



# Social Work & Dementia Training

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## Learning Objectives:

- History of Social Work in the US
- Role of Social workers in the present
- Learn about AD and related dementias
- Risk and risk reduction in AA and Latino communities
- Providing care to dementia patient and family
- Identify risk of patients that predispose them to develop cognitive impairment
- Benefits, home and community-based services, and social services

## History of social Work Profession

For more than 120 years, the social work profession in the United States has helped bend the arc of justice, making our nation a more equitable and inclusive place, (NASW, 2021)

Originating in volunteer efforts for social betterment in the late 19th century in Europe and North America Social Work became an occupation in the early 20th century and achieved professional status by the 1920s

The 1930 census classified social work as a profession for the first time.

Began as one of several attempts to address the increasing poverty in a productive and prosperous economy.

In the 21<sup>st</sup> century, social work was licensed in all 50 states.

In 1969, NASW, which had previously required the MSW for full membership, opened full membership to individuals with a baccalaureate degree from programs approved by CSWE.

Over 800,000 people in the United States identified themselves as social workers. However, many of those employed as social workers were not professionally educated.

There are more than 700,000 professional social workers employed in the United States.

Social Workers contribute to interdisciplinary care teams in schools, hospitals, mental health centers, nonprofits, corporations, the military—and in local, state, and federal government.

Many social work professionals also own private consultation practices.

Public opinion distorted "takes kids away"

## Throughout U.S. history, social workers have:

Fought for civil and voting rights for people of color.

Protested American intervention in wars

Achieved the minimum wage and safer workplaces for poor people.

Expanded reproductive and employment rights for American women

Supported marriage and employment protections for LGBT people

Advocated for immigrants seeking asylum

Pushed for sensible gun laws and antiviolence initiatives Raised awareness about HIV/AIDS prevention and treatment

Fought for client privacy and mental health services

## Social work today

Social Workers are a vital part of a multidisciplinary team

#### Medical:

- Pediatrics Specialties
- Post Op
- Discharge to Community
- Geriatric

#### Psychiatric

- Clinical -
- Individual
- Group Therapy

Community Services

Governmental

State
County
City Agencies

Non-Profit Agencies

Private Organizations

# Social Work and Dementia

Unites all three areas when a Patient is diagnosed

- Medical (Neurology)
- Psychiatric (Neuro-Psychiatry)
- •Community (Resources and Benefits)

Direct Patient Care

Supportive Counseling and Early-Stage Groups

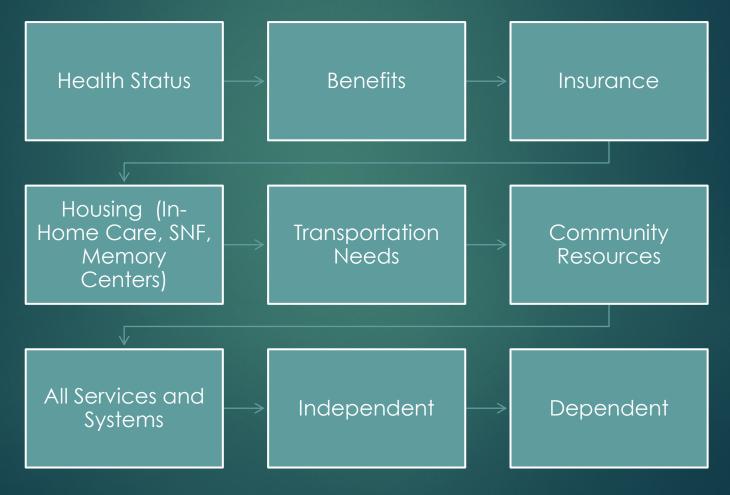
Caregiver is primary focus

Support Groups, Education, Therapy

Long Term Care Planning

Referrals, More Education, Economics

## Assessment of needs: Elder Care





# What is Dementia?

- Dementia is the term applied to a set of symptoms affect memory, thinking, and behavior.
- The symptoms are severe enough to interrupt everyday life and daily activities.
- Dementia is NOT and psychiatric condition!

## Dementia: Cognitive and Psychological changes

#### Cognitive Changes:

- Memory loss
- Difficulties with:
  - communicating
  - visual and spatial abilities
  - Reasoning/problem-solving
  - handling complex tasks
  - planning and organizing
  - coordination and motor functions
- Confusion and disorientation

### Psychological changes

- Personality changes
- Depression
- Anxiety
- Inappropriate behavior
- Paranoia
- Agitation
- Hallucinations

## Causes of Dementia

- Dementia is caused by destruction to or loss of nerve cells and their connections in the brain.
- Depending on the area of the brain, dementia can affect people differently and cause different symptoms.
- Dementias are grouped by what they have in common, such as the protein or proteins deposited in the brain, or the area of the brain affected.
- There are 2 types of dementias: Progressive and reversible

## Types of Dementias

## Progressive (neurodegenerative):

- Alzheimer's disease
- Vascular
- Mixed
- Frontotemporal
- Lewy body
- Other Dementias:
  - ► Huntington's disease.
  - ► Traumatic brain injury (TBI).
  - Creutzfeldt-Jakob disease
  - Parkinson's disease.

#### Reversible:

- Infections
- Immune disorders.
- Metabolic problems
- Endocrine abnormalities.
- Nutritional deficiencies.
- Medication side effects
- Subdural hematomas
- Brain tumors.
- Normal-pressure hydrocephalus.

## Dementia Risk Factors

#### Risk Factors that Can't be Changed:

- Age
- Level of Education
- Family history
- Down syndrome
- Intellectual abilities

#### Modifiable Risk Factors

- Diet
- Exercise
- Cardiovascular risk factors
- High Blood Pressure
- Depression
- Diabetes management
- Excessive alcohol use
- Tobacco Smoking



# What is Alzheimer's Disease

- Most common cause of dementia.
- Not all causes of Alzheimer's disease are known.
  - a small percentage are related to gene mutations.
- Cause plaques and tangles in specific areas of the brain.

## Alzheimer's Disease Changes

#### Cognitive:

- Memory Loss
- Difficulty thinking and understanding
- Mental decline
- Confusion
- Delusion
- Disorientation
- Difficulty concentrating
- Inability to do simple math

#### Behavioral:

- Aggression
- Agitation
- Unable to self care
- Irritability
- Repetition
- Personality changes
- Restlessness
- Lack of restraint
- Wandering and getting lost

## Alzheimer's Disease Changes

#### Mood:

- Anger
- Apathy
- General discontent
- Isolation
- Mood swings

#### Psychological:

- Depression
- Hallucination
- Paranoia

#### Also common:

- Unable to coordinate muscle movement
- Jumbled speech
- Loss of appetite

## Vascular Dementia

#### Causes:

- Narrowing and blockage of the small blood vessels
- Reduced blood flow
- Strokes (single or multiple TBAs)
- Brain cell (neurons) death

These tend to be more noticeable than memory loss.

(Most people with Vascular Dementia also have Alzheimer's disease)

#### Symptoms

- Slowness of thought
- Difficulty with planning
- Problems with concentration
- Changes in mood, personality or behavior
- Disorientation and confusion
- Difficulty walking and keeping balance
- Memory and language issues (not as noticeable as others)

### Mixed Dementia

#### Cause:

- Mixed dementia is a condition in which brain changes as the result of more than one cause of dementia occur simultaneously.
- Most Common:
  - Alzheimer's and vascular
  - Alzheimer's and Lewy Body

#### Symptoms:

- Mixed dementia symptoms may vary, depending on the type of brain changes involved and the brain areas affected.
- A person with mixed dementia experiences a mixture of the symptoms associated with the types of dementia they have.

## Fronto-Temporal Dementia (FTD)

#### Risks:

- An umbrella term for a group of rare brain disorders that affect the frontal and temporal lobes.
- Both areas of the brain are generally associated with personality, behavior, and language.
- Starts between 40-65 years
- Genetic Predisposition

Clusters of symptom tend to occur together, and people may have more than one cluster of symptoms.

## Fronto-Temporal Dementia (FTD)

#### Causes:

- Atrophy of the frontal and temporal lobes of the brain
- Accumulation of proteins in the brain.
- Genetic mutations

#### Symptoms:

- May have speech and language problems
- May have problems with movement
- Behavior
- Personality
- Thinking
- Judgment
- May become impulsive
- Emotionally indifferent
- Hygiene issues

## Lewy Body Dementia (LBD)

#### Causes:

- Mainly Unknown
- Changes in the brain due to deterioration (shrinking)
- Genetic Mutations
- Frontotemporal dementia is often misdiagnosed as a psychiatric problem or as Alzheimer's disease.

#### Risks:

- Age
- ▶ Gender.
- Family history

## Lewy Body Dementia LBD

#### Causes:

- Protein deposits, called Lewy bodies
- This protein is also associated with Parkinson's disease
- People who have Lewy bodies in their brains also have the plaques and tangles associated with Alzheimer's disease
- The second most common type of progressive dementia after Alzheimer's disease

#### Symptoms:

- Hallucinations (all types)
- Movement disorders.
- Poor regulation of body functions (autonomic nervous system).
- Cognitive problems.
- Sleep difficulties.
- Inconsistent attention
- Depression.
- Apathy.

# How are Dementias Diagnosed

- Doctors diagnose Alzheimer's and other types of dementia based
  - Family History
  - Medical history
  - Physical examination
  - Neurological exam
  - Memory Screening
  - Laboratory tests
  - Imaging
  - Changes in thinking, behavior, and function.

#### Challenges Diagnosing

- PCPs can diagnose a person with dementia with a high level of certainty.
- May not be able to determine the exact type of dementia due to:
  - the symptoms
  - brain changes of different dementias can overlap.
  - In some cases, a doctor may diagnose "dementia" and not specify a type.
- It may be necessary to see a neurologist, psychiatrist, psychologist or geriatrician.

## CDR Clinical Dementia Rating

## The Clinical Dementia Rating (CDR)

- is a widely utilized clinical tool for grading the relative severity of dementia with scores that range from 0 (no impairment) to 5 (terminal impairment)
- Patients with MCI/Early-Stage Dementia typically have a CDR of 0.5

#### Scale in Points

- Normal (No symptoms)
- 0.5 Mild Cognitive Impairment ( MCI )
- 1 Mild
- ▶ 2 Moderate
- ▶ 3 Severe
- ▶ 4 Profound
- ▶ 5 Terminal

# Alzheimer's Association & stages

- No Impairment
- ▶ 2 Very Mild Decline
- ▶ 3 Mild Decline
- 4 Moderate Decline (Mild or Early)
- ▶ 5 Moderately Severe Decline
- ▶ 6 Severe Decline ( Mid Stage )
- ▶ 7 Very Severe Decline

## 3 Stage Model

- ▶ 1 Mild/Early Stages
  - ▶ 2-4 years
- 2 Moderate/Middle Stage
  - ▶ 2-10 years
- ▶ 3 Severe/Late Stages
  - ▶ 1–3+ years

### Treatments

#### Medication:

Neurodegenerative dementias of all types are progressive, and fatal.

- Medications cannot cure them, however there are currently two types available for treatment:
  - One new treatment attacks the source of the disease, plaques.
  - ► The Other treatments may help decrease some of the symptoms, such as memory loss and confusion.

#### FDA approved therapies

- The U.S. Food and Drug Administration (FDA) has approved medications that fall into two categories:
  - ► Therapies that may alter the progression.
  - Therapies that temporarily diminish some symptoms of the disease.

## Approved Therapies and Use:

## Therapy that <u>may</u> modify the <u>progression</u> of the disease

- ► Aducanumab (Aduhelm™): is an anti-amyloid antibody intravenous (IV) infusion therapy approved for Alzheimer's disease.
- Available for Early-stage dementia and MCI
- Patient must be able to consent to the treatment, due to side effects.

Therapies that <u>may</u> modify the <u>symptoms</u> of the disease:

- Cholinesterase inhibitors:
- ► All Stages:
  - Donepezil (Aricept®)
- Mild to Moderate Stages:
  - Rivastigmine (Exelon®)
  - Galantamine (Razadyne)
- Glutamate regulators:
- All stages:
  - Namenda (Memantine®)

# What to Expect Post Diagnosis:

#### **Patients**

- Anger
- Relief
- Denial
- Depression
- Resentment
- Fear
- Isolation
- Sense of loss

#### Caregivers:

- New role (s), (depending stage)
- Confusion on what to do
- Emotional burden
- Care Planning (financial, Legal, etc.)
- Work together
- Avoid stress
- Make a positive changes
- Ask for support from family and friends.
- Work with medical providers

# Dementia Rates among AA and Latino populations

Prevalence of Alzheimer's disease and related dementias among people ages 65 and older (CDC, 2018)

- African Americans have the highest prevalence (13.8 percent)
- Hispanics (12.2 percent)
- Non-Hispanic whites (10.3 percent)
- American Indian and Alaska Natives (9.1 percent)
- Asian and Pacific Islanders (8.4 percent)
- AA and Latinos are less likely to be diagnosed

## Risk factors for AD and Related Dementias:

- African American community High blood pressure and diabetes
- Diabetes is more prevalent in the Hispanic community.
- ► These conditions, among others, may contribute to the greater prevalence of Alzheimer's among these two groups
- Can it be prevented?
- Can the risk be reduced?
- Racial and ethnic differences in dementia risk may result from biological, behavioral, sociocultural, and environmental factors including socioeconomic determinants such as education, income, occupation, wealth, and access to health care

## Risk Factors for African Americans

#### Risk Factors

- Age
- Genetics
- Race
- Gender
- ▶ High Blood Pressure
- Diabetes
- Alcohol/Tobacco use
- Social Determinants of health

## Risk Reduction (modifiable Factors)

- Control pressure/cholesterol
- Manage blood sugar levels
- Stay physically active
- Eat a healthy diet
- Socialize
- Brain simulation
- Stress reduction
- Sleep well
- Avoid tobacco and alcohol

## Risk Factors for Latinos

#### Risk Factors

- Age
- Genetics
- Race
- Gender
- High Blood Pressure
- Diabetes
- Alcohol/Tobacco use
- Social Determinants of health

## Risk Reduction (modifiable Factors)

- Control pressure/cholesterol
- Manage blood sugar levels
- Stay physically active
- Eat a healthy diet
- Socialize
- Brain simulation
- Stress Reduction
- Sleep
- Avoid tobacco and alcohol

# 5 Pillars of Brain Health Risk Reduction



## Caregiver Assessment

### What are the caregivers needs

- Prepare for the duration of the disease
- New roles- lots of emotions
- Care Plan planning and organizing all patient's needs
- Resources Available
- Financial Needs
- Legal Needs
- Social Needs
- Medical Needs
- Care and Support System

## Therapeutic Interventions

#### What Social Workers do:

- Therapeutic Sessions:
  - Short
  - ▶ Episodic/crisis
  - Emergent Needs
- Supportive Counseling
  - Advice
  - Direction
  - Needs
- Appropriately Selected Referrals
- ▶ Telephone/telehealth "Checking in/get updated
- Regular Re-Assessment

## Resources for Caregivers

#### What is available:

- Self Help Books
  - "A Dignified Life"
  - ▶ 36 Hour Day
- Support/Education In person, video platform, or telephone
- Legal Services Free and sliding scale
- Adult Day Care Centers/Resource Centers
- In Home Help Public and Private
- Placement Services
  - Memory Centers
  - Nursing Facilities

## Understanding Medical Insurance

### Medical Insurance:

- Medicare (federal retirement plan)
  - ▶ Part A In-patient
  - ▶ Part B Outpatient
  - Part C Medicare Advantage
  - ▶ Part D Prescription
- Medicaid Medi-Cal (in California) (Low-income plan)
  - No cost out of pocket
  - Shared cost out of pocket
  - Access to Medi-Cal driven programs
- Private Insurance Plans
  - Employment

## Additional Resources

- In Home Supportive Services (IHSS)
- Adult Protective Services (APS)
- Mandated Reporter
  - When to report
  - How to report
- Legal
  - Advance Directives
  - ► Trusts
  - Power of Attorney (POA)

# We Are In the "Bad News" Business

#### Bad news while supporting hope.

- Most will get a devastating diagnosis
- Rarely have a "good news" interaction
- Care for chronic slowly deteriorating patients
- Death is hastened by the "problem"
- Difficult to do alone
- Teamwork can make anything positive

## Erikson Stages

- Older Adult
- Middle-Aged Adult
- Young Adult
- Adolescent
- School-Age Child
- Preschooler
- Toddler
- Infant

- Normal Function
- Mild Cognitive Impairment
- Confusion No Initiative
- Irritable Angry Impulsive
- Dis-Oriented Mistakes
- Needs to Go Home
- Reduced Language
- Bed Bound Dependent

## Early Stages Care

- Support for Patient
  - Driving
  - Work
  - ▶ Home/Family Responsibilities
- Support for Caregiver
  - What to expect
- Education
  - Books
  - Videos
  - ▶ Films
- Structure Set-Up
  - Legal F
  - Financial

## Middle Stages Care

- Additional Education for Caregiver
- Support Groups for Caregiver
- Introduce In Home Help
  - ► Learning to allow others to assist
- Adult Day Care
  - Structured Activities
  - Socialization
  - Stimulation
- Companion Care
  - No Initiative
- Review Safety issues at home

## Late-Stage Care

- ▶ More In Home Help
  - Patient can not be alone
  - Needs close supervision
- Placement?
  - Memory Care Facilities
  - Skilled Nursing Facilities
  - ▶ Hospice
- Prepare For Eventual Death
- Funeral Arrangements Brain Autopsy
- Grieving
  - Normal
  - Complicated
  - Extended

## Social Worker as a Support in Dementia Care

- Social worker is a great source of support for individuals and families living with dementia.
- A social worker is a jack-of-all-trades:
- Social workers have learned and mastered skills effective to manage work that is challenging, engaging, and inspiring.
- More Social workers are needed to drive, and support dementia care.
- Social Workers understand
  - Disease
  - Family Dynamics
  - ▶ Effective Communication
  - Able to develop and implement comprehensive care plans with family input.

## Across the Disease Continuum: The Role of Clinical Social Workers

- Emotional support
- Evaluate patient capacity and competency
- Education about the disease process
- Providing strategies to address many of the challenges brought on by dementia, including but not limited to, behavioral and psychiatric behaviors associated with dementia
- Counseling/Therapeutic process
- Assisting with case management and help identifying resources throughout the disease trajectory
- Assess persons living with dementia for risk for neglect, abuse and/or exploitation
- Provide an initial and often ongoing role with care partners for assessment and interventions