to encourage persistence
- Adherence increases with level of self-efficacy[2]
- Women and those having a relapsing form of MS have higher levels of self-efficacy[3]

Fear of needles/injection anxiety

- Baseline injection anxiety predicts lower levels of adherence[4]
- Perception of task: doing something "to" self, rather than "for" self

Cognitive Dysfunction

- "I forgot" my injection: 58% in a 2009 survey[5], 50.6% in the Global Adherence Project; forgetting to take meds is common across disease states
- Nonadherence associated with greater cognitive impairment

1. Caon et al. (2010). Injectable disease-modifying therapy for RRMS: A review of adherence data. *Journal of Neuroscience Nursing, 42*(5S), S5-S9. 2. Fraser et al. (2004). A prospective study of adherence to glatiramer acetate in individuals with MS. *Journal of Neuroscience Nursing,* 36(3), 120-129. 3. Fraser & Polito. (2007). A comparative study of self-efficacy in men and women with MS. *Journal of Neuroscience Nursing,* 39(2), 102-106. 4. Turner et al. (2009). Injection anxiety remains a long-term barrier to medication adherence in MS. *Rehabilitation Psychology, 54*(1), 116-121. 5. Treadway et al. (2009). Factors that influence adherence with disease-modifying therapy in MS. *Journal of Neurology, 256,* 568-576.

PSYCHOSOCIAL FACTORS[1]

Depression
- MS patients with mood or anxiety d/o ~5 times more likely to exhibit adherence problems[2]
- Lack of hope and faith

Sense of control over disease

Life changes
- Role change, marriage, pregnancy, other chronic illnesses
- Is life stable for the person living with MS?

Ease of use
- Storage
- Travel
- Establishing a routine
- Frequency of dosing; monitoring required for safe administration

1. Saunders, C. (2010). Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *Journal of Neuroscience Nursing, 42*(5S), S10-S18. 2. Bruce et al. (2010). Treatment adherence in MS: association with emotional status, personality, and cognition. *Journal of Behavioral Medicine, 33*(3), 219-227.

PHYSICAL FACTORS

Greater disability associated with adherence to therapy[1]

Physical factors that may affect ability to self-inject:
- Weakness
- Sensory loss
- Ataxia, tremor
- Visual disturbance

1. Rio et al. (2005). Factors related with treatment adherence to interferon beta and glatiramer acetate therapy in MS. *Multiple Sclerosis, 11*(3), 306-309.

SYSTEM ACCESS

Level of trust in healthcare providers[1]

- How was the diagnosis delivered?
- Is adequate time spent in educating patients?
- "Is my MS care provider for me?"

Specialty Pharmacy involvement

- Are deliveries reliable?

Accessibility of MS care

- Do patients get called back in a reasonable time frame?
- How hard is it to get an urgent appointment?

1. Saunders, C. (2010). Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *Journal of Neuroscience Nursing, 42*(5S), S10-S18.

OPPORTUNITIES TO IMPROVE ADHERENCE[1]

Individualized DMT selection based on state of MS ± other medical conditions/medications AND

- Psychosocial Needs
  - Level of education, underlying mood disorder, support system, baseline quality of life, daily schedule, expectations of therapy
- Physical Needs
  - Dexterity, safety of home environment
- Financial Concerns
  - Is therapy affordable?
  - What patient and copayment assistance programs are available?

1. Saunders, C. (2010). Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *Journal of Neuroscience Nursing, 42*(5S), S10-S18.

OPPORTUNITIES TO IMPROVE ADHERENCE

More frequent contact improves adherence

- Nurse contact from office, from pharmaceutical patient support programs[1,2]
- Make office accessible to patients, particularly if concerned about adverse events

Education

- Realistic expectations of DMT
- Injection technique, even re-training[3], use of autoject devices[4]
- Use of DMTs with less frequent dosing if appropriate
- Provide hope about future of MS therapies

1. Kennedy, P. (2007). *Partnership between Shared Solutions® and SM office nurses: Adherence enhancement program.* Presented at the 21st Annual Meeting of the Consortium of MS Centers, May 30-June 2, Washington, DC. 2. Schapiro, R. (2004). Adherence to interferon beta-1b: BETA Nurse Program. *International Journal of MS Care, 6,* 66. 3. 1. Saunders, C. (2010). Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *Journal of Neuroscience Nursing, 42*(5S), S10-S18. 4. Lugarese, A. (2009). Addressing the need for increased adherence to MS therapy: can delivery technology enhance patient motivation? *Expert Opinion on Drug Delivery, 6*(9), 995-1002.

OPPORTUNITIES TO IMPROVE ADHERENCE

In a meta-analysis of adherence to oral therapies in chronic disease, daily dosing schedules were associated with higher adherence[1]

Educate patients about goals of therapy and risk management to improve health literacy[2]

Poor communication = 19% greater risk of nonadherence. COMMUNICATE.[3]

Use dose titration, autoject devices, engage social network, simplify regimen, auto-refill meds when appropriate to risk strategy, and provide opportunities for reduced cost[3,4]

1. Srivastava, K., Arora, A., Kataria, A., et. al. (2013). Impact of reducing dosing frequency on adherence to oral therapies: a literature review and meta-analysis. *Patient Preference and Adherence. 7:* 419-434. 2. Zhang, N, Terry, A., & MchHorney, C. (2014). Impact of health literacy on medication adherence: a systematic review and meta-analysis. *Annals of Pharmacotherapeutics,* Epub ahead of print 2014 Mar 11. 3. Iuga, A. & McGuire, M. (2014). Adherence and health care costs. *Risk Management and Healthcare Policy, 7:* 35-44. 4. Viswanathan, M., Golin, C., Jones, C., et. al. (2012). Interventions to improve adherence to self-administered medications for chronic disease in the United States: a systemic review. *Annals of Internal Medicine, 157*(11): 785-795.

STRATEGIES TO IMPROVE ADHERENCE[1]

Address common barriers:

- Polypharmacy
- Forgetfulness
- Lack of knowledge
- Side effects/Adverse events
- Complexity of regimen
- Cultural/Religious Barriers
- Financial Barriers
- Depression
- Low Health Literacy

1. Neihesel, MB, Wheeler, KJ, & Robers, ME. (2014). Medication adherence part three: strategies for improving adherence. *Journal of the American Academy of Nurse Practitioners, 26:* 281-287.

STRATEGIES TO IMPROVE ADHERENCE[1]

Active listening

Emotional Support

Creating a culture of trust

Acknowledge difference between your beliefs and beliefs of patient/family

1. Neihesel, MB, Wheeler, KJ, & Robers, ME. (2014). Medication adherence part three: strategies for improving adherence. *Journal of the American Academy of Nurse Practitioners, 26:* 281-287.

NURSING ROLE IN CAM

Complimentary and Alternative Medicine (CAM):

- -"The combination of products and therapies found outside the medical treatments commonly taught in medical schools or found in traditional hospitals"[1]
- -Can be used in combination with conventional medical therapies or instead of them
- -Used by 33-80% of people living with MS, moreso among women, those with higher education levels, and those who report poorer health[2]
- -Types of CAM therapy established by NIH[1]
  - Biologically-based (diet, supplements)
  - Mind-body medicine (meditation, hypnosis, spirituality)
  - Manipulative and body-based systems (massage, chiropractic)
  - Alternative medical systems (Chinese medicine, Ayurveda)
  - Energy therapies (magnets, therapeutic touch)

1. Kennedy, P. (2011). Incorporating complementary and alternative medicine in symptom management. In Halper, J., and Holland, N. J. Eds.), *Comprehensive nursing care in Multiple Sclerosis* (pp. 123-130). New York: Springer Publishing Company. 2. Yadav, V., et. al. (2014). Summary of evidence-based guideline: complementary and alternative medicine in multiple sclerosis. *Neurology, 82,* 1083-1092.

NURSING ROLE IN CAM

Alternative and complimentary does not necessarily mean harmless

Nurses are in a unique position to provide education about CAM due to the holistic philosophy that underlies nursing

-Tremendous amount of information available, and of variable quality, depending on who is delivering the information

-Help patients to understand evidence (anecdotal, laboratory, animal, experimental) and to learn to recognize claims

-Is the therapy effective? Is it safe? How much does it cost? Will it cause interactions with traditional medical therapy?

-In educating and recommending CAM, be sure to understand the goal of the patient, and the reasoning for choosing CAM so as to foster good rapport and enhance trust

1. Kennedy, P. (2011). Incorporating complementary and alternative medicine in symptom management. In Halper, J., and Holland, N. J. Eds.), *Comprehensive Nursing Care in Multiple Sclerosis* (pp. 123-130). New York: Springer Publishing Company. 2. Yadav, V., et. al. (2014). Summary of evidence-based guideline: complementary and alternative medicine in multiple sclerosis. *Neurology, 82,* 1083-1092. 3. Bowling, A. C. (2001). *Alternative Medicine and Multiple Sclerosis.* New York: Demos.

NURSING ROLE IN CAM

Review evidenced-based guidelines from the American Academy of Neurology, available online at www.aan.com

Keep several sources on-hand for easy reference:

Comprehensive Nursing Care in Multiple Sclerosis (June Halper & Nancy Holland)

Alternative Medicine and Multiple Sclerosis (Allen Bowling, MD, PhD)

PDR for Herbal Medicines, PDR for Nutritional Supplements

Familiarize yourself with current research

-Vitamin D

-High sodium diets

-Effects of exercise and yoga on MS

WHY ARE WE IMPORTANT?

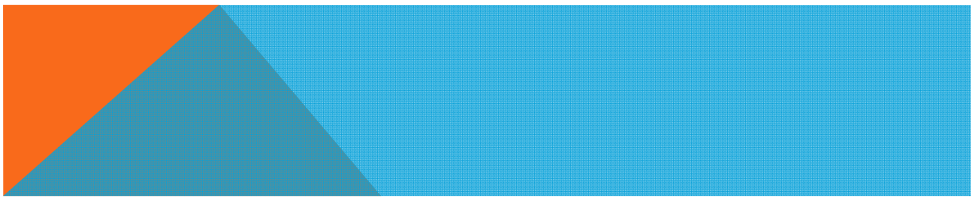
For all of reasons mentioned in this presentation!

Nurses are the frontline of MS care

Often the first source to provide information about living with MS, the first point of contact when something changes with disease course, and the greatest source of hope for people living with MS and their care partners

As nurses, we are: patient and public policy advocates, counselors, social workers, educators, caregivers, researchers

Proving we are important through research, publications, community service and outreach, and continued collaboration with other members of the MS care team




IT IS A BEAUTIFUL
thing when a career
AND
a passion
COME TOGETHER

Thank You!