ALZHEIMER’S DISEASE & EMERGENCY PLANNING CHALLENGES FOR STATE AND LOCAL HEALTH PROFESSIONALS AND COMMUNITY PARTNERS

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LEARNING OBJECTIVES

• What is Alzheimer’s Disease?
• How big a public health problem is this?
• How does it affect the older adult and their caregivers?
• What are the implications for emergency preparedness?
• What can we do about it?

PROGRESSION OF MEMORY CHANGES

The continuum of Alzheimer’s disease

Sperling et al. (2011): Alzheimer’s & Dementia
Causes of dementia (types)

Dementia is a group of brain disorders that results in the loss of intellectual and social skills severe enough to interfere with day-to-day life.

There are many causes of dementia.

Most common causes:

- Alzheimer's disease: 50-80%
- Vascular disease: 10-20%
- Dementia with Lewy bodies: 5-10%
- Frontotemporal dementia: 12-25%

Alzheimer’s disease

Age usually >65 in sporadic cases (Late Onset AD).
- 11% of older persons may have Alzheimer's Disease
- 60-70% of persons living in nursing facilities may have Alzheimer's
- F>M
- Mean duration ~8 yrs. Range 2-20 yrs.
- Early Onset AD in 50s is extremely rare
- Genetic mutations in Amyloid Precursor Peptide
- Increased risk associated with ApoE e4 allele

APOE AND ALZHEIMERS

[Image of a graph showing risk of Alzheimer's disease with different ApoE genotypes over age]


THE ALZHEIMER’S BRAIN

[Image of a brain scan showing Alzheimer's disease]

THE ALZHEIMER’S BRAIN

DIAGNOSTIC FEATURES

• Memory impairment
• One or more of the following:
  • Aphasia—(problems with communication)
  • Apraxia—(problems with movements despite intact motor function)
  • Agnosia—(problems recognizing faces/objects despite intact sensation)
  • Disturbance in executive functioning (planning, problem solving, anticipating outcomes)
• Represent a decline from prior levels of function
• Interfere with social/occupational functioning
• Slowly progressive
• No other etiology per neuro exam, labs, imaging


ALTERNATIVE GUIDELINES

- Memory criteria reflects an “Alzheimerization” of dementia
- AD presents with early, severe memory impairment, other dementias may not
- Alternative is impairment in multiple domains that impact daily function

STAGES

- 1. Decline in memory
  - personality change
  - executive impairment
- 2. Cortical phase
  - Aphasia
  - Apraxia
  - Agnosia
- 3. Physical decline
  - Incontinence
  - Gait d/o
  - Dysphagia
  - Mute

ALZHEIMER’S IS GROWING!

- Today, 5.3 million Americans are living with Alzheimer’s disease, more than 95% of them are over the age of 65. By 2050, up to 16 million will have the disease.
- Within the next 10 years, 19 states will see a 40 percent or greater growth in the number of people with Alzheimer’s.

MORE WOMEN ARE AFFECTED

ALMOST TWO THIRDS of Americans with Alzheimer’s disease are women.

POOR AWARENESS!

- Only about half have ever been diagnosed.
- Among individuals diagnosed with the disease, only 33% are aware they have it.

ALZHEIMER’S CARE IS EXPENSIVE

2015 Costs of Alzheimer’s = $226 Billion

In 2015, Alzheimer’s and other dementias will cost the nation $226 BILLION.

By 2050, these costs could rise as high as $1.1 TRILLION.

Average per-person Medicare spending is three times higher for those with Alzheimer’s compared to all other seniors.

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ALZHEIMER’S KILLS

- 6th leading cause of death in the United States.
- Deaths from Alzheimer’s increased 71% from 2000 to 2013, while deaths from other major diseases (including heart disease, stroke, breast and prostate cancer, and HIV/AIDS) decreased.
- In 2013, over 84,000 Americans officially died from Alzheimer’s; in 2015, an estimated 700,000 people will die with Alzheimer’s — meaning they will die after having developed the disease.
- Alzheimer’s is the only cause of death among the top 10 in America that cannot be prevented, cured, or even slowed.

TOLL ON CAREGIVERS

- In 2014, 15.7 million family and friends provided 17.9 billion hours of unpaid care to those with Alzheimer’s and other dementias — care valued at $217.7 billion.
- 34% of Alzheimer’s caregivers are over 65 years old.
- 60% of Alzheimer’s and dementia caregivers rate the emotional stress of caregiving as high or very high; about 40 percent suffer from depression.
- Three-quarters of Alzheimer’s and dementia caregivers report that caregiving made their health worse.

IMPACT ON FAMILY CAREGIVER

- The number with Alzheimer’s disease and other dementias in the USA in 2013 is predicted to more than double by 2050 (13.8 million).
- Caring for someone with Alzheimer’s can lead to deterioration in caregivers’ physical health, psychological well-being and social relations.
- Two-fifths of baby boomer caregivers in our study reported having high blood pressure or arthritis.
- Caregivers of persons with dementia experience greater burden and strain from dementia caregiving compared to those of people without dementia.
CAREGIVER ROLE IN BPSD

- Research has demonstrated that a reduction in neuropsychiatric symptoms decreases patient injuries, hospitalization rates, and caregiver burden.
- Group education programs and interactive coaching tailored to the unique needs of the caregiver is effective at decreasing BPSD.
- Short-term outcomes of such a program include increased caregiver knowledge, improved caregiver perceived self-efficacy, and positive attitudes regarding non-pharmacological therapy.
- Non-pharmacological therapy, including music, exercise, aromatherapy, and massage, is safe and effective.


RISK AND PROTECTIVE FACTORS

- Plassman et al, 2010 – NIH Conference
- Observational studies
  - Increased risk associated with depression, diabetes, smoking, ApoE e4
  - Decreased risk associated with Mediterranean diet, vegetable intake, physical activity, cognitive engagement
- RCT’s
  - Physical activity, cognitive training/engagement
  - ACTIVE study (Ball et al., 2002; JAMA 288(18):2271-2281)
RISK FACTORS AND WHAT THEY SUGGEST

- Observational studies
  - Increased risk associated with depression, diabetes, smoking,
  - Alzheimer's co-morbidity: depression, anxiety, delusions, hallucinations, agitation and aggression
- Memory Issues
  - Confusion
- Impaired Functioning - ADLs related to lower mobility, urinary incontinence, Steadiness on feet, Vision impairment
- Inability to meet basic needs
- Inability to communicate basic needs

ALZHEIMER'S AND SHELTERING-IN-PLACE

- Many older persons prefer to shelter-in-place during disasters
- Isolated seniors with Alzheimer's are likely to be among that group
- Louisville experience
  - They may require family or first responders to check on them
- May have heightened needs for food, water, medications
  - Not able to understand public communication so they may not have any idea what has happened
- Connect to service providers as soon as possible—
  - Area Agencies on Aging, Home Health providers, Meals on Wheels, Neighbors

PLANNING FOR PERSONS WITH ALZHEIMER'S

- Establish emergency plans for Individuals and Family Members
- Include functioning and memory issues on the plan, if possible
  - Be sure to include contact information for caregivers, service providers, family members and health care providers
- Update medication list on plan as often as possible
  - Be sure to include all assistive devices on the list, including eyeglasses, hearing aids, walkers, etc.
- Put plan in plastic sleeve on refrigerator door or other easy access if evacuation is necessary
  - First responders—don’t forget to bring meds, plan, assistive devices if evacuating person
PLANNING FOR PERSONS WITH ALZHEIMER’S

• Enroll in the Medic Alert System, and
• the Alzheimer’s Association Safe Return Program for 24-hour nationwide response for wandering and medical emergencies

EMERGENCY GO-KIT

• The kit might contain:
  • warm clothing
  • sturdy shoes
  • spare eyeglasses
  • hearing aid batteries
  • incontinence undergarments, wipes, and lotions
  • pillow, toy, or something the person can hold onto
  • medications
  • water

EMERGENCY GO-KIT

• The kit might also contain:
  • favorite snacks and high-nutrient drinks
  • zip-lock bags to hold medications and documents
  • copies of legal, medical, insurance, and Social Security information
  • physician’s name, address, and phone number
  • recent photos of the person with Alzheimer’s

PLANNING FOR PERSONS WITH ALZHEIMER’S

• Develop a Buddy Plan
  - Establish at least one person living in proximity as a Buddy
  - The Buddy will check on the person regularly and agrees to check on the person with Alzheimer’s in the event of a disaster
  - The Buddy is aware of the emergency plan for the person
  - Have a Buddy Agreement signed and in place
  - Family members can communicate with the Buddy in a disaster

EMERGENCY SHELTERING AND PERSONS WITH ALZHEIMER’S

• It is estimated that over 50% of persons evacuating to emergency shelters are over 60 years old.
• An estimated 11% of older persons have Alzheimer’s Disease plus an additional percentage with related dementias
• In an 80-bed emergency shelter, approximately 4+ persons may have Alzheimer’s
• In a 200-bed shelter, approximately 10+ persons may have Alzheimer’s

EMERGENCY SHELTERING AND PERSONS WITH ALZHEIMER’S

• Keep in mind two-thirds (67%) of persons with Alzheimer’s are not aware of their diagnosis
• They may not present as confused initially
• Assessment may be difficult as they may be so adaptive
• Once assessed in the shelter, try to connect with a caregiver, family member or service provider
• In the absence of a caregiver, try to connect a volunteer, etc. to monitor the person on a regular basis
• Family caregivers may be more stressed to manage the person in the shelter and may need support
Emergency Sheltering and Persons with Alzheimer’s

The person with Alzheimer’s might present in a shelter as:
- Very anxious
- Behaving erratically
- Withdrawn
- Or, highly adaptive

Shelter staff can manage effectively by:
- Remaining calm and supportive
- Set an even tone of voice to reassures
- Be sensitive to his or her emotions
- Stay close, offer your hand, lower yourself to their eye level
- Do not leave him or her alone

To lessen potential for chaos or crisis in the shelter
- Make sure obstacles, wiring, barriers are managed as falls risk is very high
- Select a separate room or space for persons with Alzheimer’s to allow for:
  - Persons with Alzheimer’s benefit from a regular sleep schedule so lighting needs to be adjusted at bedtime
  - Lots of noise or loud noises can exacerbate behavioral symptoms
  - Routine is very beneficial to persons with Alzheimer’s. Eating schedules, toileting schedules, sleep schedules
  - Security is very important for shelter operators to avoid Golden Alerts
  - Persons with Alzheimer’s may wander off if exits are not monitored

Ideally, shelters may assign one-to-one volunteers to the persons with Alzheimer’s
- Train shelter intake / assessment staff and teams about the Alzheimer’s Association Safe Return Program to connect evacuee with family
- Create a shelter toolkit for Persons with Alzheimer’s
  - Games
  - Playing cards
RESOURCES AND PARTNERS

- Local Alzheimer’s Association
- Groups of Alzheimer’s caregiver alumnus
- Area Agencies on Aging
- Nursing students
- CNA faculty at community colleges
- Churches
- Retired social workers, nurses, CNAs
- Geriatricians

RESOURCES AND PARTNERS

- Alzheimer’s Disease and Disaster Preparedness;
  [Link](http://www.nia.nih.gov/alzheimers/publication/alzheimer-disease-and-disaster-preparedness)
- Alzheimer’s Association, Disaster Preparedness;
  [Link](http://www.alz.org/national/documents/topicsheet_disasterprep.pdf)
- Alzheimer’s and Dementia Caregiver Center
  [Link](https://www.alz.org/care/alzheimers-dementia-disaster-preparedness.asp)
- Prepares for a Disaster—For Seniors By Seniors
  [Link](http://www.redcross.org/images/MEDIA_CustomProductCatalog/m16740732_sdarc_senior_disaster_booklet.pdf)

SUMMARY

- Alzheimers is one form of dementia
- Can be due to abnormal proteins or energy metabolism
- It takes a toll on caregivers
- It can affect how patients respond to emergencies
- Awareness and preparation will aid in response
References:


We welcome all questions---
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