

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

January 12, 2023



Practice Improvement Team

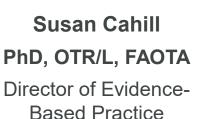


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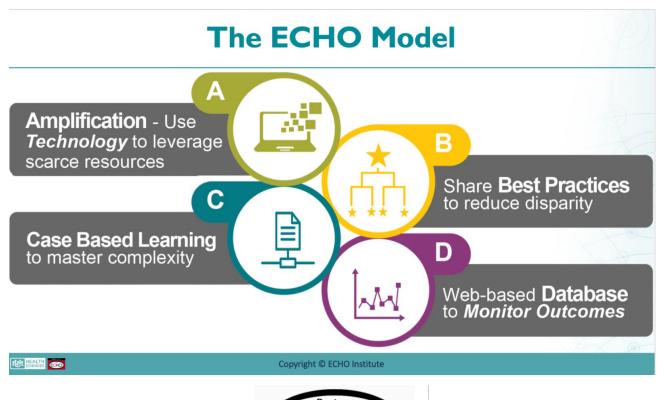


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Project ECHO®

- Sharing best practices
- Case-based learning
- "All teach, all learn"
- Multiple Sclerosis
 Practice Guidelines

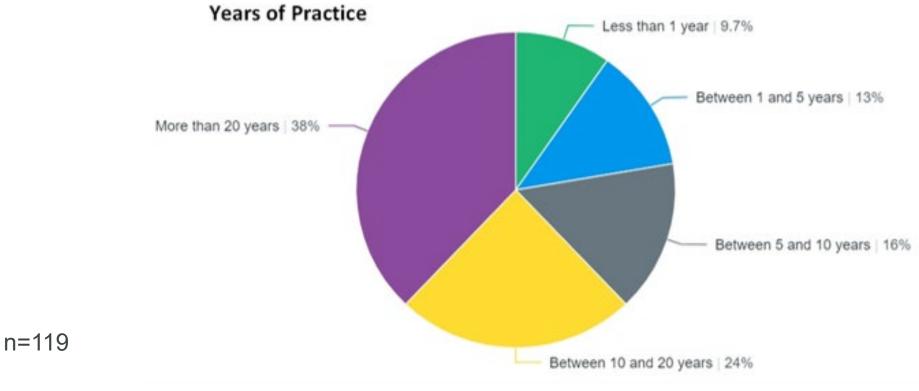






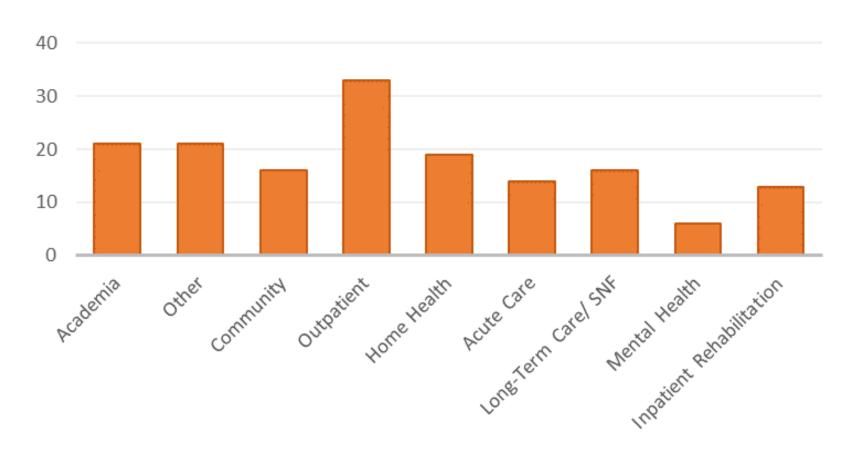
Participant Background Information

- OTs, OTAs, OT/OTA students, people with MS, care partners and family members, and other health care professionals (e.g., DPT, SW)
- 38 states and 4 countries (3 outside of the U.S.)





Participant Background Information



Communities Served:

- Urban 44%
- Suburban 53%
- Rural 22%
- Underserved 16%



n=119

Participant Background Information

- 94% of participants are familiar with the needs of clients with MS.
- Participants joined this ECHO session to:
 - Learn more about MS
 - Learn about the MS practice guidelines
 - Hear from the speakers
 - Learn from the collaboration with the MS Society
 - For the opportunity to collaborate with others
 - No cost opportunity to learn about MS







Preparing for the session



To ensure sessions run smoothly, please follow the <u>AOTA Event Code of Conduct</u>.



Use the Q&A feature to submit questions and "up vote".



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



Reminder: The session is being recorded.



Objectives

- Use the findings from AOTA systematic reviews and Practice Guidelines to support and inform interventions
- Identify the key elements associated with the Occupational Profile
- Describe the occupation of health management
- Describe OT's role in addressing health management with individuals with MS



Today's Speakers



Rebecca Cunningham OTD, OTR/L, MSCS



Ashley Uyeshiro Simon OTD, OTR/L, MSCS



Caitlin Synovec OTD, OTR/L, BCMH



Overview of Multiple Sclerosis



Multiple Sclerosis Prevalence

- Approximately 2.5 million people with MS globally
- Approximately 75% are female
- Nearly 1 million people living with MS in the United States
- Northeast and Midwest regions of U.S. have highest MS prevalence rates

(Koch, 2019; Wallin et al., 2019)



Multiple Sclerosis Prevalence

- Prevalence of MS increases with latitude – countries farthest from the equator have highest rates
- Historically thought to primarily affect Caucasians, especially those of northern European descent
- Historically thought that Caucasians have highest prevalence rates and highest mortality rates in MS community



(Koch, 2019)



Multiple Sclerosis Demographics

Hispanic

- Younger age of onset compared to Caucasians and African Americans
- High risk for early disability and worse prognosis compared to Caucasian Americans
- Increasingly reported in pediatric cohorts

African American

- 47% increased incidence risk compared to Caucasian Americans
- African American women show highest risk
- Second highest mortality rate

Asian & Pacific Islander

- Increasing incidence rates of Asian females in Canada
- Mortality rates 10x
 lower than Caucasians



(Amezcua et al., 2018; Amezcua & McCauley, 2020; Langer-Gould et al., 2013)

Impact of Health Disparities

African Americans with MS 30% less likely to see neurologist

Hispanics with MS were 40% less likely to see a neurologist

30% of low-income minorities had never seen an MS specialist

30% of low-income minorities were not taking DMT due to poor compliance and understanding of the drug

(Amezcua & McCauley, 2020)



LGBTQ+ Community and MS

- Associated with fewer psychological consultations
- Less comfortable discussing sexual health with their physician
- More likely to change MS centers
- Higher number of MS centers visited
- Lower satisfaction with care





(Khayambashi et al., 2020; Lavorgna et al., 2017)



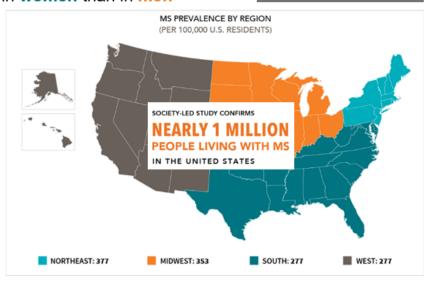
National MS Society (NMSS) Infographic

Multiple sclerosis (MS) is a disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body.



Most people are diagnosed between the ages of

20 to 50



Misconceptions

about MS in minority groups may impact the care they receive and their journey living with MS



MS prevalence is similarly high among Black and White individuals. Risk of MS is 47% greater among Black women



Black individuals are **30**% less likely to see a neurologist in clinic and more likely to seek care in an ER



Black patients may experience greater severity of MS symptoms and faster disease progression



Comorbidities can delay MS diagnosis and accelerate progression and relapse rates



Black and Hispanic individuals are underrepresented in **MS** research

Langer-Gould, AM. et al. Neurology. 2022;98:e1818-e1827; Amezcua L, et al. JAMA Neurol. 2021;78(12):1515-1524; Amezcua L, et al. Mult Soler. 2020;26(5):561-567; Amezcua L, et al. Neuroepidemiology. 2016;50(1-2):35-40; Amezcua L, McCauley JL. Mult Soler. 2020;26(5):561-567; Wallin Mr. et al. Neurology. 2017;09(10):E1022-E1040; Langer-Gould, A. et al. Neurology. 2017;82(12):361-367; Alfa FS. et al. Neurology. 2017;88(14):268-2275

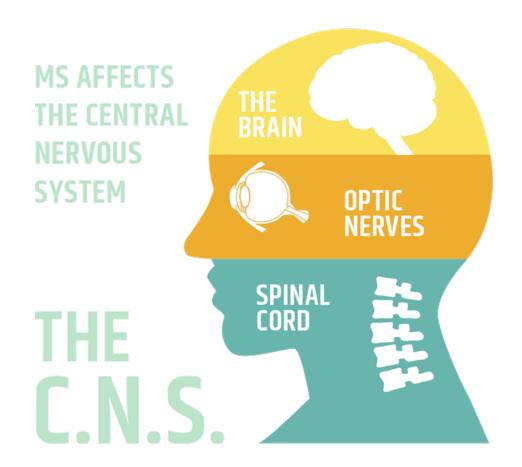


Together We Are Stronger.



MS Pathophysiology

- Demyelinating disease of the Central Nervous System (CNS)
- Oligodendrocytes affected
- Relapsing-remitting and progressive forms, clinically isolation syndrome (CIS)
- McDonald Criteria used to confirm diagnosis





More Common MS Symptoms

Bladder Paresthesia Weakness Spasticity **Fatigue** dysfunction Cognitive Bowel Sexual Vertigo or Vision dysfunction dysfunction dizziness changes **Emotional** Pain and Gait Depression MS hug changes itching changes

(McGinley & Stone, 2019; National MS Society)



Less Common Symptoms

Speech problems

Dysphagia

Seizures

Hearing loss

Loss of taste

Tremor

Breathing problems

(McGinley & Stone, 2019; National MS Society)



MS Medical Care

Disease Modifying Therapy (DMT)

- Oral DMT
- Injection DMT
- Infusion DMT

Monitoring

- MRI and OCT imaging
- Neurological assessment
- Labs

Symptom Management

- Medications (chronic symptoms and relapse)
- Rehab intervention (OT, PT, ST)
- Mental health services
- Surgical or invasive intervention





MS and Multidisciplinary Care

- "The most efficacious management of chronic disease benefits from access to highquality comprehensive care teams of skilled professionals that include attention to symptom management and quality of life."
- Multidisciplinary Care Model
- Comprehensive MS Care Model

Neurology team Behavioral Rehabilitation medicine services Patient + Care Partner **National** Administrative organizations assistance

(Sullivan, 2019)



Occupational Impacts of MS

More Common MS Symptoms

Bladder Paresthesia Weakness Spasticity **Fatigue** dysfunction Cognitive Bowel Sexual Vertigo or Vision dysfunction dysfunction dizziness changes **Emotional** Pain and Gait Depression MS hug changes itching changes

(McGinley & Stone, 2019; National MS Society)



Imagine living with...

Chronic fatigue

- Do you have enough energy to shower?
- Make food?
- Socialize with friends or family?
- What if you had to choose just one of those occupations?

Cognitive changes

- Focus, processing, memory, problem-solving can be impacted
- Can you drive safely? Navigate the community?
- Follow conversations, remember names?
- Are you able to do your job in the same way?

Fatigue ← Cognition



Imagine living with...

Bowel, bladder, &/or sexual dysfunction

- Urgency, frequency, sensory, motor difficulties
- Catheterization needs
- Average age at diagnosis is between 20 and 50 y/o
- How would you socialize differently?
- Would dating and/or sex-related occupations be different?

Depression and MS

- Often occurs after diagnosis, during exacerbations, or when major changes in function occur
- MS can impact emotion centers of the brain
- Depression and immune functions can be related
- Can intensify impact of fatigue, pain, cognitive changes

B,B,S Function ↔ Depression



Imagine living with...

All of the above!

- Most people experience multiple symptoms concurrently
 - Relapsing-Remitting: symptoms may get worse, then go back to baseline (or almost baseline)
 - Progressive: symptoms may persist and slowly worsen



Remember the Pathophysiology?

- Some lesions in brain (due to demyelination) have clinical impacts, some lesions may be "clinically silent"
- Location matters
 - And size
 - And inflammation
- MS is progressive and chronic need to think ahead and not just plan for right now



So what does this mean?

Occupational performance impacts are unique to each person based on:

- Pathophysiology
- Type of MS
- Presenting symptoms
- Prognosis and future goals
- Dependent on the day, too



Added Health Management Occupations

- Neurology visits
 - Disease-Modifying Therapies (oral, infusion, injectable)
 - MRIs
- Multidisciplinary care visits
 - OT
 - PT
 - Psych, neuropsych, and/or SW
 - Other possible specialists: psychiatry, pharmacy, urology, speech

- Medication management
- Exacerbation/relapse treatment
- Changes in lifestyle

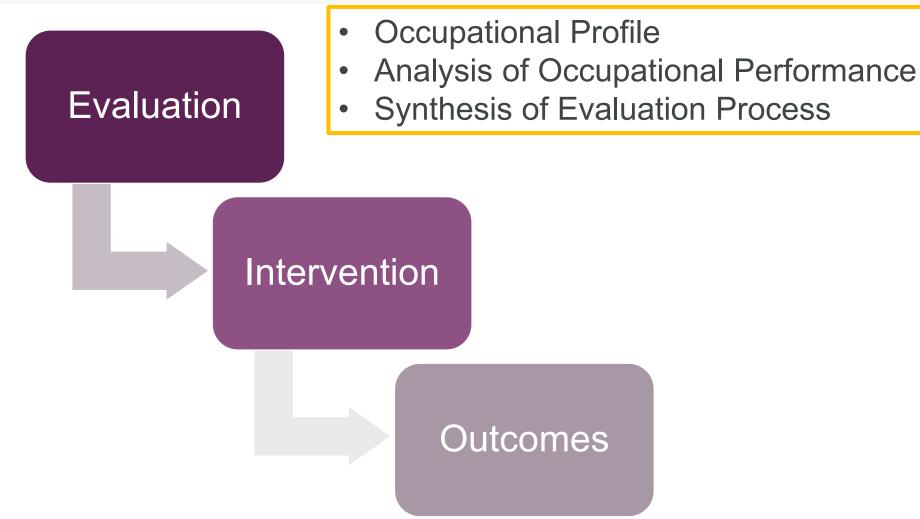
We will talk about these occupations more!





The Occupational Profile

Occupational Therapy Practice Framework v.4 (OTPF-4)





Occupational Profile

- The Occupational Profile is a summary of a client's occupational history and experiences, patterns of daily living, interests, values, needs, and relevant contexts.
- Developing the Occupational Profile provides the occupational therapy practitioner with an understanding of the client's perspective and background.

(OTPF-4 p.21)

Note: The term client includes persons, groups, or populations.



Occupational Profile

Exhibit 2. Operationalizing the Occupational Therapy Process

Ongoing interaction among evaluation, intervention, and outcomes occurs throughout the occupational therapy process.

Evaluation

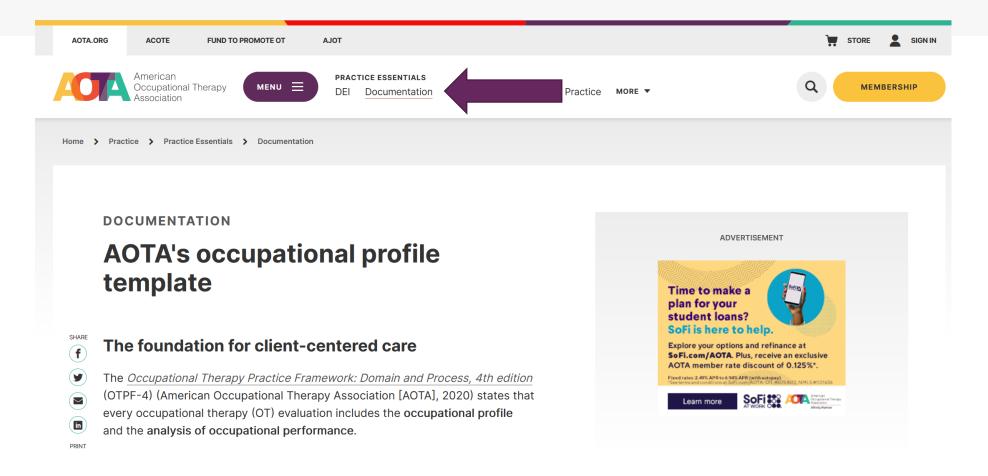
Occupational Profile

- Identify the following:
 - Why is the client seeking services, and what are the client's current concerns relative to engaging in occupations and in daily life activities?
 - In what occupations does the client feel successful, and what barriers are affecting their success in desired occupations?
 - What is the client's occupational history (i.e., life experiences)?
 - What are the client's values and interests?
 - 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?
 - How are the client's performance patterns supporting or limiting occupational performance and engagement?
 - What are the client's patterns of engagement in occupations, and how have they changed over time?
 - What client factors does the client see as supporting engagement in desired occupations, and what aspects are inhibiting engagement (e.g., pain, active symptoms)?
 - What are the client's priorities and desired targeted outcomes related to occupational performance, prevention, health and wellness, quality of life, participation, role competence, well-being, and occupational justice?

(OTPF-4, p.16)



Occupational Profile: Where to Find It





Occupational Profile

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.)
	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?
	Occupational history (p. 16)	What is the client's occupational history (i.e., life experiences)?
	Personal interests and values (p. 16)	What are the client's values and interests?
		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?



Contexts	Environment (p. 36) (e.g., natural environment and human-made changes, products and technology, support and relationships, attitudes, services, systems and policies)	Supporting Engagement	Inhibiting Engagement
	Personal (p. 40) (e.g., age, sexual orientation, gender identity, race and ethni- city, cultural identification, social background, upbringing, psychological assets, educa- tion, lifestyle)	Supporting Engagement	Inhibiting Engagement



Performance Patterns	Performance patterns (p. 41) (e.g., habits, routines, roles, rituals)	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.)		
		What client factors does the client see as supporting engagement in desired occupations, and what aspects are inhibiting engagement (e.g pain, active symptoms)?		
Factors	Values, beliefs, spirituality (p. 51)	Supporting Engagement	Inhibiting Engagement	
Client Fac	Body functions (p. 51) (e.g., mental, sensory, neuro- musculoskeletal and movement-related, cardiovascular functions)	Supporting Engagement	Inhibiting Engagement	
	Body structures (p. 54) (e.g., structures of the nervous system, eyes and ears, related to movement)	Supporting Engagement	Inhibiting Engagement	



	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
		Prevention
oals		Health and Wellness
Client Goals		Quality of Life
Clie		Participation
		Role Competence
		Well-Being
		Occupational Justice



- Application to ECHO project
 - Case template
- Tool to gather information on factors influencing health management and needs of adults with multiple sclerosis
- Promotes collaborative goal setting
- Aligned with best practice and most recent AOTA Choosing Wisely recommendations



Health Management as an Occupation

Health Management and OT

New in the OTPF-4: Health Management as an Occupation

Exhibit 1. Aspects of the Occupational Therapy Domain

All aspects of the occupational therapy domain transact to support engagement, participation, and health. This exhibit does not imply a hierarchy.

Occupations	Contexts	Performance Patterns	Performance Skills	Client Factors
Activities of daily living (ADLs) Instrumental activities of daily living (IADLs) Health management Rest and sleep Education Work Play Leisure Social participation	Environmental factors Personal factors	Habits Routines Roles Rituals	Motor skills Process skills Social interaction skills	Values, beliefs, and spirituality Body functions Body structures



Health Management and OT

Health Management: Activities related to developing, managing, and maintaining health and wellness routines, including self-management, with the goal of improving or maintaining health to support participation in other occupations.



Health Management and OT

Social & emotional health promotion & maintenance

Symptom and condition management

Communication with the health care system

Medication management

Physical activity

Nutrition management

Personal care device management



Occupations and Activities

Occupations

 Developing a medication routine to manage multiple medications, including using a pillbox, reading medication instructions, and developing a schedule to call for refills, and reminders.

Activities

 Client practices folding and putting away clothes to prepare to return to work with modifications to apply strategies for energy conservation.



Interventions to Support Occupations

PAMS & Physical Modalities

 Addressing pain prior to completing more physically difficult occupations

Orthotics and Prosthetics

 Education and training for completing occupations while using an AFO

Wheeled Mobility

 Adjusting seating and positioning to compensate for increased risk of wounds and skin breakdown



Interventions to Support Occupations

Assistive Tech & Environmental Modifications

 Identifying and incorporating Smart Home technology to compensate for decreased energy and endurance

Self-Regulation

 Completing deep breathing exercises before completing a challenging or stressful task



Education & Training

Education

 Demonstrating how to safely use DME for bathing and dressing

Training

 Partnering with the RN to teach a client experiencing cognitive changes how to organize and remember to take medications using compensatory strategies



Advocacy

Advocacy

 Ensuring that sidewalks and entrances near the person's home are fully accessible

Self-Advocacy

 Submitting paperwork for ADA accommodations to allow for additional breaks and modified workspaces



Group and Virtual

Group Interventions

 Providing a weekly falls prevention training and support group for people diagnosed with MS

Virtual Interventions

 Completing a virtual home tour to identify places to incorporate energy conservation strategies and modifications





Application and Case Example

Case Example: Social History

Kate (she/her/hers) is 39 years old

Kate lives with her wife, two young sons, and two dogs

 Kate works part-time as a substitute teacher and spends much of her day completing home management and caregiver tasks for her children and pets

(Case from Uyeshiro Simon & Cunningham, 2022)



Case Example: Health History

Kate was diagnosed with relapsing-remitting MS six years ago

Kate identifies fatigue as her most challenging MS symptom to manage

Kate also experiences occasional weakness and occasional difficulty with memory



Case Example: Health History

- Kate stopped adhering to her prescribed MS disease-modifying therapy (DMT) 10 months ago due to her busy schedule and high frequency of injections
- Kate identifies fatigue as the primary symptom interfering with occupational engagement
- Kate's MS neurologist referred her to OT to address occupational deficits secondary to fatigue and improve adherence with DMT routines



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.) Kate is seeking treatment due to a recent increase in her symptoms secondary to multiple sclerosis (MS). The main symptom that Kate identifies as interfering with occupational engagement is fatigue. Kate also experiences occasional weakness and occasional difficulty with memory.
		In what occupations does the client feel successful, and what barriers are affecting their success in desired occupations? Kate loves being involved in her sons' after school activities and takes pride in completing home management and caregiver tasks for her children and pets. Kate stopped adhering to her prescribed disease-modifying therapy (DMT) 10 mo ago due to her busy and varied schedule and the high frequency of injections. Currently, Kate identifies fatigue as her main barrier to successful occupational engagement.
		What is the client's occupational history (i.e., life experiences)? Kate is a 39-yr-old woman who lives with her wife, two young sons, and two dogs. She works part time as a substitute teacher and spends much of her day completing home management and caregiver tasks for her children and pets. Kate was diagnosed with relapsing-remitting MS six years ago.
	Personal interests and values (p. 16)	What are the client's values and interests? Kate's foremost personal value is family, which includes her pets. Kate also paints for leisure.

		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?		
Contexts	Environment (p. 36) (e.g., natural environment and human-made changes, products and technology, support and relationships, attitudes, services, systems and policies)	Supporting Engagement Flat environment conducive to physical activity outdoors Support of family Financial support from wife	Inhibiting Engagement Hot temperatures in the summer exacerbate fatigue and limit outdoor activities	
Con	Personal (p. 40) (e.g., age, sexual orientation, gender identity, race and ethnicity, cultural identification, social background, upbringing, psychological assets, education, lifestyle)	Supporting Engagement Desire to be physically active Higher education (based on role as substitute teacher)	Limited knowledge in types of physical activity that support fatigue management and reduce risk for overexertion Busy and varied schedule	

Performance Patterns	Performance patterns (p. 41) (e.g., habits, routines, roles, rituals)	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.) Kate's daily life roles include mother to her children, wife, and home management. Kate is also a substitute teacher. When she discontinued use of DMT, she identified increase in MS symptoms, including fatigue.		
What client factors does the client so in desired occupations, and what as engagement (e.g., pain, active symptom)			it aspects are inhibiting	
	Values, beliefs, spirituality (p. 51)	Supporting Engagement Commitment to family	Inhibiting Engagement Busy schedule and frequency of injections impacting medication health management routines	
Client Factors	Body functions (p. 51) (e.g., mental, sensory, neuro- musculoskeletal and movement-related, cardiovascular functions)	Supporting Engagement Higher cognitive functioning Sensory functions intact	Inhibiting Engagement Fatigue Occasional Weakness Cognition (memory)	
	Body structures (p. 54) (e.g., structures of the nervous system, eyes and ears, related to movement)	Supporting Engagement Gross motor Fine motor Functional mobility	Inhibiting Engagement None identified	

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 –home management IADLs		
	Prevention – Medication health management routines		
	Health and Wellness – Physical activity health management routines		
	Quality of Life – Improvements in child rearing IADLs, pet care IADLs, home management IADLs, and community participation		
	Participation – Community participation		
	Role Competence – Child rearing IADLs, pet care IADLs, home management IADLs		
	Well-Being – Physical activity health management routines		
	Occupational Justice		
	•		

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?





What are the client's health management challenges?



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



 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?



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?



The analysis of occupational performance involves one or more of the following:

- Synthesizing information from the Occupational Profile to determine specific occupations and contexts that need to be addressed;
- Completing an occupational or activity analysis to identify the demands of occupations and activities on the client



- Selecting and using specific assessments to measure:
 - the quality of the client's performance or performance deficits while completing occupations or activities relevant to desired occupations, noting the effectiveness of performance skills and performance patterns;
 - client factors that influence performance skills and performance patterns;
 - the client's contexts and their impact on occupational performance.



Wrap Up

- Post-Session Questionnaire
- Survey Link
- Questions and Cases for Discussion
- A submission link will be included in the follow-up email
- Questions: ebp@aota.org
 - Or see <u>Welcome Packet</u>



Next Session

 Don't forget to join us for the next AOTA ECHO session on January 19th.

Clinical Recommendations from AOTA's MS Practice

Guidelines



Rebecca Cunningham OTD, OTR/L, MSCS



Ashley Uyeshiro Simon OTD, OTR/L, MSCS



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