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- Email customerservice@OccupationalTherapy.com
Julia Wood MOT, OTR/L

Occupational Therapy Approach to Assessment and Intervention in Dementia

Learning Outcomes

- Identify changes in cognition that impact function in Alzheimer’s Disease, Parkinson’s Disease Dementia (PDD), Dementia with Lewy Bodies (DLB) and Frontotemporal Dementia (FTD).
- Identify and list appropriate screening and outcome measures to create a person-centered approach to the evaluation and treatment of people with dementia.
- Describe occupation-based, task-oriented treatment strategies to address the participation challenges for people living with dementia.
What is Dementia?

- Clinical syndrome with variable manifestations
- Chronic, acquired loss of 2 or more cognitive abilities (executive, visuospatial, memory, language) caused by brain disease or injury
- Decline of cognitive abilities from the prior level of function
- Impairment in day to day functional abilities (social, occupational, self care)
- DSM-5 recognized that dementia can involve impairment in a single domain

(Arvanitakis, Shah, & Bennett, 2019)
Alzheimer’s Disease

- Progressive neurological disorder that results in the irreversible loss of neurons, especially in the hippocampus and cortex
- The most common neurodegenerative condition
  - Constitutes 2/3 of dementia cases overall
  - Prevalence is about 1% in ages 65-69; increases with age to 40-50% in persons 95 years or older
  - About 7% of early onset cases are familial with an autosomal dominant

Parkinson’s Disease Dementia (PDD)

- Executive function deficits
- Memory
- Construction and Praxis (Clock-Drawing Test) impairments
- Visuo-spatial deficits
- Impaired attention
- Hallucinations in 45% to 65% of cases (25% in PD)
Core clinical features (first 3 tend to occur early)

- **REM sleep behavior disorder**, which may precede cognitive decline.
- **“Fluctuating” cognition** with pronounced variations in attention and alertness.
- **Recurrent visual hallucinations**—typically well formed and detailed.
- One or more spontaneous cardinal features of **parkinsonism**:
  - Bradykinesia (defined as slowness of movement and decrement in amplitude or speed)
  - Rest tremor
  - Rigidity

Dementia with Lewy Bodies (DLB)

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Essential for a clinical diagnosis of probable and possible DLB:

- Dementia
- Deficits in attention, executive function, and visuo-spatial can occur early and be very prominent
- Memory impairment may not occur early in the disease but often presents with progression
Frontotemporal Dementia (FTD)

- Three Clinical Variants:
  - Behavioral- most common
  - Language
  - Motor
- Diagnosis: *(Differential)* history of the progression of behavioral changes, family history, behavior during interviews, neuro-psych testing, labs, and neuroimaging
- Most common form of dementia under the age of 60
- 40% of those diagnosed with FTD have a family history with at least one other relative with a neurodegenerative disease; 10% have a gene mutation

FTD: Behavioral Variant

- Decline in socially appropriate behavior
- Poor self control/disinhibition
- Poor judgement
- Decline in executive function
- Apathy
- Lack of empathy
- Compulsive or ritualistic behaviors
- Changes in eating behaviors and/or diet
FTD: Language Variant

- **Primary Progressive Aphasia** – ongoing loss of ability to speak, read, write, and understand speech
  - **Logopenic variant** – difficulty finding the right words
  - **Semantic variant** – loss of the meaning of words
  - **Nonfluent/agrammatic variant** – decrease in speech with increase grammar impairments

FTD: Motor Variant

- Parkinsonism - most common in those with the behavioral variant
  - May have features of atypical parkinsonism: corticobasal syndrome or progressive supranuclear palsy
  - Up to 40% have mild motor neuron disease
    - LMN – muscle atrophy, weakness, fasciculations
    - UMN – spasticity, hyper-reflexia, extensor plantar response
Caregiver Strain

- Physical and mental health problems
- Difficulties maintaining employment
- Financial difficulties
- Barriers to leisure engagement
- Difficulty with family interactions
- Reduced quality of life

(Bennett, Laver, Voigt-Radloff, Letts, Clemson, Graff, Wiseman & Gitlin, 2019)

Impact on Participation

- Increased time for task completion
- Increased dependency for self care and home management
- Difficulty with new learning
- Decreased social participation
- Impaired communication
Occupational Therapy Assessment

Client Centered-Top Down Approach

- Develop an occupational profile--focus on the key issues of the person with dementia and their carer
- Patterns, routines and roles in daily activities
- Determine values, interests and needs of the person
- Identify areas of concern or difficulty in daily activities
- Select outcomes meaningful and relevant to the client
  (Weinstock-Zlotnick & Hinojosa, 2004)
- Collaborate with client/family to prioritize meaningful goals (Leach et al., 2005)
Cognitive Screening

- MOCA
- Short Blessed
- Dementia Rating Scale
- Cognitive Linguistic Quick Scale
- Mini Mental Status Examination
- St. Louis University Mental Status Examination (SLUMS)
- Parkinson’s Disease Cognitive Rating Scale

ACDS- ADL

- Assesses the competence of patients with Alzheimer’s Disease (AD) in basic and instrumental activities of daily living (ADLs).
- It can be completed by a caregiver in questionnaire format, or administered by a clinician as a structured interview with a caregiver.
- The 19-item version (ADCS-ADL 19), covering mainly basic ADL, is used for the assessment of patients with more severe AD
- The 23-item version (ADCS-ADL 23) includes more complex ADL for the assessment of mild to moderate AD, such as reading books or magazines, pastime activities, or household chores
  - http://www.medafile.com/cln/ADCSADLm.htm
Activity Card Sort, 2nd Edition (ACS)
(Baum & Edwards, 2008)

- 89 photographs of individuals performing activities
- Promotes choosing client centered interventions, based on client interests
- Measures changes in participation
- Guides discussion about current and prior interests and perceived roles
- Includes 20 instrumental activities, 35 low-physical-demand leisure activities, 17 high-physical-demand leisure activities, and 17 social activities

Modified Interest Inventory

- Gathers information on a client's strength of interest and engagement in 68 activities in the past, currently, and in the future.
- The main focus is on leisure interests that influence activity choices.
- The checklist can be used by adolescents or adults.

http://moho.uic.edu/resources/files/Modified%20Interest%20Checklist.pdf
Routine Task Inventory (RTI-E)

- An evidence-based, semi-standardized assessment tool developed within the framework of the cognitive disabilities model.
- Comprised of 25 ADLs and IADLs.
- Functional cognition is assessed based on therapists’ direct observation of performance in naturalistic contexts or on the perceptions of performance reported by the client or a caregiver using a checklist or standardized interview questions.
- Scores are associated with the Allen Scale of cognitive levels 1-6 and a mean score is calculated for each subscale

(Katz, 2006)

Performance Assessment of Self-Care Skills (PASS)

(Chisholm, Toto, Raina, Holm, & Rogers, 2014)

- 26 tasks in four different domains
  - Functional mobility, ADL & IADL (physical & cognitive)
  - Each subtask is rated for independence, safety, and adequacy on a scale from 0-3.
  - A higher score indicates greater independence, safety, or adequacy.
- Level of assistance needed and frequency of prompts
- Frequency of prompts and types of assistance are recorded to aid in intervention planning
- Therapist may administer only those tasks deemed relevant to client
- Therapist may use PASS template to develop new PASS items
Barthel Index

A simple to administer tool for assessing self care and mobility activities of daily living.

Widely used in geriatric assessment settings. Reliability, validity and overall utility are rated as good to excellent.

Information is gained from observation, self report or informant report. [https://www.sralab.org/rehabilitation-measures/barthel-index](https://www.sralab.org/rehabilitation-measures/barthel-index)

Bayer Activities of Daily Living Scale

- Consists of 25 items that are answered by the caregiver.
- The first items evaluate the patient’s ability to handle the ADL and capacity for self-care.
- Performance is rated on a scale of 1 “never” to 10 “always” has difficulty
- Other items evaluate specific tasks.
- Considers short and long term memory and performance in familiar and unfamiliar environments.
- Items assess cognitive functions that are important for performing activities of daily living.
In order to improve his participation lower body dressing and improve his independence, Albert will...

<table>
<thead>
<tr>
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<th>Description</th>
</tr>
</thead>
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</tr>
<tr>
<td>-1</td>
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<tr>
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</tr>
<tr>
<td>+1</td>
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</tr>
<tr>
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-2 Much less than expected level:
Complete lower body dressing routine with set up and max physical assist from spouse within 4 weeks.

-1 Less than expected level:
Complete lower body dressing routine with set up and mod physical assist from spouse within 4 weeks.

0 Expected level performance:
Complete lower body dressing with set up and no more than 1 verbal cue from spouse within 4 weeks.

+1 Better than expected level:
Complete lower body dressing routine with set up and no verbal cues from spouse within 4 weeks.

+2 Much better than expected level:
Complete lower body dressing routine with no more than 1 verbal cue from spouse within 4 weeks.

Timed Up and Go (TUG) & Timed Up and Go – Cognition (TUG-cog)

- Quick and simple to administer
- Strong reliability and validity
- Readily accessible equipment
- Involves transfer to stand, walk short distance, turn and return to sit

(Podsiadlo & Richardson, 1991)
Five Time Sit to Stand Test

- Use a straight back chair with a solid seat that is 16” high. Ask participant to sit on the chair with arms folded across their chest.
- “Stand up and sit down as quickly as possible 5 times, keeping your arms folded across your chest.”
- Quick and easy to administer

(Duncan, Leddy, & Earhart, 2011)

Home Environmental Assessment Protocol (HEAP)

- Grounded in the competence-environmental press framework
- Consists of 192 items summed into separate indices representing the number of hazards, adaptations and level of clutter and comfort in up to eight areas of the home that is used by the person with dementia.
- It relies on both structured observation and self-reports from family members to derive ratings.
Caregiver Burden Assessments

- Caregiver Burden Scale (Macera, Eaker, Jannarone, Davis, Stoskopf, 1993)
- Canadian Occupational Performance Measure (COPM)
- Multidimensional Caregiver Strain Index – Stull (1996) • 18 question survey
- Caregiver Strain Index – Sullivan • 13 Questions

Occupational Therapy Intervention
How Can OT help people with Dementia?

<table>
<thead>
<tr>
<th>Health Promotion</th>
<th>By focusing on maintaining strengths of clients and promoting wellness of care providers, OTs can enrich lives by promoting maximal performance in preferred activities.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remediation</td>
<td>The remediation of cognitive skills is NOT expected. OTs can incorporate routine exercise into interventions to improve the performance of ADLs and functional mobility, and help restore range of motion, strength, and endurance (Forbes, Forbes, Blake, Theissen, &amp; Forbes, 2015).</td>
</tr>
<tr>
<td>Maintenance</td>
<td>Provide supports for habits and routines that are working well for the person with dementia to prolong independence.</td>
</tr>
<tr>
<td>Modification</td>
<td>Ensure safe and supportive environments through adaptation and compensation, including verbal cueing, personal assistance, and/or social supports.</td>
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</table>

Cognitive Rehabilitation

- **Cognitive restoration/retraining**
  - Repetitive practice of tasks that require targeted cognitive process with the goal of strengthening that cognitive process and improving functional performance
  - Not shown to translate to function in people with dementias

- **Strategy based-approach**
  - Provides approaches for accomplishing desired tasks and activities despite the present of cognitive deficits
  - Trains use of metacognitive, problem-solving, or compensatory strategies for use in everyday life to cope with cognitive challenges
Evidence-based occupational therapy for people with dementia and their families: What clinical practice guidelines tell us and implications for practice (Laver et al., 2017)

“Occupational Therapists should avoid spending time on activities that have not demonstrated improved outcomes for the person with dementia, such as cognitive retraining”

**Content/Approach**
- Most studies utilized an approach to assessment and intervention involving both the carer and person with dementia; individually tailored and goal-directed interventions
- The carer and person with dementia were supported to choose activities (activities of daily living or other meaningful activities) they wanted to improve.
- Carers were coached or trained to problem solve, present, cue and simplify activities, use compensatory strategies, generalize strategies and modify the environment to support activity engagement.
- Carers also received training/information to address their identified concerns (e.g., stress management, understanding dementia).

**Number of sessions**
- Median=8 sessions

**Most common length of time**
- Range=1–12 sessions, with 1 trial providing 24 sessions
- 1–1.5 hours/session (10 studies)

**Timeframe**
- Total intervention time ranged between 8-12 hours
- 5 weeks-6 months; one study providing intervention across 2 years
Efficacy of OT for Dementia

People with mostly moderate stage dementia who received 8-12 hours (avg 8 sessions) of multicomponent occupational therapy at home had improvements in:

- Improvement in ability to carry out ADL and IADL tasks
- Carers reported fewer behaviors and psychological symptoms
- Carers reported improved quality of life

(Bennett et al., 2019)

The Role of the Occupational Therapist in the Management of Neuropsychiatric Symptoms (NPS) of Dementia in Clinical Settings

- The “DICE” (Describe, Investigate, Create, and Evaluate) approach is a patient- and caregiver- centered intervention approach
- DICE offers a clinical reasoning approach through which providers can more efficiently and effectively choose optimal treatment plans.

(Fraker, Kales, Blazek, Kavanagh & Gitlin, 2014)
DICE: Describe

- An occupational performance analysis may include a review of the person’s abilities, environmental setting, caregiver communications and interactions, and demands of an activity.
- The activity demands include required actions, performance skills, body functions, body structures and environmental context.
- In addition to in-person evaluation, caregivers can be encouraged to record issues and the context in which they occur in diaries for later review by the OT.

(Fraker et al., 2014)

DICE: Investigate

- Assess the patient’s cognitive level using OT-based standardized assessments
- Interview the caregiver to understand the patient’s past roles including other occupations or hobbies, participation in religious or other organization, and role in the family.
- Inquire as to what was motivating for the patient in both the past and present, and review daily routines with the caregiver, including times of the day the patient is more active and alert.
- Evaluate range of motion, strength, and mobility, including fall risk.
- Assess the environment in which NPS occurs.

(Fraker et al., 2014)
DICE: Create

- Educate the caregiver about dementia and behavioral symptoms.
- Build skills in effective communication and modify the environment to reduce or minimize external contributors to the behavior.
- Help the caregiver understand the patient's functional level, including limitations and abilities, how to improve communication, and how to introduce and use activities as a way to prevent and minimize NPS.
- Recommend ways to simplify the environment to support the best functioning of the person with dementia and minimize confusion in use of objects or way finding in the home.

(Fraker et al., 2014)

DICE-Evaluate

- Consult with the caregiver to determine the outcome: what strategies were implemented, what worked, what did not, and unexpected results both positive and negative.
- Help differentiate and evaluate reasons why strategies are not working:
  - Did the caregiver implement the strategy incorrectly?
  - Was there a change in the patient's status that made implementation difficult?
  - Was it not the right strategy for this particular caregiver-patient relationship?
- Consult and coordinate with other team members.
- Report symptoms of worsening cognition to the physician.
- Increased home services and resources may need to be explored.
Tailored Activities Program (TAP)

- Up to eight home sessions over 3 months
- Evaluate the person with dementia, caregivers, and living environment
- Develop activity prescriptions tailored to the individual’s capacities
- Caregivers learn to manage situational stressors, optimize function, and manage behavioral and psychological symptoms
- Provides education for caregivers on realistic expectations of person with dementia; caregivers tend to overestimate abilities and have a poor understanding of impact of dementia on behaviors

(Gitlin et al., 2009, 2016, 2019)

TAP Phase 1 : Assessment

- Completed during sessions 1-2
- Standardized assessments used to evaluate the person with dementia, caregivers, and environment
- Therapist collaborates with caregivers and person with dementia (when appropriate) to identify three activities of interest
- Activities are tailored to the capabilities and context of the individual with dementia
- Caregivers are educated about the disease process and learn simple stress reduction techniques

(Gitlin et al., 2009, 2016, 2019)
TAP Phase 2: Implementation

- Sessions 3-6
- OT reviews assessment results with caregiver
- Provides three activity prescriptions (typed document) which describe the activity, goal, person’s abilities and implementation steps
- Therapist demonstrates how to set up and implement activities
- Caregiver practices strategies (e.g., help with initiation)
- OT uses skilled observation to modify the prescriptions as necessary
- Caregiver practices with the person with dementia between sessions

(Gitlin et al., 2009, 2016, 2019)

TAP Phase 3: Generalization

- Sessions 7-8
- OT assists the caregiver to identify ways to simplify the activities with disease progression
- Therapist helps the caregiver brainstorm ways to generalize the activity strategies to other care challenges
- May involve training in strategies to simplify communication or adapt the environment

(Gitlin et al., 2009, 2016, 2019)
Characteristics of Activities for Persons With Dementia at the Mild, Moderate, and Severe Stages

- Examined relationships of disease stage with types and characteristics of meaningful activities
  - Cueing needs, assist with initiation, recommended engagement time
  - 158 activity prescriptions for 56 families
- Mild dementia
  - Complex arts & crafts; cognitive activities
  - 28 mins activity; cueing 68.3% of time
- Moderate dementia
  - Music & entertainment, domestic/homemaking
  - 24 mins activity; cueing 78% of time
- Severe Dementia
  - Simple physical exercises; manipulation/sensory/sorting activities
  - 15 mins activity; cueing 78% of time

(Regier, Hodgson, & Gitlin, 2016)

Considerations for TAP

- TAP should align preserved functional and cognitive abilities with environment and interests to design activities to maximize engagement
- Identify previous and current interests of the individual to promote a sense of self, even in severe dementia
- Consider stage of the disease when choosing activity design and set up
- Educate and train caregivers in varied needs for cueing techniques and time for engagement with disease progression
- Consider the time of day to introduce activities to maximize engagement and well being (activities with increased cognitive demand in am with lower demand at end of day)

(Regier, Hodgson, & Gitlin, 2016)
Goal-orientated cognitive rehabilitation for dementias associated with Parkinson’s disease—A pilot randomized controlled trial (Hindle et al, 2018)

Goal orientated cognitive rehabilitation uses goal setting and evidence-based strategies focusing on improving function in everyday activities in people with dementia.

Showed that cognitive rehabilitation was superior to treatment-as-usual and relaxation therapy for primary outcomes in dementias associated with Parkinson’s.

Cognitive Rehabilitation is feasible and potentially effective for dementias associated with Parkinson’s but requires further study.

Effects of nonpharmacological interventions on functioning of people living with dementia at home: A systematic review of randomised controlled trials (Scott et al., 2019)

“Person-centered approaches, which optimize the environment and activities, support family carers, and are needs and goal-based, enable self-management where possible, and are underpinned by a responsive case management service model; are the models that appear to be most likely to be effective.”
Treatment Strategies

- Focus on a strength-based approach
  - Identify strengths and abilities rather than deficits and limitations
  - Use familiar and functional activities that rely on long term and procedural as therapeutic activities and exercises rather than new and unfamiliar tasks and equipment (Ries 2018)
- Utilize “errorless” learning
  - Practice performing tasks in the same way, with consistent cues in the same environment (when possible) to reduce the possibility of mistakes
  - Focus on learning by DOING rather than thinking about HOW to do them
- Speak clearly and slowly
  - Processing time is slower and will be even slower in those with a hearing impairment

Communication/Cueing Strategies

- Present one step or idea at a time
- Speak calmly in a normal tone of voice
- Speak slowly and simply
- If you need to repeat something, use the same words
- Stand in front of the person and maintain eye contact (gaze will lower with progression)
- Gently touch and arm or shoulder to gain attention
- Approach the individual from the front to avoid startling
- Utilize color; neon green is easiest to see, use high contrast for visibility
Strategies for Dementia & Psychosis

- Establish familiar, consistent routines
- Facilitate gradual transitions
- Utilize music to support transitions and orientation
- Coach frequent re-orientation
- Schedule contact with family & friends (phone, video)
- Utilize meaningful hobbies & activities
- Store belongings in predictable, familiar places
- Mark items with pictures
- Maintain a highly visible calendar (refrigerator)
- Decrease clutter/distractions
- Establish cognitive stimulation activities
- Simplify the environment
- Address lighting concerns

Safety

- Train in safe measures for control of medication intake
- Address safe use of home appliances
- Prevention of wandering (GPS monitoring); bed/door alarms
- Limit access to firearms
- Assess fitness to drive
- Monitor for elder abuse
- Address need for supervision when necessary
Nonpharmacologic Approaches to Dementia

- Cognitively stimulating activities
- Social engagement
- Physical exercise- both aerobic & resistance
- Healthy diet (Mediterranean diet)
- Adequate sleep
- Safety (home appliances, driving)
- Medical & advanced care directives (LSW)
- Long-term health care planning
- Financial planning
- Effective communication (visual aids)
- Participation in meaningful activities

Sundowning

*Restlessness, agitation, irritability, or confusion that can begin or worsen as daylight begins to fade*

- Reduce noise, clutter, or the number of people in the room.
- Try to distract the person with a favorite snack, object, or activity.
- Make early evening a quiet time of day. You might play soothing music, read, or go for a walk. Schedule a call with a family member or friend call during this time.
- Close the curtains or blinds at dusk to minimize shadows and the confusion they may cause. Turn on lights to help minimize shadows.
Tips to Prevent Sundowning

- Go outside or at least sit by the window — exposure to bright light can help reset the person’s body clock
- Schedule physical exercise each day
- Get daytime rest if needed, but keep naps short and not too late in the day
- Promote good sleep at night.
- Avoid things that seem to make sundowning worse:
  - Do not serve coffee, cola, or other drinks with caffeine late in the day.
  - Avoid serving alcoholic drinks. They may add to confusion and anxiety.
  - Do not plan too many activities during the day. A full schedule can be tiring

Cognitive Stimulation

- Promotes engagement in activities to stimulate general cognitive and social functioning in a non-specific manner.
  - Participation in group discussions, book clubs
  - Games and trivia
  - Music-related activities
  - Train care partner/aides in client centered activities!
Music & Memory®

- Training for care professionals on how to set up personalized music playlists, delivered on iPods and other digital devices.
- Musical favorites tap deep memories not lost to dementia and can bring participants back to life, enabling them to feel like themselves again, to converse, socialize and stay present.

musicandmemory.org

Life Stories

- An activity in which the person with dementia is supported by staff and/or family members to gather and review their past life events and build a personal biography.
- Can help people with dementia share their stories and enhance their sense of identity.
- Can help encourage better communication and an understanding of the person's needs and wishes, supporting person-centered care.
- It can help the person develop closer relationships with family carers and staff through sharing stories
- Dementia Uk.org
  https://www.dementiauk.org/for-professionals/free-resources/life-story-work/
- Legacy Project.org
  https://www.legacyproject.org/guides/lifeintquestions.html
DLB: Case Example

80-year old male diagnosed 6 months ago with Dementia Lewy Bodies

Lives in single level apartment home with access to exercise facility in building.

Strengths: Supportive spouse and family; financial means to obtain additional help as needed

Challenges: Rigidity, FOG, difficulty with transfers, bed mobility and dressing. Decreased social engagement

Goal Attainment Scaling

https://www.sralab.org/rehabilitation-measures/goal-attainment-scale

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* In order to improve his participation lower body dressing and improve his independence, Albert will...
Summary

- Dementia can significantly impact many aspects of participation and quality of life for both the individual with dementia and care partners.
- Occupational therapists are perfectly suited to provide person centered care by addressing strategies to optimize the person, enrich the environment and maximize engagement in meaningful occupation.
- Focus on creating person-centered approaches to assessment and intervention that are needs and goals based, promote self management, optimize engagement, and support family carers.
- Educate and empower care partners to understand and effectively support the needs of their loved one with dementia combined with resources to support their own wellness and self care.
- Foster a responsive case management service model through collaborative, interdisciplinary care.
Questions?

jmwood525@gmail.com

References:

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