

Adherence

How and Why We Stay the Course



IOMSN

International Organization
of Multiple Sclerosis Nurses
International Organization
of Multiple Sclerosis Nurses

Adherence vs. Compliance

- **Adherence:** Faithful attachment; devotion; the process of sticking to something, of sticking together; collaborative ¹
 - Implies belief in a process, “it takes a village”
- **Compliance:** The act of yielding to a wish, request, or demand; acquiescence ²
 - Lonely

1. Namey, M. 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, 2007.
2. The Free Dictionary. Compliance. www.thefreedictionary.com.

Adherence vs. Compliance

**“Drugs don’t work
in patients who don’t take them.”**

C. Everett Koop

Health Care Definitions

- **Adherence:** degree to which medication behaviors align with health care provider instructions (time, dose, frequency)
- **Persistence:** duration of time patient takes prescribed medications
- **Partial Adherence:** occurs when symptoms exacerbate, or surrounding the time of an office visit; once better, med is stopped

Health Care Definitions (cont.)

As defined by the World Health Organization

- **Preventable Nonadherence:** nonadherence due to forgetting, misunderstanding directions, barriers to obtaining medication
- **Nonpreventable Nonadherence:** nonadherence due to serious mental illness, intolerance due to side effects or adverse events

Adherence & the US Health Care System

- **Nonadherence accounts for \$100-300 billion of avoidable health care costs yearly¹**
- **Half of 3.2 billion Rx's issued annually in US are not taken as prescribed²**
- **There is a small but statistically significant positive association between health literacy and medication adherence³**

1. Iuga, McGuire. Adherence and health care costs. *Risk Manag Healthc Policy*. 2014;7:35-44.

2. Neiheisel, Wheeler, Roberts. Medication adherence part one: understanding and assessing the problem. *J Am Assoc Nurse Pract*. 2014;26:49-55.

3. Zhang NJ, Terry A, McHorney CA. Impact of health literacy on medication adherence: a systematic review and meta-analysis. *Ann Pharmacother*. 2014 Jun;48(6):741-51.

Common Reasons for Nonadherence

- **Forgetfulness is most common reason**
- **Others include:**
 - Perceived side effects
 - High drug costs
 - Perception of effect on disease
 - Injection-related reasons (anxiety, pain, skin reaction)
 - Cognitive impairment or depression
 - Treatment fatigue

Iuga, McGuire. Adherence and health care costs. *Risk Manag Healthc Policy*. 2014;7:35-44.

Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis*. Hackensack, NJ: International Organization of Multiple Sclerosis Nurses; 2013.
<http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.

Adherence in Multiple Sclerosis

- **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**

Adherence in Multiple Sclerosis

- 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 years¹
- Retrospective review of pharmacy database revealed 80% compliance with interferon beta-1a (both administration types), interferon beta-1b, and glatiramer acetate²
- Discontinuation of treatment usually occurs during the first 2 years of treatment³
- Global Adherence Project (n=2646, 179 sites, 22 countries) reported 25.3% nonadherence rate after 6 months⁴

1. Costello et al. *Medscape J Med*. 2008;10(9), 225.

2. Reynolds et al. *Curr Med Res Opin*. 2010;26(3), 663-674.

3. Rio et al. *Mult Scler*. 2005;11(3), 306-309.

4. Devonshire et al. *Mult Scler*. 2006;12(Suppl.), S82.

Factors Affecting Adherence

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

- **Patient-related Factors**
 - Psychosocial
 - Physical
 - System Access

DRUG-RELATED FACTORS

Side Effects/Adverse Events

- Adverse events account for 14-51% of treatment discontinuations among the injectable DMTs
- Injection site reactions, flu-like symptoms of interferons, “flush” associated with glatiramer acetate
- 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

Costello et al. *Medscape J Med*. 2008;10(9), 225.

Caon et al. *J Neurosci Nurs*. 2010;42(5S), S5-S9.

Saunders. *J Neurosci Nurs*. 2010;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 adherence³
 - Coinsurance v copayment

1. Saunders. Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *J Neurosci Nurs.* 2010;42(5S):S10-S18.
2. Dor et al. (2010). Cost sharing, benefit design, and adherence: the case of MS. *Adv Health Econ Health Serv Res.* 2010;22:175-193.
3. Lafata et al. Measuring adherence and persistence to disease-modifying agents among patients with RRMS. *J Am Pharm Assoc.* 2008;48(6):752-757.

Cost

- **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 disease¹**
 - Periods of relapse and remission with paroxysmal symptoms
 - Uncertainty and unpredictability
 - Low health literacy²

1. Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis*. Hackensack, NJ: International Organization of Multiple Sclerosis Nurses; 2013. <http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.
2. Wheeler, Roberts, Neiheisel. Medication adherence part two: predictors of nonadherence and adherence. *J Am Assoc Nurse Pract*. 2014;26:225-32.

Education

- **Realistic and Unrealistic expectations of DMTs^{1,2}**
 - Perceived lack of efficacy was cause of suspended therapy in 29% of interferon patients³
 - “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 months⁴

1. Caon et al. *J Neurosci Nurs*. 2010;42(5S):S5-S9.

2. Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis*. IOMSN; 2013. <http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.

3. Portaccio et al. *Eur Neurol*. 2008;59(3-4):131-135.

4. Turner et al. *Mult Scler*. 2007;13:1146-1152.

Education

- **No symptoms or minimal symptoms = no disease?**
 - Patients with stable disease demonstrate poorer adherence and more missed appointments¹
 - Meds no longer needed once symptoms resolve²

1. Hancock et al. Exacerbation history is associated with medication and appointment adherence in MS. *J Behav Med.* 2011;34(5):330-338.
2. Neiheisel, Wheeler, Roberts. Medication adherence part one: understanding and assessing the problem. *J Am Assoc Nurse Pract.* 2014;26:49-55.

PATIENT-RELATED FACTORS

Psychosocial Factors

■ Self-efficacy^{1,2}

- 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-efficacy³
- Women and those having a relapsing form of MS have higher levels of self-efficacy⁴

1. Caon et al. *J Neurosci Nurs*. 2010;42(5S):S5-S9.

2. Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis*. IOMSN; 2013. <http://www.nxtbook.com/nxtbooks/iomsmn/monograph/>.

3. Fraser et al. *J Neurosci Nurs*. 2004;36(3):120-129.

4. Fraser, Polito. *J Neurosci Nurs*. 2007;39(2):102-106.

Psychosocial Factors

- **Fear of needles/injection anxiety¹**
 - Baseline injection anxiety predicts lower levels of adherence²
 - Perception of task: doing something “to” self, rather than “for” self

1. Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis*. IOMSN; 2013. <http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.

2. Turner et al. Injection anxiety remains a long-term barrier to medication adherence in MS. *Rehabil Psychol*. 2009;54(1):116-121.

Psychosocial Factors

- **Cognitive Dysfunction¹**

- “I forgot” my injection: 58% in a 2009 survey², 50.6% in the Global Adherence Project; forgetting to take meds is common across disease states
- Nonadherence associated with greater cognitive impairment

1. Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis*. IOMSN; 2013. <http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.
2. Treadaway et al. Factors that influence adherence with disease-modifying therapy in MS. *J Neurol*. 2009;256:568-576.

Additional 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 (self-efficacy)**

Saunders. *J Neurosci Nurs.* 2010;42(5S):S10-S18.

Bruce et al. *J Behav Med.* 2010;33(3):219-227.

Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis.* IOMSN; 2013. <http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.

Additional Psychosocial Factors

- **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

Saunders. Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *J Neurosci Nurs.* 2010;42(5S):S10-S18.

Physical Factors

- **Greater disability associated with adherence to therapy¹**
- **Physical factors that may affect ability to self-inject:**
 - Weakness
 - Sensory loss
 - Ataxia, tremor
 - Visual disturbance

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

System Access

- **Level of trust in healthcare providers¹**
 - 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. Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *J Neurosci Nurs.* 2010;42(5S):S10-S18.

IMPROVING OUTCOMES

Risk Management Principles

- **Newer MS Therapies require a greater degree of patient responsibility because of risk/benefit ratio and serious adverse events**
 - STRATIFY study: Ability to check JC Virus antibody positivity
 - Dosage and Administration language in the product information for fingolimod is stringent
 - CBC, LFT monitoring with teriflunomide

Tysabri (natalizumab). [product information]. Biogen Idec, 2013. <http://www.tysabrihcp.com/anti-jcv-antibody-test-hcp.xml>.

Gilenya (fingolimod) [product information]. Novartis Pharmaceuticals Corporation, 2014. <http://www.pharma.us.novartis.com/product/pi/pdf/gilenya.pdf>.

Aubagio (teriflunomide) [product information]. Cambridge, MA: Genzyme Corporation; 2012. <http://products.sanofi.us/aubagio/aubagio.pdf>.

Opportunities to Improve Adherence

- **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?

Saunders. Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. *J Neurosci Nurs.* 2010;42(5S):S10-S18.

Opportunities to Improve Adherence

- **More frequent contact improves adherence**
 - Increase nurse contact from office, from pharmaceutical patient support programs^{1,2}
 - Make office accessible to patients, particularly if concerned about adverse events

1. Kennedy, P. *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, 2007, Washington, DC.
2. Schapiro, R. Adherence to interferon beta-1b: BETA Nurse Program. *Int J MS Care*. 2004;6:66.

Opportunities to Improve Adherence

▪ Education

- Discuss realistic expectations of DMT
- Demonstrate injection technique, even re-training¹, use of autoinjector devices²
- Prescribe DMTs with less frequent dosing if appropriate
- Offer education about goals of therapy and risk management to improve health literacy³
- Provide hope about future of MS therapies

1. Saunders. *J Neurosci Nurs*. 2010;42(5S):S10-S18.

2. Lugaresi. *Expert Opin Drug Deliv*. 2009;6(9):995-1002.

3. Zhang et al. *Ann Pharmacother*. 2014;48(6):741-751.

Opportunities to Improve Adherence

- In a meta-analysis of adherence to oral therapies in chronic disease, daily dosing schedules were associated with higher adherence¹
- Poor communication = 19% greater risk of nonadherence. **COMMUNICATE.**²
- Use dose titration, autoinjector devices, engage social network, simplify regimen, auto-refill meds when appropriate to risk strategy, and provide opportunities for reduced cost^{2,3}

1. Srivastava et al. *Patient Prefer Adherence*. 2013;7:419-434.

2. Iuga, McGuire. *Risk Manag Healthc Policy*. 2014;7:35-44.

3. Viswanathan et al. *Ann Intern Med*. 2012;157(11):785-795.

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

Roberts, Wheeler, Neiheisel. Medication adherence Part three: Strategies for improving adherence. *J Am Assoc Nurse Pract.* 2014;26(5):281-287.

Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis.* IOMSN; 2013. <http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.

Strategies to Improve Adherence

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

Roberts, Wheeler, Neiheisel. *J Am Assoc Nurse Pract.* 2014;26(5):281-287.

Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis.* IOMSN; 2013. <http://www.nxtbook.com/nxtbooks/iomsn/monograph/>.

Outcome Measures for Adherence

- **Multiple Sclerosis Functional Composite (MSFC)**
 - Has excellent test-retest reliability
 - Correlates well with MRI changes

- **Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ)**
 - A self-report questionnaire that helps health care providers quantify adherence and identify barriers to adherence

CONCLUSION

Why Do We Stay the Course?

- **As MS nurses**

- We believe in **HOPE**
- We believe in the benefits of the care that we have to offer to people living with MS and their families
- We believe that the work we do is worthwhile
- We get support from one another to have the energy to offer our best selves to our patients

Summary/Nursing Implications

- **Educate & Communicate**
- **Address Barriers to Adherence**
 - Drug-related
 - Patient-related
- **Enhance Trust through increased communication with patients**
 - If no time for office visit, schedule follow up calls
 - Have patients return when feeling well, not just for relapses/increased symptoms

Resources for Strategies to Improve Adherence

- Roberts et al. Medication adherence Part 3: Strategies for improving adherence. *J Am Assoc Nurse Pract.* 2014;26(5):281-7.
- Wheeler et al. Medication adherence part 2: predictors of nonadherence and adherence. *J Am Assoc Nurse Pract.* 2014 Apr;26(4):225-32.
- Neiheisel et al. Medication adherence part 1: understanding and assessing the problem. *J Am Assoc Nurse Pract.* 2014;26(1):49-55.
- Harris et al, eds. *Moving Forward: Adherence to Therapy and the Role of Nursing in Multiple Sclerosis.* IOMSN; 2013.
<http://www.nxtbook.com/nxtbooks/iomsn/monograph/>
- Brelje B et al. Addressing the new adherence challenges in MS therapy. *Counseling Points.* Winter 2014, Vol. 9, No. 4.

QUESTION AND ANSWER SESSION

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