# Connecting with Caregivers: Occupational Therapy's Role in Enhancing Caregiver Self-Efficacy

ASIA KIM, CHES®, OTS-II THURSDAY, MARCH 18, 2021 7:00-8:00PM

### Course Objectives:

#### By the completion of this webinar, participants will be able to:

- Define "caregiving" as per the Occupational Therapy Practice Framework: Domain and Process (4th ed.)
- 2. Identify barriers to integrating caregivers into the intervention team
- 3. Discuss strategies to enhance collaboration and build relationships with clients and caregivers
- 4. Describe elements necessary for effective caregiver education
- Value the expertise of occupational therapy practitioners in addressing the needs of caregivers

### What is caregiving?

"Caregiving is a co-occupation that requires active participation by both the caregiver and the recipient of care... [It can be defined as] providing care for others, arranging or supervising formal care (by paid caregivers) or informal care (by family or friends) for others."

Occupational therapy (OT) practitioners understand and focus intervention to include the issues and concerns surrounding the complex dynamics between the client, caregiver, family, and community.

### What are barriers to integrating caregivers into the intervention team?

- Providers' lack of recognition of caregivers as a type of client
- Providers say they do not have time to talk to or train family caregivers
  - ► The culture of medicine and health care could perceive families as intrusive and time consuming
- Poor communication skills among providers and family members break down trust
- ➤ Privacy rules under the Health Insurance Portability and Accountability Act of 1996 (HIPAA; Pub. L. 104-191) have been misunderstood and misapplied, leaving family members without enough information to be active members of the care team

# Why should we focus on addressing the needs of caregivers?

#### After a Stroke: Addressing the Needs of Caregivers

#### ► <u>Increased Role Responsibilities</u>

- Caregivers were overwhelmed by the expectation that they would take on additional roles that were held by their spouse before stroke
- The need to constantly be with their spouse due to safety concerns added to their stress

#### Lack of Formal Training

- Caregivers did not feel knowledgeable about effects of stroke
- ▶ Most common training = verbal directions and handouts from OT. However, this type of education was not sufficient.

#### Being Unprepared for Emotional/Behavioral Changes

- Caregivers were surprised at how stroke changed their spouse's behavioral and emotional presentation
- ▶ Felt unappreciated, frustrated, lonely, and stressed
- Caregivers were instructed only about medication and when to bring spouse in for rehab

# Why should we focus on addressing the needs of caregivers?

An Innovative Approach to Promote Health and Well-Being of Caregivers of Children With Autism Spectrum Disorder (ASD)

#### Caregiver Stress

- Many parents are unaware of how to manage stress and access resources to support child's needs (Karst & Van Hecke, 2012)
- ► Caregivers of children with ASD are more likely to report depressive symptoms and high stress levels, and are at higher risk for developing depression than parents of typically developing children (Bekhet, 2016; Harrop et al., 2016)
- ▶ Unique challenges associated with children with autism include behavioralissues and limitations in social play and communication (Estes et al., 2013)

### What are caregivers' learning priorities?

Information about available services and activities

Stress management and coping strategies

Information on the care recipient's condition

Training in care tasks

Education on communication and behavior strategies for care recipients

Training in medication management

Assistance in realistic goal setting and prioritization of goals

Ways to engage clients in care

# What are effective caregiver treatment approaches?

- Integration of education about the condition, behavior management strategies, communication skills, environmental modification, stress management, and coping skills
- Provision of information on respite options (in-home support and day care services)
- Delivery of professionally led in-person support groups to increase caregiver preparation and confidence
- Interaction with caregivers to explain, discuss, and practice educational content
- Delivery of caregiver training and practice using assistive devices with or for the client to promote long-term use and carryover

# How can OT practitioners build strong relationships with caregivers?

Make Caregivers
Part of the Team

2

Teach the "Why" and "How" of Modifications and Adaptations

3

Provide Motivational Tools 4

Help Manage the Daily Details

5

Promote Self Care

### **Panel Discussion**

- Jessica Kronberg, MS, OTR/L M Street Pediatric Therapy
  - Practice settings: Early Intervention (EI) and Pediatrics
- Lisa Knecht-Sabres, DHS, OTR/L Midwestern University
  - Practice settings: In-Patient Rehabilitation, Acute Care, Out-Patient, Day Rehabilitation, Home Health, and Adult Day Care
- Kimberly Bryze, Ph.D., OTR/L Midwestern University and L'Arche Chicago
  - Practice settings: Developmental Disabilities, Sensory processing/sensory integration

### Danny Ryan, OTS-III, Midwestern University

- Capstone Project: "Preparing to Return Home Safely Caregiver Resources"
- Doctoral Internship Site: Northwestern Memorial Hospital
- On-Site Mentor: Andrea Connolly, OTR/L
- Collaborated with staff members, caregivers, and patients about the caregiver education process
- Created resources that are easily accessible for caregivers to use once the patient is discharged.

# Additional resources and conclusion

AOTA Caregivers Toolkit: How Occupational Therapy Can Help

You: <a href="https://www.aota.org/About-Occupational-Therapy/Patients-Clients/Caregivers.aspx">https://www.aota.org/About-Occupational-Therapy/Patients-Clients/Caregivers.aspx</a>

- AARP Family Caregiving: <a href="https://www.aarp.org/caregiving/">https://www.aarp.org/caregiving/</a>
- ► Family Caregiver
  Alliance: https://www.caregiver.org/

### **THANK YOU!**

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