Advance Care Planning for Dementia Patients

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Objectives

• Describe current gaps in the quality of care for dementia patients near the end of life
• State the advantages of advance care planning for dementia patients
• Identify models of care and clinical tools available for advance care planning with dementia patients

The Clinical Course of Advanced Dementia

• 6th leading cause of death in the US
• Under recognized as a terminal disease
  • 30% of all decedents aged 65+ die from or with dementia
• Characterized by a prolonged trajectory of severe disability
• Complications are protean and devastating
  • Cognitive decline and loss of language
  • Eating and swallowing problems, weight loss, aspiration pneumonia
  • Urinary and fecal incontinence, recurrent infections
  • Neuropsychiatric complications
  • Immobility and falls, pressure ulcers
  • Caregiver strain and burnout

Costs of Dementia

$157 to $215 billion = Total annual cost of care for dementia
  ◦ Expected to double by 2040

$61,500 = Average out-of-pocket costs for families of persons with dementia in last 5 years of life
  ◦ 81% more than persons without dementia

18.5 billion = Hours of unpaid care for persons with dementia in 2018


Quality issues in dementia end-of-life care

- Lack of diagnosis and disclosure
- Lack of identified proxy decision-maker or caregiver in EHRs
- Under-recognition and management of caregiver strain
- Burdensome care transitions and interventions in last few months of life
- Use of feeding tubes in advanced dementia
- Use of antipsychotics or other sedatives for behavioral symptoms
- Worse care among racial/ethnic minority groups
- Lack of advance care planning and access to outpatient palliative care
- Geriatric and palliative care workforce shortages

Dementia diagnosis and disclosure

- Late diagnosis limits opportunities for early advance care planning
- Low uptake of cognitive assessment in Medicare Annual Wellness Visit
  - 19% of beneficiaries in 2016
- National probability survey of adults 65+ (N=1954) and 1000 primary care physicians
  - 28% had received a cognitive assessment
  - 82% reported important to have memory checked
  - 90% of providers wanted more guidance on cognitive assessment
- Tools for dementia diagnosis
  - American Academy of Family Physicians Cognitive Care Kit
  - The Alzheimer’s Association Cognitive Assessment Toolkit
  - Minnesota’s Act on Alzheimer’s® Provider Practice Tools

Caring for the caregiver

- Lack of identified proxy decision-maker and caregiver in EHRs
- Under-recognition and management of caregiver strain
  - More likely to assist with ADIs (85 vs. 71%), perform medical tasks (63% vs. 52%), coordinate care (86 vs. 72%)
  - 57% of family caregivers provide care for 4+ years; 41% provide caregiving alone
  - 59% rated emotional stress of caregiving as high
- Evidence-based interventions for caregivers
  - Education and training
  - Counseling
  - Support groups
  - Respite care
  - Multi-component, longitudinal approaches

Burdensome care at end of life

- Decrease in in-hospital death (2000 to 2009)
  - 32.6% to 24.6%
- Increased ICU use in last month of life
  - 24.3% to 29.2%
- More care transitions in last 3 days of life
  - 10.3% vs. 14.2%
- Hospitalization in last 3M (63% vs. 52%)
- Site of death for persons with dementia
  - 23% home
  - 18% hospital
  - 49% nursing home

- Burdensome transitions were associated with poorer care
  - Feeding tubes
  - ICU care in last month of life
  - Stage IV decubitus ulcer
  - Late enrollment in hospice


No benefit of feeding tubes in advanced dementia in observational studies

- No improvement in:
  - Survival
  - Nutritional status
  - Wound healing
  - Aspiration pneumonia
  - Functional status

Harms include:
- Worsening pressure ulcers
- Patient discomfort, agitation
- Increased physical and pharmacological restraint use
- Family less likely to report excellent end of life care


Feeding tubes in Advanced Dementia

**CHOOSING WISELY®**

Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding.

Careful hand-feeding, small frequent meals, liberalize diet


Disparities in Advanced Dementia Care

- Nonwhite race is the consistently associated with poor quality and more aggressive end-of-life care
  - Greater use of tube feeding
  - In-hospital death
  - Lack of advance directives
- Worse care quality in Southeastern US


Quality Measures for End-of-Life Care

**Measuring What Matters Project**

- 10 indicators for hospice and palliative care
- Modified Delphi rating process by technical advisory panel, clinical user panel, membership of 2 professional societies (AAMPM and HPNA)

1. Comprehensive assessment
2. Screening for physical symptoms
3. Pain treatment
4. Dyspnea screening and management
5. Discussion of emotional or psychological needs
6. Discussion of spiritual/religious concerns
7. Documentation of surrogate
8. Treatment preferences
9. Care consistency with documented care preferences
10. Patient/family perception of care

Dementia Quality of Care Measures

HHS-ASPE/RTI Framework for Models of Dementia Care

1. Detection of possible dementia
2. Diagnosis
3. Assessment and ongoing reassessment
4. Care planning
5. Medical management
6. Information, education, and informed and support decision making
7. Acknowledgement and emotional support for the person with dementia
8. Assistance for the person with dementia with daily functioning and activities
9. Involvement, emotional support, and assistance for family caregivers
10. Prevention and mitigation of behavioral and psychological symptoms of dementia
11. Safety for the person with dementia
12. Therapeutic environment, including modification to the physical and social environment of the person with dementia
13. Referral and coordination of care and services that match needs of the person with dementia and family caregivers; collaboration among agencies and providers


End-of-Life Care Processes for Dementia

<table>
<thead>
<tr>
<th>Goal of care discussion</th>
<th>ACOVE-3</th>
<th>AAN/APA</th>
<th>CMS QPP</th>
<th>NQF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Documentation of advance care planning</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Identifying a proxy decision-maker</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Palliative care counseling</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Comprehensive assessment for anticipated death (symptoms, pain, spiritual needs, caregiver burden)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>


Goal-concordant care: A new way to measure quality

• Achieving concordance between patients’ goals and their medical care

A Goal-Oriented Approach to Care

Elicit values and care preferences

Identify a SMART health goal

Action Plan

Measure goal attainment

Reassess and revise goal over time

Measuring Goal Attainment: Patient-Defined Outcomes

• Patient-reported outcome measures (PROMS)
• Goal attainment scaling

Aligning treatments with patient goals
One Approach to Goal-Directed Care: Goal Attainment Scaling

- Way to make a personalized health goal S.M.A.R.T.
  - Specific, Measurable, Attainable, Relevant, Time-bound
- Framework for care planning
  - Action Plan
- Measure goal achievement
  - Goal is individualized, measurement is standardized

<table>
<thead>
<tr>
<th>Goal</th>
<th>Much less than expected (−2)</th>
<th>Less than expected (−1)</th>
<th>Expected goal attainment (0)</th>
<th>More than expected (+1)</th>
<th>Much more than expected (+2)</th>
<th>Action Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interact more with grandchildren</td>
<td>No contact with grandchildren</td>
<td>Contact with grandchildren every 2 months (current state)</td>
<td>Contact with grandchildren bi-weekly</td>
<td>Contact with grandchildren weekly</td>
<td>Make call schedule for each grandkid. Set reminder on phone.</td>
<td></td>
</tr>
</tbody>
</table>

Another Approach to Measurement: PROMs

Selecting a validated PROM that matches a patient’s goal
- Functional status (e.g., ADLs, SF-8)
- Symptom control (e.g., PHQ-9, pain scale)
- Health-related quality of life (e.g., PROMIS Global Health)

Pros: Validated, self-administered; good for symptoms; can be followed longitudinally

Cons: Cannot always find a PROM that matches a patient’s goal, may be too generic, may not fit well if decline is expected, proxy may not be able to complete, qualitative meaning of score may not be clear

Perceptions of Goal Setting

Patient-Caregiver Dyads (structured interviews)
- 74% met or exceeded their expected level of goal attainment
- 85% felt goal setting was helpful for planning for future care
- 74% felt process got at something different from usual care
- 57% had discussed goals with another healthcare provider
- 83% planned to continue to work on their goals after the study

Nurse Practitioner Dementia Care Managers (focus group)
- Improved understanding of what was most important to patients
- Helped set expectations about disease progression & care needs
- Goal revision was valuable when goals were not met
- Empowered caregivers
- Takes time and practice to do well

"It was helpful to realize what he could do successfully and what his limitations are...I think the doctor has a better understanding of where he is at. He was looked at more as a whole person than just prescribed a medication."

"The times that it was most helpful for me was when I was surprised by their goal. When it was something I didn't find out in an annual visit..."

Advance Care Planning (ACP) in Dementia

- Strongest modifiable risk factor associated with avoiding unwanted or unnecessary treatments
- Aggressive interventions (CPR, intubation) are the default in US acute care settings if care preferences are unknown

Lack of advance directives associated with poorer outcomes for persons with dementia

- Multiple care transitions in last 3 months of life
- Receipt of ICU care in last month of life
- In-hospital death
- Feeding tube placement
- Lower hospice use
- Higher health care expenditures
- Worse family satisfaction with end-of-life care

Advantages of Early ACP and Palliative Care in Dementia

- Opportunity to plan for future care
- Allows person with dementia to participate while they are still able
- Anticipatory guidance about prognosis and complications
- Understand person’s values, goals, care preferences
- Make treatment decisions aligned with goals
- Discuss living situation, financial resources
- Education about hospice care and community resources
- Improve symptoms
- Identify proxy decision maker and involve them in conversation
- Lessen caregiver burden, reduce proxy anxiety about decision making

ACP in Dementia: Recommendations for Healthcare Professionals

- Review of 67 publications and expert opinion
- Developed 32 recommendations in 8 domains
  1. Initiation of ACP
  2. Evaluation of capacity
  3. Holding ACP conversations
  4. Role of persons close to person with dementia
  5. ACP with persons who have difficulty communicating verbally
  6. Documentation of wishes and preferences, including information transfer
  7. End-of-life decision making
  8. Preconditions for optimal implementation of ACP
- Concluded little high-quality evidence on ACP in dementia

ACP Practical Recommendations for Providers

- Start early, ideally when patient can still participate
- Establish directives in writing, including appointment of proxy
- Talk about anticipated complications, including swallowing and infection
  - Most common proximate causes of death in advanced dementia
- Solicit treatment preferences before complications arise, if possible
- Consider a structured conversation guide
- Often takes more than 1 visit
Tools to Aid Advance Care Planning

Selected evidence-based tools for ACP in serious illness
- Decision aids
- Communication training for providers
- Conversation guides
- Physician Orders for Life Sustaining Treatment

Evidence for Decision Aids for ACP in Dementia

Four RCTs of decision aids (nursing homes and primary care)
- Better knowledge and communication about end-of-life care
- More medical orders defining scope of treatment
- More directives for no tube feeding and comfort care
- Fewer hospital transfers
- Higher rates of directives that align with care preferences
- Greater stability of care preferences over time, less decisional conflict

VitalTalk
https://www.vitaltalk.org
- Evidence-based training to build clinicians’ communication skills

Center to Advance Palliative Care (CAPC)
www.capc.org
Low engagement in ACP for persons with dementia

Older adult engagement in ACP has increased over time

- Decedents with advance directive increased from 47% in 2000 to 72% in 2010 (Health and Retirement Study)

However, some groups remain less likely to engage in ACP

- Minority (black 39%, Latino 30% vs. white 66%)
- Poorly educated (high school or less 52% vs. 69%)
- Low income (<$25,000 annual income 52% vs 66%)
- Persons with dementia (54% vs. 62%)

- Nationally representative sample of community-dwelling Medicare beneficiaries (National Health and Aging Trends Study 2012)

### Barriers to High Quality Advance Care Planning in Dementia

- Takes time and primary care is busy with short office visits
- Other competing chronic conditions
- Conversations can be emotional and challenging
- Stigma of dementia diagnosis and death
- Lack of treatment options
- Often requires triadic communication (patient, caregiver, provider)
- Care preferences may change as disease progresses


### Medicare Advance Care Planning Billing Codes

- Codes (99497, 99498) launched Jan 2016
- Analyses of Medicare Part B claims for all FFS beneficiaries in 2016-2017
- Low uptake nationally
  - 2.2% of beneficiaries in Q1-3 of 2017
  - 0.1% to 10.9% of decedents across states
  - 35.9% of hospice and palliative medicine specialists used ACP code at least once
- Need additional strategies to integrate ACP more widely into practice


### Increasing Hospice Use in Dementia

- Increasing over last 20 years
  - 21.6% in 2000 vs. 42.2% in 2009
  - But late referral still a problem: 28.4% enrolled within 3 days of death
- In 2014, nearly 50% of hospice recipients had a primary or comorbid diagnosis of dementia


### Benefits of Hospice Care in Dementia

- Lower probability of hospitalization in last 30 days of life (19% vs. 39%)
- More likely to receive regular treatment for pain (44% vs. 27%)
- Die in location of choice (OR 9.7; 95% CI 2.6-37.0)
- Caregivers more likely to rate care as very good or excellent (OR 5.6; 95% CI 2.6-10.3)

National Survey of Hospice and Palliative Care Programs

• Surveyed 426 hospice or palliative care programs
• 94% of hospices & 72% of palliative care programs served patients with dementia
• Barriers to use:
  • Lack of awareness of palliative care by families and referring providers
  • Reimbursement policies—lack of palliative care coverage earlier in disease; prognostication difficult
• Highly rated needs:
  • Family information, Assistance with caregiver burden, Behavioral symptoms, Respite
• Successful strategies: Interdisciplinary teams, Collaboration with community organizations

Prognostication: Medicare Criteria for Hospice Use in Dementia

Stage 7 on Functional Assessment Staging (FAST) scale
  • Unable to ambulate, dress, bathe without assistance;
  • Urinary and fecal incontinence intermittent or constant;
  • Lacks meaningful verbal communication (stereotypical phrases only or ≤6 words)
AND At least 1 medical complication in the prior year:
  • Aspiration pneumonia
  • Septicemia
  • Recurrent fever after antibiotics
  • Multiple decubitus ulcers ≥ stage 3
  • Inability to maintain fluid/calorie intake with 10% weight loss in 6 months or albumin < 2.5

Challenges in hospice use in dementia

• Difficult to predict rate of decline
• Medicare hospice eligibility guidelines poorly predict death in 6-months
  • 89% specificity and 20% sensitivity
• Advanced Dementia Prognostic Tool (ADEPT)
  • 12-item score uses age, gender, function, nutritional status, symptoms, conditions
  • Created from Minimum Data Set
  • Validated in 606 nursing home residents with advanced dementia
  • Only slightly better than Medicare guidelines (89% specificity, 27% sensitivity)
• Late hospice referrals and long length of stays with discontinuation of services
• Shift focus from life expectancy to preferences for comfort/quality of life

One proposed solution: Integrating Palliative Care Across the Clinical Course of Dementia

Mild Cognitive Impairment
  • Primary care screening

Mild Dementia
  • Geriatric & palliative care approaches integrated into primary care

Moderate to Severe Dementia
  • Specialty palliative care consultations added to care team

Advanced Dementia
  • End-of-life and hospice care


Challenges to Integrated Palliative Care

- Limited availability in community settings
- Lack of sustainable payment models
  - Will value-based reimbursement shift incentives of healthcare systems to invest in palliative care and care management programs?
- Workforce shortage
- Provider burnout
- Need for training of non-specialty clinicians to grow workforce
- Efforts to destigmatize dementia in healthcare and communities
- Increase awareness of palliative care services; can co-exist with other treatments

Another proposed solution: Dementia Care Management Programs

- Disease management programs effective for several chronic conditions
- Comprehensive, focused on dementia
- Improved quality of care & health outcomes for persons with dementia and family caregivers
- Include advance care planning and referral to palliative care and/or hospice

UCLA Alzheimer’s and Dementia Care Program

- Based on RCTs of collaborative care models for dementia
- Supports the patient and caregiver
- Longitudinal care management model
- Co-management model with NP dementia care specialist
- Clinic and home visits
  - 90-minute initial intake visit
  - In-person & telephone follow-up based on acuity
  - Personalized dementia care plan revised over time
  - 24/7/365 telephone access
- Partners with community-based organizations for services

Outcomes of Dementia Care Management

Quality Outcomes
- 40% of recommended care with primary care providers
- 92% adherence to dementia quality indicators; greater use of community services

Clinical and Cost Outcomes
- Reduced patient neuropsychiatric symptoms and caregiver strain/depression
- Reduced long-term nursing home admissions by 40% and was cost-neutral to deliver

Patient/Caregiver Experience
- 90% agree intake visit was time well spent
- 95% would recommend program to others
**End-of-Life Outcomes**

- **EMR abstraction of 322 decedents enrolled in UCLA ADC program**
- **Last 6 months of life**
- **Nearly all (99.7%) had a goals-of-care conversation (median = 3)**
- **64% had advance care preferences recorded in EMR.**
- **Most patients limited care:** 88% DNR; 89% limited artificial nutrition
- **High hospice use in last 6M of life (69%)**
- **Over half (54%) had no hospitalizations or ED visits; only 5% had ICU stays**
- **Most died at home (66%)**
- **POLST completion associated with hospice care (74% vs 62%; p=.03) and death at home (70% vs 59%; p=.04)**

**UCLA ADC Program: Components of Advance Care Planning and End-of-Life Care**

- **ACP introduced at first visit and readdressed as disease progresses**
- **Identification of caregiver(s) and proxy decision-maker**
- **Elicit goals and care preferences**
- **Complete POLST and scanned into EMR in a dedicated tab**
- **Care plan sent to primary care provider for sign off**
- **Screening for caregiver strain and depression**
- **Partnership with community-based organizations for services and education (vouchers)**
- **Hospital, ED, SNF, home visits by dementia care managers (care transitions)**
- **Dementia Care Manager training in communication skills**
- **Difficult case conference**
- **Internal tracking of outcomes (red, yellow, green light system)**

**Summary**

- **Gaps exist in the quality of care for dementia patients near the end of life**
- **Advance care planning can help improve end-of-life outcomes for dementia patients**
- **Evidence-based clinical tools available**
- **More comprehensive models, policy initiatives, and new payment models may be needed to promote wider dissemination**

**Thank you**

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