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* in order to:
- Ensure appropriate interventions are received
- Direct patients to appropriate care to improve outcomes, and help them navigate the healthcare system
- 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

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

“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 diagnosis¹
- 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 progression²
- They aren’t good for the nervous system, either!


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 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


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

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

Adherence: Faithful attachment; devotion; the process of sticking to something, of sticking together; collaborative
- Implies belief in a process, “it takes a village”

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

“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

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

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\(^4\)

FACTORS AFFECTING ADHERENCE

Drug-related Factors
- Side Effects/Adverse Events
- Cost
- Education

Patient-related Factors
- Psychosocial
- Physical
- System Access

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4. Devonshire et al. (2006). The Global Adherence Project - A multicentre observational study on adherence to disease-modifying therapies in patients suffering from RRMS. Multiple Sclerosis, 12(Suppl. 1), S82.
SIDE EFFECTS/ADVERSE EVENTS

Adverse events account for 14-51% of treatment discontinuations among the injectable DMTs1

Injection site reactions2, 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


COST

Economic feasibility1,2

- Is the patient insured?
- What is the burden of medication cost?
  - Increased drug copayments associated with decreased adherence3
  - Coinsurance vs 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

EDUCATION

Understanding of disease
- Periods of relapse and remission with paroxysmal symptoms
- Uncertainty and unpredictability
- Low health literacy

(Un)Realistic expectations of DMTs
- Perceived lack of efficacy was cause of suspended therapy in 29% 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

No or minimal symptoms = no disease?
- Patients with stable disease demonstrate poorer adherence and more missed appointments
- Meds no longer needed once symptoms resolve

PSYCHOSOCIAL FACTORS

Self-efficacy
- 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
- Women and those having a relapsing form of MS have higher levels of self-efficacy

Fear of needles/injection anxiety
- Baseline injection anxiety predicts lower levels of adherence
- Perception of task: doing something “to” self, rather than “for” self

Cognitive Dysfunction
- “I forgot” my injection: 58% in a 2009 survey, 50.6% in the Global Adherence Project; forgetting to take meds is common across disease states
- Nonadherence associated with greater cognitive impairment
PSYCHOSOCIAL FACTORS

Depression
- MS patients with mood or anxiety d/o ~5 times more likely to exhibit adherence problems
- 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

PHYSICAL FACTORS

Greater disability associated with adherence to therapy

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


SYSTEM ACCESS

Level of trust in healthcare providers\textsuperscript{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?

\textsuperscript{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\textsuperscript{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?

\textsuperscript{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 programs1,2
- Make office accessible to patients, particularly if concerned about adverse events

Education
- Realistic expectations of DMT
- Injection technique, even re-training3, use of autoject devices4
- Use of DMTs with less frequent dosing if appropriate
- Provide hope about future of MS therapies

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OPPORTUNITIES TO IMPROVE ADHERENCE

In a meta-analysis of adherence to oral therapies in chronic disease, daily dosing schedules were associated with higher adherence1

Educate patients about goals of therapy and risk management to improve health literacy2

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 cost4

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STRATEGIES TO IMPROVE ADHERENCE

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


STRATEGIES TO IMPROVE ADHERENCE

Active listening
Emotional Support
Creating a culture of trust
Acknowledge difference between your beliefs and beliefs of patient/family

NURSING ROLE IN CAM

Complementary 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 health²
- Types of CAM therapy established by NIH¹
  - 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)

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


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!