

“NON-MEDICAL” PLANNING IN COGNITIVE IMPAIRMENT

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DISCLOSURES

- No financial disclosure or industry relationships to report
- Cases are real, names have been changed

LEARNING OBJECTIVES:

- Identify resources and strategies for integrating advance care planning into clinical practice
- Identify areas for anticipatory guidance for older adults with cognitive impairment
- Describe and practice discussing non-medical guidance with patients and caregivers

- Mr. K is a 78 yo gentleman with known mild cognitive impairment, diagnosed about 6 months ago after concerns from wife. He has been independent in all ADLs, needed help with finances, but otherwise functioning well (despite a MOCA of 17/30). He lives with his wife alone in a single family home.
- He is still driving, as wife does not have her license, but does not drive alone. He continues to manage his own medication and helps with household chores.

- What should we be talking to Mrs. and Mr. K about right now?
- Do you have any concerns about his current place of living or activities?

MR. K CONTINUED...

- Hospital admission: Delirium—late at night attempted to pack toiletries and get in the car to drive to Alabama. Wife unable to redirect him, had to call 911
- Since hospitalization (2 days post discharge): told could not assign an MDPOA, needs a guardian, difficulty with dressing himself; told not to drive; home health initiated
 - Are all of these statements true? Are these actions necessary? How would you advise?

DRIVING:

- Level of cognitive impairment very important for safety
- Biggest issues: executive function (planning, problem solving), speed of information processing, navigation/directionality
- Driving evaluations: NOT for cognitive impairment, for vision, reaction time, processing, etc.
- Research and provide alternative transportation methods while discussing limiting driving

MEDICATION MANAGEMENT

- Caregivers may perceive this as a “simple” task to be preserved for patient dignity and autonomy
- Medication errors may cause serious side effects and/or worsen cognition
- Pill boxes with supervised self administration are likely best choice
- Pill reminders, electronic boxes, are not the answer

ANTICIPATORY GUIDANCE

- Use clear and concrete words: progressive, chronic, degenerative, etc
- Discuss previous personal experiences with dementia or other cognitive decline
- Discuss need for support, caregiver wellness and increased in home services as an absolute, not possibility
- Encourage social, mental and physical activities and engagement—not pills, special diets or repetitive imaging/testing

MAIN TAKEAWAYS:

- Even in early cognitive impairment clinical a patient can have rapid changes in functional levels so early planning is imperative
- Delirium may accelerate cognitive decline, but takes days/weeks to clear and may not be the new baseline (i.e do not take away full capacity or given new diagnosis)
- Driving needs to be discussed early and often. Cognitive impairment presents a very different set of challenges than visual or physical impairments

- Mr. F is an 79 year old gentleman diagnosed with mild cognitive impairment after family out of state noted changes in memory loss and organizational skills. He lives independently with his wife and commute between two retirement communities in Arizona seasonally. He is independent in ADL/IADLs, does all the financing, but has cut down on driving significantly. His wife is 10 years younger, and has minimal health conditions of her own. All of their children live at least a 12 hour drive away.

- Although he is functional, what type of financial considerations should Mr. and Mrs. F consider now?
- How would you counsel the caregiver specifically?
- How do most people plan on paying for long term care or support services?

FINANCIAL CONSIDERATIONS IN EARLY DEMENTIA

- Cost of care at home, eligibility, and limitations:
 - Medicare pays for very little!
 - Home care limited to acute needs in most cases and “graduate” from services
 - 24/7 care is always private pay
- Long term care:
 - Medicaid or self-pay. National average for monthly cost: \$\$ 90+K/year
 - Spouse may keep house, car, some liquid assets when other is applying for Medicaid
- Management and Exploitation:
 - Financial POA vs. conservatorship, vs fiduciary
 - High risk of exploitation, theft, etc → <https://www.consumerfinance.gov>

MR. F CONTINUED...

- 6 years later is in moderate to late stage disease with frequent falls and agitation/anxiety. He is already on anti-psychotics to control “behaviors”.
- Wife has spent most of savings and taken on debt to modify their modular home; he has also incorrectly paid taxes for 3 years resulting in 5K owed
- She assumed Medicare would pay for services
- Cannot identify any circumstance that would require her to place him in a memory care environment

DISCUSSING SAFETY AND MEMORY CARE OPTIONS

- What is the worst case scenario to anticipate?
- What are the emotional factors that drive a caregiver's decision to transition a person to long term care?
- How do you begin the conversation early?

DISCUSSING SAFETY AND MEMORY CARE OPTIONS

- What is the worst case scenario to anticipate?
 - Wandering, aggression, recurrent falls/injury, caregiver health status changes
- What are the emotional factors that drive a caregiver's decision to transition a person to long term care?
 - Grief, fear/anxiety, financial concerns, dedication/love
- How do you begin the conversation early?
 - Exploring current support systems, dispelling myths (Medicare) or unrealistic expectations early, screening continuously for "worst case scenarios"

MAIN TAKEAWAYS:

- Dementia and other progressive illness in late life are EXPENSIVE
- Medicare does not pay for long term services (#1 misunderstanding in this population)
- Although there are ways to protect assets and spouses, without proper planning care needs could devastate a family

Thank you for your time and attention!

Questions????

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Caregiver Outreach and Community Resources

Kirbie Hartley, LCSW

Learning Objectives

- Identify commonly used screening tools to assess for caregiver stress and burnout
- Discuss workflow for caregiver outreach and reassessment
- Discuss commonly referred to community resources in both rural and urban communities
- Identify safety and living considerations when discussing caregiver support and outreach

Dementia Facts & Figures

- 1 in 3 older adults will pass away with a diagnosis of dementia
- Approximately 46 million individuals globally are diagnosed with a dementia
- Expected to be 131.5 million by 2050
- Factors affected by dementia include lower quality of life, financial strain, and social isolation
- At a greater vulnerability for abuse/neglect
- In 2015 – cost of care for individuals with a functional was approximately \$23,497/individual and \$7,223/individual without functional impairment

In Colorado

| Year | 65-74 | 75-84 | 85 and Older | TOTAL |
|------|--------|--------|--------------|--------|
| 2016 | 10,000 | 28,000 | 28,000 | 67,000 |
| 2020 | 13,000 | 32,000 | 31,000 | 76,000 |
| 2025 | 14,000 | 43,000 | 35,000 | 92,000 |

- 6th leading cause of death in Colorado
- 85% increase in Alzheimer’s deaths since 2000

Caregivers Facts & Figures

- Much of the responsibility falls on unpaid caregivers
- Alzheimer's Association estimates there are more than 15 million individuals providing care for persons with dementia
- Estimate the value of this care totals over 236 billion dollars in 2016
- Unpaid caregivers are at risk for higher rates of depression, isolation and physical health concerns.
- Caregivers are often spouses, adult children and in-laws
- Two-thirds are women

Defining “Caregiver Burden”

- Burden is defined as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning”
- 35 percent of caregivers report their health has declined as a result of their caregiving responsibilities
- Most caregivers do not receive any formal training for individuals with dementia
- As individuals with dementia decline, so too does the caregiver burden and there is a correlation with decline in patient quality of life
- This increases risk of unnecessary hospitalizations and placement in higher levels of care
- In the primary care setting fewer than half of the caregivers receive any counseling or support regarding dementia

Outline for Assessment of Caregiver Stress in the Primary Care Setting

- Patients in clinic are 75 and older
- Receive direct referral from primary care provider
- Meet with caregiver face-to-face through warm handoff in clinic after provider identifies caregiver stress
- Initial meeting – discussion of social work role in the clinic and role of social work as part of the care team
- Follow-up conversations – at least monthly with availability as needed

Goals for Caregiver Outreach and Support

- 1) Assess the health, as it relates to dementia, of the patient
- 2) Provide support and psychoeducation to caregivers (either in person or by phone)
- 3) Assess caregiver burden using the Zarit Burden Interview
- 4) Assess patient's Dementia related behaviors using the Cohen-Mansfield Agitation Inventory

Follow-up Conversations in Caregiver Outreach Program

- Caregiver outreach at least monthly
- Always have direct contact intermittently for caregiver support
- Focus on primary concern or behavior
- Utilization of assessment tools monthly or as indicated

Overall wellbeing: how is the patient doing per the caregiver’s report?

| | | | | |
|----------------|--------|-------|------|-----|
| Sleep: | Better | Worse | Same | New |
| Meds Activity: | Better | Worse | Same | New |
| Co-Morbid: | Better | Worse | Same | New |
| Activity: | Better | Worse | Same | New |
| Mood: | Better | Worse | Same | New |
| Behaviors: | Better | Worse | Same | New |
| Appetite: | Better | Worse | Same | New |

Zarit Burden

- The purpose of the ZBI is to capture how caregiver stress may be impacting the patient and to support the caregiver so that they can better provide for the patient.
- Re-assess monthly

1. Do you feel that because of your relative that you don't have enough time for yourself?

| | | | | |
|-------|--------|-----------|------------------|---------------|
| Never | Rarely | Sometimes | Quite Frequently | Nearly Always |
|-------|--------|-----------|------------------|---------------|

2. Do you feel stressed between caring for your relative and trying to meet other responsibilities (work, home)?

| | | | | |
|-------|--------|-----------|------------------|---------------|
| Never | Rarely | Sometimes | Quite Frequently | Nearly Always |
|-------|--------|-----------|------------------|---------------|

3. Do you feel strained when you are around your relative?

| | | | | |
|-------|--------|-----------|------------------|---------------|
| Never | Rarely | Sometimes | Quite Frequently | Nearly Always |
|-------|--------|-----------|------------------|---------------|

4. Do you feel uncertain about what to do about your relative?

| | | | | |
|-------|--------|-----------|------------------|---------------|
| Never | Rarely | Sometimes | Quite Frequently | Nearly Always |
|-------|--------|-----------|------------------|---------------|

Cohen Mansfield

- Purpose – Assess frequency and type of behaviors
 - Aggressive, Physically nonaggressive, and verbally agitated
- Allow focus on “most concerning” behavior currently
- Assess for severity of disruptiveness
- Use assessment on as needed basis or approximately every 3 months
- Narrow down to focused, most concerning
 - Allow for solution focused, in the moment intervention

Continued

THE COHEN-MANSFIELD AGITATION INVENTORY - short form

Please read each of the agitated behaviors, and check how often (from 1-5) they were manifested by the participant over the last 2 weeks; if more than one occurred within a group, add the occurrences, e.g., if hitting occurred on 3 days a week, and kicking occurred on 4 days a week, $3 + 4 = 7$ days; circle 4, once or several times a day.

| | Never 1 | Less than once a week 2 | Once or several times a week 3 | Once or several times a day 4 | A few times an hour or continuous for half an hour or more 5 |
|---|------------|----------------------------------|--|---|---|
| 1. Cursing or verbal aggression | 1 | 2 | 3 | 4 | 5 |
| 2. Hitting (including self), Kicking, Pushing, Biting, Scratching, Aggressive Spitting (include at meals) | 1 | 2 | 3 | 4 | 5 |
| 3. Grabbing onto people, Throwing things, Tearing things or destroying property | 1 | 2 | 3 | 4 | 5 |
| 4. Other aggressive behaviors or self abuse including: Intentional falling, Making verbal or physical sexual advances, Eating/drinking/ chewing inappropriate substances, Hurt self or other | 1 | 2 | 3 | 4 | 5 |
| 5. Pace, aimless wandering, Trying to get to a different place (e.g., out of the room, building) | 1 | 2 | 3 | 4 | 5 |
| 6. General restlessness, Performing repetitious mannerisms, tapping, strange movements | 1 | 2 | 3 | 4 | 5 |
| 7. Inappropriate dress or disrobing | 1 | 2 | 3 | 4 | 5 |
| 8. Handling things inappropriately | 1 | 2 | 3 | 4 | 5 |
| 9. Constant request for attention or help | 1 | 2 | 3 | 4 | 5 |

Cohen Mansfield cont.

| | Never 1 | Less than once a week 2 | Once or several times a week 3 | Once or several times a day 4 | A few times an hour or continuous for half an hour or more 5 |
|--|------------|----------------------------------|--|---|---|
| 10. Repetitive sentences, calls, questions or words | 1 | 2 | 3 | 4 | 5 |
| 11. Complaining, Negativism, Refusal to follow directions | 1 | 2 | 3 | 4 | 5 |
| 12. Strange noises, (weird laughter or crying) | 1 | 2 | 3 | 4 | 5 |
| 13. Hiding things, Hoarding things | 1 | 2 | 3 | 4 | 5 |
| 14. Screaming | 1 | 2 | 3 | 4 | 5 |

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Social Work Role in Caregiver Outreach

- Integrated Care model
- Allow for same visit meeting
- Rapport building
- Approach as another member of the care team in the clinic
- Non-medical lens and perspective to care
- Communication with community resources and referrals to community care
- Assessment of social determinants of health that play a role in care

Social Work Perspective

- Biopsychosocial lens in social work
 - Biological, psychological and social factors
 - These complex interactions all play a role in the patient and caregivers care and ability to provide care
- Broader, more in-depth social analysis affecting care
- Assessment of predisposing factors
 - Relationship of the caregiver and patient
 - Living arrangements, rural/urban location
 - Availability to resources such as transportation
 - Medical insurance, long-term care insurance, Medicaid
- Relationship between the external factors and the biological experiences and shaping the caregiver experience

Applying the Bio-psycho-social Approach

- Allows for the provision of multidimensional treatment
- Rapport building – recognizing that building and growing relationships is essentially in providing whole person care to the patient and the caregiver
- Gather historically relevant information
 - What significant experiences are shaping the patient/caregiver relationship
 - Life circumstances
- Decide which aspects of the biological, psychological and social determinants are the most important to the patient and caregiver's health and well-being

Brief, Solution Focused Interventions

- Understanding and consolidating positive solutions
- Focus on highlighting strengths as opposed to problems
- Notice what is going right and well and focusing on positive interventions that have had a positive outcome
- Focus on noticing when things are going well
 - What were you doing when that intervention worked?
 - What is different about the times when things are working versus when they are not?
 - What have you tried in the past? Was it effective?
- Empowering the caregiver
- Provide compliments, reward positive outcomes

Applied Behavioral Analysis

- Understand the individual and the behaviors and then tailor our strategies to address them
- Attempt to understand why a behavior occurs
 - Often as a form of communication or a response to a stimuli
- Attempt to predict and control a behavior and assess how the environment plays a role in the outcome
- ABC's of behavior
 - Antecedent Stimuli – What happens before the behavior
 - Behavior – What was the behavior
 - Consequences – What occurs right after the behavior
- Encourage caregiver to use a journal or log these events

Commonly Used Resources

1. Availability
 - Are the services available in the patient's service area?
2. Accessibility
 - Is the service accessible for the caregiver and patient?
3. Appropriateness
 - Remaining cognizant of the specific needs of the caregiver
4. Acceptability
 - Is the caregiver open to this suggestion?
5. Affordability
 - Financial costs, as well as service cost including time, effort, and any potential conflicts

Commonly Used Resources Cont.

Alzheimer's Association

- Alzheimer's Association
- 24/7 Helpline – 800-272-3900
 - Phone support
- Alz.org/co
 - Videos, education, tip sheets for caregivers
- Caregiver support groups
 - Throughout community daily
- Educational programs throughout community
- Family meetings and care planning
- Rapid Referral

alzheimer's  association™

RAPID REFERRAL

No Cover Sheet is Needed

FAX NUMBER: 303-962-9069

DATE: _____

Person to Contact: _____ Phone: _____

Language Preference: _____

Please contact within: ☐ 2-3 Business Days ☐ 1-2 weeks ☐ Other (_____)

☐ I am a person diagnosed with dementia.

or

☐ I am a caregiver for a person with dementia.

Person with Dementia's Name: _____

Contact's Relationship to the Person with Dementia: _____

Issue/Concern: ☐ Wants General Information ☐ New Diagnosis ☐ Early Stage ☐ Caregiver Stress

☐ Other (Specify: _____)

I give my permission to:

Provider Name: _____ Title: _____

Phone: _____ E-Mail/Fax: _____

Give my name and telephone number to the Alzheimer's Association Colorado Chapter, so that a representative from the Colorado Chapter can contact me about the support and educational opportunities that are available.

I understand that my name and phone number will not be given to any other agency other than for the purpose stated above. This form will expire on the following date: _____

I understand that I can revoke my permission at any time by contacting the above named referring provider.

Signature: _____

Verbal Permission Was Given: ☐

6/2012

ALZHEIMER'S ASSOCIATION COLORADO CHAPTER

Phone: 303.813.1669 Fax: 303.962.9069

24-Hour Helpline 800.272.3900

Web site: alz.org/co

Seniors Clinic
University of Colorado Hospital
1635 Aurora Court F-750
Aurora Colorado 80045
Office 720-848-3400



Area Agency on Aging

- DRCOG – Denver Regional Council of Governments
- Fund number of community resources and referral sources throughout area including –
 - Adult Day services
 - Case management program
 - Counseling Services
 - Hearing aids and eyeglasses
 - Handyman/Chore services
 - Health promotion: Disease prevention/education/wellness programs
 - In-home services
 - Legal services – Colorado Legal Services
 - Ombudsman program
 - Nutrition services
 - Respite support services
 - Transportation
 - Visually impaired services

Transportation

- VEYO – Service under Colorado Medicaid benefit for no cost transportation to and from medical appointments
- Access-a-Ride - \$4.90 each way to and from medical appointments
- Go-Go Grandparent – Lyft/Uber service for individuals without a smart phone
 - <https://gogograndparent.com/>
- Senior Resource Center
- “Getting There Guide”
 - Provided by the Denver Regional Mobility and Access Council
 - Local transportation services throughout Metro area
 - 303-243-3113 – Can request copy be sent directly to caregiver

Seniors Blue Book

- Provides a number of resources in one resource booklet
- Includes the following –
 - Adult Day Care Centers
 - Non-skilled home care
 - Cooking, cleaning, dressing, medication reminders
 - Skilled Home Care
 - Physical, occupational, speech therapy, nursing, CNA, social work
 - Independent living, assisted living and skilled nursing facilities
 - Community resources and services
- <https://www.seniorsbluebook.com/local/denver/>

Colorado Respite Coalition

- Provide respite information, resources and referrals to family caregivers and community partners
- Establish a network among respite providers and other organizations to maximize respite services
- Educate family caregivers and the public about benefits of respite care
- Spearhead efforts to develop and establish new respite programs
- Identify sustainable respite care services in several parts of the state
- Invest in the expansion and access to respite services statewide to agencies and family caregivers
- Offer training opportunities for respite providers, caregivers, and employers across Colorado
- Coordinate local and regional coalition efforts across the state to establish a united respite network in Colorado
- Family Voucher Programs

Senior Resource Center

- Number of resources in one place
- Adult day programs
- Transportation
- In-home care
 - Medicaid, private pay or grant funded to provide assistance with bathing, dressing, medication reminders, meal prep, housekeeping, laundry, errands and socialization
- Care management
- Mental health and well-being – Senior Reach hotline
 - Senior Reach offers assistance with counseling, care management, wellness coaching, depression screening and treatment
- Chore services
- Volunteer services

Focus on Rural Communities

- Financial concerns, geographic barriers, and lack of dementia-specific services
- Smaller population including less available caregivers
- Utilizing relationships in the community
 - Workplace, churches, neighbors, immediate family
- Working with caregivers on when to ask for help
- Contacting local county departments and asking about services
- Utilizing any volunteer organizations and non-profits

Safety Considerations - Wandering

- 6 in 10 individuals who have dementia will wander
- Who is at risk – Warning signs to look for
 - Individual returns from a regular walk or drive later than usual
 - Forgetting how to get to a familiar place
 - Discussing talking about fulfilling former obligations – “I’ve got to get to work”.
 - Talking about “wanting to go home” even when at home
 - Restlessness, pacing, repetitive movements
 - Difficulty locating familiar rooms in the home
 - Asking for the whereabouts of past friends or family
 - Acting as if they are completing a task, but not accomplishing anything (moving things from one place to another)
 - Becoming nervous or anxious in crowded areas

Wandering Cont. - Tips for Prevention

- Carry out daily activities and maintain a routine
- Keep track of times when wandering is most common and plan activities during this time
- Provide reassurance – Focus communication on exploration and validation
- Ensure all basic needs are met – Restroom? Pain? Hunger?
- Avoid busy places
- Place locks either high or low, out of line of sight
- Have devices on doors and windows that alert when opened
- Provide supervision, particularly in unfamiliar places
- Keep car keys out of sight

Safety Plan for Wandering

- Keep list of people to call for help
- Ask neighbors, friends and family to notify caregiver if they see the individual alone
- Keep a close-up phone and updated medical information at hand
- Become familiar with the neighborhood
- Is the individual right or left handed? – Wandering will generally go in the direction of the dominant hand
- Keep list of potential wandering locations – jobs, former homes, church or favorite restaurants
- Enroll in the MedicAlert + Alzheimer's Association Safe Return Program
- Call 911 – 94 percent of people who wander are found within 1.5 miles of their home
- File a report with the Safe Return Program – 800-625-3780
 - First Responders are trained to check the Safe Return registry if they locate an individual who has wandered

Safety Considerations Cont. - Gun Safety

- Estimated 33% of all adults 65 and older own a gun and 12% live in a home with someone who owns a gun
- 60% of individuals with dementia live in a household with a firearm
- Estimated 7.8 – 11.8 million people with dementia will live in a home with a gun by 2050
- Locking or disabling a gun may not be enough
 - May misperceive danger
 - Many are able to use learned memory to handle a gun
- Consider removing guns completely from the home
- Receive a Free Gun Lock from a local police department - <http://www.projectchildsafe.org/for-law-enforcement>
- Consider this conversation as important as early conversations related to legal, financial care and driving plans
- Have plan in place for what will be done with firearms or weapons when individual is no longer able to handle safely

Living Considerations

- Caregiver moving from out of state to be primary caregiver for individuals with dementia
- Moving individual with dementia from out of state to Colorado
- Discussions on Medicare and Medicaid coverage
- Differences between independent, assisted and skilled nursing facilities
- In 2017, Alz Assoc. estimated 5.5 million individuals living with dementia

Table 1. Estimated Distribution of People with Dementia by Living Arrangement, 2017

| Prevalence | Total living in the community | Living in the community with others | Living alone in the community | Living in residential care settings | Living in nursing homes | Total |
|--|-------------------------------|-------------------------------------|-------------------------------|-------------------------------------|-------------------------|-------|
| Estimated number of people with dementia (thousands) | 4,479 | 3,135 | 1,344 | 331 | 690 | 5,500 |
| Percent of people with dementia | 81 | 57 | 24 | 6 | 13 | 100 |

Source: Authors' estimates based on Alzheimer's Association, 2017; Harris-Kojetin et al., 2016; and Okura et al., 2011. People living in the community were calculated by subtracting number of people living in RCSs and nursing homes. People living alone were calculated as 30 percent of people living in the community.

Questions?

Thank you!

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