ADVANCE CARE PLANNING & DEMENTIA

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OBJECTIVES

Â Learn about the different types of dementia
Â Highlight necessary components of assessment relevant to ACP
Â Learn about clinical considerations regarding ACP for people living with dementia and their support system
Â Discuss contraindications for ACP when a person has dementia
Â Discuss how ACP can occur when the patient is unable to directly participate
Â Provide information on community resources for people living with dementia and for their support team
Â Allow time for discussion and questions
BRIEF OVERVIEW OF DEMENTIA

Dementia is not a disease in itself. The term dementia is used to describe a collection of symptoms caused by disorders affecting the brain.

There are more than 100 different disorders causing dementia. The most common are:

- Alzheimer's Disease: ~20%
  Most common cause of dementia: 50-70%

- Vascular Dementia

- Dementia with Lewy Bodies: ~15%

- Fronto-temporal Dementia: ~5%

FROM: HTTP://WWW.GOLDENCARERS.COM/BLOG/WHAT-IS-DEMENTIA/
Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain.

- Alzheimer's disease
  - Most common type of dementia; accounts for an estimated 60 to 80 percent of cases.
  - Symptoms: Difficulty remembering recent conversations, names or events; apathy, and depression are often early clinical symptoms. Later symptoms include impaired communication, poor judgment, disorientation, confusion, behavior changes, and difficulty speaking, swallowing, and walking.

- Vascular dementia
  - Previously known as multi-infarct or post-stroke dementia, vascular dementia is less common than Alzheimer’s, accounting for about 10 percent of dementia cases.
  - Symptoms: Impaired judgment or ability to make decisions, plan or organize is more likely to be the initial symptom, as opposed to the memory loss often associated with the initial symptoms of Alzheimer's. Occurs because of brain injuries such as microscopic bleeding and blood vessel blockage. The location, number and size of the brain injury determines how the individual's thinking and physical functioning are affected.
BRIEF OVERVIEW OF DEMENTIA

ï **Dementia with Lewy bodies (DLB)**
   Å **Symptoms:** Memory loss and thinking problems (also common in Alzheimer's), but are more likely to have early symptoms such as sleep disturbances, well-formed visual hallucinations, muscle rigidity, and/or parkinsonian movement features.

ï **Mixed dementia**
   Å Abnormalities linked to more than one type of dementia occur simultaneously in the brain. Recent studies suggest that mixed dementia is more common than previously thought.

ï **Frontotemporal dementia (FTD)**
   Å Includes dementias such as behavioral variant FTD (bvFTD), primary progressive aphasia, Pick's disease and progressive supranuclear palsy.
   Å **Symptoms:** Changes in personality and behavior and difficulty with language. Nerve cells in the front and side regions of the brain are especially affected.
FACTORS THAT IMPACT ABILITY TO PARTICIPATE IN ACP FOR A PERSON WITH DEMENTIA

- Type of Dementia and Degree of Cognitive Impairment

- Lack of Insight vs. Awareness

- Defensiveness and/or Denial vs. Acceptance

- Lack of Understanding of Diagnosis vs. Understanding Of Diagnosis

Other factors similar to general population:

Cultural Factors
Co-Occurring Mental Health Challenges
Family Relational Problems
Etc.
ASSESSMENT KEYS FOR ACP WITH DEMENTIA PATIENTS

Degree of Cognitive Impairment
Å Some (of the many) areas of cognitive function that can be affected:
  í Processing of information
  í Learning new information
  í Retaining information
  í Ability to understand and express language
  í Ability to receive, process, and tolerate sensory stimulation
  í Mental flexibility vs. rigidity
  í Attention
  í Ability to sequence fluidly between thoughts and tasks
  í Emotional regulation and empathy
  í Reality testing
  í Orientation
  í Reasoning
  í Executive function

Å Alzheimer’s Disease
  í What stage are they at 1-7
    Å ACP will be different for people in stage 3 vs. stage 6...
Lack of Insight vs. Awareness

Based upon impact of disease process on cognitive function.

Ask questions regarding their perspective on their current situation and health.
   Do they have knowledge of any changes in cognitive ability and/or functional status?

People often have partial or fragmented insight regarding changes, as they have some awareness of change, but can not grasp fully how this impacts their functioning, relationships, everyday life, etc..

Some people lack the ability to have any conception of changes with their cognitive and/or functional status.
Defensiveness and/or Denial vs. Acceptance

Defensiveness and/or Denial

- Start with the perspective that the patient’s defensiveness and/or denial is a mechanism by which they fight to survive - to preserve their dignity and identity.
  - Can be a conscious or subconscious process

- Usually based upon fear of vulnerability or change
  - Can be culturally based: family of origin, religion, place of origin, etc...
  - Can be feature of a person’s character or learned behavior over time
  - Can be associated with mental health challenges
  - What is this patient’s coping style when dealing with emotional vulnerability?
    - Stoicism? ... Isolation? ... Distraction? ... Open expression? ...
    - Seeking out supports? ... Pragmatic? ... Acceptance? ... Anger? ...

- Key factor: Family history or past personal experience with dementia.
  - Frame of reference and perspective based on observed experience
Understanding of Disease Process:

- What is the known diagnosis?
  - Per patient
  - Per family/support team
  - Per Medical Record

- May need to coordinate appointment for assessment or consultation with care providers. This may need to occur before ACP can proceed.

- If working with patient separate from care team, it may be indicated to request and review applicable medical records.

- A recent report from the Alzheimer’s Association revealed that 55% of people with Alzheimer’s and their caregivers report not being told the diagnosis, and that doctors were more likely to tell patients and their caregivers the diagnosis in later stages of the disease process – often when patients were too impaired to participate meaningfully in advance care planning.

ACP FOR A PERSON WITH DEMENTIA – CONSIDERATIONS

People with dementia (as it progresses) have an increasingly finite amount of “cognitive reserve”, that is the mental space and capacity to perform such functions as: absorb stimuli, process information, remember, formulate thoughts, and express themselves. The best approach is one that is focused and direct, and that makes efficient use of a person’s cognitive reserve.

- As the facilitator, consider ‘what are the most important items to discuss’ and gear conversation to those topics.

- Less is more: ask questions simply, avoid long explanations of Advance Care Planning, avoid asking more than one question at a time, and if needed give extra time for the person to respond.

- Some people with dementia can participate more fluidly when talking about beliefs and scenarios in general/abstract terms.

- When talking about specific interventions at time of life threatening illness/injury, discuss with patient their beliefs about acceptable vs. unacceptable outcomes from emergency medical care.
ACP FOR A PERSON WITH DEMENTIA – CONSIDERATIONS

- Can’t force this process
- Schedule ACP appt at time of day the patient is most able
- Atmosphere should be calm - limit distractions
- Try to control for any factors that could encourage or hinder comfort
  - Has the patient eaten? Are they hydrated? Did they have a chance to use the bathroom before the ACP appt? Do they live with chronic pain, and if so did they get their medication that day? Etc.
- Allow extra time
- Recognize if the person is getting overwhelmed and either stop or take breaks if needed.
- Recollect past experiences witnessing loved ones with aging process and end of life to elicit meaning, and how it may inform opinions about personal beliefs or wishes.
  - Would they want it the same or different from how their parents (or other loved ones) experienced end of life care?
ACP FOR A PERSON WITH DEMENTIA – CONSIDERATIONS

- Person needs to feel comfortable and safe in process.
  - Start slow without expectations of outcome
  - Start with understanding their perspectives and goals for ACP
  - Address fears and concerns as they arise with warmth, reassurance, and honesty. People with Dementia often have heightened emotional sensitivity, and can respond more to how you make them feel than the words you say.
  - Make sure patient remains at the center of discussion
  - Intervene if family members are speaking for the patient more than they should.
  - People with Dementia might not like going to see health professionals. The patient will assess whether or not you really care about them, and if they think you can help.
What is the person’s definition of good quality of life? The living well questions are often received well and are effective in leading to discussion about goals of care if quality of life were reduced or unobtainable.

How they would ideally picture their care if they had increased challenges with ADLs (Activities of Daily Living) and the need became imminent for increased support with care, such as:
  - preference for in home care vs. moving to a care facility
  - exploring their specific fears about needing more supportive care and
  - how family can best assist with these challenges

Does the patient have strong value of not “being a burden” to others?
  - sometimes this translates to desiring facility care instead of care at home with family.

Written documents can be confusing and/or overwhelming:
- The Honoring Choices document can be overwhelming for some (too many details).
- Consider using the shorter state HCPOA form instead.
- After deciding the agents, go through the document concisely, so as to leave cognitive reserve for the conversation.
WHEN IS IT CONTRAINDICATED TO HAVE THE PERSON WITH DEMENTIA PARTICIPATE?

Â If the person already has a Statement of Incapacity*

Â If it would increase distress in ways that would be too difficult for the person to tolerate

Â If the person no longer has the tools to understand or participate meaningfully in conversation

Â Consider baseline ability to participate including education level, and cognitive and emotional intelligence

Â If the person is unable to feel safe in process

Â If they are participating against their will

*Note: Some people can still express preferences for care even if they have clinical incapacity.

Â Common to have fluctuations in cognition
ACP WHEN PATIENT CANNOT DIRECTLY PARTICIPATE

• Meeting with health care agents and those that know the patient well
• Is Incapacity Statement completed?
• What do the advance directives indicate?
• What has the patient discussed with their agents and/or family?
• Did they express beliefs about end of life care they would/would not want based upon times they observed loved ones at end of life?
• Are there any religious or spiritual beliefs that could impact care decisions?
• What is their current quality of life?
ACP WHEN PATIENT CANNOT DIRECTLY PARTICIPATE

Â What do the agents understand about diagnosis and prognosis?
   ï Do they have questions for patient’s health providers? Make list.

Â Identify any gaps in knowledge regarding options for supportive care.

Â Identify gaps in knowledge pertaining to care decisions when a person is at risk of dying. Offer this information factually without facilitator bias.

Â Make sure the conversation is focused on what the patient would say for themselves if they could, and not on what the agent thinks is best from their perspective.
Lack of experience by physicians


ACP is not often considered part of dementia services provided by health professionals, and when ACP is offered it is usually at later stages in the disease trajectory, which makes ACP challenging if not contraindicated.


For nursing home residents with dementia, ACP primarily limited to a few choices regarding code status upon admission to facility – wider range of personal preferences and expectations not discussed.


Health professionals have anxiety about initiating ACP discussions, due to lack of knowledge, personal discomfort, lack of time, and communication difficulties.


ACP perceived as relevant only at terminal phase of illness.

COMMUNITY RESOURCES

- Alzheimer’s and Dementia Alliance  608-232-3400  www.alzwisc.org
  - Serving many counties in South Central Wisconsin
  - Care Consultations
  - Support Groups
  - Resource Library
  - Caregiver Grants
  - And more...

- Alzheimer’s Association  www.alz.org
  - Serving all locales nationwide
  - 24/7 care consultation helpline  1-800-272-3900
  - Exceptional online educational resources
  - Caregiver connect online support groups and message boards
  - Information on clinical trials and research opportunities
  - Local support groups and educational seminars
COMMUNITY RESOURCES

Â Aging and Disability Resource Centers  www.dhs.wisconsin.gov/adrc
   - Serving all counties in Wisconsin
   - Information and referral assistance for community services and resources
   - Many counties have Dementia Specialists that provide specialized Care Consultation and Education

Â Wisconsin Alzheimer’s Institute  www.wai.wisc.edu
   - Organizing hub for all Memory Diagnostic Clinics in Wisconsin
   - Research Institute – WRAP Study
   - Good source of Information and Education for all audiences
   - Educational Events
   - Training for professionals assessing and caring for patients with cognitive impairment

Â Alzheimer’s Disease Research Center  http://www.adrc.wisc.edu/
   - Research and educational opportunities for patients, family members, and caregivers
COMMUNITY RESOURCES

• Alzheimer’s Disease Education & Referral Center  www.nia.nih.gov/alzheimers
  • Online information library, free publications by mail or download

• The Association for Frontotemporal Degeneration  www.theaftd.org/
  • Information and Education, free publications by mail or for download
  • Helpline: 1-866-507-7222
  • Local support groups, telephone support groups, online support groups and forums
  • Conferences
  • Caregiver grant

• Lewy Body Dementia Association  www.lbda.org/
  • LBD Caregiver Link – 1-800-539-9767
  • Information and Education, free publications by mail or for download
  • Local support groups, telephone support groups, online support groups and forums
Questions?

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