



American
Occupational Therapy
Association

AOTA ECHO Series on Occupational Therapy Interventions for Adults with Multiple Sclerosis

February 2, 2023



Preparing for the session



To ensure sessions run smoothly, please follow the [AOTA Event Code of Conduct](#).



Use the Q&A feature to submit questions.



Comments in the chat will go to AOTA staff and speakers.



Reminder: The session is being recorded.

Objectives

- Describe how the use of evidence to inform clinical practice enhances service quality
- Identify gaps in the current Practice Guidelines
- Describe strategies practitioners can use to address gap areas in the current Practice Guideline

Today's Speakers



Kathleen Zackowski
PhD, OTR



Rebecca Cunningham
OTD, OTR/L, MSCS



Ashley Uyeshiro Simon
OTD, OTR/L, MSCS

Practice Guidelines and OT Service Quality

MS Practice Guidelines Clinical Gaps

Using PG Clinical Gap Information

Questions to Ask

What evidence exists?

What are my client's preferences and values?

What experience and expertise do I have that can help guide my decisions?

Will the health system or system organization be supportive of this intervention?

MS Practice Guidelines Clinical Gaps

Fatigue Management Interventions

Interventions to Address Social and Emotional Regulation

Interventions to Address Cognition

Bowel and Bladder Management Interventions

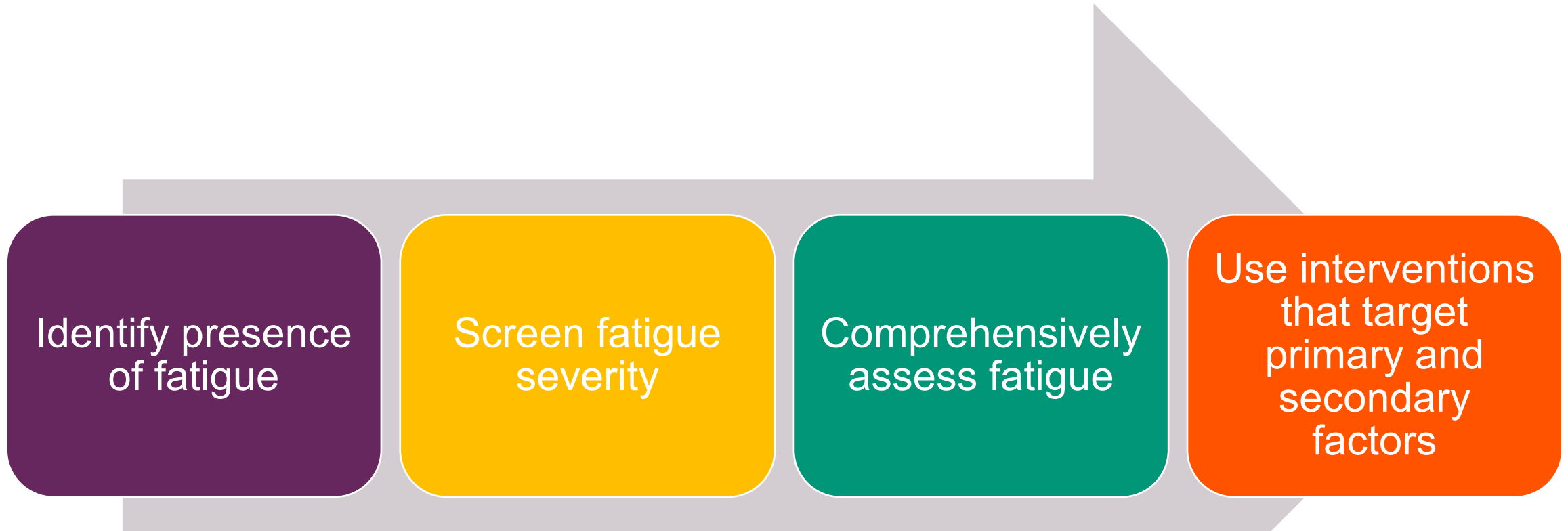
Caregiver Involvement

Clinical Gap – Fatigue Management Interventions

- Fatigue is a subjective lack of energy that interferes with people's usual and desired activities
- Experienced by 75% - 90% of people with MS
- 60% of people with MS identify fatigue as their most challenging symptom to manage

(Plow & Nicka, 2019)

Clinical Gap – Fatigue Management



(Plow & Nicka, 2019)

Clinical Gap – Fatigue Management

- In addition to pharmacotherapy, behavior change interventions considered front-line non-pharmacological approach
- Fatigue self-management interventions delivered by OT practitioners facilitate learning strategies and skills that reduce impact of MS-related fatigue on daily activities

(Asano & Finlayson, 2014; Ehde et al., 2015; Finlayson et al., 2011)

Clinical Gap – Fatigue Management



(Ehde et al., 2015)

Clinical Gap – Fatigue Management

Fatigue overview

Communication skills

Body mechanics,
tools, technology

Activity
analysis, prioritization,
decision-making

Life balance, taking
control, analyzing &
modifying day

Goal setting &
discussion

(Finlayson et al., 2011)

Clinical Gap – Fatigue Management



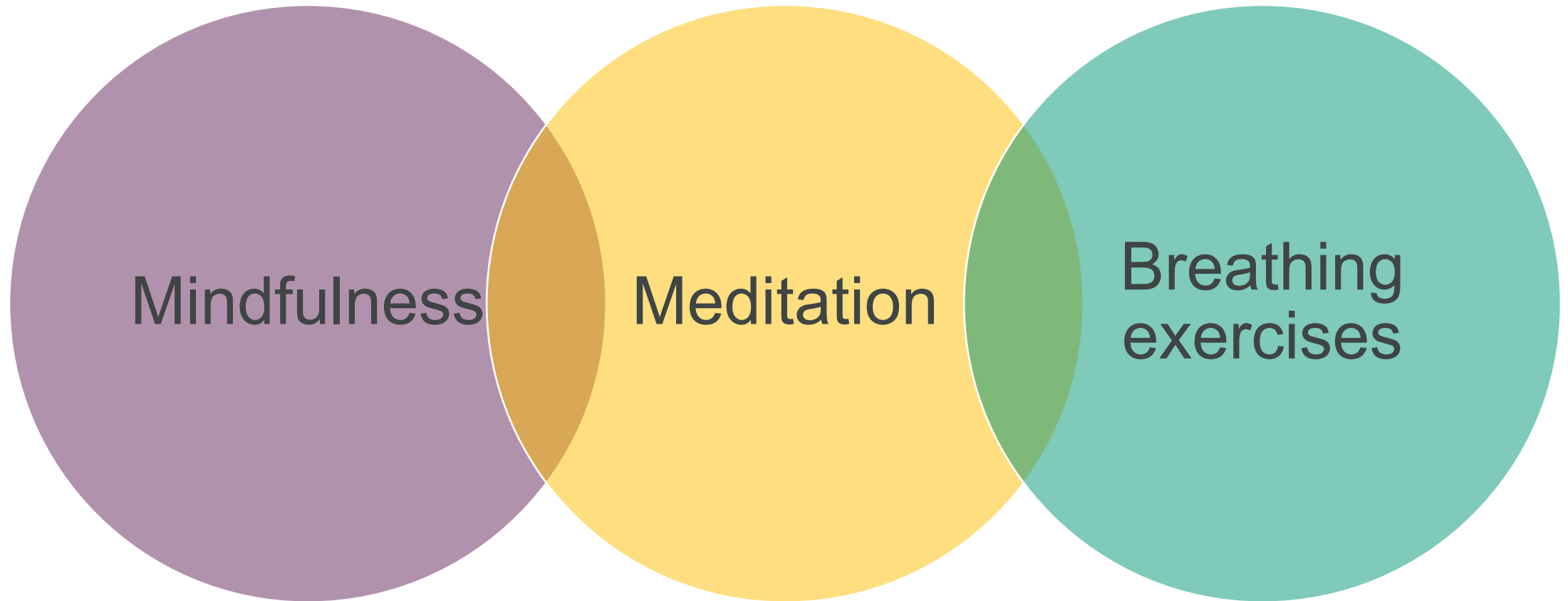
[This Photo](#) by Unknown author is licensed under [CC BY-NC](#).

Clinical Gap – Emotional Regulation Interventions

- Stressful life events can contribute to the exacerbation of MS symptoms and existence of new lesions in brain and spinal cord
- As many as 54% of people with MS experience depression
- 22% of people with MS have an adjustment disorder within 2 months of being diagnosed with MS
- Prevalence rate of generalized anxiety among people with MS is 18.6%

(Khawam & Sacco, 2019)

Clinical Gap – Emotional Regulation



(Agland et al., 2018; Artemiadis et al., 2012; Bogosian et al., 2015; Cavalera et al., 2019; Crescentini et al., 2018; Kolahkaj & Zargar, 2015)

Clinical Gap – Emotional Regulation

Quality of
life

Stress

Depression

Anxiety

(Agland et al., 2018; Artemiadis et al., 2012; Bogosian et al., 2015; Cavallera et al., 2019; Crescentini et al., 2018; Kolahkaj & Zargar, 2015)

Clinical Gap – Emotional Regulation

Self-monitoring
of daily stress

Cognitive
restructuring

Problem-solving

Relaxation
techniques

Other: time
mgmt., social
support, pain
mgmt.

(Reynard et al., 2014)

Clinical Gap – Cognition Interventions

- Cognitive impairment occurs in 43% - 65% of people with MS
- Commonly underrecognized or misdiagnosed as depression, stress, or a personality disorder
- Cognitive difficulties contribute significantly to:
 - Unemployment
 - Motor vehicle accidents
 - Challenges with ADLs
 - Loss of social contacts

(Rao, 2019)

Clinical Gap – Cognition

- Cognitive rehabilitation interventions and programs designed to remediate abilities and support integration of compensatory strategies into daily activities
- Rigorous RCTs support use of cognitive rehabilitation techniques with MS population

(das Nair et al., 2016; Rosti-Otajarvi & Hamalainen, 2014; Sandry et al., 2016)

Clinical Gap – Cognition

Story Memory Technique

- 10-session behavioral intervention
- 2x/wk for 5 wks – 45-60 minutes per session
- Teaches context and imagery to facilitate learning and memory
- Treatment effects lasting over 6-month period

(Chiaravalloti et al., 2013)

Computerized programs for retraining attention

- Home-based computerized program
- 60-minute sessions, 2x/wk for 3 months or 2x/wk for 6 wks
- Addressed multiple attentional types
- Improved sustained attention and affects neural plasticity

(Amato et al., 2014; Cerasa et al., 2013)

Compensatory Cognitive Interventions

(From Benedict et al., 2018)

Challenge	Compensatory Strategy
Attention/concentration	<ul style="list-style-type: none"> Minimize distractions: reduce clutter; work in a quiet area (low traffic, low noise) Reduce interruptions: establish 'ground rules' with family and friends; let answering machine or voice mail pick up phone calls; use timers
Memory	<ul style="list-style-type: none"> Notepads, planners, calendars Voice recorders Personal alarms Memory buddy/partner Colored baskets for specific items; always to be found in the same place Locating devices for parked cars
Word retrieval	<ul style="list-style-type: none"> Describe the item Substitute one word for another Free associate words Use gestures
Visuoperceptual skills	<ul style="list-style-type: none"> Finger or index card when reading Large print books Books on tape Use brightly colored markers to mark left and right margins on a page Highlight numbers that are frequently used in the phone book
Speed of information processing	<ul style="list-style-type: none"> Ask others to slow down when they speak Rephrase what others say Repetition of information Use voice recorders—go back and review information several times
Executive functions	<ul style="list-style-type: none"> Make lists, and rank in order of priority Write things down and make sure steps or ideas are in proper order Take a moment to organize thoughts before responding

Clinical Gap – Bowel and Bladder Interventions

- Bladder dysfunction reported by 50% of people with MS at time of diagnosis and reported by 75% six years after diagnosis
- 53% of people with MS report constipation, and 29% - 51% report fecal incontinence
- Behavioral changes and related interventions are indicated as front-line interventions to address bowel and bladder symptoms

(Moore, 2019; Newman & Wein, 2009)

Clinical Gap – Bowel and Bladder

Fluid routine
modifications

Modifying timing
of diuretic
medications

Scheduled
voiding

Dietary
modifications

Bladder
retraining

Pelvic floor
rehabilitation

Intermittent
catheterization

(Moore, 2019; Newman & Wein, 2009)

Clinical Gap – Bowel and Bladder

Eliminate
dietary
irritants

High-fiber diet

Adequate
fluid intake

Timed bowel
regimen

Incorporating
fiber & bulking
agents

Pelvic floor
rehabilitation

(Cotterill et al., 2018; Moore, 2019)

Clinical Gap – Caregiver Involvement

- Caregiver: a person who helps with physical and psychological care for a person in need
 - Caregivers are often family members who are unpaid and spend 20+ hrs/wk completing caregiving related tasks
 - Caregivers are at risk for:
 - Significant depression and anxiety
 - Social isolation
 - Lack of support from others
 - Reduced participation in preferred occupations
- (Buhse, 2008; Sullivan, 2019)

Clinical Gap – Caregiver Involvement

- Strongly encourages healthcare providers to refer caregivers to supportive programming and resources available from local or national-level organizations to address health and well-being needs
- Wellness programs that foster engagement in self-care are recommended to support caregivers' physical and emotional health and quality of life

(Holland et al., 2011; Sullivan, 2019)

Clinical Gap – Caregiver Involvement

Physical
activity

Balanced
nutrition

Sufficient
sleep and
rest

Social
activities

Leisure

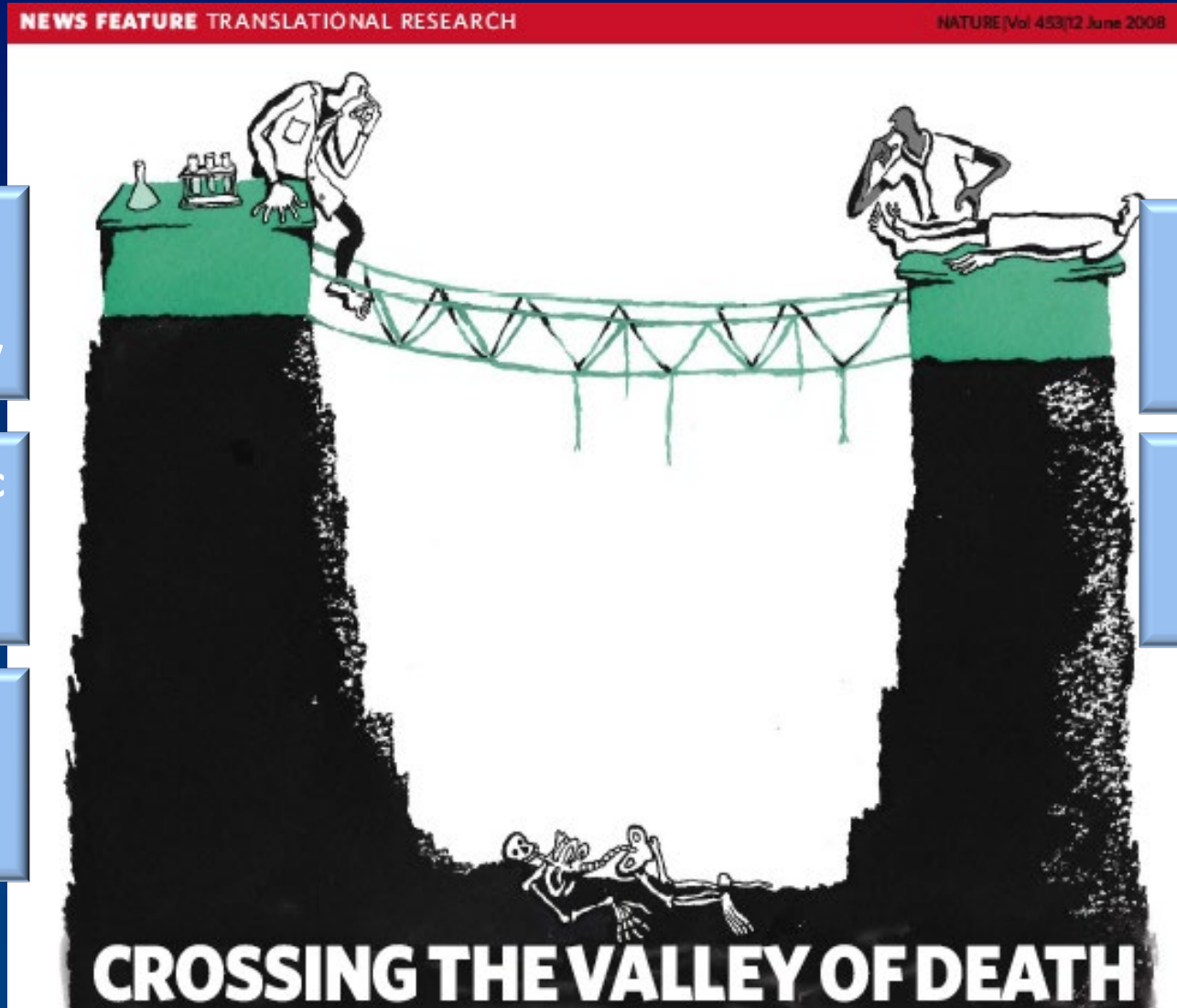
Spiritual
practices

(Holland et al., 2011; Sullivan, 2019)

Q & A

Research and Clinical Gaps

Challenges with translation of research into clinic



Disease
Discovery
and Biology

Therapeutic
Target
Discovery

Disease
Model
Systems

Natural
History

Clinical
Trials

Challenges with translation of research into clinic

NEWS FEATURE TRANSLATIONAL RESEARCH

NATURE | Vol 453 | 12 June 2008

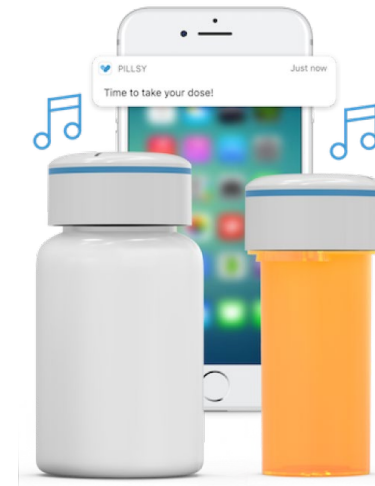


Products that result from research

- **Electronic Pill Bottle & Cap** – Non-invasive monitoring and helps improve adherence to oral DMTs

Pillsy™ Smart Bottle and Pill Cap

- **Light Therapy** – Safe, feasible, and well-tolerated in people with MS associated fatigue



<https://www.pillsy.com/smart-pill-bottle-and-app>

Products that result from research

- **Walking Bike Without Pedals – The Alinker**



www.thalinker.com

People are needed to do research

- Occupational Therapists can be a part of this.

A focus on pain

- 50-60% of people with MS experience pain
- Pain can come from MS and other sources
- Chronic pain usually requires a multi-modal approach
- Rehabilitation and other behavioral interventions can help treat pain and improve function.



Dawn Ehde, PhD
University of Washington
Anna Kratz, PhD
University of Michigan

* Relaxation, Cognitive Behavioral Therapy, Mindfulness Training

A focus on self-management



Marcia Finlayson, PhD, OTR
Queens University, Ontario

**Building capacity for MS self-management
research and knowledge translation**

Use of walking aids



Michelle Cameron, MD, PT
Oregon Health Sciences University

A Randomized Controlled Trial of a Multicomponent
Walking Aid Program for People with MS

A focus on bladder dysfunction



Valerie Block, DPTSc, PT
University of California San Francisco

Moving MS bladder dysfunction into the 21st Century:
developing novel and accessible ways to treat,
predict and prevent dysfunction in the home

Why Outcome Measures Matter

- Literature to guide OT-specific interventions and dosing is limited, and presentation between patients can be highly variable.
- The lack of sensitive outcome measures
- Occupational therapists are trained to utilize outcome measures and add to the research
- Specific outcome measures will be described with information to translate to your clinical practice.
- Outcome measures allow you to track progress and provide a benchmark for how your interventions are working or need to be modified
- Objective measures help assess intervention effectiveness, change over time including regression, and help drive dosing and best practice guidelines



How do you find research you are interested in?

ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world.

Explore 440,140 research studies in all 50 states and in 221 countries.

See listed clinical studies related to the coronavirus disease (COVID-19)

ClinicalTrials.gov is a resource provided by the U.S. National Library of Medicine.

IMPORTANT: Listing a study does not mean it has been evaluated by the U.S. Federal Government. Read our [disclaimer](#) for details.

Before participating in a study, talk to your health care provider and learn about the [risks and potential benefits](#).

Find a study (all fields optional)

Status ⓘ

Recruiting and not yet recruiting studies
 All studies

Condition or disease ⓘ (For example: breast cancer)

X

Other terms ⓘ (For example: NCT number, drug name, investigator name)

X

Country ⓘ

X



YOU can make a difference:

- Appropriately implementing the *best* outcome measures for your patient population
- Understanding impairment-based treatment and the specific needs of your patients based on literature that is available, no matter how little
- Asking questions to patients, families, clinician researchers and experts in the field
- Participate in National Conferences and information sessions
- Developing your own clinical question(s) and get into research!

Keeping Up With MS Research Progress



- Visit: www.nationalmssociety.org/research for full coverage on everything from research breakthroughs to clinical trials near you.
- Contact me anytime: kathleen.zackowski@nmss.org

Q & A

Participant Questions

- How do you address executive function impairment in MS? - **Answered during session 2**
- What are effective goals for "just right challenge" with MS when signs or symptoms are not clear and vary depending on the day in the same individual? - **Answered during session 2**
- Does the red marrow of the brain have anything to do with MS? - **Answered during session 2**
- How do you recommend addressing a person's fatigue and preventing over-exertion in the context of a high-intensity inpatient rehab setting where patients are seen for 75-90 minutes 5x/week?

Participant Questions

- What are some short-term goals for patients with MS regarding cognitive integration such as sensory processing?
- Why is it that other countries' treatment protocols cannot be available or considered appropriate for people in our country with MS?
- What are the broader roles and functions of occupational and physical therapy for the ongoing treatment of clients with MS?

Participant Questions

- Do you have any recommendations for adaptive equipment for self-catheterizing or specific brands for people who have fine motor deficits?
- Could you explain what infusion is and what the benefits are for people with MS?
- Work at a MS center in the Eastern part of the US - we notice that hand function many times is an early indicator of further/future MS symptoms. What evaluations do you use and what treatments do you find are most effective for maintaining or preventing decline in hand function?

Participant Questions

- Any evidence regarding the use of weights to limit tremors?
- In our health system we have multi-D clinics where multiple providers (rehab, psych, MD, respiratory, etc.) will see a client on the same day. This can maximize real time collaboration with populations such as individuals with ALS. Have you seen this model adopted for clients with MS?
- What have you found is the most common concern expressed among clients with MS?

Participant Questions

- Is poor insight (into abilities/deficits) more common in MS than in other cognition-affecting diagnoses?
- When working with a person with MS do you have any suggestions for differentiating between DM associated neuropathy or MS neuropathy like pain?
- Can you briefly say more about pseudobulbar affect impact and how that may alter your treatment approach?

Participant Questions

- How can OT and the rest of the care team approach patient burnout? (i.e., - I have a client who's had MS for 25+ years and has become more "noncompliant" in recent years)
- Various types of stress can trigger many chronic illnesses. What are the strategies used to address stress for health management? (i.e., realistic to prevent relapses by managing stress)
- What are some cognitive behavioral management [strategies/methods] involved with short term goals with MS clients?

Participant Questions

- Would the five senses sensory integration CBT be great for MS clients in various sessions?
- Is there a formal definition for activity intolerance?
- It was stated that 2.5 million people globally are affected by MS. 1 million living in the U.S. with MS. Why such a high number of people in the U.S. as compared to globally?
- What are some excellent CBT long-term mindfulness meditations for clients with MS?

Application and Case Example

Case Example: Social History

- Victor (he/him/his) is 66 years old
- Victor lives alone in a one-story house with two steps leading inside – he denies concerns ambulating the front steps and related falls
- Victor is retired
- Victor falling ~4x/month often due to urinary symptoms

Case from Cunningham, Uyeshiro Simon, & Preissner (2022). <https://doi.org/10.5014/ajot.2022.050088>

Case Example: Health History

- Victor has been living with MS for 30 years
- Victor identifies the following MS symptoms: RLE weakness with foot drop, BLE spasticity, fatigue, urinary symptoms (urgency, nocturia)
- Victor has a hx of anxiety which has worsened recently due to increased frequency of falls
- Victor reports disrupted sleep due to anxiety and spasticity and is inconsistent with sleep prep routine (which includes stretching)

Case Example: Health History

- Victor uses an AFO and single point cane for ambulation in the community
- Victor's anxiety has resulted in self-imposed restrictions during ADL and IADL participation
- Victor used to walk 2-3 miles per day, and identifies that lately physical activity comes from community outings, chores, and stretching
- Victor has been referred by his primary care physician to OT to address falls prevention, sleep, and health management concerns

Case Example: Occupational Profile

Client Report

Reason the client is seeking service and concerns related to engagement in occupations (p. 16)

Why is the client seeking services, and what are the client's current concerns relative to engaging in occupations and in daily life activities? (This may include the client's general health status.)

Victor is seeking OT services to address his disrupted sleep, increase participation in physical activity routines, and develop emotional regulation skills. Victor has a history of anxiety, which has worsened lately due to his increased frequency of falls.

Occupations in which the client is successful and barriers impacting success (p. 16)

In what occupations does the client feel successful, and what barriers are affecting their success in desired occupations?

Victor currently participates in physical therapy to address lower extremity weakness and spasticity, but identifies difficulties following through with the PT HEP due to fatigue. Victor also currently engages in stretching during his sleep prep routine to address spasticity, but reports inconsistency which contributes to more spasticity and related sleep disruption. Victor has recently experienced an increase in falls (about 4 times per month), often due to his urinary symptoms. Victor's anxiety has resulted in self-imposed activity restrictions during ADL and IADL participations.

Occupational history (p. 16)

What is the client's occupational history (i.e., life experiences)?

Victor is a 66-yr-old White man who has been living with MS for 30 years. Victor is retired and lives alone in a one-story house with two steps leading inside. Victor reports no concerns about ambulating the two front steps and no related falls. Victor utilizes an AFO and single point cane to ambulate in the community. Victor has good insight into his deficits and how they affect his occupational performance. Victor historically walked 2-3 miles per day as his physical activity.

Personal interests and values (p. 16)

What are the client's values and interests?

Victor values engagement in physical and mental health, as well as safety.

Contexts

	<i>What aspects of their contexts (environmental and personal factors) does the client see as supporting engagement in desired occupations, and what aspects are inhibiting engagement?</i>	
Environment (p. 36) (e.g., natural environment and human-made changes, products and technology, support and relationships, attitudes, services, systems and policies)	<p><i>Supporting Engagement</i></p> <p>Physical Therapist</p> <p>Single-level home</p> <p>AFO and single point cane</p>	<p><i>Inhibiting Engagement</i></p> <p>Victor mentions no social support</p>
Personal (p. 40) (e.g., age, sexual orientation, gender identity, race and ethnicity, cultural identification, social background, upbringing, psychological assets, education, lifestyle)	<p><i>Supporting Engagement</i></p> <p>Desire to be physically active</p> <p>Insight into personal factors affecting occupational engagement</p> <p>Victor is retired and reports minimal occupational engagements outside of improving his health</p>	<p><i>Inhibiting Engagement</i></p> <p>Anxiety and self-imposed restrictions on occupational engagement</p>

Performance Patterns	<p>Performance patterns (p. 41) (e.g., habits, routines, roles, rituals)</p>	<p><i>What are the client's patterns of engagement in occupations, and how have they changed over time? What are the client's daily life roles? (Patterns can support or hinder occupational performance.)</i></p> <p>Historically, Victor walked 2-3 miles per day. Lately, Victor identifies that his physical activity comes from community outings, chores, and stretching. Victor was previously independent with all ADLs and IADLs, but has recently experienced an increase in fear of falling, which has resulted in self-imposed activity restrictions during ADLs and IADLs.</p>	
		<p><i>What client factors does the client see as supporting engagement in desired occupations, and what aspects are inhibiting engagement (e.g., pain, active symptoms)?</i></p>	
Client Factors	<p>Values, beliefs, spirituality (p. 51)</p>	<p><i>Supporting Engagement</i></p> <p>Physical activity</p> <p>Sleep</p> <p>Safety</p>	<p><i>Inhibiting Engagement</i></p> <p>Anxiety</p>
	<p>Body functions (p. 51) (e.g., mental, sensory, neuro-musculoskeletal and movement-related, cardiovascular functions)</p>	<p><i>Supporting Engagement</i></p> <p>No cognitive symptoms or concerns</p>	<p><i>Inhibiting Engagement</i></p> <p>Anxiety</p> <p>Fatigue</p> <p>Urinary symptoms (urgency, <u>nocturia</u>)</p> <p>BLE spasticity</p> <p>RLE weakness and foot drop</p>
	<p>Body structures (p. 54) (e.g., structures of the nervous system, eyes and ears, related to movement)</p>	<p><i>Supporting Engagement</i></p> <p>No vision symptoms or dizziness reported</p>	<p><i>Inhibiting Engagement</i></p> <p>Dysregulated nervous system</p>

Client Goals

Client's priorities and desired targeted outcomes (p. 65)

What are the client's priorities and desired targeted outcomes related to the items below?

Occupational Performance – sleep, physical activity health management, self-regulation health management, functional mobility ADLs

Prevention – functional mobility ADLs, social and emotional health promotion management

Health and Wellness – physical activity health management, sleep,

Quality of Life – functional mobility ADLs, social and emotional health promotion management, sleep

Participation – functional mobility ADLs, social and emotional health promotion management


Role Competence

Well-Being – physical activity health management

Occupational Justice

Discussion

How does using the Occupational Profile support addressing the needs of clients with multiple sclerosis?



How can the Occupational Profile uncover ways multiple sclerosis may be impacting occupational performance?

Discussion



What are the client's health management challenges?



How does the client's context affect performance and participation related to health management?

Discussion

- What skills does the client need to use and/or develop to be successful with health management?
- What would the client's day to day life look like if OT was successful in supporting the client to successfully address health management?

Discussion

The next step of the evaluation process is the Analysis of Occupational Performance.

Based on the Occupational Profile, what are some ways the practitioner could then analyze occupational performance?

Wrap Up

- Post-Session Questionnaire
- https://forms.aota.org/forms/echo_ms_post_session_3_survey_overview_of_ms_and_health_management_as_an_occupation
- Questions and Cases for Discussion
- A submission link will be included in the follow-up email

- Questions: ebp@aota.org
 - Or see Welcome Packet

Next Session

- Don't forget to join us for the next AOTA ECHO session on **February 9th.**
- **Approaches for Facilitating Change**



Rebecca Cunningham
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Ashley Uyeshiro Simon
OTD, OTR/L, MSCS

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