Dementia Caregiving Across the Continuum: What Clinicians and Practitioners Need to Know

Mary M. Kenan, Psy.D.
Clinical Director
Amazing Place Memory Care and Wellness Center
Overview

• What is Alzheimer’s Disease (AD)
• Prevalence and Incidence
• Detection and Diagnosis
• Impact of Cognitive Impairment
• Needs, Requirements, and Challenges
• Adult day services
What is Alzheimer’s disease?

- Progressive neurological illness impairing memory, cognition, and eventually the ability to independently perform daily activities (function)
- Behavioral or psychiatric symptoms of dementia (BPSD) common
- Hallmarks: Amyloid plaques, neurofibrillary tangles, loss of connections between cells/cell death
- Variable presentation/rate of progression
- Onset begins decades before clinical symptoms detected\(^1\)
- Leading cause of dementia
- Not a normal consequence of aging

Prevalence & Incidence

• 5.4 million in America (35.6 million globally)\textsuperscript{1,2}
• 454,000+ new cases each year
• 340,000 Texans\textsuperscript{3}
• 200,000 younger than age 65 years
• Prevalence doubles every 10 years:
  – Age 65 (up to 12%)
  – Age 75 (up to 24%)
  – Age 85 (up to 48%)

\textsuperscript{1} Alzheimer’s Association, 2010 Alzheimer’s Disease Facts and Figures, Alzheimer’s & Dementia, Volume 6
\textsuperscript{2} Alzheimer’s Disease International (ADI): World Alzheimer Report 2010
\textsuperscript{3} Texas Alzheimer’s Research Consortium (TARC)
What causes AD?

• In rare instances it is genetic

• 95-99% of all AD cases considered “sporadic”

• In most cases, AD results from a combination of genetic risk factors (not mutations), lifestyle practices, and environment
Detection of AD

• History of meaningful decline from previous level of functioning
• Individual may/may not complain of forgetfulness or “slipping”
• Gradual onset and worsening of memory difficulties:
  – Repeating information or questions
  – Difficulty retaining newly learned information (episodic memory)
  – Misplacing objects
• Problems estimating time frames or keeping up with appointments
• Problems performing familiar tasks or adapting when schedule is altered
• Executive dysfunction, impaired reasoning or faulty decision making resulting in problems at work, around the home, or in social relationships
• Spatial disorientation
• Language problems
• Behavioral and psychiatric symptoms of dementia (BPSD) occur in 60-93% of PwAD during course of illness

Diagnostic Delay and Pre-diagnostic Challenges

• 22.4 months between symptomatic onset/pursuit of work up\textsuperscript{1}
• Additional 10-11 mos. may pass between initial consult & diagnosis of AD\textsuperscript{2}
• Misattribution of cognitive changes by intact spouse
• Lack of support for necessity of a work-up
• Uncertainty/disagreement re: who performs the work up
• Concern regarding disclosure of diagnosis to patient

\textsuperscript{1}Wackerbarth SB, Johnson MMS. The carrot and the stick: Benefits and barriers in getting a diagnosis. Alz Dis Assoc Disord 2002;16(4):213-220.
Entry into Caregiving Role

• Four scenarios:
  – Status of caregiver defined by formal diagnosis
  – Symptoms recognized and diagnosis obtained
  – Symptoms recognized and care provided
  – Care provided prior to recognition or diagnosis

• Less abrupt entry associated with greater decrease in caregiver well-being and less likelihood of placement\(^1\)

• Protracted period of recognition/reconciliation for caregivers of PwMCI\(^2\)


Mild Cognitive Impairment due to Alzheimer’s disease

- MCI due to AD proposed (vs. Amnestic MCI – Peterson Criteria)\(^1\)
- Assumes primary underlying pathology is AD
- Complaint regarding memory impairment (patient, informant, clinician)
- Change represents a decline from previous level of functioning
- Serial assessments ideal but may infer decline from history
- Measurable impairment in one or more cognitive domains beyond what is expected for age/educational level
- Impaired episodic memory most common in those who progress to AD
- Not due to presence of neurological/psychiatric/systemic illness or developmental disability
- Functional abilities preserved; commonly mild impairment with complex tasks
- All who develop AD pass through this state
- Spouse caregivers of those with MCI experience many of the same losses and emotional responses as those caring for persons with advanced AD\(^2\)

\(^1\) Albert MS, DeKosky ST, Dickson D, Dubois B et al. The diagnosis of mild cognitive impairment due to Alzheimer’s disease: Recommendations from the National Institute on Aging and Alzheimer’s Association workgroup. Alzheimers & Dementia 2001:1-10

Impact on Care Partners of PwAMCI

1. Depression common in PwAMCI\textsuperscript{1}
2. Depression common in care partners of PwMCI (24.6\%)\textsuperscript{2}
3. Frustration, loneliness, social isolation (self-imposed), concern re: future\textsuperscript{3}
4. Uncertainty regarding diagnosis/prognosis
5. Diminishing awareness of deficits co-existing with areas of preservation
6. Gradual awareness of need to assume decision making (new learning)
7. Difficulty determining proper level of supervision required
8. Conflict with spouse and family members related to supervision efforts
9. Internal conflict regarding “therapeutic deception”
10. Diminished social relationships/finances/premature lifestyle changes\textsuperscript{4}

Impact of Cognitive Impairment on Martial Relationship

- Quality of relationship diminishes/"degrades"
- Marital satisfaction negatively impacted by alterations in communication, consensus, expressed affection, repetition as early as AMCI stage
- Lifestyle constraint and loss of self-time associated with anxiety\textsuperscript{1}
- Level of intimacy erodes\textsuperscript{2}
- Enjoyment of companionship and reciprocity diminish\textsuperscript{3}
- Mutuality may mitigate caregiver role strain and subjective stress\textsuperscript{4}

\textsuperscript{3}Gallagher-Thompson D, Dal Canto PG, Jacob T, Thompson LW. A comparison of marital interaction patterns between couples in which the husband does or does not have Alzheimer’s disease. J of Gerontology: Social Sciences 2001;56B(3):S140-S150.
Caregiving Post-Diagnosis of AD

- 75% report receiving no emotional support from family/friends
- Poverty of informational/instrumental support provided at time of diagnosis
- Majority lacked knowledge of formal services
- Majority had no plan for meeting future care needs of patient
- Caregivers recognize and report lack of preparedness or perceived competence to provide care
- Gender and kinship influence response to caregiving role
- Among first-degree relatives, knowledge base higher but accompanied by misconceptions about AD and research/treatment developments
Consequences of Unmet Informational Needs

- Contributes to patients’ and caregivers’ worry
- May impede adjustment to illness/coping
- Interferes with planning
- Results in reliance on alternative sources of information
- Impacts quality of care provided/obtained
- Unsure what questions to ask to properly inform themselves or determine if they’ve been given enough information
- Clinicians and practitioners must initiate and guide conversations
- Few psychoeducational interventions for caregivers of those w/mild-moderate dementia
- “Tailoring” or “Dosing” of information is critical

2 Ducharme FC, Levesque LL, Lachance LM et al. “Learning to Become a Family Caregiver” Efficacy of an intervention program for Caregivers following a diagnosis of dementia in a relative. Gerontologist 2011 (advance access publication)
What Families Want from Clinicians and Practitioners

- 8 “R”s:
  - “RX” for active treatment
  - Reliable expert primary medical skills
  - Recognition of family efforts and loss
  - Reassurance of continuity
  - Relevant information re: their situation
  - Retained family control
  - Reminders (reassurance)
  - Referrals to quality, reimbursable, or low-cost services

Examining Caregiver Preparedness

• Acknowledge responsibility to self and others

• Facilitate self-examination

• Barriers to functioning in role of caregiver

• Expectations

• Identify strengths

• Assess knowledge base
Variability of Response to Diagnosis and Progression

- Response to diagnosis is unpredictable
- Proactive/Information Seeking
- Validation/Relief
- Fear/Anxiety
- Pity
- Anger/Resentment
- Guilt
- Adaptation
Empowerment in Caregiving

- “I should write a book”
- Enhanced ego-strength
- Awareness of positive qualities
- New role provides purpose
- Opportunity for reminiscence and relationship building
- Strengthening of spiritual beliefs
Caregiving Questions Post-Diagnosis

• Stage of disease
• How disease will progress/what are signs of progression
• Genetic inheritance/testing
• Prevention strategies (cognitive stimulation, diet, exercise, neuroenhancements)
• How other medications/medical conditions impact disease
• How to preserve dignity, independence, “normalcy” for PwAD
• When/how to disclose diagnosis
• Safety Concerns/circumstances warranting intervention/how to intervene
• How to manage BPSD (apathy, social withdrawal, depression, anxiety)
• Resources available (readings, websites)

• Disagreements: need for second opinion and how/where to obtain, treatment options (e.g., use of holistic, off-label/unproven therapies), treatment efficacy, whether to participate in clinical trials, level of supervision required, legal and financial disputes
Caregiving Challenges as Disease Progresses

- Whether and how to obtain formal caregiving or respite services
- Adequacy of living circumstances and safety issues
- Family members’ respective levels of participation in the caregiving process
  - Inequality in provision of care/distribution of responsibilities
  - Taking advantage of the patient
  - Long-distance vs. primary caregiver
- Issues of management and advocacy
- Need for ongoing evaluation
- Persistence of therapy
- End of life decisions: tube feeding/artificial hydration/withdrawal of life support
- Autopsy
Non-pharmacological Interventions

• First line treatment for BPSD
• Environmental Engineering
• Caregiver Counseling and Assessment (ongoing):
  – safety/supervision needs
  – daily structure and socialization
  – support/spiritual needs
  – health and wellbeing
• Needs-based/Person-Centered Referrals:
  – Alzheimer’s Association
  – Legal/Financial planners/Elder Mediators/Ombudsman
  – Geriatric Care Managers
  – Respite (e.g., adult day health center, home care/companion, ST placement options)
  – LTC options/rehabilitation following hospitalization or injury/specialists/psychiatric care
  – Social Services (AAA, APS, Sheltering Arms – day care, utility assistance)
Benefits of Counseling for Caregivers of Persons with Dementia

American Academy of Neurology

Practice Parameter:

- Educational programs should be offered to family caregivers to improve caregiver satisfaction & delay time to NH placement (Guideline)

- Functional independence can be increased by graded assistance, skills practice, and positive reinforcement (Guideline)

- Behavioral Modification and the use of scheduled toileting and prompted voiding reduces urinary incontinence (Standard)

Benefits of Adult Day Services (ADS)

- Increased use of ADS associated with lower use of home-based services $^1$
- Use of ADS associated with reduction in nighttime sleep-related problems; trend toward fewer depressive symptoms and agitation $^2$
- Engagement as function of ADS may lessen restlessness and increase positive behaviors $^3$
- Improvement in patient wellbeing (rated by caregivers) $^4$
Benefits of Adult Day Services (ADS)

• ADS use results in lower levels of caregiving-related stress and improved psychological wellbeing vs. controls

• Kin relationship moderates caregiver response to ADS intervention

• Enrollment in ADS (vs. informal/formal home-based services) more effective in reducing perceived burden: respite for caregivers and opportunities for social interaction for patients
Benefits of Adult Day Services (ADS)

• Direct counseling, education, care management, support plus ADS services results in enhanced wellbeing, greater ADS use and fewer NH placements\textsuperscript{8}

• Non-pharmacological recommendations for mild/moderate dementia include caregiver education, supportive therapy for caregivers, \textit{referral to day treatment}, exercise programs, respite\textsuperscript{9}

• 54\% of those refusing ADS score as having “possible depression” on Cornell Scale for Depression in Dementia and misconceptions about ADS\textsuperscript{10}
Take Home Messages

• Communication changes and BPSD may trigger burden for care partners in pre-dementia stage
• Practitioners should be directive and refer accordingly
• Caregiving is a multidimensional experience
• Respite services (e.g., ADS) is available for all stages of dementia
### References for ADS Studies


8. Gitlin LN, Reever K, Dennis MP, Hauck WW. Enhancing quality of life of families who use adult day services: Short and long-term effects of adult day services plus program. The Gerontologist 2006;46(5):630-639


Amazing Place: Memory Care and Wellness Center
3735 Drexel Drive
Houston, Texas 77027
713-552-0420
www.amazingplacehouston.org
The Amazing Place Mission

“To provide fellowship, memory care, and wellness for adults with Mild to Moderate memory loss and support to their families and the community”
The Creative Arts Curriculum at Amazing Place incorporates the use of various artistic mediums.
Recreational Therapy in the Courtyard at Amazing Place
Daily Clubroom Activities at Amazing Place
The Cultural Arts Series at Amazing Place: Focus on the Opera

AP participants attended Opera in the Heights in February, 2011

Members of the Houston Grand Opera Studio perform annually at AP, a generous gift made possible by the Barrow family
Intergenerational Programming at Amazing Place

The Rice School Choir performs for participants

St. John’s afterschool volunteers
Founded in 1996, thirteen sponsoring churches support the mission of Amazing Place.

The Chapel at Amazing Place

Amazing Place offers daily bible study and membership in choir for interested participants.
Wellness at Amazing Place

Dinah Brown, LVN – Program nurse at Amazing Place

Anne Helton, RN, BSN, MS, Health Services Consultant at AP with her University of Texas Community Health Nursing Student students at Amazing Place
Powerful Tools for Caregivers© Course (shown below) is held bi-annually at AP along with a weekly and monthly support group, monthly Q & A with AP’s Clinical Director, and quarterly family educational forums.
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