Best Practices for Optimizing Dementia Care
for Care Coordinators

Objectives

- Understand the rationale for using cognitive assessment instruments with older clients
- Learn how to administer, score, and interpret the Mini-Cog
- Learn how to communicate assessment results to clients and prepare them for a doctor’s visit and memory work-up
- Employ best practices in care planning and care coordination for patients with dementia and their care partners

Introduction to ACT on Alzheimer’s
What is ACT on Alzheimer’s?

60+ organizations, collaboratively driven

500+ individuals, volunteer driven

IMPACTS OF ALZHEIMER’S

BUDGETARY  SOCIAL  PERSONAL

$  $  $

Focus on Quality Health Care

Quality Dementia Care for All

Dementia-competent health care systems promote timely diagnosis and options for care and support.

www.ACTonALZ.org

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/provider-practice-tools
Health Care Settings: Care Coordination

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?

http://youtu.be/ECbjK4Ra-Ys

Stages of Alzheimer’s Disease

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)
  – If disease could be detected earlier incidence would be much higher
    • Pre-clinical stage 1-2 decades

• 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
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 2-5 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

Source: Boise et al., 2004; Boustani et al., 2003; Boustani et al., 2005; Silverstein & Maslow, 2006

Rationale for Timely Detection

1. Improved management of co-morbid conditions
2. Reduce ineffective, expensive, crisis-driven use of healthcare resource
3. Improve quality of life
   - Patients can participate in decisions
   - Decrease burden on family and caregivers
4. Intervene to promote a safe and happy environment that supports independence

Identifying Cognitive Impairment
How You Can Help

- First steps are **awareness** and recognition
  - Be aware of the prevalence of dementia & importance of getting a diagnosis
  - Facilitate medical work-up
- Assess cognition
- Provide **resources** and information to patients and family members

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
  - Use of an objective tool to evaluate cognition is far superior to personal opinion

Mini-Cog Improves Physician Recognition

![Bar chart showing Mini-Cog score improvement](chart.png)


** p < .001
Identifying Cognitive Impairment

Cognitive Impairment ID

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

Borson et al., 2000; Podell et al., 1970; Nasreddine 2005; Tariq et al., 2006
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

Mini-Cog™

Contents
• Verbal Recall (3 points)
• Clock Draw (2 points)

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

Subject asked to recall 3 words
Leader, Season, Table

Subject asked to draw clock, set hands to 10 past 11

Borson et al., 2000

www.actonalz.org/sites/default/files/documents/Mini-Cog_.pdf
Mini-Cog

Pass
• ≥ 4

Fail
• 3 or less

NOTE: A cut point of ≥ 4 on the Mini-Cog has been validated for dementia screening, but many individuals with clinically meaningful cognitive impairment will score higher. When greater sensitivity is desired, a cut point of 0 is recommended as it may indicate a need for further evaluation of cognitive status.

Mini-Cog Research

• Performance unaffected by education or language
  • Borson Int J Geriatr Psychiatry 2000
• Sensitivity and specificity similar to MMSE (76% vs. 79%; 89% vs. 88%)
  • Borson JAGS 2003
• Failure associated with inability to fill pillbox
  • Anderson et al Am Soc Consult Pharmacists 2008

Mini-Cog: Colleen

http://youtu.be/DwCFtuD41eY
Colleen’s Clock

Colleen’s Score

Communicating Results of Cognitive Assessment to Patients and Healthcare Providers
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

Preparation

- Before using an assessment tool:
  – Make sure you practice and are comfortable with all administration and scoring guidelines of the tool(s)
  – Use parts or all of the scripts provided in this webinar as a basis for providing feedback to clients/patients and other healthcare providers regarding assessment results
    - Your script may vary, in part, on your unique professional role and whether you are working inside a medical clinic or in a community healthcare agency/setting

- Write down your scripts and practice delivering them until you can:
  – Provide the information clearly and succinctly
  – Offer feedback calmly, in a matter-of-fact tone, without anxiety
    - Any tension/anxiety you have will be projected onto clients/patients
  – Keep your scripts on hand at all times (with your screening tools) so you always have them for reference, when needed
**Preparation**

- Never use the words “dementia” or “Alzheimer’s disease”
  - Screening tools are not diagnostic
  - Using these terms is premature at this stage and can contribute to anxiety/fear
- Avoid
  - Being unnecessarily wordy
  - Over-explaining or rationalizing the process

**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

**Client Reactions**

- Lack of acceptance can be an effective mechanism to:
  - Preserve sense of self (idea of cognitive impairment may pose threat to identity, self-worth)
  - Manage fear and anxiety about the future
- Readiness to act
  - May be a gradual process requiring multiple interactions with the client/patient
- Positive outcomes are possible in a context in which some negative reactions/feelings occur
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 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, talk to [contact] your doctor.”

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 memory loss.”
  - “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 an 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

Care Coordination

- 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](http://www.actonalz.org/video-tutorials)
  - Follow your organization’s existing HIPAA guidelines

### Care Coordination

- Clinics have to cope with a lot of paperwork and sometimes letters get lost
  - Encourage patient/family to bring a copy of the letter to their doctor appointment
  - You may find that, in some circumstances, you have to fax or mail the provider letter to the clinic more than once

### 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. They 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 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).

Q & A

• 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 Care Coordination

ACT Practice Tool

Dementia Care Plan Checklist
Dementia Care Planning

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

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.)

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
- Refer to community agency
  - Example: Alzheimer’s Association
- Offer an educational resource
  - Example: Taking Action workbook
Taking Action Workbook

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


Medication Therapy & Management

- Discuss prescribed and OTC medications
  - Create & review medication log
  - PharmD consult: simplify medication regimen

- Create plan with care team
  - Family plan for managing meds
  - Med management aids (pill boxes, alarms)

Maximize Abilities

- ID conditions that may worsen symptoms or lead to poor outcomes
  - Diabetes, HTN, sleep dysregulation

- Recommend OT to maximize independence
  - Simplify environment, maximize independence & self-care abilities

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

Caregiver Support

• There is a strong correlation between the health and well-being of a care partner and the quality of care that he/she can provide.

• Recommend:
  – Support groups
  – Self care, respite
  – Regular doctor appointments

Health, Wellness & Engagement

Encourage lifestyle changes that may reduce disease symptoms or slow progression

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

• Develop a plan for the 6 F’s:
  ✓ Falls
  ✓ Fire
  ✓ Finances
  ✓ Firearms
  ✓ Freedom
  ✓ Freeways

• Recommend 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

• Dementia & Hospitalization
  • Reduce Unnecessary Hospitalization
    – Falls
    – UTI / other medical conditions
    – Medications / medication mismanagement
    – Dementia-related behavior
    – Hospitalization alternatives
  • Hospitalization – Pre-Planning
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

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?

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
Top 5 Resources for Patients and Families

#1 Promoting Wellness & Function

#2 Addressing Behavioral Challenges
#3: Addressing Driving

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


#4 Planning for the Future

#5 Connection to Resources

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

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

- Download ACT on Alzheimer’s practice tools at: [www.ACTonALZ.org/provider-practice-tools](http://www.ACTonALZ.org/provider-practice-tools)
- For more information
  - email: [info@ACTonALZ.org](mailto:info@ACTonALZ.org)
  - Web: [www.ACTonALZ.org](http://www.ACTonALZ.org)

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ACT on Alzheimer’s is an award-winning, nationally recognized, volunteer-driven collaborative seeking to create supportive environments for everyone touched by Alzheimer’s disease and to prepare Minnesota for its impacts.

Visit [www.ACTonALZ.org/provider-practice-tools](http://www.ACTonALZ.org/provider-practice-tools) for more information and to access supportive tools and resources.
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