Coping Strategies for Alzheimer's Disease Caregivers

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NIA-AA CORE CLINICAL DIAGNOSTIC CRITERIA FOR ALL-CAUSE DEMENTIA AND DEMENTIA DUE TO ALZHEIMER DISEASE

DEMENTIA

- The patient has cognitive or behavioral symptoms that:
  - Interfere with the ability to function at work or at usual activities
  - Represent a decline from previous levels of functioning and performing
  - Are not explained by delirium or major psychiatric disorder
  - Cognitive impairment is detected and diagnosed through a combination of:
    - History-taking from the patient and a knowledgeable informant
    - An objective cognitive assessment, either a “bedside” mental status examination or neuropsychological testing

DEMENTIA

- The cognitive or behavioral impairment involves a minimum of two of the following domains:
  - Impaired ability to acquire and remember new information
  - Impaired reasoning, judgment, and handling of complex tasks
  - Impaired visuospatial abilities
  - Impaired language functions
  - Changes in personality, behavior, or comportment

DEMENTIA

- Diagnostic criteria for DSM-5 “major neurocognitive disorder” require a significant cognitive decline in one or more cognitive domains:
  - complex attention
  - executive function
  - learning and memory
  - language
  - perceptual-motor
  - social cognition

PROBABLE DEMENTIA DUE TO ALZHEIMER DISEASE

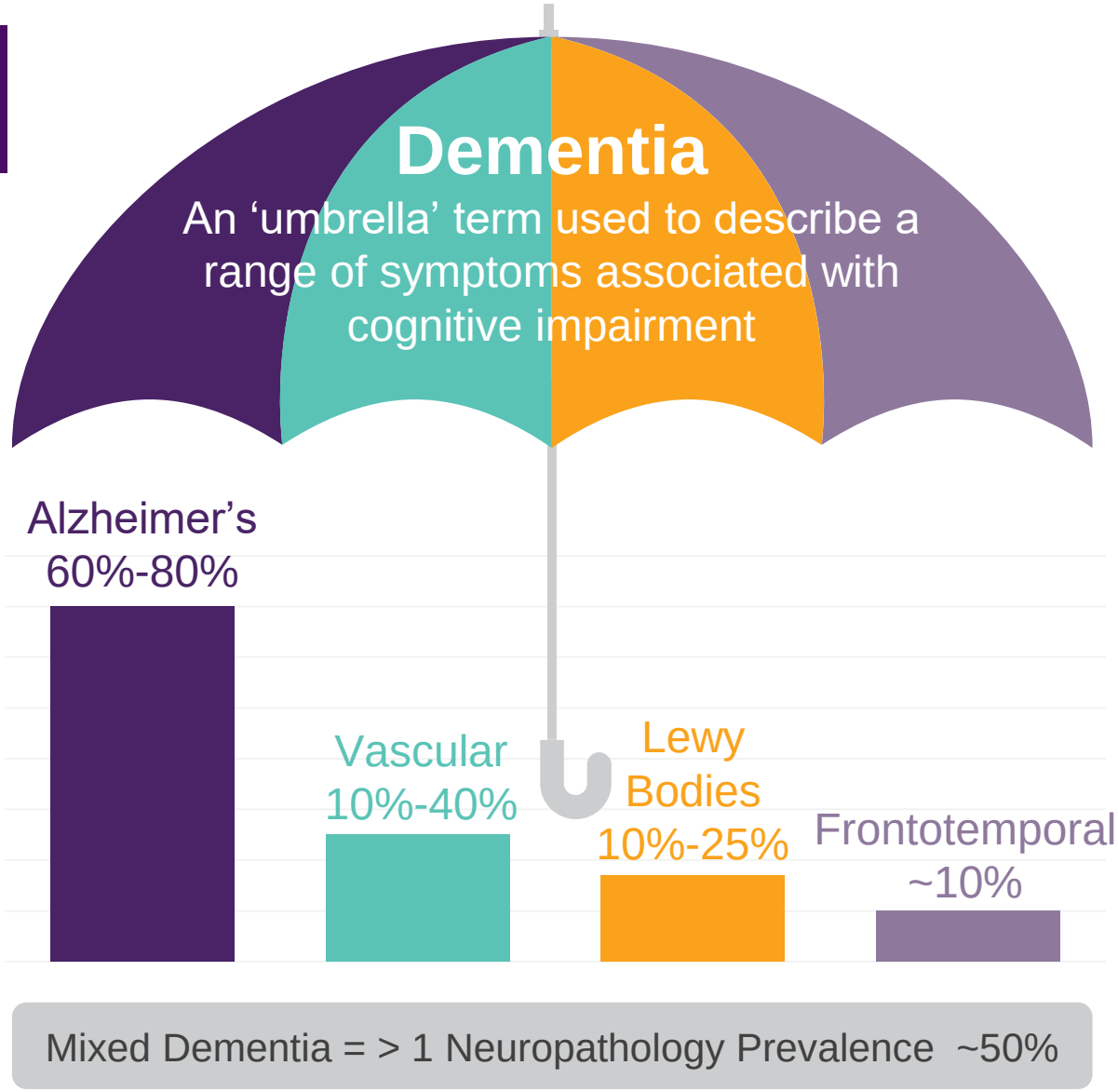
- The patient meets criteria for dementia and has the following characteristics:
  - Insidious onset over months to years, not sudden over hours or days
  - Clear-cut history of worsening cognition by report or observation
  - Initial and most prominent cognitive deficits are evident on history and examination in one of the following categories:
    - Amnestic presentation (most common presentation)—Deficits should include impairment in learning and recall of recently learned information, plus cognitive dysfunction in at least one other cognitive domain.
    - Nonamnestic presentations :
      - Language presentation—word funding
      - Visuospatial presentation—spatial cognition
      - Executive dysfunction—impaired reasoning, judgment, and problem solving
      - Deficits in other cognitive domains should be present

PROBABLE DEMENTIA DUE TO ALZHEIMER DISEASE

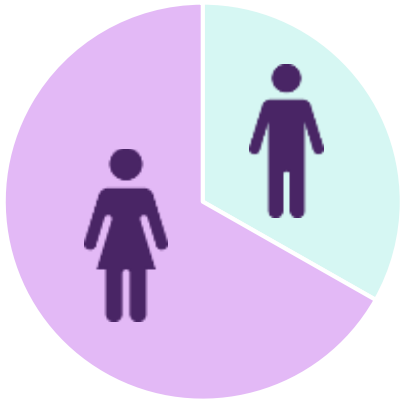
- The diagnosis of probable AD dementia should not be applied when there is evidence of:
  - Substantial concomitant cerebrovascular disease (defined by a history of a stroke temporally related to onset or worsening of cognitive impairment or presence of multiple or extensive infarcts or severe white matter hyper-intensity burden)
  - Core features of dementia with Lewy bodies
  - Prominent features of behavioral variant frontotemporal dementia
  - Prominent features of primary progressive aphasia
  - Active neurologic disease or a medical comorbidity or use of medication that could have a substantial effect on cognition

DEMENTIA IS A SYNDROME

- Dementia is a collection of symptoms related to cognitive decline
- Can include cognitive, behavioral and psychological symptoms
- Due to biological changes in the brain
- Alzheimer's is most common cause



GENDER, RACIAL & ETHNIC DISPARITIES IN ALZHEIMER'S PREVALENCE & CLINICAL TRIALS



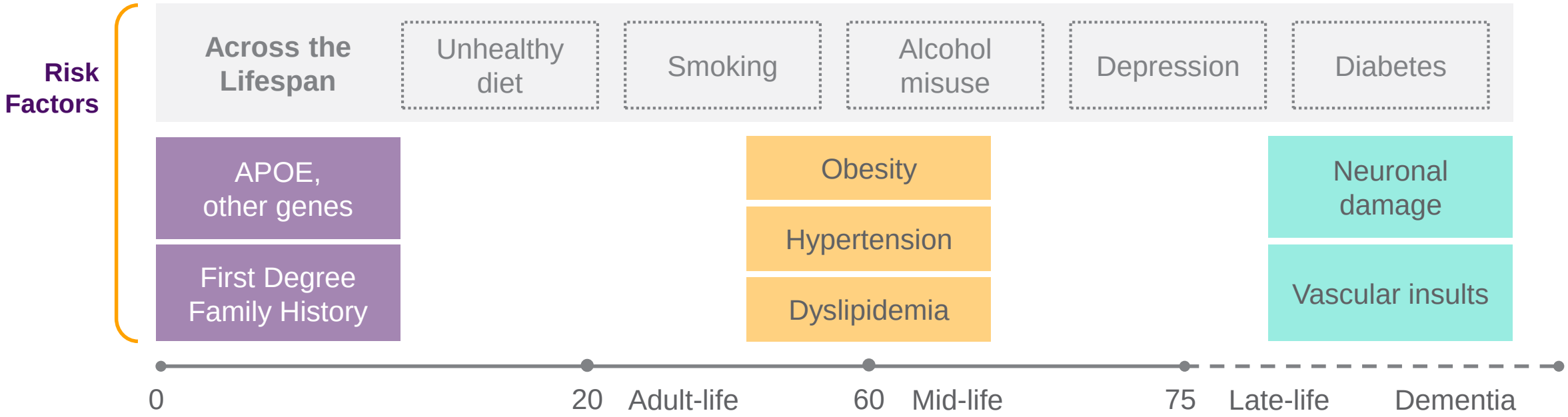
Almost **two-thirds** of Americans with Alzheimer's are **women.**

Older **Black** and **Hispanic** Americans are disproportionately more likely than older **Whites** to have Alzheimer's or other dementias.

Ethnoracial groups have been historically **underrepresented** in clinical studies, underscoring the need for more **diversity** in dementia research.

HEALTHY AND PATHOLOGICAL AGING?

Importance of Chronic Exposure to Multiple Factors



AD Risk

impact on neuron viability, inflammation, oxidative stress, glucose metabolism, endothelial cell damage, clearance of tau and b-amyloid from brain

GENETICS AND ALZHEIMER'S

alzheimer's association
AAIC 20

We need to better understand how **genes impact Alzheimer's risk in different peoples**

HISPANICS ARE

1.5

times more likely to develop dementia than non-Hispanic whites

The **ApoE-e4** gene is the strongest known predictor of Alzheimer's risk for White, European-descended populations.

ACCORDING TO NEW RESEARCH REPORTED AT #AAIC20, this gene seems to be a less accurate predictor of risk for some Latin American populations.

Additionally, genes that determine Alzheimer's risk **MAY DIFFER AMONG HISPANICS OF VARIOUS ORIGINS**

This suggests **testing positive for ApoE-e4**

MAY NOT MEAN THE SAME FOR ALZHEIMER'S RISK ACROSS RACIAL/ETHNIC GROUPS

Caregivers and burden

- The stress and burden associated with caring for people with Alzheimer disease (PwAD) not only affects the health of caregivers and increases their mortality risk, but also reduces the quality of caregiving.

- Caregivers of PwAD report more stress, burden and depression compared to caregivers of people with other dementias.

- Coping may modify the impact of stressful situations on quality of life.

Coping

- Coping strategies are defined as specific behavioral and psychological efforts to handle or minimize stressful events.

- Coping is a dynamic process, as
  - It consists of a series of reciprocal responses through which the individual and the environment interact and influence each other, and
  - It includes a series of intentional actions, both cognitive and behavioral, meant to control the negative impact of the stressful event or situation.

- Coping strategies may be an important and theoretically modifiable determinant of psychological morbidity.

Types of coping

- They include all the cognitive, emotional and behavioral measures adopted by an individual in response to specific internal and/or external demands that are deemed to exceed his or her normal resources.

People with AD may exhibit the following behaviors:

- Extreme anxiety about daily life, which may be exhibited by
  - asking questions and repeating information about once familiar events and/or people,
  - preparing for appointments/day care well ahead of time
  - using notes and reminders endlessly

People with AD may exhibit the following behaviors:

- Apathy or a lack of initiative about tasks that used to be routine, though now feel overwhelming.
  - For example, the person who always enjoyed puzzles but no longer does them because they are too overwhelming and require skills he/she no longer possesses.

- Frequent agitation may occur as people become less able to interpret their environment and control or express their feelings.
  - For example, a person with AD may strike out at a caregiver.

Coping strategies

1. Set realistic and attainable goals

- Often, caregivers try to make everything all right and strive for unrealistic goals and end up exhausted and frustrated.
- Perhaps your goal is to be sure that your patient is clean, comfortable and well fed.
- But accepting success at 80 percent, for example, will allow you to enjoy time you might have otherwise spent fretting about not reaching your goals.
- Although difficult, try to be comfortable with a less than perfectly groomed spouse or perfectly organized home.

2. Anticipate misinterpretation by your patient.

- A person with AD may no longer be able to accurately interpret verbal or non-verbal cues, which can cause anxiety and frustration for both you and your patient.
- Try to be clear and concise in your communications—repeating things as needed using the same words or message.
- Reduce extraneous noise and distractions when trying to communicate.
- Do not use confusing pronouns, such as he, she or it, but rather names and specific titles.

3. Remember that all behavior has a purpose.

- Many experts believe that some of the behavioral symptoms that people with AD exhibit, such as shouting or striking out, are meaningful.

- Although the person does not generally intend to disrupt things or to hurt someone, they do intend to be noticed and perhaps communicate a need that is not being met.

3. Remember that all behavior has a purpose.

- In addition, it is important to remember that while these behaviors are meaningful, they are not intentional and the person is not doing this "on purpose," but more likely trying to convey a message that they can longer explain in words.

- Slowing down, trying to see the world through their eyes and trying to respond to the "feeling" behind the behavior, rather than the behavior itself, may prevent an emotional crisis.

4. Enjoy the good times.

- Many people with AD remain physically fit and retain their ability to be comfortable and involved in social situations quite late in the disease.
- Therefore, continue to socialize, travel, be physically active and participate in activities that are enjoyable to both you and your patient.
- Often, familiar activities will continue to be enjoyable for a person with AD and should be encouraged.
- However, trying to learn new tasks or starting new hobbies may be frustrating or overwhelming.

5. Reminisce about the past

- **Reminisce about the past** and encourage discussions about people and places that are familiar and evoke pleasant feelings for both you and your patient.
- Memories from the distant past are not usually affected and watching family videos, looking at photographs or reviewing travels from the past can allow you and your patient to continue to share experiences and feelings.
- Allow your patient to share the history they remember with family members, grandchildren and friends.
- This is fun for everyone and helps your patient feel connected to their loved ones.

6. Be flexible

- Remember that AD is a progressive disease.
- Your patient's symptoms and needs will change over time.
- If strategies such as notes or reminders are no longer working, don't use them.
- A successful intervention at one stage may become a frustration and disaster at another.

6. Be flexible

- Seek help, ask for advice and learn from others who have had similar experiences.
- More challenging behavioral symptoms of a patient with AD, such as resisting care or being aggressive, can be particularly difficult for a caregiver and often require a very individualized approach.
- Talk to your doctor about treatment approaches, both pharmacological and non-pharmacological.

Safety

- Your patient's safety is an important priority.
- As the disease progresses, memory and judgment become impaired and patients are often unable to anticipate or avoid dangerous situations.
- This can be an overwhelming responsibility for a caregiver and requires creative strategies for coping.
- The following recommendations may help ensure your patient's safety.

Supervision

- **Supervision** may become necessary for people with AD as they become more forgetful and their judgment decreases.
- It is best to assess each situation individually and gradually increase your patient's level of supervision as needed.
- This will help them maintain as much independence and autonomy as possible in as safe a setting as possible.
- It is often difficult to determine the level of supervision needed.
- It involves evaluating the risks and consequences of your patient's current and potential behavior and the ease/discomfort involved in protecting your patient.

Supervision

- When evaluating your patient's need for supervision, behaviors to review include:
  - Ability to handle emergencies when left unsupervised
  - Ability to use appliances safely
  - Ability to safely answer the phone or door when left alone
  - Tendency to wander.

Supervision

- Tendency to wander.
  - This may occur in later stages when patients are confused about where they are or are trying to find a familiar person or place.
  - If there is a concern about this, enrolling your patient in the Safe Return program should be considered.
  - This program, which is administered by the Alzheimer's Association, provides national registration and identification of people with AD to assist in locating them should they wander away or become lost.

Supervision

- Supervision strategies may include:
  - Simple reminder phone calls for medications
  - Alarms on doors to prevent exiting
  - Personal supervision to prevent physical injury or harm

Modifying the environment

- **Modifying the environment** to limit your patient's exposure to potentially dangerous situations can allow them to continue to be independent and safe.

- Especially in the early stages of AD, reminders and cues in your patient's environment may be enough to ensure their safety.

- For example, posting the steps involved in a task or labeling where things are kept may be extremely helpful to your patient.

Modifying the environment

- In the later stages of the disease, you may need to employ strategies that limit your patient's exposure to potentially dangerous situations, such as installing childproof handles on cupboards containing potentially dangerous materials.

Vision: A world without

Alzheimer's disease

and all other dementia.™

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