Best Practices for Optimizing Dementia Care for Care Coordinators

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Objectives

- Understand the value of timely detection
- Employ simple approaches to assessing cognition among older patients and communicating assessment results
- Describe medication and non-medication treatments
- Employ best practices in care coordination for patients with Alzheimer’s disease

Introduction to ACT on Alzheimer’s

Focus on Quality Health Care

ACT Tool Kit

- Evidence- and consensus-based best practice standards for Alzheimer’s care
- Tools and resources for:
  – Primary care providers
  – Care coordinators
  – Community agencies
  – Patients and care partners

www.ACTonALZ.org

www.actonalz.org/provider-practice-tools
FAQ

What is the difference between dementia and Alzheimer’s disease?

Dementia and Alzheimer’s

Dementia Diagnoses

- Alzheimer’s disease: 60-80%
  - Includes mixed AD + VD
- Lewy Body Dementia: 10-25%
  - Parkinson spectrum
- Vascular Dementia: 6-10%
  - Stroke related
- Frontotemporal Dementia: 2-5%
  - Personality or language disturbance

Disease Education: What is AD?

What is Alzheimer’s disease?

Stages of Alzheimer’s Disease

- Mild Cognitive Impairment (MCI)
- Alzheimer’s Disease Early Stage (2-6 years in duration)
- Alzheimer’s Disease Mild Stage (2-10 years in duration)
- Alzheimer’s Disease Moderate Stage (3-12 years in duration)
- Alzheimer’s Disease Late Stage (1-12 years in duration)

http://youtu.be/ECbjK4Ra-Ys
Alzheimer’s Disease: Challenges and Opportunities

Alzheimer’s: A Public Health Crisis

- Scope of the problem
  - 5.4M Americans with AD in 2016
  - Growing epidemic expected to impact 13.8M Americans by 2050 and consume $1.1 trillion in healthcare spending
  - Almost 2/3 are women (longer life expectancy)

- Some populations at higher risk
  - Older African Americans (2x as whites)
  - Older Hispanics (1.5x as whites)

Base Rates

- 1 in 9 people 65+ (11%)
- 1 in 3 people 85+ (32%)

Ages of People with Alzheimer’s Disease in the United States

Patients with Dementia

- A population with complex care needs
  - 2.5 chronic conditions (average)
  - 5+ medications (average)
  - 3 times more likely to be hospitalized
  - Indisputable correlation between chronic conditions and costs

- Many admissions from preventable conditions, with higher per person costs

Challenges & Opportunities

- AD under-recognized by providers
  - Fewer than 50% of patients receive formal diagnosis
    - Millions unaware they have dementia
  - Diagnosis often delayed on average by 6+ years after symptom onset
  - Significant impairment in function by time it is recognized
    - Poor timing: diagnosis frequently at time of crises, hospitalization, failure to thrive, urgent need for institutionalization

Identifying Cognitive Impairment
Practice Tips

- Often signs and symptoms are not recognized until they are quite pronounced
  - Attribution error: “What do you expect? She is 80 years old.”
  - Red Flag: Subjective impressions FAIL to detect dementia in early stages

Practice Tips

- Intact older adult should be able to:
  - Describe at least 2 current events in adequate detail (who, what, when, why, how)
  - Describe events of national significance
    - 9/11, New Orleans disaster, etc.
  - Name or describe the current President and an immediate predecessor
  - Describe their own recent medical history and report the conditions for which they take medication

Identifying Cognitive Impairment

Workflow: The Big Picture

1. Administer cognitive assessment tool
2. Discuss results with client/patient
3. Recommend next steps, follow-up
4. Consider providing written documentation to:
   - Client/patient and family
   - Physician/medical provider

Cognitive Impairment ID

Administration Best Practices

- Try not to:
  - Use the words “test” or “memory”
    - Instead: “We’re going to do something next that requires some concentration”
  - Allow patient to give up prematurely or skip questions
  - Deviate from standardized instructions
  - Offer multiple choice answers
  - Be soft on scoring
    - Score ranges already padded for normal errors
    - Deduct points where necessary – be strict
**Cognitive Assessment Tools**

- Wide range of options
  - Mini-Cog™ (MC)
  - Mini-Mental State Exam (MMSE)
  - St. Louis University Mental Status Exam (SLUMS)
  - Montreal Cognitive Assessment (MoCA)
  - Rowland Universal Dementia Assessment (RUDAS)

- All but MMSE free, in public domain, and online [www.actonalz.org/screening-diverse-populations](http://www.actonalz.org/screening-diverse-populations)

**Mini-Cog™**

**Contents**

- Verbal Recall (3 points)
- Clock Draw (2 points)

**Advantages**

- Quick (2-3 min)
- Easy
- High yield (executive fx, memory, visuospatial)

**Mini-Cog**

**Pass**

- ≥ 4

**Fail**

- 3 or less

**Mini-Cog Research**

- Performance unaffected by education or language
  - Borson Int J Geriatr Psychiatry 2006

- Sensitivity and specificity similar to MMSE (76% vs. 79%; 89% vs. 88%)
  - Borson JAGS 2003

- Does not disrupt workflow & increases rate of diagnosis in primary care
  - Borson JGIM 2007

- Failure associated with inability to fill pillbox
  - Anderson et al Am Soc Consult Pharmacists 2008

**Mini-Cog Improves Physician Recognition**

Cognitive Impairment Predicts Readmissions

Mini-Cog Performance Novel Marker of Post Discharge Risk Among Patients Hospitalized for Heart Failure (Patel, 2015; Cleveland Clinic)

- **Method:** 720 patients screened with MiniCog during hospitalization for HF
- **Results:** 23% failed screen (M age 78, 49% men)
  - MiniCog best predictor of readmission over 6 mos.
  - Among 55 variables
    - Stronger than length of stay, cause of HF, and even comorbidity status
    - Readmission rate 2 times higher among screen fails
    - Fails discharged to facility (vs. home) had lower readmission rates within first 30 days

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1. **Case Study: Colleen**
   - 66 y/o presents to primary care with memory complaints
   - Daughter c/o short-term memory is poor
   - Began 1-2 years ago, getting worse
   - Hx Low blood sugar, history of heart attack, repeat hospitalizations for atrial flutter
   - Frequent medication changes, managing independently
   - Patient is a retired accountant for family business
   - Lives with husband who is still running the family business
   - Referred to Care Coordination

2. **Mini-Cog: Colleen**
   - Colleen’s Clock
   - Colleen’s Score
   - Mini-Cog Exercise
     - Form groups of 2
     - Review Mini-Cog Form
     - Administer Mini-Cog to each other
     - Score sample clocks
Montreal Cognitive Assessment (MoCA)
- Sensitivity: 90% for MCI, 100% for dementia
- Specificity: 87%

St. Louis University Mental Status (SLUMS)
- Sensitivity: 92% for MCI, 100% for dementia
- Specificity: 81%

Mini-Mental Status Exam (MMSE)
- Sensitivity: 18% for MCI, 78% for dementia
- Specificity: 100%
**Family Questionnaire**

**Family Questionnaire**

**Communicating Results of Cognitive Assessment to Patients and Healthcare Providers**

**Client Reactions**
- You should plan for a wide range of client reactions to assessment results
- Responses may range from acceptance to rejection
  - Some already worried about their memory and are interested in getting answers
  - Others may be surprised by results, but willing to follow-up
  - Some may not be aware of problem (forgetting they are forgetful) or ready to accept the information

**Sample Script: The Purpose**
- Regardless of a passing or failing score, explain the patient’s test result by first reminding them of the assessment purpose:
  - “The purpose of this task was to check on the health of the brain and determine if there is any need for further evaluation of your thinking or memory.”

**Sample Script: Passing Score**
- “You obtained a normal score on this measure, which is good news. No additional action is needed.”
- “However, if you have concerns about your thinking or memory or thinking, talk to [contact] your doctor.”
Sample Script: Failing Score

• In clinic (Nurse>Allied health professional):
  – “Your doctor will review the results with you today during your visit.”

• Additional option
  – Explain assessment results just as you would any other medical test.
  – For example, when lab results do not come out as we expect, we typically do a follow-up evaluation or order specific tests to help us understand what may be going on from a medical perspective.

Sample Script: Failing Score

• Outside clinic
  – “Your score on the measure was a little bit low today. This means it would be good to contact your doctor so that he/she can be proactive and take a closer look at how you are doing.”
  – “There are many reasons why someone might receive a low score. A person might be tired, have a lot on their mind, feel stressed or be distracted. In other cases, they might be taking medications, have a shortage of certain vitamins or nutrients, or have a medical condition that is causing problems with thinking or memory.”
  – “Contacting your doctor is important so potential problems can be identified as early as possible. This is a vital part of staying healthy.”

Opening Up Conversation

• Use the assessment process as a opportunity to discuss memory issues openly and to work from the perspective of your patient/client:
  – “Are you having any trouble with your memory or thinking?”
  – If yes, “What do you think might be causing this?”
  – “Have you talked with anyone about it?”
  – “Have you talked with your doctor about this?” If so, “What happened?”

Care Coordination

• Help facilitate an appointment with the doctor as much as the client/family will allow and/or as much as you are able to within your role.
  – The more you can do, the more likely follow-up will occur
    • Sit with family while a call is made to set up doctor appointment and/or
    • Call client/family in 1 week to check on progress
    • Accompany client to the doctor

• Promote positive, health-focused messages
• Encourage involvement of family members
  – Family member(s) should accompany patient/client and participate in doctor visit
  – Write down their observations re: cognitive, behavioral, and functional changes in bullet point style and give to doctor during appointment
• Close the loop
  – “I would like to see/talk with you again after you follow-up with your doctor about this. Does that sound reasonable to you?”
Care Coordination

- Consider providing written documentation to the client/family and/or their doctor, if appropriate
  - Sample letters are available for download at www.actonalz.org/video-tutorials next to the thumbnail for this webinar
  - Follow your organization’s existing HIPAA guidelines

Q & A

- What will the doctor do when I see him/her?
  - He/she will work with you to decide what additional tests or follow-up care is needed to address this issue and keep you well. Sometimes a work-up involves:
    - Answering questions about your health history, including any observations you might have about your memory or thinking
    - Medication review
    - Performing blood tests to see if you have a shortage of certain vitamins or nutrients in your body that could be causing changes in your memory or thinking
    - Completing an x-ray of your head so the doctor can take a closer look at how your brain is doing

Q & A

- Do you think I have dementia/Alzheimer’s disease?
  - The tool we used today does not tell us what is causing a person’s memory difficulties and cannot be used to diagnose dementia/Alzheimer’s disease.
  - There are many reasons why someone might be experiencing trouble with their memory or thinking. He/she may not be getting adequate sleep at night or might be under a lot of stress or be depressed. Other causes include medication side effects, medical problems like an infection in the body, and vitamin deficiencies.
  - Not all memory/thinking problems are caused by dementia/Alzheimer’s disease. But, it is important to see a doctor so we can identify the cause and find out what, if any, treatment might be needed.
Q & A

• My family complains about my memory but I do not have a problem. Everyone my age is a little forgetful.
  – You are right that a lot of people experience memory changes as they get older. How much varies from person to person. We all want to stay as healthy as possible and maintain our independence as long as possible. Having a brain check-up is a part of staying healthy (and might be a good way to show your family there is nothing wrong with you - to put this issue to rest once and for all).

• I think I am doing fine. Why should I see a doctor?
  – It is important to check the health of the brain as we get older, just like we routinely check on the health of other organs, such as the heart. Sometimes, memory difficulties can be reversed with treatment. In other cases, early diagnosis of a problem offers the best chance to treat symptoms and stay well.

Dementia Work-up

• H&P
• Objective cognitive measurement
• Diagnostics
  – Labs
  – Imaging?
  – More specific testing (e.g., neuropsychometric)?
• Diagnosis
• ‘Family’ meeting

Treatment: Medications

• Cholinesterase Inhibitors
  – Donepezil, Rivastigmine, Galantamine, Cognex
  – Possible side effects: nausea, vomiting, syncope, dizziness, anorexia
• NMDA receptor antagonist
  – Memantine
  – Possible side effects: tiredness, body aches, dizziness, constipation, headache

• Antipsychotics
• Antidepressants
• Mood stabilizers

Managing Behaviors Flow Chart: actonalz.org/pdf/Figure1.pdf
Care and Treatment

- The care for patients with Alzheimer’s has very little to do with pharmacology and much to do with psychosocial interventions
- Care Coordination

Dementia Care Coordination

Care Coordination

What are some of the challenges you face when working with people with dementia and their families?

ACT Practice Tool

Dementia Care Plan Checklist

Identify Care Partner(s)

- Educate the patient: Dementia dx. require a team approach
- Ask the patient to identify a support system
  - Think outside the box:
    - Family, friends, neighbors, religious congregation members, colleagues, community organization volunteers or workers
  - Task specific (e.g., doctor visits, managing meds.)
Comprehensive Assessment

- Patient & Primary Care Partner / Caregiver
  - Identify language, cultural, health equity barriers
  - Identify physician(s)
  - Assess substance use / misuse
  - Behavioral health, depression
    - PHQ9, CES-D, GDS

- Primary Care Partner / Caregiver
  - Consider assessing cognition (if over 65 or signs / symptoms present)
  - Caregiver burden (Zarit Burden Interview Short)

Dementia Care Planning

- Build a care team (patient & care partners)
- Avoid unnecessary hospitalization
- Educate, support & connect to resources
- Maximize abilities
- Promote health, wellness & social engagement
- Encourage planning, preparedness
- Ensure safety
- Reduce excess disability
Disease Education

• **ASK the patient / care partner:**
  - What the doctor told them about their memory loss / diagnosis
  - What they know about the disease / questions about the diagnosis / disease
  - Biggest concerns; barriers to care / health

Dementia & Hospitalization

• More preventable hospitalizations
• Higher rates of:
  - Delirium, falls, new incontinence, indwelling urinary catheters, pressure ulcers, functional decline & new feeding tubes
• Significantly less likely to regain preadmission functional abilities at 1, 3, or 12 months after discharge
• 3-7 times more likely to be living in a nursing home 3 months after discharge

Dementia & Hospitalization

• **Reduce Unnecessary Hospitalization**
  - Falls
  - UTI / other medical conditions
  - Medications / medication mismanagement
  - Dementia-related behavior
  - Hospitalization alternatives

• **Hospitalization – Pre-Planning**

Home & Personal Safety

• **Develop a plan for the 6 F’S:**
  - Falls
  - Fire
  - Finances
  - Firearms
  - Freedom
  - Freeways

Home & Personal Safety

• **Refer to OT or PT**
  - Fall risk assessment
  - Sensory / mobility aids
  - Home safety inspection / modifications
  - Driving evaluation

• **Encourage Medic Alert® Safe Return®**
  - 6 out of 10 people with dementia will wander at some point during the disease

Home & Personal Safety

• **Encourage emergency plans**
  - Key phone numbers labeled / programmed
  - Fire plan
    - Ask: *What would you do if there was a fire at your house?*
  - ER / Hospital Medical Emergency Kit - @ bedside
    - POLST, POA, Health Care POA, Living Will
    - Updated Medication List + allergy list
    - Slippers / Clothes (including adult diapers, if worn)
    - List of important contact numbers (doctors, family, minister, helpful friends)
    - Comfort objects (music, photos, blanket, etc.)
Medication Therapy & Management

• Discuss prescribed and OTC medications
  ✓ simplify medication regimen
  ✓ reduce / eliminate anticholinergics, benzodiazepines, hypnotics, narcotics

• Create plan with care team
  ✓ Family plan for managing meds
  ✓ Med management aids (pill boxes, alarms)
  ✓ Create & review medication log

Case Example: Medications

https://youtu.be/3lp0n9DOEWQ

Care Coordination: Colleen

• Discussion
  – Observations? What did you notice?
  – What was done well?
  – What could have been done differently, better?
  – What recommendations / referrals would you make to Colleen?

Maximize Abilities

• ID/treat conditions that may worsen symptoms or lead to poor outcomes
  ✓ Diabetes, HTN, sleep dysregulation

• Refer to OT to maximize independence
  ✓ simplify environment, maximize independence & self-care abilities

• Offer strategies to reduce behavioral symptoms
  ✓ Communication strategies, wellness & social engagement, routine

Dementia-Related Behavior

• Studies identify that 50%-90% of persons with dementia will develop “challenging behaviors”
• Anxiety is the most prominent in the earlier stages of dementia
• 42% become physically aggressive
• 50% have depressive symptoms
• Prevalence of behavior is directly associated with the approach used by the care partner
**Common Dementia-Related Behaviors**

- Repeating
- Anger, Anxiety, Agitation
- Daytime sleeping / night-time wakefulness
- Wandering, Pacing, Shadowing
- Apathy
- Resisting Care
- Aggression (yelling, hitting, biting)
- Socially inappropriate behaviors (e.g., things that may be ok in private, but not in public – like disrobing)

**Causes of Challenging Behaviors**

- Physical Health (Medical)
  - Pain
  - Urinary Tract Infection
  - Illness
- Environment
  - Unfamiliar surroundings/environment
  - Over/under stimulation
- Other
  - Communication
  - Unmet needs/boredom
  - Task-related
  - Emotional health

**Reduce Behavioral Symptoms**

**REMEMBER:**
- behavior is communication
- communication impacts behavior

- Think like a behavioral analyst
  - Detective work, ask:
    - Who (is involved/present)
    - What (exact description, be specific)
    - When (time dependent? only in morning? triggers?)
    - Where (location specific?)
    - Why (what happens right before, right afterwards? what do family think is cause? Has anything changed recently?)

**Considerations**

- Ask: Is this behavior really a problem?
  - Is it hurting anyone?
- Help care partners know what to expect and normalize these reactions.
  - Avoid: unrealistic, non-dementia expectations, arguing, correcting, rushing
  - Advise: Take a deep breath, slow down, step back, simplify, smile, redirect, reassure, try again later

**Maximize Abilities: Routine**

**Health, Wellness & Engagement**

Encourage lifestyle changes that may reduce disease symptoms or slow progression

- Exercise
- Nutrition
- Stress reduction
- Meaning & purpose
- Relationships
- Health management
- Routine

Health, Wellness & Engagement

- Understanding the disease
- Partnering with doctors
- Telling others about the diagnosis
- Strategies for managing symptoms & coping
- Safety
- Legal / financial issues


Patient Engagement: Research Participation

- Alzheimer’s Association Trial Match
  - Free, easy-to-use clinical studies matching service that connects individuals with Alzheimer’s, caregivers, healthy volunteers and physicians with current studies.
  - http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp
- National Institute of Health (NIH)
  - http://clinicaltrials.gov

Legal & Financial Planning

- Encourage patient / care partner to assign durable POA
  - Refer to Elder law attorney
- Encourage patient / care partners to talk about long-term care and when they would access support

Case Example: Legal Planning

https://youtu.be/a-gojhzGOY

Care Coordination: Colleen

- Discussion
  - Observations? What did you notice?
  - What was done well?
  - What could have been done differently, better?
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Advance Care Planning

- Encourage patient to discuss / document preferences for care in a health care directives
  - Connect patient with advance care planning facilitator
  - Document choices (Honoring Choices, MN Healthcare Directive)
- Discuss palliative and hospice options
  - Palliative Care Consultation Program
  - When is the right time?

http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp
Care Coordinator: Visit Frequency & Communication

- Schedule regular check-ins
- Educate patient / care partner WHEN to contact you
  - Change in condition
  - Assistance with med management
  - Before / after hospitalization
  - Change in living environment
  - New needs

Care Coordinator: Visit Frequency & Communication

- Facilitate physician appointments
  - Reminders, transportation
- Educate on physician engagement strategies
  - Encourage care partner(s) to attend medical appointments
  - Educate about HIPAA, as needed
  - Educate on use of appointment log, medication log

Appointment Log

Top 5 Resources for Patients and Families

#1 Promote Wellness & Function

- #2 Manage Behavioral Challenges

  - Coping with Behavior Change in Dementia
  - Coach Broyle’s Playbook for Alzheimer’s Caregivers
  - The Alzheimer’s Action Plan

  - ACT on Alzheimer’s resources, “Mid-Late Stage Practice Tool”
    - [Link](http://www.alz.org/pdf/Table1.pdf)
    - [Link](http://www.alz.org/pdf/Table2.pdf)
    - [Link](http://www.alz.org/pdf/Figure1.pdf)
#3: Address the 6 F’s

Falls, Finances, Fire, Firearms, Freedom, Freeways

Alzheimer’s Association Driving Center
www.alz.org/alzheimer-s-dementia-and-driving.asp

#4 Assist with Planning

#5 Connect to Resources

Alzheimer’s Association
24/7 Helpline | 800.272.3900
www.alz.org/mnnd

Senior LinkAge Line
800-333-2433
www.minnesotahelp.info

Case Study: Colleen

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- Referred to Care Coordination

Case Study

Care Plan Exercise

In small groups, develop a 3-5 step care plan for Colleen and her family.

Consider:
- Which areas of the care plan tool should be incorporated in Colleen’s plan?
- What educational materials would you give?
- What referrals would you make?
- When would you like to see Colleen again?
- How would you communicate Colleen’s plan to the care team (physicians, family, patient, etc.)
Watch the Complete Session:

https://youtu.be/5Kxj-5Ezhw?list=PLGu3PyEtbnKWTqW8rR5SfCeOtDg9T

References & Resources


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