Dementia Care Management: The Collaborative Role of Occupational Therapy

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Constance Welcome, MOT, OT and Kourtne Donnaud, OTR

Disclosures
Constance Welcome, MOT, OT
Clinical Services Specialist
Financial Disclosures: None.
Salaried employee of Reliant Rehabilitation
Non-Financial Disclosures: None

Kourtne Donnaud, OTR
Clinical Services Specialist
Financial Disclosures: None.
Salaried employee of Reliant Rehabilitation
Non-Financial Disclosures: None

Learning Objectives
1. Explain regulatory requirements related to dementia care.
2. Identify behaviors and characteristics associated with dementia and strategies for care planning.
3. Describe inter-professional planning and care for individuals with dementia.
Dementia Care Management in Long-Term Care

• Caring for persons living with dementia (PLWD) can be challenging in long-term care (LTC) facilities.
  – More effort is required to establish personalized services.
  – Staff must be well versed in the disease process and equipped with strategies to achieve successful outcomes.
• Improper care of persons living with dementia (PLWD) may:
  – Expedite the loss of abilities.
  – Create caregiver/staff burnout.
  – Create safety issues for other residents and staff members.
  – Cause survey deficiencies.
  – Create negative outcomes for the resident and the facility.

Requirements of Participation (RoP)

What are the Requirements of Participation?
– Regulations to ensure systems, policies, and procedures are functioning with modern practices
– Regulations to reduce re-hospitalizations
– Federal regulations passed in 2016 for nursing facilities (NF) who wish to participate in Medicare and Medicaid programs
– Build on the Omnibus Budget Reconciliation Act (OBRA) of 1987 (implemented in 1991)
– Focus on person-centered care planning, resident’s choice, quality of life, and quality of care for all residents

Requirements of Participation (Cont.)
– Call for evidence-based, quality care at every level, according to professional standards of practice
– Mandate discharge planning focused on resident’s goal
– Require dementia and abuse prevention training for nurse aides (NAs)
– Require staff competency and Quality Assurance and Performance Improvement (QAPI) programs based on acuity of patients
– Requires facilities to provide a palatable diet based on the resident’s preferences
– Call for a reduction in use of psychotropic medications
– Ensure non-pharmacological management is utilized prior to prescribing psychotropic medications
Requirements of Participation (Cont.)

Nursing facilities are required to provide for the resident “the necessary care and services to **attain** or **maintain** the highest practicable **physical, mental, and psychosocial** well-being, consistent with the resident’s comprehensive assessment and plan of care.” § 483.24

RoP: Facility Challenges with Implementation

- Developing/implementing person-centered care plan  
  - Focusing on resident’s choice/preferences and discharge environment
- Meeting the needs of the resident  
  - Communication is primary  
  - Managing patient behaviors  
  - Ensuring use of non-pharmacological interventions
- Providing safe means of nutrition/hydration
- Preventing staff/caregiver burnout

Opportunities for OT

- Market your skills.
- Be invaluable to patients, facilities & employers.
- Be leaders for change.
- Provide solutions.
- Represent the distinct value of OT!
RoP: Challenges and Opportunities for OT

• Identifying residual abilities by the process of dementia staging
• Identifying communication abilities, routines, preferences, sensory processing issues, environmental challenges
• Developing techniques to manage neuropsychiatric behaviors or behavioral and psychiatric symptoms of dementia (BPSD)
• Ensuring strategies are implemented in the overall care plan
• Ensuring safe means of nutrition/hydration based on resident’s preferences
• Education of care partners throughout the intervention process
• Assisting the facility with implementation of overall staff education
• Decreasing care-giver burnout

RoP: Challenges and Opportunities for OT

• Providing evidence-based practice (EBP)
  • Reference AOTA/AJOT articles/EBP Directory
  • Evidence is strongest for caregiver training to allow the caregiver to be successful and to continue in their role through use of:
    • Education in Communication skills
    • Use of memory aids
    • Mindfulness
    • Stress reduction techniques

https://www.aota.org/Practice/Productive-Aging/Evidence-based/CAT-Occupation-Alz.aspx

RoP: Challenges and Opportunities for OT (Cont.)

• Obtain training and certifications to ensure you are:
  – Knowledgeable
  – Confident
  – Have techniques/tools to share with caregivers/facility
• CARES® Dementia Specialist™ (C.D.S.) credential [Website]
• essentiALZ Certification by the Alzheimer’s Association [Website]
• CPI [Website]
• Teepa Snow is an OT who has developed Positive Approach to Care (PAC). Earn various certifications. [Website]
OT is Up to the Challenge!

A study was published in France in 2017 with 421 persons living with mild to moderate dementia. They were provided outpatient OT using common OT practices as they relate to dementia care. Results:

- Cognitive scores remained steady over 6 months (no decline).
- Problematic behaviors decreased at 3 months, and the decrease was sustained at 6 months.
- Functional performance and quality of life scores improved at 3 months with a significant decline at 6 months.
- Caregiver burden decreased at 3 months, and the decrease was sustained at 6 months.

The Unique Contributions of OT

- Activity analysis
- Cognitive/mental/emotional assessments & interventions
- Functional assessments & interventions
- Finding the “Just Right Challenge”
- Meaningful/purposeful activity
- Occupational Performance (ADLs/IADLs/leisure)
- Psychosocial components (patient and caregiver)
- Sensory processing and integration (sensory/environment)
- Values, beliefs, spirituality

Dementia

- Dementia is not part of normal aging.
- Dementia is not diagnosis, but a syndrome that encompasses specific diagnoses.
- These diagnoses result in progressive disease processes that impair memory, language, problem-solving and other cognitive functions that impact the persons ability to perform everyday activities.
Types of Neurocognitive Disorders (NCD)

- Alzheimer’s dementia (AD)
- Lewy body dementia (LBD) or Dementia with Lewy bodies (DLB)
- Frontotemporal lobar dementia (FTLD)
- Mixed dementia
- Parkinson dementia
- Vascular dementia (VaD)

Diseases that Mimic Dementia or NCD

- Chronic traumatic encephalopathy (CTE) – war veterans/football players
- Parkinson’s disease – This is a motor disease, but it increases risk of developing dementia.
- Traumatic brain injury – increases risk of developing dementias.
- Wernicke-Korsakoff syndrome - deficiency in the B vitamin thiamine

Prevalence of Dementia in 2018

- ↑ in AD in the US from 5.5 million in 2017 to 5.7 million in 2018
- 1 in 10 people over the age of 65 has AD (10%)
- Nearly every minute, a person is diagnosed with AD.
### Normal Aging vs. Dementia

<table>
<thead>
<tr>
<th>Normal Aging</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fleeting forgetfulness – names/appointments</td>
<td>Significant memory loss - interferes with daily life</td>
</tr>
<tr>
<td>Occasional errors with planning/problem solving (balancing checkbook)</td>
<td>Planning/problem solving difficulties - following a familiar recipe or locking a door</td>
</tr>
<tr>
<td>Needs occasional assistance with operating microwave or remote for TV</td>
<td>Difficulty completing familiar tasks – driving to familiar location</td>
</tr>
<tr>
<td>May forget day/week, but later recall</td>
<td>Not oriented to time or place – unable to recall</td>
</tr>
<tr>
<td>Vision loss due to diagnosis (cataracts, macular degeneration, etc.)</td>
<td>Difficulty interpreting visual stimuli and spatial relations unrelated to visual diagnosis</td>
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### Normal Aging vs. Dementia

<table>
<thead>
<tr>
<th>Normal Aging</th>
<th>Dementia</th>
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</thead>
<tbody>
<tr>
<td>Occasional word finding problems</td>
<td>Difficulty with written/spoken words and/or conversations. Extreme word finding issues.</td>
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<tr>
<td>Misplaces items, but able to retrace steps</td>
<td>Misplaces items – unable to retrace steps</td>
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<tr>
<td>Poor judgement/decision making on occasions</td>
<td>Overall, decrease in judgement or decision-making (decreased grooming/hygiene)</td>
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<td>Occasional weariness of commitments - work/family/social/leisure</td>
<td>Social withdrawal from or lack of interest in typical activities - work/family/social/leisure</td>
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<td>May become irritable with disruption of routine</td>
<td>Personality and/or mood fluctuations/changes, especially when out of their comfort zone or routine</td>
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### Risk Areas

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<tr>
<td>ADLs/IADLs (Grooming, hygiene, toileting etc.)</td>
<td>Nutrition/hydration</td>
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<tr>
<td>Cognition – short term memory, recall, problem solving, perceptual skills, attention, orientation etc.</td>
<td>Psychosocial (hobbies/leisure, socialization, church activities, depression, anxiety; behavioral, personality, and mood changes etc.)</td>
</tr>
<tr>
<td>Communication – language, word finding, slower processing etc.</td>
<td>Sensory processing (over/under stimulation, visual deficits - decreased peripheral vision, depth perception etc.)</td>
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<tr>
<td>Medication management</td>
<td>Sleep cycles</td>
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<tr>
<td>Mobility</td>
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The Overall Process

- Assess
- Identify Residual Abilities
- Establish POC
- Assess

Screening and Assessment Process

- Establish rapport and trust.
- Use stage of dementia to guide the process.
- Interview family, friends, caregivers, and staff.
- Utilize standardized screens/assessments to provide quantitative data for baseline measures.
- Assessing communication is primary – collaborate with SLP
- Identify problematic behaviors and intervention options

Focus of the POC

- Focus on adaptations, compensation and maintaining vs. restoration
  - Maintenance/Habillitative: Improvement potential is not considered.
  - Restoration/Rehabillitative: Improvement potential is considered.
- Any treatment approach and goal must be:
  - Functional (physical, mental & psychosocial)
  - Measurable in objective terms, even when restoration is not the goal.
  - Meaningful to the resident/patient
The Therapy Plan of Care (POC)

• Include routines & preferences of the patient, both present and when in their prime.
• Consider their personal history – accidents, abuse etc.
• Include goals to address the individual’s common behaviors and triggers
• Allow for engagement in occupational performance that is purposeful/meaningful to the individual:
  • Setting the dinner table
  • Distributing the mail
  • Watering the plants
  • Completing “honey-do” lists
  • Feeding the birds

Carryover

When developing strategies, ensure they are:
• **Realistic** for implementation
• **Relevant** to the individual patient
• **Relative** to the skills within facility
  – Staff
  – Departments
  – Resources

Care Plans are Living Documents

• Consider any advance care planning in place.
  – Keep up with local laws that may change your approach.

• Ensure your assessment findings and recommendations are incorporated into the Care Plan.

• Ensure Care Plans are updated frequently to include new information/techniques as the patient progresses/regresses.
Self-feeding – Things to Consider

- Patient and family choice – advanced directives
- Environment and sensory issues
- Prior and present personal preferences, beliefs, religious values etc.
- **Visual deficits** and adaptive equipment needs
- Your approach to assisting with self-feeding
- Communication strategies that encourage intake
- Educate caregivers/staff.
  - A nod “yes” to the question “are you finished” may not be a true “yes”.

Grooming, Dressing, Bathing, Toileting & Hygiene

- Experiment with environmental modifications
- Discourage creating “excess disability” or learned helplessness!
- Assistance with task **initiation**, cues to **follow through**, **sequence** and/or **terminate** may be all the help a person requires.
  
  The more you do for me, the more you take from me!

Psychosocial and Leisure

- Explore personal interests of psychosocial, hobbies and leisure
- Utilize tools to identify leisure/hobbies
  - Activity Card Sort (ACS)
- Utilize resources for activities:
  - AOTA, Alzheimer’s Association, The Alzheimer’s Store, and Montessori
- Engage caregivers with implementation
- Collaborate with activities about patient interests
Decreasing Caregiver Burnout

- Educate on **communication techniques** with the individual resident
- Educate on **coping strategies**:
  - Deep breathing, mindfulness, counting to 10, yoga, stretching, taking a walk, having a snack, taking a break (time-out), journaling, getting a massage, listening to music, meditating, etc.
  - Staff and caregivers need breaks.
  - Encourage staff rotation as needed.
  - Encourage self-care!
- Create a multi-sensory room for all to enjoy and provide education. (Snoezelen - https://www.snoezelen.info/)

Common Behaviors

- Aggression
- Fidgeting
- Pacing
- Paranoia
- Reduced PO intake
- Repetition
- Sexually inappropriate behaviors
- Shadowing
- Verbal outbursts
- Wandering

Contributing Factors

- **Cognitive or Communication**
  - Visual field deficits
  - Bold approach by caregiver
  - Interrupted routine
  - Too many choices/commands
  - Lack of cognitive stimulation
- **Time of the day**
  - Morning/mid-day/evening
  - Bedtime or mealtime
  - Sundowning
- **Physiological**
  - Bowel/bladder
  - Fatigue
  - Hunger/thirst
  - Boredom/lack of movement
  - Pain/discomfort
  - Circadian rhythms - sleep
Contributing Factors (Cont.)

- Task at hand
  - Bathing
  - Dressing
  - Grooming
  - Self-feeding
  - Toileting
  - Transfers
  - Walking
  - W/C Mobility

- Environment & sensory system
  - Bright lights
  - Cluttered environment
  - Loud noises
  - Multiple noises at once
  - Physical touch
  - Pungent odors
  - Textures
  - Under-stimulation

Gathering Information/Tracking

In order to identify the possible antecedent/cause of the behavior(s), collaboration with family/caregivers/facility staff is key!

- Interview family/staff/caregivers
- Track behaviors over 24+ hour period
  - Provide a form to gather information
- Formulate and test a hypothesis
- Implement strategies
- Educate staff/family/caregivers
- Frequent revisions may be required!

Decreasing Behaviors

- Use nonverbal communication first
  - Show vs. Tell

- Consider sensory processing changes

- Consider visual field changes
Visual Deficits

The Process

Collaboration Defined

“1. General: Cooperative arrangement in which two or more parties (which may or may not have any previous relationship) work jointly towards a common goal.

2. Knowledge management (KM): Effective method of transferring ‘know how’ among individuals, therefore critical to creating and sustaining a competitive advantage. Collaboration is a key tenet of KM.

3. Negotiations: Conflict resolution strategy that uses both assertiveness and cooperation to seek solutions advantageous to all parties. It succeeds usually where the participants’ goals are compatible, and the interaction among them is important in attaining those goals.”
Collaborative Co-workers
The Inter-disciplinary Team (IDT):
• Administration
• Physicians: medical doctor, psychiatrist
• Psychologists/social workers
• Nurses and NAs
• Dietary
• Activities
• Family, personal caregivers
• Housekeeping
• Therapy staff

Formula for Collaboration

Education – Integration = Conversation

Cooperation + Education + Integration = Collaboration

Collaborate to Impact Change

• Become part of the process.
• Get the facility buy-in.
• Establish rapport with departments heads and staff.
• Ask them about their needs with implementation of RoP.
• Increase your knowledge/skills.
**Collaborate to Impact Change**

- Show them!
  - Decrease behaviors
  - Decrease use of psychotropic meds
  - Decrease staff complaints
  - Increase positive outcomes for patient, family, caregivers, staff

- Reach out to those with whom you already connect.
  - Ask them for their assistance.
- Use a drop box for communication.
  - Develop a user friendly form that can be placed in the drop-box.
- Market an open-door policy in therapy.
  - Provide immediate answers/feedback.
- Host a monthly open house for Q & A and/or referrals.
  - Offer snacks.

**Education: An Opportunity to Impact Change**

- Include caregivers in your evaluation or treatment sessions.
- Provide monthly education talks with various dementia-related topics.
- Provide a workshop concerning techniques to decrease burnout.
- Lead a caregiver support group.
- Lead an exercise group.
- Implement environmental modifications within the facility to assist residents and caregivers.
- Develop an education program to ensure all staff are properly trained
Primary Topics for Education

• The importance of nonverbal communication

• The importance of routines, preferences and purposeful activity

• The importance of “not taking it personally”
  – Changes in mood and increased behaviors are typically not personal, but are reactionary.

Conclusions: Collaboration is key!

• To influence change that will increase quality of life for our residents/patients:
  – Step outside of comfort zones – be a part of the process – speak up!
  – Be a champion for your patients – collaborate to gather information.
  – Develop or sharpen skills.

• To market our skills within the facility:
  – Assist with implementation of the RoP to increase success.
  – Unify staff for common goals/purposes.
  – Collaborate with the OT by providing valuable input.
  – Bridge the gap between patient and facility needs.
  – Educate staff in patient identification for referral to therapy.

Don’t forget the “marshmallow”!

Collaborate to Advocate!

Be a part of the solution and the distinct value of OT will become apparent!
Addendum: Establish Rapport: Things to Keep in Mind

- Acknowledge – do not ignore obvious distress
- Agree - never argue
- Convey respect - consider dignity
- Introduce the task (use visual aids/gestures)
- Invite - never command or force
- Redirect – never reason
- Reassure - never shame or lecture
- Repeat - never say “remember” or “I already told you”
- Speak slowly and avoid too many questions
- Simplify directions (one task and one step at a time)

Addendum: Standardized Tools

- Allen Cognitive Scale
- Disability Assessment in Dementia (DAD)
- EQ – various versions (SD-3L, SD-5LVS) – patient’s quality of life questionnaire
- Mini-Mental State Examination (MMSE)
- Neuropsychiatric Inventory (NPI) Questionnaire
- Montreal Cognitive Assessment (MoCA) Less specific (MCI-Severe)
- St. Louis University Mental Examination (SLUMS) Less specific (MCI-Severe)
- Zarit scale – questionnaire to assess caregiver burden

References


References


Medicare and Medicaid Programs; Reform of Requirements for Long-Term Care Facilities. Final Rule. Federal Register Vol. 81, No. 192 (2016).

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<td><a href="mailto:cwelcome@reliant-rehab.com">cwelcome@reliant-rehab.com</a></td>
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