The National Academies of Sciences, Engineering, and Medicine Virtual Meeting

Living Well with Dementia: Disease Trajectory, Retaining Cognitive Capacities, Maximizing Quality of Life, and Measurement Issues

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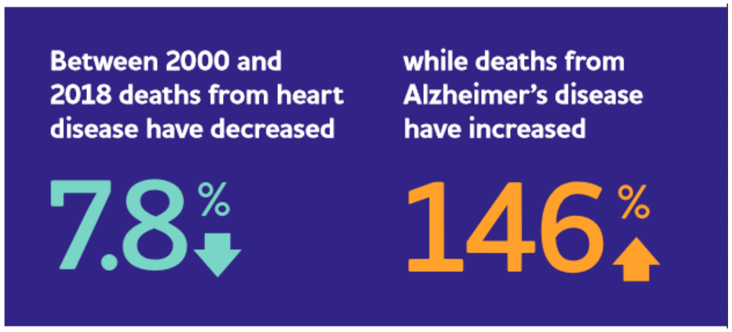
What do we know about the trajectory of Alzheimer's and other dementias, and what questions should be addressed?

- Progressive
  - No cure → terminal
- Although symptoms depend on many factors
  - Dementia type
    - Alzheimer’s vs. Non-AD Dementias
  - Co-morbidities
    - Cardiovascular disease, diabetes, COPD, etc.
  - Access to care
    - Geography
    - Insurance coverage
    - Transportation
    - Reliable caregiver/help



Between 2000 and 2018 deaths from heart disease have decreased

7.8% ↓

while deaths from Alzheimer’s disease have increased

146% ↑

Facts and Figures 2020,
Alzheimer’s Association

Stages of Dementia

Mild

Difficulty with:

- Finances
- Driving
- Medications
- ↓ insight & judgement
- Short term memory
- Social withdrawal
- Mood changes

Moderate

Difficulty with:

- Instrumental ADLs
- Some Basic ADLs
- Gait and balance
- Disorientation
- Worsening memory
- Getting lost
- Repeating questions
- Delusions/Agitation

Severe

Difficulty with:

- Basis ADLs
- Mobility
- Swallowing
- ↓ verbal output
- Remote memory
- Recognizing family
- Apathy/depression
- Sundowning

What do health care providers understand about the trajectory of dementia and how does it effect the interactions with and quality of life of these patients?

- Physicians are unaware of cognitive impairment in more than 40% of their cognitively impaired patients. (Chodosh J, Petitti DB, Elliott M, et al. 2004)
- More than one-quarter (27%) of PCPs surveyed report being only sometimes or never comfortable answering patient questions about Alzheimer’s or other dementias. (Alzheimer’s Association Facts and Figures, 2020)
- If a provider doesn’t understand the impact of dementia beyond the diagnosis, then they run the risk of failing to meet the needs of their patient.

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In the UCLA Alzheimer’s and Dementia Care Program caregivers were surveyed and felt:

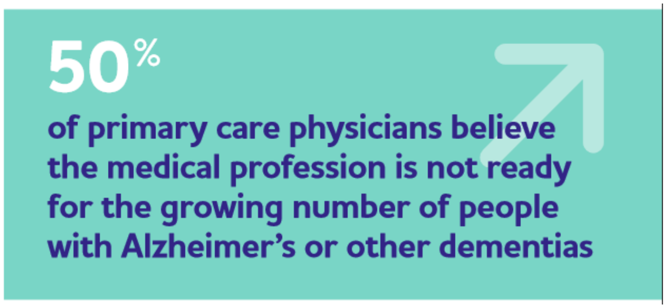
79% felt that the patient’s regular doctor understands how memory or behavior problems complicate other health conditions

28% felt they had a healthcare professional who helps them work through dementia care problems

(Jennings LA, Reuben DB, Evertson LC, et al., 2015)

What do health care providers understand about the trajectory of dementia and how does it effect the interactions with and quality of life of these patients?

- Recognize that dyads need support and education, not always able to provide
- Time allowed per patient and for family caregivers may be inadequate
- May not know about resources available beyond the medical model
  - Outpatient
  - Hospital/ER
  - Home Health
  - Hospice



50%

of primary care physicians believe the medical profession is not ready for the growing number of people with Alzheimer's or other dementias

Facts and Figures 2020, Alzheimer's Association

What do health care providers understand about the trajectory of dementia and how does it effect the interactions with and quality of life of these patients?

- Often the caregiver is not a the patient of the provider which can get in the way of treatment
- Poor estimation of life expectancy (i.e. when to consider hospice)
- May not understand what patients with mild dementia can still do
  - Preparing for decisions to live alone
  - Driving
  - Travel

What do we know about strategies for retaining cognitive capacities to the greatest extent possible following the onset of dementia symptoms?

More education does not protect people from getting dementia, but it may lessen the expression of dementia before death. (EClipSE Collaborative Members, Brayne C, Ince PG, et al., 2010)

A review of 15 randomized controlled trials of cognitive stimulation for dementia showed benefit for maintenance of cognitive function and self-reported quality of life associated with cognitive stimulation which seemed to remain evident 1 – 3 months after the end of treatment. However, there is a lack of quality and standardization of the types of cognitive stimulation. (Woods B, Aguirre E, Spector AE, Orrell M., 2012)

What do we know about strategies for sustaining engagement in hobbies and other leisure activities following the onset of dementia symptoms?

- Difficult at times due to:
  - Lack of insight
  - Apathy
  - Access and resources
    - Transportation
    - Finances
    - Availability of activities (i.e. rural vs urban, technology)
  - Need for family caregiver or other cheerleader
  - Routine

- Activity must be appropriate for the person living with dementia
  - What are their interests?
  - How severe is their dementia?
  - Can they afford it?
  - Is it safe for them to continue?
  - Will someone help encourage them?

What does high quality of life following a dementia diagnosis look like?

- WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/
- Health care providers should not assume their own values are the same as that of their patients. It may not be what the person living with dementia wants.
  - Medications
  - Therapy
  - Exercise
  - Lifestyle changes

How can we measure the subjective experience of individuals with dementia related to quality of life?

- If possible ask what is QOL to them? If the patient cannot discuss – start the conversation with the family.
- What matters most? (Age Friendly Health Systems, IHI)
  - Document and share it with the care team

    http://www.ihi.org/Engage/Initiatives/Age-Friendly-Health-Systems/Documents/IHIAgeFriendlyHealthSystems_GuidetoUsing4MsCare.pdf
- Quality of Life-AD
  - Patient self administered
  - Caregiver administered version (family) https://www.cogsclub.org.uk/professionals/files/QOL-AD.pdf

Research to consider

- What do health care providers understand about the trajectory of dementia and how does it effect the interactions with and quality of life of these patients?
    - The journey begins with the providers. Trust and rapport helps.
    - Intervene early, with confidence. Not only medications and medical care, but education to help with informed decision making and advance care planning.
    - On-going support. In order to continue to clinically support their patients with dementia, providers need to continue to address the diagnosis with their patient through the various stages. Needs and concerns for both the patient and family will change based on symptoms and severity.

Research to consider

Goal Attainment Scaling is one method of specifying personal health goals and measuring their attainment.

- 101 dyads (person with dementia and their caregiver)
    - 84% **non-medical**
    - 47% **quality of life**
    - 29% **caregiver support goals**
- 88% of participants felt the goal was meaningful
- 74% felt is captured something different from usual care
- 85% felt the process helpful in planning future care

(Jennings LA, et al., 2018)