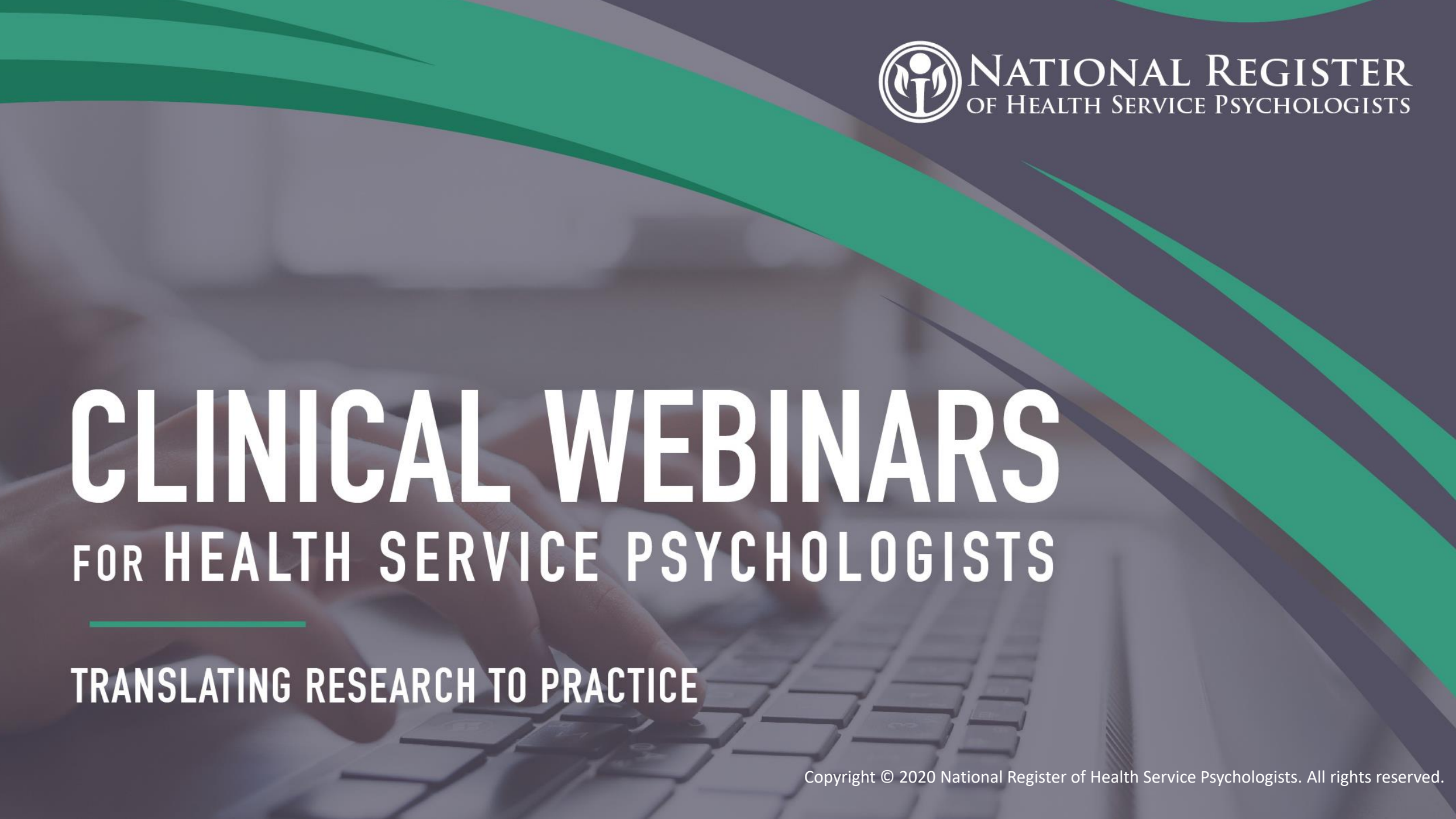

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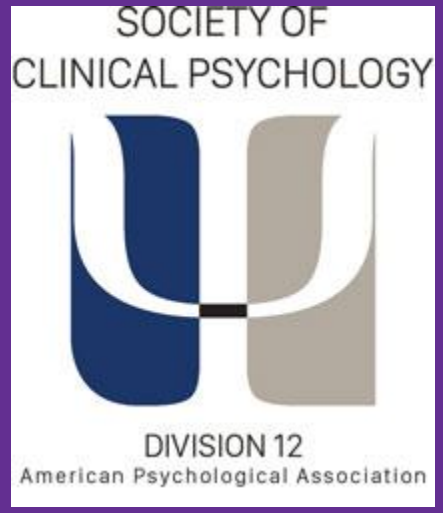
Empowerment of Clients Living with Multiple Sclerosis (MS)

Pearl B Werfel, PhD
Linda Trettin, PhD

Presented in Collaboration With APA Division 12



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Pearl B. Werfel, PhD
Linda J. Trettin, PhD

- Dr Werfel is a clinical psychologist in private practice in San Francisco. She is a consultant for Can Do Multiple Sclerosis, a member of the National MS Society Healthcare Provider Council and was inducted into the NMSS Hall of Fame for Healthcare Providers.
- Dr. Trettin is a clinical neuropsychologist with Mercy Outpatient Rehabilitation Center, Dignity Health (California). She is a Partner in Care with the National MS Society and serves on their Healthcare Provider Council. She is also a consultant with Can Do Multiple Sclerosis.
- They are co-authors of *Multiple Sclerosis*. *Advances in Psychotherapy-Evidenced-Based Practices* (2016; Hogrefe) and *Working with Clients with multiple sclerosis*. (2020: *J Health Serv Psychol* **46,** 5–12).

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Disclosures/Conflicts of Interest

- Drs. Werfel and Trettin are consultants for Can Do Multiple Sclerosis and members of the National Multiple Sclerosis Society Provider Council

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Today's Focus

Culturally sensitive approach and interventions to increase resiliency and enable clients to better self-manage and more fully participate in their lives.

Learning Objectives

1. List common symptoms of MS that can present as psychological diagnoses or resistance.
2. Identify two interventions for management of common MS symptoms.
3. Identify cognitive challenges that may impact a client's capacity to participate in therapy.

Multiple Sclerosis (MS)

- Neurological disorder that can effect the central nervous system (brain, spinal cord and optic nerves)

HALLMARK: UNCERTAINTY

- Symptoms may be mild, moderate or severe
- Course can include relapses and remissions or progressively increasing symptoms
- Some people may experience only a few symptoms, while others may have significant disability
- Symptoms and ability can vary from day to day, year to year
- No known cause or cure or singular treatment

About MS

- Usually diagnosed between ages 20 and 50. (Has been diagnosed as young as 2 years, as old as 78.)
- 2-3 times more common in women than men.
- Occurs in most ethnic groups but more common in Whites of northern European ancestry
- Although mobility issues may be the most obvious, they may not be as prevalent or bothersome

Hallmark: Hidden Disability

- Fatigue
- Incontinence
- Pain
- Depression, anxiety
- Cognitive impairment
- Numbness
- Sight impairment
- Sensitivity to touch, light, sound

Common Symptoms that can be Confused with Depression, other MH Dx, or Resistance

- Fatigue
- Pain
- Headache
- Memory loss
- Poor concentration
- Poor attention span
- Social Disengagement

- Difficulty multi-tasking
- Disorientation
- Loss of motivation
- Loss of sex drive
- Low Self Esteem
- Feelings of hopelessness
- Inconsistent abilities

How People with MS Can be Disempowered

- Medical model of MS:

  Done *to*, rather than *with*
- Labeled; Pathologized: yoga example
- Women/ POC/ LGBTQII, immigrants, low SES, non-English speakers interacting with medical professionals; medical gaslighting: symptoms dismissed, minimized, not addressed as thoroughly, micro/macro-aggressions
- Disparities in health care access and treatment can significantly prolong diagnosis and impact outcomes

Healthcare from a W/holisic Perspective

- Considers the whole person -- body, mind, spirit, and emotions/ ethnicity, culture, gender identification, sexual orientation, age
- The blending of complementary/ alternative medicine (CAM) with conventional practice.
- Considers the person who has the illness/disability rather than focusing on the illness/disability the person has.
- Person-first language: clients or patients living with MS rather than MS patients.
- Empowers clients to participate in their own health care
- Enhances the integrity and the spirit of dignity in the healing encounter

Self-Management Model

- Encourage self-management: education, skill-building, symptom management, problem solving, communication and relaxation.
- Partnering with healthcare professionals
- Effective for increasing self-efficacy, improving health status and decreasing pain
- Additional role of the therapist: assessment, encouraging advocacy, education of health care providers
- Not all clients will be able to self-manage

Malachy Bishop & Michael Frain, 2014

Meade & Chronin (2012)

Clinical Focus

- Evaluating and treating anxiety, depression, trauma, grief and cognitive issues
- Increase coping flexibility
- Identity, intersectionality, disability identity and self-esteem
- Medical treatment decisions, treatment team development, self-management
- Wellness and self-care plan
- Symptom, pain and stress management
- Support system development
- Family, relationships, sexuality, safety
- Disclosure
- Financial and Occupational decisions

- Gay manager with fatigue and pain. Standing presentations at evening meetings. Isn't asking for accommodation or using pain meds during work.

- POC isn't sharing concerns with neurologist or following recommendations

- Neurologist labeled woman treatment resistant –she cancelled her infusion appts

Pain/Stress Management

- Stress management: important component of MS and pain management. Association between stressful life events or chronic stress and increase in MS symptoms. Adaptive coping strategies may decrease MS inflammation
- Pain Management: Complex process- best addressed in a multimodal approach.
- No one singular intervention is effective for everyone or managing every type of pain.
- Interventions tend to lose their veracity over time.

Briones-Buixassa, L., Milà, R., et al. (2015), Mohr (2012)

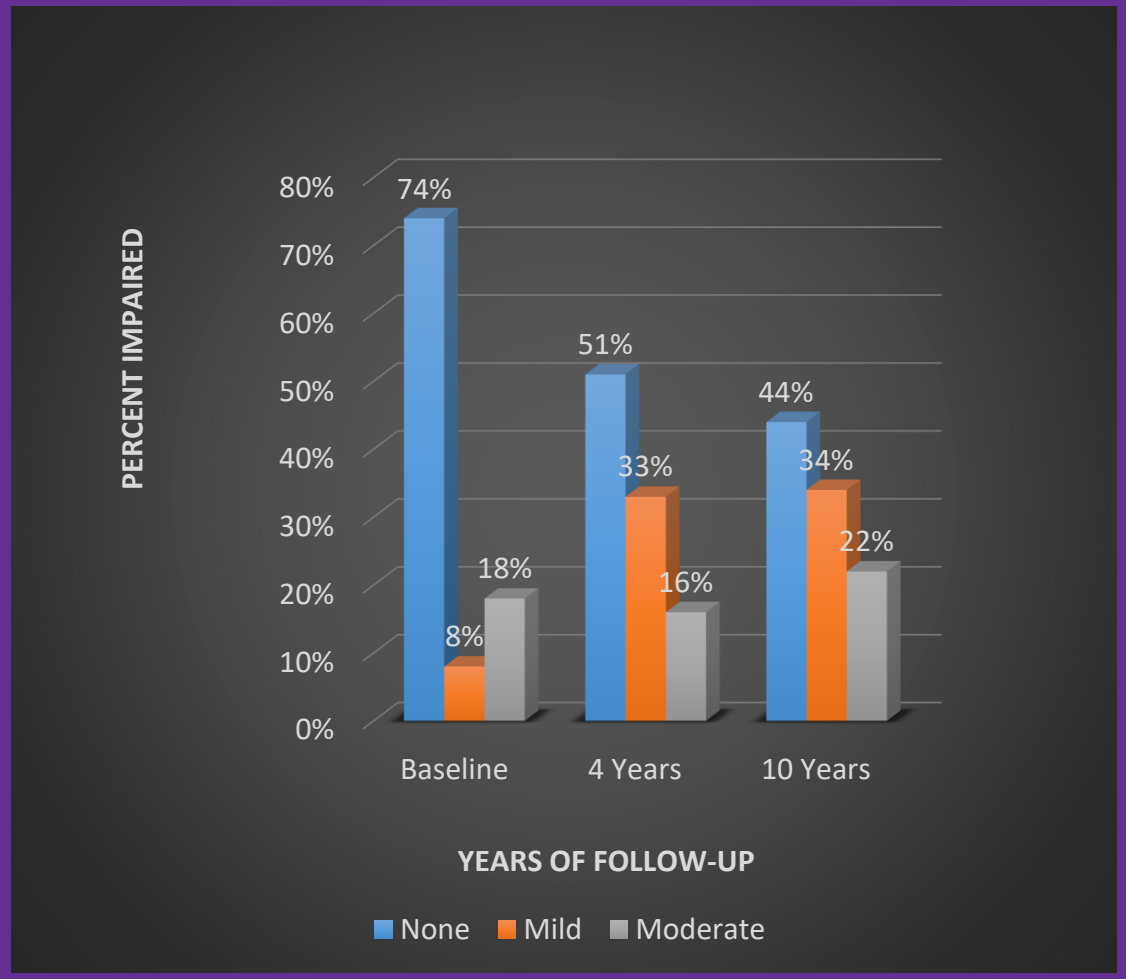
Mind/Body Interventions

- Hypnosis (Jensen- MS) Jensen, M. P., Ehde, D.)
- Imagery (Achtenberg and Rossman)
- Mindfulness/meditation- MBSR (Jon Kabat-Zinn/Grossman, et al- MS)
- Somatic Experiencing (Peter Levine)
- Breathing and relaxation
- Energy Psychology, EFT
- Biofeedback

Awareness

- Many mind/body interventions begin with awareness
- Awareness of how the body responds when emotional or physical discomfort is encountered
- Awareness of stress reactions to everyday thoughts, occurrences or people in our life
- Awareness of how even a small movement or light, compassionate attention to our thoughts, can bring increased comfort
- It doesn’t have to be dramatic or complicated- sometimes the simplest mind/body intervention, is the most effective

Cognitive Impairment -Overview



Amato, MP et al, *Archives of Neurology* 2001;58:1602-1606 cited by National MS Society

Prevalence: 34% to 65%

Cognitive dysfunction can occur at any time but is more common later in the disease

Slightly more likely in progressive MS

Exacerbation - risk factor for cognitive dysfunction

Variability - waxing and waning of MS symptoms

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Cognitive Challenges

Processing Speed

- Losing track of time/time management issues
- Long explanations
- Response delays
- Difficulty keeping up with the flow of conversations

Attention

- Problems screening out distractions
- Difficulty with dividing attention (interruption)
- Difficulty sustaining mental effort
- Difficulty following multi-step instructions

Memory

- Difficulty learning new material
- Neglecting to do planned tasks
- Tracking/working memory
- Word retrieval

Social Cognition - Challenges

Executive Functions

- Insight
- Neurologically-based pathologic lack of concern
- Organization and planning
- Initiation
- Reasoning, judgment
- Inhibition/impulse control
- Mental Flexibility

- Theory of mind (understanding and predicting the mental states of others)
- Social perception (i.e., facial recognition/nonverbal cues)
- Emotion regulation

Interior Cingulate: Motivation

Dorsolateral prefrontal

Mediates Executive Functions

Orbitofrontal

Mediates socially appropriate behavior, impulse control, & empathy

Address Weaknesses

Assess:
- Impact on relationships
- Impact on functioning
- Misinterpretations

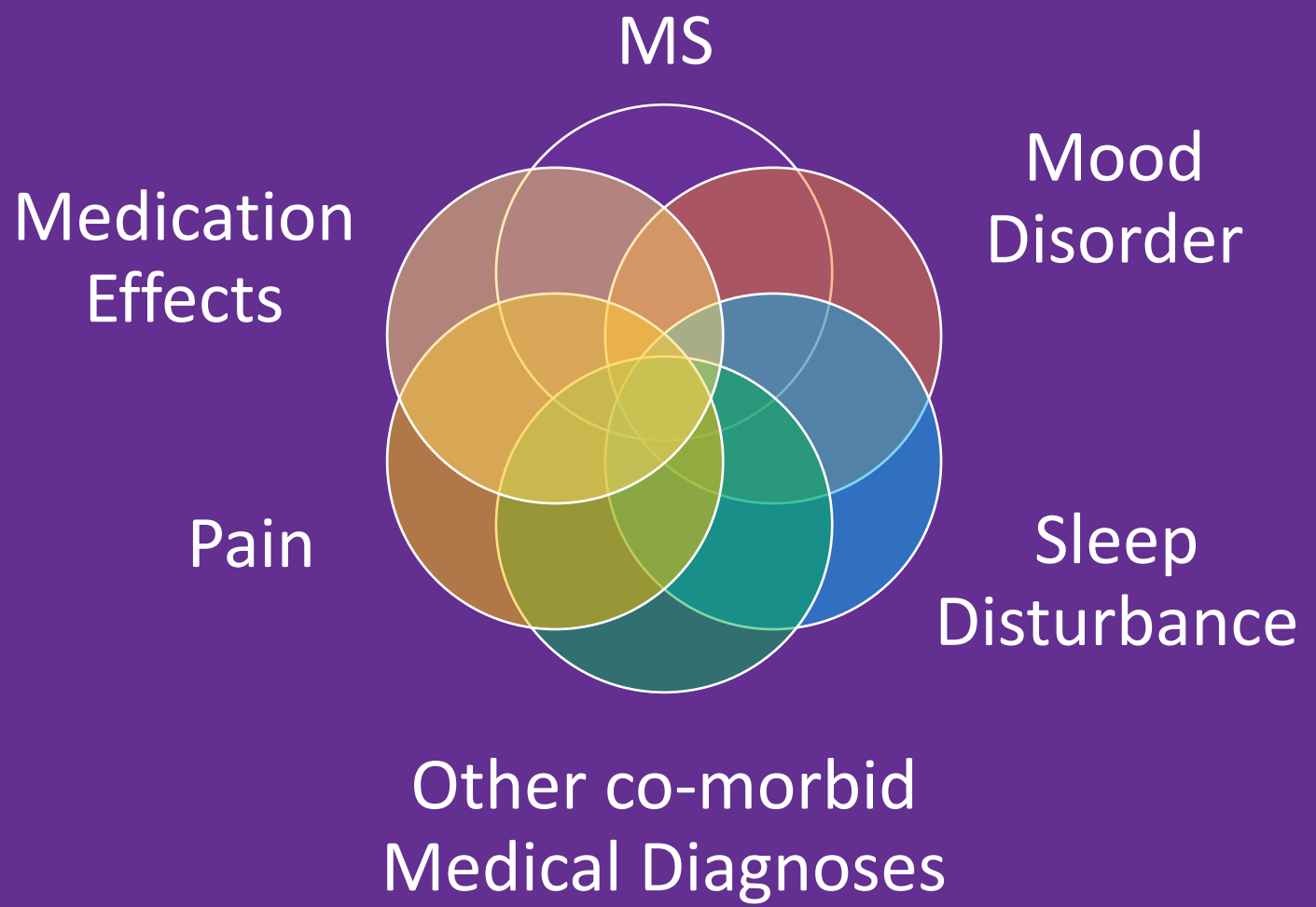
Validate and Process:
- Emotional Reaction
- Self-doubt and identity

Educate:
- Relationship to physical symptoms
- Magnifying effect of emotional reaction
- Neurorehabilitation resources
- Appropriateness for neuropsychological evaluation

Encourage and Reframe:
- Self-management
- Use of compensatory strategies

Modifications:
- Slow pace
- Repeat and verify
- Provide appointment reminders
- Write down specific instructions, notes
- Remind clients to write down their questions
- Invite clients to bring a family member or friend to some appointments
- Encourage active listening skills
- Take an active and direct role

Educate - Contributing Factors



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Fatigue & Cognition

- *Physical fatigue* has less impact on cognitive performance than people think.
- *Cognitive fatigue* refers to a decline in cognitive performance following cognitively challenging tasks (e.g., vigilance).
- Cognitive fatigue (reduced cognitive stamina) can occur even in the absence of physical fatigue.

NMSS; DeLuca, J. 2006.

Addressing Fatigue

Description	• **A subjective lack of physical/&or mental energy that is perceived by individual or caregiver to interfere with usual & desired activities** • **Most common symptom**
Pharmacology	Amantadine, modafinil (Provigil), SNRI
Rehabilitation	• Exercise • Energy conservation • Physical Therapy • Assistive devices • Cooling techniques • Cognitive Compensatory Strategies; Delegating; Limit-setting; Task analysis and modification • Screen for depression • Screen for sleep apnea
Psychosocial	• Stress management, social support, client/family education • Psychotherapy • Evaluate and treat depression

Diagnosis of Depression in MS: The Challenges

Among symptoms of depression, 4 are symptoms of MS[1]

- ✓ Inability to sleep or sleeping too much
- ✓ Motor agitation or significant slowing
- ✓ Fatigue or loss of energy
- ✓ Problems with thinking or concentrating

Depression in MS often presents with irritability/frustration rather than the more typical withdrawal, apathy, and guilt[1]

Depression can be difficult to distinguish from the grieving process that is part of life with MS[2]

[1]Minden et al., 1987; Feinstein & Feinstein; 2001; [2]Kalb & Miller, 2008

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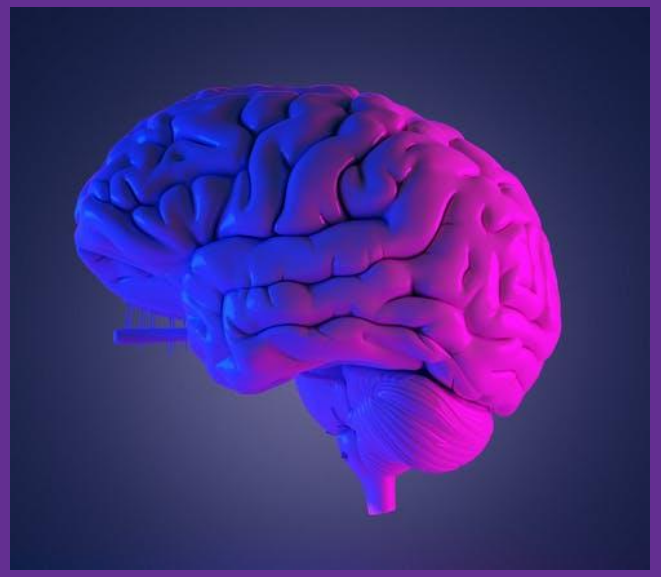
Cognitive Reserve



Cognitive Ability

Everyday Functioning

Encourage Neurogenesis & Neuroplasticity

- Cognitive Remediation
- Active lifestyle
- Brain-Gut
- Good sleep hygiene
- Physical exercise

Address:

- Depression
- Co-morbid medical (cardiovascular) risk factors
- Substance abuse

Management of Cognitive Dysfunction

- Screening for cognitive dysfunction is recommended at least annually
  - Screen use readily available tools like the symbol digit modality test (SDMT)[1]
  - Multiple Sclerosis Neuropsychological Screening Questionnaire (MSNQ)[2]

- Referral to SLP, OT, Neuropsychologist
- Disease-modifying therapy to reduce relapses
- Cognitive rehabilitation (primarily compensatory)
- Depression and anxiety can cause worsening cognition and should be treated.

[1]Crabtree-Hartman E., 2018 [2]Benedict et al., 2003

Q&A

Dr. Pearl B. Werfel
pwerfelphd@gmail.com

Dr. Linda Trettin
linda.trettin@dignityhealth.org

- Dr. Sammons will read select questions that were submitted during the presentation.
- Due to time constraints, we will not be able to address every question asked.

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