Clinical Social Workers and Clinical Psychologists: Practicing with Persons Living with Dementia and Their Care Partners

MODULE 13

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Learning Objectives

After reviewing this module, learners will be able to:

- List two best practices in dementia assessment performed by clinical psychologists
- List two best practices in cognitive testing performed by both clinical social workers and clinical psychologists
- Recognize the fundamentals of coaching persons affected by dementia to manage the cognitive, psychosocial, and behavioral changes in persons living with dementia
- Identify strategies utilized by clinical social workers and clinical psychologists who practice with persons affected by dementia
- Identify resources available to support persons affected by dementia to best meet their care needs during the dementia continuum

Key Take-Home Messages

- Clinical social workers and clinical psychologists conduct comprehensive biopsychosocial assessments and help persons with dementia and their care partners cope and manage along the disease continuum and across care settings.
- Clinical social workers and clinical psychologists provide education, individual, family, and/or group counseling, care partner support and guidance, advance care planning, and linkage to helpful resources.
- Clinical social workers and clinical psychologists often serve as part of an interdisciplinary care team.

Outline

- **Introduction**
- Roles of clinical social workers and clinical psychologists in providing care
- Fundamentals of clinical social work and clinical psychology practice
- Strategies to assist and counsel PLwD and their care partners
- Home and community-based services and social services

Across the Disease Continuum: The Roles of Clinical Social Workers and Psychologists

- Help from Clinical Social Workers and Clinical Psychologists often come in the form of:
  - Emotional support
  - 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
  - Assisting with case management and offer assistance identifying resources throughout the disease trajectory
  - Assess persons living with dementia (PLwD) for risk for neglect, abuse and/or exploitation
  - Evaluate PLwD capacity and competency
  - Provide an initial and often ongoing role with care partners for assessment and interventions (APA, n.d.-c; NASW]. (n.d.-b)

Outline (2)

- Introduction
- **Roles of clinical social workers and clinical psychologists in providing care**
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Role of Clinical Social Workers

- Clinical social work is a specialty practice area of social work which concentrates on the assessment, diagnosis, treatment, and prevention of mental illness, emotional, and other behavioral disturbances.
- Individual, group, and family therapy are common treatment modalities.
- Social workers who offer these services are required to be licensed or certified at the clinical level in their state of practice.
- Clinical social workers perform services in a variety of settings including private practice, hospitals, community mental health, primary care, and agencies.
- Social workers can hold a bachelor's degree and/or master's degree from an accredited school of social work and may specialize in working with older adults, without holding a license or certification. Social workers practicing clinical social work need to be licensed.

(NASW, n.d.-a)

Role of Clinical Psychologists

- Clinical psychologists hold a doctoral degree such as a PhD or PsyD, study both normal and abnormal functioning and treat persons with mental and emotional problems.
- Psychologists who offer these services are required to be licensed or certified at the clinical level in their state of practice.
- They study and encourage behaviors that build wellness and emotional resilience.
- More psychologists are teaming with other health care providers to provide whole-person health care.

(APA, n.d.-e)

Role of Specialty Practice in Clinical Psychology: Geropsychologist Practicing with Persons affected by Dementia

"Professional geropsychology is a specialty in professional psychology that applies the knowledge and methods of psychology to understanding and helping older persons and their families to maintain well-being, overcome problems and achieve maximum potential during later life."

(APA,n.d.-d; APA, n.d.-e)

Role of Specialty Practice in Clinical Psychology: Geropsychologist Practicing with Persons Affected by Dementia (continued)

Geropsychologists specialize in assessing older adults with the following:

- Mental disorders such as depression and anxiety
- Dementia and related behavioral/lifestyle changes
- Changes in decision making or everyday living abilities
- Coping with and managing chronic illness
- Behavioral health concerns such as insomnia, pain
- Grief and loss
- Family caregiving strains
- Adjustment to aging-related stresses including marital/family conflict, changing roles
- End-of-life care

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Fundamentals of Social Work and Psychological Practice with Persons Affected by Dementia

- Cultural competence and ethical practice are important hallmarks of social work and psychological practice.
- Other modules in the curriculum on cultural competence (Module 3) and ethics (Module 11) are available for more information.

(APA, 2010; NASW, 2017; NASW, 2015)

PERSON-Centered Approach and Care

- Clinical social workers and clinical psychologists utilize a person-centered and strengths-based approach to guide, counsel, and teach persons affected by dementia how to manage stress, remember the PERSON living with dementia, and cope with the disease.
- Research suggests that many families and service providers do not adequately incorporate the voice of persons living with dementia into the care planning and decision-making process; this is essential to person-centered care.
- Too often it is assumed that persons living with dementia (PLwD) cannot contribute to these decisions and so they are excluded from the discussion or their perspectives are not taken into account, even though the decisions are about them and affect them.

(Administration for Community Living, 2014)

What is PERSON-Centered Care?

- Components of person-centered care include:
  - Respecting the individual's personal goals and preferences, considering the person's community and family supports, financial resources, and other areas important to him/her
  - Striving to maintain personhood in spite of declining cognitive ability
  - Treating people as individuals
  - Seeing the world from the perspective of the person with dementia
  - Recognizing the needs of people with dementia in terms of opportunities for more activities and social interaction that can compensate, in part, for their impairment and give them room to grow
  - Valuing the person living with dementia and his or her care partners

What is PERSON-Centered Care? (continued)

- Involving family members/care partners in care and offering shared decision-making
- Knowing the person
- Applying detailed knowledge of the individual (biological, behavioral, biographical, and social) to tailor care
- Collecting and using personal experiences of life and relationships to individualize care and the environment
- Maximizing choice and autonomy
- Providing quality care
- Maintaining a supportive physical and organizational environment
- Prioritizing relationships as much as care tasks

Case Vignette- Daughter of Person with Mild Cognitive Impairment (MCI) Seeking Help: Social Work Response

A call comes into a Local Area Agency on Aging and the intake social worker of the day answers to hear, "I need help. I do not know where to turn. I live out-of-state and my mother lives in your area. Her neighbors are calling me and saying she is getting lost, forgetting to eat and now she has run her car into the garage door. She is angry and does not want to talk about anything. My siblings think she is fine. I know she is not. She is not safe to live alone any longer and I do not know what to do. I guess her doctor is right, she really has Alzheimer's disease. What can I do?"

Elizabeth, age 48

Social Work Response

- Kiera, the intake social worker Kiera responds to Elizabeth by listening to her story, asking questions as she gathers an assessment and offering emotional support to Elizabeth about her challenges of being a care partner of a person living with dementia (PLwD).
- When Elizabeth is ready, Kiera begins to make suggestions to address the dilemma by asking if the family has met with her mother's physician to understand her diagnosis. And if the diagnosis is dementia, Kiera refers Elizabeth to a local counselor who works with PLwD who will:
  - help the family come together to help their mother's condition;
  - offer support resources for her mother and adult children;
  - help make her home safe and assess if she is safe to drive or not;
  - locate any community resources to assist her mother at home for the present time until a safer plan can be developed.
- The area where her mother lives has an integrated health program for PLwD that specializes in diagnosis and treatment, and runs early stage support groups for PLwD and caregiver training and support programs. Elizabeth feels she has some tools to begin helping address the situation.
(NIA, 2010)

Interprofessional Teamwork

- Clinical social workers and clinical psychologists often serve as part of care teams providing care or responding to crises of persons living with dementia and their care partners—for example, being part of a care team in an adult day health center or a psychiatric unit, consulting, and educating direct care workers on best practices in long term care settings, mobile crisis units, court systems, and community health and mental health programs.
- Clinical social workers and clinical psychologists serve as team members and resources in helping colleagues understand the cognitive, emotional, social, and behavioral considerations presented in care of persons affected by dementia.

(Judge et al., 2014)

Case Vignette: A Residential Nursing Facility Resident Living with Dementia: How a Psychologist can Help

Mrs. Jones is a 91-year-old woman in a residential nursing facility who has advanced dementia and is completely dependent upon the residential nursing facility staff for all her care. Due to her dementia, she has lost her ability to communicate and cannot tell others what she wants or needs. Rather, she calls out, "Nurse, nurse!" throughout the day, but when staff tries to respond, Mrs. Jones cannot tell them what she needs.

Mrs. Jones' calling out is upsetting to other residents, frustrating to the staff, and Mrs. Jones herself frequently appears distressed and upset. Yet, no one can figure out how to soothe her or diminish her calling out. The doctor suggests asking the psychologist for assistance. However, due to the advanced dementia, Mrs. Jones has limited ability to participate in an assessment and is not a candidate for counseling or other traditional intervention. How can the psychologist help?

Case Vignette: A Residential Nursing Facility Resident Living with Dementia: How a Psychologist can Help (continued)

The interventions that could be helpful include:

- Creating a behavior tracking system to determine if there is a trigger to Mrs. Jones' calling out. Once identified, the trigger could be eliminated or an alternative approach could be used to decrease her distress. In addition, the psychologist could work with Mrs. Jones' family to identify music or other sensory stimuli that she has appreciated in the past, and create options to engage her in sensory stimulation regularly during the day. As an example, the family might create a playlist of comforting music that could be delivered to her through earphones or on a device in her room. The psychologist would also work with staff to identify how to improve their support for quality of life for Mrs. Jones (e.g., activities such as Namaste Care, care staff).
- Education for staff on how to interact with Mrs. Jones. Relying less on verbal skills and more on non-verbal cues and interactions can be helpful to improve understanding when language is diminished. The activities staff could include her in appropriate group activities to increase the rate of prosocial stimulating activities.
- Creating a person-centered plan of care for responding to the challenging behavior. Interventions by staff that take into account who Mrs. Jones is, what she likes and dislikes, and the triggers to her behavior, can help to reduce the frequency and intensity of her calling out.

First Step—What are We Dealing With?

This module has helped define both the clinical social worker's and psychologist's roles in dementia care and some fundamentals in practice for both disciplines. Now this module examines how clinical social workers and clinical psychologists practice with persons suspected of/assessed as having dementia and their care partners across the illness continuum.

(NIA, NIH, 2008)

What is Normal Aging vs. What is Not: Assessing for Mild Cognitive Impairment (MCI) and Dementia

- Clinical social workers and clinical psychologists can play a significant role in actively assessing for dementia symptoms/MCI and practicing with the person with potential dementia and their care partners to provide evaluation and treatment.
- Clinical social workers and clinical psychologists can assist in coordinating this care, counsel concerned care partners of a person with memory loss or other signs of cognitive impairment to seek medical attention and to pursue a diagnostic evaluation.
- Family conflicts and dynamics can occur surrounding a dementia diagnosis and the care needed for the PLwD. Clinical social workers and clinical psychologists can assist with working through these dynamics and helping find a degree of acceptance, and constructing a plan for the future.

(NIA, NIH, 2008)

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Tools, Guidelines, and Resources to Assess for MCI and/or Suspected Dementia

- Clinical social workers and clinical psychologists often provide testing to assess for cognitive impairment.
- Dementia Screening tools, guidelines, and resources include:
  - Mini cog, SLUMS exam, Rapid Cognitive Screen or Short Blessed Test, most of which can be completed under 5 minutes.
  - Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change
  - What Mental Health Practitioners Should Know About Working with Older Adults publication
  - Advanced Practice in Mental Health Settings Teaching Module
  - Alzheimer's Disease Center (ADC) or Tertiary Care Center's Memory Clinic
  - National Institute on Aging Diagnostic Guidelines

(National Institute on Aging [NIA], n.d.-c; n.d.-e)

Guidelines and Resources for Assessing Adults with Intellectual Disability

- Clinical social workers and clinical psychologists may often encounter adults who have been referred or admitted who seem to have an lifelong intellectual disability.
- Having familiarity with adults with intellectual disability can help the clinicians serve a consultants to care staff, undertake assessments, and help formulate care plans. Staff from intellectual disability agencies can be useful informants as to the nature of the person's particular behaviors and what techniques the person responses to for compliance and calming. They can also inform on residual expressive and receptive language skills.
- For assessment, the NTG-related guidelines can identify instruments that may be used to better understand residual function (Jokinen et al., 2013; Moran et al., 2013) and stage of dementia. For dealing with BPSDs, NTG-related and other resources can help in understanding and applying non-pharmaceutical and behavioral interventions (British Psychological Society, 2009; Jokinen et al., 2013)

Assessment

- The assessment completed by clinical social workers and clinical psychologists guides the interventions (i.e., counseling, behavioral management, long-term care planning) provided.
- Clinical social workers and clinical psychologists need to understand and be able to articulate the neurobiology as well as cognitive and behavioral manifestations across stages of dementia, to the best of their knowledge and ability, taking into consideration that each person living with dementia experiences different symptoms of the disease.

(Alzheimer's Association, 2009; APA, 2009); NASW, 2015)

Assessment Tools

- A Person-Directed or Person-Centered Assessment Tool
- Elements of a biopsychosocial assessment
- Dementia Practice Guidelines

Mini-cog©

The **Mini-Cog** test is a 3-minute instrument to screen for cognitive impairment in older adults in the primary care setting. During the Mini-cog, a person is asked to complete two tasks:

- Remember, and a few minutes later, repeat the names of three common objects.
- Draw the face of a clock showing all 12 numbers in the right places and a time specified by the examiner.
- The results of this brief test can help a physician determine if further evaluation is needed.
- The Mini-Cog is copyrighted, and permission must be granted for its use.

(Alzheimer's Association. (n.d.))

Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change

The American Psychological Association (APA) provides information for clinical psychologists to evaluate persons for dementia- and age-related cognitive change. (APA, 2011)

For persons with intellectual disability, the National Task Group on Intellectual Disabilities and Dementia Practices provides information on evaluating persons with suspected or diagnosed dementia.

(Jokinen et al., 2013)

What Mental Health Practitioners Should Know About Working with Older Adults

The publication, *What mental health providers should know about working with older adults*, is intended to provide psychologists and other health care practitioners with resources, tools and information to enhance their work with older adults (defined as persons 65 years of age and older).

(APA, 2014)

Advanced Practice in Mental Health Settings Teaching Module

Advanced Practice in Mental Health Settings is a teaching module, with PowerPoint, and includes assigned readings and a video recommendation titled: Improving Assessment & Management Of Dementia: How To Administer The Mini Mental Status Exam.

(Council on Social Work Education, n.d.)

Alzheimer's Disease Center (ADC) or Tertiary Care Center's Memory Clinic

- Memory Clinics, including Alzheimer's Disease Research Centers, which are funded by the National Institute on Aging, can:
  - Provide guidance on complicated cases and clinical trial participation, and
  - Assist with diagnosis and testing.

(National Institute on Aging, National Institutes of Health. (n.d.-c))

National Institute on Aging Diagnostic Guidelines

- The National Institute on Aging and the Alzheimer's Association (2011) charged a workgroup with the task of revising the 1984 criteria for dementia.
- These guidelines help practitioners assess for dementia (McKhann, et al., 2011).

Clinical Psychology Assessment of Persons Living with Dementia

- A thorough geriatric assessment is preferably an interdisciplinary one, focusing on both strengths and weaknesses of the assessment, determining how problems interrelate and taking account of contributing factors.
- In evaluating older adults it is useful to ascertain the possible influence of medications and medical disorders since, for example, medical disorders sometimes mimic psychological disorders.
- Other possible influences to review include immediate environmental factors on the presenting problem(s), and the nature and extent of the individual's familial or other social support.

(APA, 2013)

The Early Stages of Dementia: The Role of Clinical Social Workers and Clinical Psychologists

- Clinical social workers and clinical psychologists can provide interventions to persons in the early stages of dementia with (Grand et al., 2011):
  - Education of person living with a dementia diagnosis about dementia
  - Emotional support and guidance
  - Advance care planning and decision making
  - Resource learning and navigation—how to find the care and help they need

The Early Stages of Dementia: The Role of Clinical Social Workers and Clinical Psychologists (continued)

- Family conflict can occur when there are differences of opinion regarding planning and decision making among various members (see caregiving modules on decision-making).
- A dementia diagnosis highlights the importance of advance care planning, family or care partner support and identifying sources of help and counseling.
- Clinical social workers and clinical psychologists are instrumental in guiding and counseling PLwD and their care partners to navigate helpful support services and resources and create a plan of care.

Case vignette: Working with Couples When One is in Early Stages of Dementia

Mr. Connors is a 76-year-old man who has been diagnosed with early stage Alzheimer's disease. His wife reports that he is frequently tearful and short tempered and they are concerned that he may be depressed. He has a history of depression and demonstrates symptoms of depression at this time; however, his memory is so poor that he cannot derive long-term benefit from counseling services at this time, i.e. he cannot recall what was discussed. His wife struggles to manage his temper and his "mood swings." Moreover, she states that she will need to place her husband in a "home" if she cannot better manage his challenging behavior.

How Can the Psychologist Help Mr. Connors?

Brief counseling for the couple that focuses on providing education about dementia and strategies for coping with the behavioral changes that accompany dementia can be helpful. Also, there are a number of community resources that might benefit Mr. Connors and his wife as they cope with the onset of his dementia but families often do not know about them nor do they know how to access them. Assistance in guiding them through their adjustment to the disease and connecting the couple to these resources can be helpful. Mr. Connors might benefit from being referred to a psychiatrist for treatment of depression if the clinical psychologist does not have prescription privileges.

Assessing Diminished Capacity and Competency

- Clinical psychologists trained in geropsychology or neuropsychology may perform comprehensive cognitive assessments.
- Clinical psychologists may explain the findings of the assessment and provide education to persons living with dementia, as well as to family and caregivers if permission is granted by the person with the dementia diagnosis.

Tools and Resources for Assessing Diminished Capacity and Competency

- Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists (American Bar Association and American Psychological Association)
- The APA Family Caregiver Briefcase
  - Information is available on both assessment and evidence-based interventions for both care partners of PLwD and the PLwD.
  - There are assessment tools, questionnaires, and material about reliability and validity.

Suspected Neglect, Abuse, and Exploitation

- Clinical social workers and clinical psychologists, as are all health care professionals, are mandated reporters for suspected abuse, neglect or exploitation of children and adults.
- PLwD are at risk for neglect, abuse and/or exploitation due to their diminished cognitive and functional capacity. PLwD in the early stages are vulnerable to neglect and abuse in other domains, especially financial exploitation and abuse as there is evidence that diminished financial capacity or decision-making is one of the early signs of cognitive decline.

(ABA/APA 2016; APA, n.d.-a; APA, n.d.-b; NIA, NIH, 2015)

Suspected Neglect, Abuse, and Exploitation (continued)

- Areas of abuse include:
  - Physical: causing physical pain or injury
  - Emotional: verbal assaults, threats of abuse, harassment and intimidation
  - Neglect: failure to provide necessities, including food, clothing, shelter, medical care or a safe environment
  - Confinement: restraining or isolating the person
  - Financial: the misuse or withholding of the person's financial resources (money, property) to his or her disadvantage or the advantage of someone else
  - Sexual abuse: touching, fondling or any sexual activity when the person is unable to understand, unwilling to consent, threatened or physically forced
  - Willful deprivation: willfully denying the person medication, medical care, food, shelter or physical assistance, and thereby exposing the PLwD to the risk of physical, mental or emotional harm
  - Self-neglect: Due to lack of insight and cognitive changes, PLwD may be unable to safely and adequately provide for day-to-day needs, and may be at risk for harm, falls, wandering and/or malnutrition.

(Alzheimer's Association, n.d.; APA, n.d.-c)

Resources to Learn More or to Assess for Abuse and Neglect

- The National Center on Elder Abuse: information on how to report alleged abuse, neglect or exploitations of PLwD or older adults in general

- Alzheimer's Association – Alzheimer's and Dementia Caregiver Center: Abuse

- Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists
  - Chapter: Assessing Financial Capacity (Page 72)
  - Chapter: Undue Influence (Page 114)

Case Vignette Suspected Abuse of Person Living with Dementia

Jose and Lydia have been married for 51 years and came from their native Puerto Rico to the USA as newlyweds. Jose has often found alcohol to be his best crutch to get through tough times and stress, but he believes he has controlled his drinking and been a good spouse and father.

Jose and Lydia are both 72-years-old now and retired. Five years ago, Lydia was diagnosed with Alzheimer's disease when her memory started failing and she missed payments for bills. While Jose agreed that Lydia could benefit from medication to hopefully slow the progression of the disease, he has not learned more about the disease process and how PLwD behaviors and cognitive abilities can diminish over time. He still communicates with Lydia as if she has all of her cognitive and behavioral capacities prior to the diagnosis.

Lydia has become argumentative if Jose does not listen to her the first time she speaks to him. They have no friends and their home has become cluttered because Jose has never cleaned a home before. Lydia has become incontinent and has soiled furniture all over the house. Jose has increasingly turned to alcohol on a nightly basis to numb himself from the daily grind of caring for Lydia. She has started yelling and repeats herself constantly. They no longer get out of the home except for medical appointments, even though Lydia is ambulatory. Jose spends hours on the computer and attends to Lydia's meals in between. Jose has begun hitting Lydia when she will not be quiet.

The home health nurse visiting Lydia for her diabetes hears Lydia yell that Jose has hit her when she "won't shut up." The home health nurse calls Adult Protective Services and asks the home health social worker to see the couple. The nurse also found that Lydia was not taking her insulin to help control her diabetes and Jose only reminded Lydia to check her blood sugars and eat. The nurse has found despite her efforts to educate both Lydia and Jose that Lydia often missed her insulin medication.

Case Vignette Jose and Lydia: Social work and Psychologist Response

- Social worker's report to Adult Protective Services for assessment of abuse
- Social worker's assessment of Lydia's and Jose's needs
- Social worker's recommendations for respite/education for Jose
- Social worker's referral for Lydia's physician to assess agitation/paranoia and help her better manage her diabetes
- APS visit and recommendations for psychiatric evaluation, inpatient stay and subsequent treatment for Lydia

Driving Cessation Education and Counseling

- The focused concentration and quick reaction time needed for safe driving tends to decline with age.
- Clinical social workers and clinical psychologists can help care partners address concerns about safe driving and work with doctors and PLwD on driving assessments.
- These professionals can provide counseling regarding change in identity from giving up driving.

(ABA/APA, 2008; Mayo Clinic, 2015; National Highway Traffic Safety Administration. (n.d.))

Driving Cessation Education and Counseling (continued)

- Engage PLwD and care partners in problem-solving regarding transportation needs.
- Referrals to Driving Assessment Programs, Division of Motor Vehicles driving test, Physician Intervention. States have different mandatory reporting laws.
- Clinical psychologists may also conduct portions of driving assessments to determine level of cognitive function.

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Support and Counseling Can Help

- This module now looks at support and counseling as primary interventions provided by clinical social workers and clinical psychologists to persons affected by dementia.

Counseling Strategies for PLwD and Care Partners

- Clinical social workers and psychologists can employ a range of counseling strategies to help persons living with early to moderate stages of dementia and their care partners, including:
  - Grief and bereavement counseling
  - Communication strategies and counseling
  - Interpersonal therapy
  - Spiritual and/or faith counseling
  - Conflict resolution
  - Reminiscence therapy
  - Cognitive behavioral therapy

(Grand et al., 2011)

Counseling Strategies for PLwD and Care Partners (continued)

- Validation therapy-The goal of validation therapy is to promote and stimulate communication skills in persons living with dementia, and to provide the individual with insight into their external reality.
- Group therapy
- Family therapy/systems
- Disease education
- Management of difficult behaviors
- Support therapies such as pet or music therapy
- Referrals for pharmacologic assessment to treat mental health conditions

Treating Anxiety and Depression in PLwD in the Early Stages of Dementia

- Anxiety and depression are common among persons living with dementia and mild cognitive impairment. These conditions are treated by clinical social workers and clinical psychologists. Anxiety and depression may be treated by a psychiatrist in advanced stages of dementia.
- Older adults with illness, particularly those living with dementia, are especially vulnerable to mood disturbances, as increasing cognitive impairment causes a loss of ability to engage in rewarding and enjoyable activities, which in turn leads to increased depression and decreased quality of life.
- Depression rates vary by severity and disease stage and can occur in up to 50% of PLwD.

(Grand et al., 2011; Logsdon, 2007)

Treating Anxiety and Depression in PLwD in the Early Stages of Dementia (continued)

- In the early stages of dementia, depression may be attributed to awareness of the individual's cognitive changes.
- Behavioral therapy interventions that can improve depression:
  - Focus on teaching care partners specialized skills to increase pleasant events for the PLwD.
  - Develop strategies to increase involvement in meaningful activities.
  - Prevent or reduce depressive behaviors in the PLwD.

(Grand et al., 2011)

Behavioral Disturbances in Dementia

- Clinical social workers and clinical psychologists often respond to care partners and professionals living or working with dementia to address behavioral disturbances with non pharmacologic modalities. Some facts about concerning behaviors in PLwD:
  - Behavioral and psychiatric symptoms are common in PLwD.
  - In the early and later stages of dementia, features related to apathy may appear, but are often confused with depression, particularly by care partners.
  - Apathy is associated with significant care partner distress and greater use of health care services in dementia.
  - Psychosis generally occurs later in the disease course.
  - Delusions are predominantly paranoid in nature, with fears of personal harm or mistreatment, theft of personal property (usually related to financial matters), and marital infidelity.
  - Hallucinations are less common than delusions, and tend to be visual.
  - Other behavioral symptoms include agitation, wandering, and sleep disturbances.
  - The primary treatable behavioral and psychiatric symptoms in dementia include psychosis, agitation, depression, aggression, anxiety, and insomnia.

(Grand et al., 2011)

Case Vignette—George

George is an 89-year-old male who lives with his daughter, Lucy. George has dementia with an onset of visual hallucinations and delusions. Lucy has taken care of her mother, Irene, who died from AD ten years ago, and her sister, Connie, who died one year ago from cancer. Lucy is trying to follow her father's wishes and keep him at home, but his behavioral symptoms have become increasingly difficult to live with. He is talking to his wife often just as if she is right in front of him. George also talks to his accountant and says that Lucy is stealing from him. The accountant has not been engaged with the family for 10 years. George accuses Lucy of stealing from him daily. Lucy feels like her life is like the movie, Groundhog Day, because she is stuck and not able to get away.

Lucy does take her father to the adult day health center that focuses on PLwD and their care partners. Lucy attends a caregivers' support group weekly and George participates in the adult day health program for stimulation and socialization. George has refused Lucy's repeated suggestions that he receive psychiatric care and she does not want to make her father go.

Carter, a psychologist, and Eve, a social worker co-facilitate the caregivers support group. Eve also serves as the social worker at the adult day health center, where George has voiced to care providers and other attendees that his daughter is stealing from him.

Case Vignette George: Social Work and Psychology Response

Carter works with Lucy to address her long-term role as primary care partner to her mother, sister and now her father. Lucy says she is exhausted and she is not sure “how much more she can take” and thinks she needs to consider placing her father in a memory care unit at an assisted living facility. Carter recommends that Lucy take her father to be evaluated by his primary care physician and a geriatric psychiatrist. Lucy knows if she makes these appointments, her father will get in the car and go see the physicians. Carter helps Lucy understand that medication may help to address his hallucinations and delusions.

Eve, in collaboration with Carter, counsels Lucy as she shares her pent-up frustration and grief with cumulative losses. Eve serves as a resource to Lucy in seeking supported decision making services and possible power of attorney for her father (advising to use an elder care lawyer) and weighing the joint decision to help her father remain at home or consider a move to an assisted living facility. She explains to Lucy that in-home help, including personal care workers, environmental modifications and chore services may help her father remain at home longer. She also informs Lucy that a short-term stay in assisted living may be a way for George to try and see how he adapts in assisted living and how Lucy is able to adjust. Lucy meets with Carter, Eve, and her dad a few times to talk about home and community-based services, and discuss consideration of a near-by assisted living facility that offers dementia-related services including pet therapy as George loves dogs. Lucy is counseled to understand that she has tried to care for her father at home, but it may be time to bring in help or even talk about a move..

Interventions to Improve Depression and Quality of Life of PLwD

- Clinical social workers and clinical psychologists can train care partners on helpful responses to dementia symptoms.
  - Progressively Lowered Stress Threshold (PLST)
  - Physical exercise and mobility
  - Cognitive stimulation
  - Socialization and engagement for PLwD and care partners
  - Driving assessment

(Logsdon et al., 2007)

Early-Stage Dementia Support Groups—A Psychological/Supportive Intervention

- Benefit of early diagnosis of dementia
  - Coping with diagnosis
  - Participation in decision-making
- Early Stage Support Groups (ESSGs)
  - Support for PLwD and their care partners
  - Family coping
  - Understanding the disease and its effect
  - Caregiving strategies for managing and responding to PLwD

(ACL, 2017; Logsdon, 2007; Wingbermuehle, 2014)

Caring for the Care Partner

- Clinical social workers and clinical psychologists provide much of their practice with care partners.
- The care partners' health and well-being are affected by the caregiving demands of the PLwD, and clinicians address the importance of self-care with care partners as they are challenged to adjust and incorporate the losses and role changes into their lives.
- Care partners can benefit from support, counseling and education, especially on strategies to minimize and manage the occurrence of behavioral and psychological symptoms of dementia.

(Pearce, 2010)

Resources for Clinical Social Workers, Psychologists and Persons Affected by Dementia

- The **APA Family Caregiver Briefcase** is a helpful resource for identifying the interventions that are most effective for caregivers.
- The National Association of Social Workers provides guidelines for **Social Work Practice with Family Caregivers of Older Adults**
- The **Alzheimer's and Dementia Caregiver Center** provides information on day-to-day help, support and caregiving services in local areas, and financial and legal information.

Technology as a Tool for PLwD, Care Partners, and Professional Support and Education

- Well-developed social media resources can provide information on:
  - Practical tasks such as how to help someone safely ambulate and transfer
  - Biological and emotional aspects of dementia
  - Providing care and support for persons affected by dementia
  - Dementia treatments and services, including home and community-based services, and how to access these resources
  - Education for social work and psychology students and professionals

Special Groups

- Complicating factors that may require intensive assessment, treatment planning and/or counseling.
  - Low socioeconomic status or uninsured
  - Low academic achievement
  - Adults with intellectual disability (including Down syndrome)
  - Existence of multiple chronic conditions
  - Existence of frailty
  - Veterans who served during times of active conflict
  - Older and frail adult care partners challenging physical and mental health conditions

Special Groups (continued)

- PLwD who have no care partners
- PLwD who are PCGs (primary caregivers) of partners/close others with acute or chronic conditions or adult disabled children
- Culturally diverse groups
- Prisoners
- LGBT
- Undocumented individuals

Case Vignette: Charlie, Who has No Care Partner

Charlie is a 90-year-old male with moderate dementia who has lived with his wife, Carmelita, for several years. Carmelita serves as Charlie's primary care partner; they have no children and their extended family members have all died. Charlie was admitted to the hospital after the mail carrier noticed that Charlie and Carmelita had not retrieved their mail for a few days. The mail carrier called the police because he could see Charlie through the window, crying and sitting in his chair.

The police responded to the carrier's call for a well-person check and entered the home to find that Carmelita had fallen and hit her head in the garage and died. Charlie was taken to the hospital and admitted as he was found to be confused, tearful, and scared, and that his blood pressure was very high.

Case Vignette Charlie: Social Work and Clinical Psychology Responses

Upon admission to the hospital, both psychology and social work were consulted to assess how to help Charlie's adjustment and grief over the death of his wife. The psychologist met with Charlie and helped him address his grief, even if he repeated the same conversation. Charlie liked the music channels on the TV so the staff was asked to see what type of music he would like to listen to. He was also very spiritual and answered positively when a chaplain was offered for visits and prayers, also providing a memorial service in his hospital room to remember his wife.

The social worker identified a neighbor who was able to bring in a picture of Carmelita to post in Charlie's room and some of their blankets from home. The social worker suggested that a hospital volunteer visit with Charlie each day, as the hospital had a group of trained volunteers that would visit and sit with patients for part of the day, being trained in sensitivity to dementia care and grief.

The social worker also worked with Charlie's primary care physician in the community and adult protective services to see how to proceed with helping Charlie remain in the community with oversight by a trusted friend to help Charlie make decisions, and explore working with an attorney specializing in elder law to explore other supportive services. The psychologist completed an assessment for concern of Charlie's diminished capacity and inability to live safely alone, without services and supports. Both the social worker and psychologist included Charlie in the process, respecting that he was able to express preferences and contribute to the discussion of where he wanted to live and being part of his transitioning back to the community.

Case Management with PLwD

- Case management (care management, care coordination, patient or systems navigation):
  - Engages the client in a collaborative process with the therapeutic relationship as an integral component
  - Focuses on identifying, planning, accessing, advocating for, coordinating, monitoring, and evaluating resources, supports, and services

(NASW, 2013)

Case Management

- Short-and-long-term care needs include:
  - Developing current and future person-centered care plans
  - Identifying PLwD's preferences at all stages of the dementia
  - Assisting with addressing financial and legal matters
  - Addressing potential safety issues
  - Learning about living arrangements/housing options
  - Identifying community resources
  - Navigating systems of care and assistance
  - Developing support networks
  - Investigating clinical trials and research studies

(National Institute on Aging [NIA], n.d.-a)

Aging in Place and Understanding Long-Term Care

- Clinical social workers and clinical psychologists can advise and assist persons affected by dementia with care planning and decision-making across the continuum of care.
- Most persons want to live the remainder of their life at **home**.
- Social workers and psychologists can discuss aging in place and long term care options and costs with PLwD and care partners.

What is Daily Living Assistance?

- Assistance with activities of daily living (ADL) might include:
  - Bathing
  - Dressing
  - Using the toilet
  - Transferring (to or from bed or chair)
  - Caring for incontinence
  - Eating

(Administration on Aging, 2017f;2017g)

What is Daily Living Assistance? (continued)

- Other common supports are assistance with everyday tasks, sometimes called Instrumental Activities of Daily Living (IADL) including:
  - Housework
  - Managing money
  - Taking medication on time and in correct dosages
  - Preparing and cleaning up after meals
  - Shopping for groceries or clothes
  - Using the telephone or other communication devices
  - Caring for pets
  - Responding to emergency alerts such as fire alarms

Care Options for Persons Living with Dementia

- Types of care and programs include:
  - Home and community-based services (e.g., personal care, home-delivered meals, etc.)
  - Community Rehabilitation Services
  - Skilled Home Health Care
  - Senior Centers and Adult Day Health Centers/Services
  - PACE—Program for All Inclusive Care for the Elderly (where available)
  - Assisted Living Facility Care
  - Nursing Home Care
  - Veterans Benefits and Care Options
  - Palliative and/or Hospice Care

Personal Care and Assistance Services (Home or Facility Based Care)

- Types of support services and care for PLwD include:
  - Private duty nursing
  - Companion or aide services—i.e., private pay, Medicaid “waiver”, community programs
  - Transportation to and from appointments
  - Respite care--Respite is planned or emergency care provided to an adult with special needs in order to provide temporary relief to family care partners who are caring for that adult.
  - Available through private or public (based on eligibility) programs and services

(Administration on Aging, 2016; Arch National Respite and Resource Center, n.d.)

Habilitation and Rehabilitation Therapy/Services

- Habilitation and rehabilitation services help clients acquire, retain, improve skills needed to reside successfully in home and community-based settings.
- They include:
  - Physical and occupational therapy
  - Speech and language therapies
  - Nursing, nutrition, and other services
  - Employment supports

Home Health Care

Home health care services are provided in a person's home after an illness or injury and may include:

- Nursing
- Occupational Therapy (O.T.)
- Speech Therapy (S.T.)
- Physical Therapy (P.T.)
- Nutrition
- Social work
- Behavioral health services
- Home health aide

(Centers for Medicare and Medicaid Services [CMS], n.d.)

Senior/Community Centers and Adult Day Health

- The programs aim to delay/prevent institutionalization, to enhance self-esteem and to encourage socialization.
- There are two types of adult care and services:
  - Senior/community centers
  - Adult day health services

(Administration for Community Living [ACL], n.d.-a)

Medicare-Medicaid Programs for All-Inclusive Care

- PACE programs are available in some areas to support older adults.
- PACE provides comprehensive medical, home and community-based and social services to certain frail, community-dwelling older adults, most eligible for both Medicare and Medicaid.
- PACE provides all Medicare and Medicaid covered items and services and other services determined necessary by the beneficiary's interdisciplinary team to improve and maintain overall health status.
- The PACE organization is required to develop and implement a plan of care in collaboration with the participant and/or care partner to meet the individual's medical, physical, emotional and social needs (which is based on a comprehensive assessment).

(CMS, 2017)

PACE Eligibility

- Individuals can join PACE if they meet certain conditions:
  - Age 55 or older
  - Live in the service area of a PACE organization
  - Eligible for nursing home care
  - Are able to live safely in the community
- The PACE program becomes the sole source of Medicare and Medicaid services for eligible enrollees. Individuals can leave the program at any time.
- People need to have Medicare, Medicaid, or both to participate in PACE.

(CMS, 2017)

Types of Residential Care Available for PLwD

Long-term care options for PLwD needing extensive care or supervision:

- Home and community-based services
- Assisted living
- Nursing homes
- Respite care
- Board and care homes (Group homes)
- Adult foster care
- Inpatient care

(Administration on Aging, 2017d; CMS, 2018)

The Needs of PLwD in Long-Term Care Facilities

- CMS National Partnership to Improve Dementia Care in Nursing Homes
  - Initial goal: reduce use of antipsychotic medications
  - Larger mission: enhance use of non-pharmacologic approaches and person-centered dementia care practices, and maximize quality of life.
- Since the launch, significant reductions in the prevalence of antipsychotic use in long-stay nursing home residents have been documented.
- CMS National Partnership to Improve Dementia Care in Nursing Homes (CMS, 2015; 2018)

Veterans Administration Programs

- Care for veterans with dementia is provided throughout the full range of U.S. Department of Veterans Affairs (VA) health care services.
- Depending on the veteran's needs, services may include home based primary care, homemaker and home health aide, respite, adult day health care, outpatient clinic, inpatient hospital, nursing home, or hospice care.
- Caregiver support is an essential part of all of these services.

(U.S. Department of Veterans Affairs, n.d.)

Defining Veterans Administration Programs

- VA pays for long-term care services for **service-related disabilities** and for certain other eligible veterans, as well as other health programs such as nursing home care and home and community-based services for aging veterans with long-term care needs.
- The VA also pays for veterans who do not have service-related disabilities, but who are **unable to pay for the cost of necessary care**. Co-pays may apply depending on the veteran's income level.

(U.S. Department of Veterans Affairs, n.d.)

Defining Veterans Administration Programs (continued)

- The VA has two more programs to help veterans stay in their homes:
  - **The Housebound Aid and Attendance Allowance Program**
  - **A Veteran Directed Home and Community Based Services program (VD-HCBS)**
  - Some Veteran programs and Medicaid provide for self-direction, which allows Veterans and Medicaid beneficiaries to hire, supervise, train, and dismiss direct care workers and other professionals who work in their homes.

(Administration on Aging, 2017e)

Palliative and/or Hospice Care

Hospice Care provides short-term, supportive care for individuals who are terminally ill.

Palliative Care prevents and treats symptoms and side effects of disease and treatment for persons with serious illnesses. Palliative care also treats emotional, social, practical, and spiritual problems that illnesses can bring up.

(Administration on Aging, 2017d; What is Palliative Care?, 2016)

Cost of Care and the Role of Care Planning

- Dementia care costs Americans billions of dollars in paid and unpaid care — and that number is growing.
  - The burden of costs for long-term care (LTC) falls to families and Medicare and Medicaid.
  - Clinical social workers and clinical psychologists in practice with persons affected by dementia are knowledgeable about community and government resources to best meet the person's needs and care, and refer to appropriate financial resources for help with long-term care costs.
  - Clinical social workers and clinical psychologists in long-term care settings and social service/community agencies advise persons affected by dementia on care planning and financial resources.
  - Clinical psychologists provide psychotherapy in long-term care settings for mental health issues in PLwD as well as consulting with staff and care partners for behavior management.

(ACL, n.d.-d; Hurd et al., 2013; PLTC, n.d.)

A Snapshot of Long-Term Care Costs in the USA

- Average costs for long-term care in the United States (in 2012):
  - $222 per day or $81,030 annually for a semi-private room in a nursing home
  - $248 per day or $90,520 annually for a private room in a nursing home
  - $3,550 per month for care in an assisted living facility (for a one-bedroom unit)
  - $21 per hour for a home health aide
  - $20 per hour for homemaker services
  - $70 per day for services in an adult day health care center

(Administration on Aging, 2017a; Metlife, 2012)

Financial Resources and Considerations for Persons Affected by Dementia: The Role of Social Workers

- Social workers practicing with persons affected by dementia are aware of the financial considerations and resources to assist in the care planning process.
  - Spousal or adult disabled child asset protection
  - Medicare and Medicaid
  - Long-term care insurance and annuities
  - Public vs. Private Assistance, when assets are depleted
  - Family financial planning and division of assets
  - Wills and trusts
  - Social Security Disability Insurance
  - Insurance coverage during SSDI 2-year wait period for Medicare
  - Health Insurance Marketplace Coverage

(NIA, n.d.-b)

Public and Private Resources for Dementia Care and Support

- **Medicare**-- Medicare pays for health care for people age 65 years and older, people under age 65 with certain disabilities, and people of all ages with end-stage renal disease (permanent kidney failure that requires dialysis or a kidney transplant). Medicare only covers medically necessary care and focuses on medical acute care, such as doctor visits, drugs, and hospital stays. Medicare coverage also focuses on short-term services for conditions that are expected to improve, such as physical therapy to help you regain your function after a fall or stroke.
- **Medicaid** is a joint federal and state partnership that helps people with low income and assets pay for some or all of their health care bills. It covers medical care, like doctor visits and hospital costs, long-term care services in nursing homes, and home and community-based services, such as personal care and home-delivered meals. Unlike Medicare, Medicaid does pay for custodial care in nursing homes and at home, but only to eligible beneficiaries, and some states have waiting lists.
- **Community grants/programs**--Many states have programs to pay for home and community-based long-term care services for older adults, generally 60 and older, and their families. States often draw on funds from county, state and federal sources such as the Older Americans Act. The focus of these programs is to help older adults remain in the community as independently as possible.
- **Private pay**— When someone can afford to pay out-of-pocket for their care from their own income and assets.
- **Long-term care insurance—**These are policies which reimburse policyholders a daily amount (up to a pre-selected limit) for services to assist them with activities of daily living such as bathing, dressing, or eating. You can select a range of care options and benefits that allow you to get the services you need, where you need them.

(ACL, n.d.-a; 2018; n.d.-c)

Insurance and Long-Term Care

- **VIDEO**: Long-term care: Does health insurance cover it?

Advance Care Planning

- Many clinical social workers and clinical psychologists practicing with persons affected by dementia have training in advance-care planning in order to address the important wishes and decisions that are best discussed and documented.
- Clinical psychologists can assess for competency and capacity of PLwD to engage in these discussions and decision-making processes. Both disciplines often recommend working with an elder law attorney for guidance on some of the ethical and legal needs and decisions.

Advance Care Planning (continued)

- By putting financial and legal plans in place early on in the dementia diagnosis, if decisions had not been made before diagnosis, this action and documented decisions allows the PLwD to express wishes for future care and decisions. It also allows time to work through the complex issues involved in long-term care.
  - Advance directives/health care agents
  - Powers of Attorney (POA): financial and medical
  - Person living with dementia- choice of POA—family member, friend or lawyer
  - Will and trusts
  - Funeral expenses and decisions
  - Short- and long-term care plans
  - Medicare covers voluntary Advance Care Planning during the free Annual Wellness Visit.

(NIA/NIH, 2013)

Advance Directives Video

- **VIDEO**: Advance care directives

End of Life Care Planning and Guidance

Clinical social workers and clinical psychologists in healthcare, long term care, hospice and palliative care provide end-of-life care planning.

- Advance directives
- Health care power of attorney
- Living will
- Do-Not-Resuscitate (DNR) order
- Physician Orders for Life-Sustaining Treatment (POLST) form

(NIA, n.d.-d)

Summary

- This module provided:
  - Review of clinical social workers' and clinical psychologists' roles with persons affected by dementia.
  - Information and resources on current knowledge, research and evidence-based practices for working with PLwD and care partners
- The module intended to help clinical social workers and clinical psychologists:
  - Understand best practices in dementia detection, assessment and cognitive testing.
  - Educate and counsel persons affected by dementia to better manage and respond to the cognitive, psychosocial, and behavioral changes associated with PLwD.
  - Identify effective and available interventions, tools, practice standards and resources.

Evaluation

1. **Which of the following are roles performed by clinical social workers and clinical psychologists as part of an interprofessional care team?**
   a. Providing care in an adult day care center or psychiatric unit
   b. Educating direct care workers on best practices in long term care settings, mobile crisis units, court systems, and community health and mental health programs.
   c. Helping colleagues understand the cognitive, emotional, social, and behavioral considerations presented in care of persons affected by dementia
   d. All of the above

Evaluation (continued)

2. Which statement is false?

a. Clinical social workers and clinical psychologists are not mandated to report suspected abuse, neglect or exploitation of persons living with dementia because such persons cannot give permission to have this information released.

b. Clinical social workers and clinical psychologists often provide testing to assess for cognitive impairment.

c. Clinical social workers and clinical psychologists need to understand and be able to articulate the neurobiology as well as cognitive and behavioral manifestations across stages of dementia.

d. Clinical social workers and clinical psychologists are instrumental in guiding and counseling persons living with dementia and their care partners to navigate helpful support services and resources and create a plan of care.

Evaluation (continued)

3. Among the items listed, which of the suggested interventions is NOT recommended by clinical social workers and psychologists to be used to support persons living with a diagnosis of early dementia?

a. Identify helpful support services and resources
b. Education about dementia
c. Referral to a psychiatrist for treatment of anxiety and depression
d. Implement advance care planning methods

4. Who are persons affected by dementia?

a. Persons living with dementia
b. Care partners and families of persons living with dementia
c. Health professionals who treat persons living with dementia
d. Health professionals who treat care partners of persons living with dementia
e. All of the above

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