FACULTY GUIDE

Core Module 13:

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

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HRSA
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Slide 1:

- This curriculum module—number 13 in the series of 16—provides an overview for health care professionals who need to be able to understand the roles of clinical social workers and clinical psychologists providing care to persons living with (PLwD) dementia and their care partners. This module discusses the roles of clinical social workers and clinical psychologists through the continuum of illness, beginning with pre-diagnosis, diagnosis, early stages of the disease, and later stages of the disease. The role of clinical social workers and clinical psychologists is to provide support and counseling to PLwD and their care partners, help them understand the disease, and assist them in making decisions about care. The module consists of a 45 to 60-minute PowerPoint presentation, as well as this guide, which includes detailed faculty notes that more fully explain the information contained in each slide. This module includes case vignettes to illustrate real life scenarios experienced by PLwD who seek professional services to cope with and manage the effects of dementia, and the clinical social worker or clinical psychologist response.

Slide 3:

- Because dementia affects every part of a person's life—and that of their loved one (s)—physically, cognitively, emotionally, spiritually, socially, culturally, and financially, clinical social workers and clinical psychologists serve as frontline providers of care to help persons living with dementia and care partners cope and manage along the illness continuum, and across care settings, from pre-diagnosis to the end of life.

Slide 5:

- Module 13 addresses the roles of clinical social workers and clinical psychologists in practice with persons living with dementia and their care partners across the illness trajectory.
- There are some common elements of each discipline's practice and there are some differences.
- You will learn how clinical social workers and clinical psychologists are an integral part of teams or of individual practices in assessing, educating, guiding, and counseling persons living with dementia, or who work with persons living with dementia, and through every stage of the illness to cope and manage in as healthy of a manner as possible.
- You will learn the tools, resources, and techniques used by each discipline and the resources and supports available to persons affected by dementia to care for their loved one as safely as possible.

Slide 6:

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Slide 8:

- Social workers provide a number of skills with persons affected by dementia—often related to their psychological and social functioning.
- Clinical social workers concentrate on the assessment, diagnosis, treatment, and prevention/management of mental and/or physical illness, emotional, and other behavioral disturbances.
- They work across many practice settings and often hold master's degrees and can be licensed in their state of practice.
- Individuals should not practice clinical social work without graduate level clinical training. Individuals with bachelors of social work (BSW) non-clinically trained masters of social work do have significant roles in the lives of PLwD and their care partners, but no in the provisions of clinical services.

Slide 9:

- Clinical psychologists hold a doctoral degree and study both normal and abnormal functioning and treat persons with mental and emotional problems.
- They study and encourage behaviors and thinking that builds wellness and resilience.

Slide 10:

- This specialty within professional psychology applies psychology methods and understanding to practice with older persons and their families.
- Professional geropsychology recognizes the wide diversity among older adults, the complex ethical issues that can arise in geriatric practice and the importance of interprofessional models of care.

Slide 11:

- Geropsychologists specialize in assessment and treatment of mental and behavioral health and provide individual and family therapy.

Slide 13:

- Cultural competence and ethical practice are fundamentally part of clinical social work and psychology practice in any setting.
- Both the National Association of Social Workers and the American Psychological Association provide excellent information and resources for each respective discipline's practice.
- The **National Association of Social Workers *Code of Ethics* (NASW)** offers a set of values, principles, and standards to guide decision making and conduct when ethical issues arise.
- *The* **NASW Standards and Indicators for Cultural Competence in Social Work Practice *(2015)*** are updated standards that reinforce the concept of "culture" as being inclusive beyond race and ethnicity; inclusive of, but not limited to, sexual orientation, gender identity and expression, and religious identity or spirituality.
- The **American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct** guides psychologists in addressing ethical issues and situations that arise.

Slide 14:

- Clinical social workers and clinical psychologists use a person-centered and strengths-based approach to guide, counsel, and teach persons affected by dementia on how to manage stress, remember the **PERSON,** and cope with the disease.
- Emphasis is on including the person in care.

Slide 15:

- Person-centered care emphasizes the importance of not just the PLwD's illness and physical and medical needs, but also their social, mental, emotional, and spiritual needs. This approach involves family members and caregivers in care and shared decision making processes. It focuses on creating and maintaining a supportive and organized home environment, prioritizing relationships in addition to care tasks, and applying detailed knowledge and understanding of the individuals in order to tailor their care

Slide 16:

- Additional components of person-centered and directed care include:
    - Treating people as individuals;
    - Recognizing the importance of activities and social interaction that can compensate, in part, for their impairment;
    - Maximizing PLwD's choice and autonomy; and
    - Providing quality care.

Slide 18:

- This case vignette is an excellent example of how many care partners of persons suspected of having dementia or have been diagnosed with dementia come to accept the potential diagnosis or diagnosis and reach out for help. The social worker assists Elizabeth by listening, being supportive and helping connect her to helpful resources.

Slide 19:

- Clinical social workers and clinical psychologists serve on care teams providing care or responding to crises of persons living with dementia and their care patners—such as
    - Comprehensive care in an adult day health center
    - A psychiatric unit
    - Consulting with professionals or facilities providing care
    - Educating direct care workers on best practices in long term care settings, mobile crisis units, court systems, and community health and mental health programs

Slide 20:

- Read case study out loud.
- Mrs. Jones is a 91-year-old woman in a residential nursing facility. She 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?

Slide 21:

- The consulting psychologist developed a behavior tracking system that helped identify the cause of Mrs. Jones's calling out behavior: an infected tooth that was causing her pain, but that she could not describe to others. An individualized plan of care was developed to respond to her distress and behaviors. The plan reflected Mrs. Jones' interests and addressed potential triggers. The infected tooth was treated and the activities staff were taught how to engage Mrs. Jones in appropriate group activities to increase her rate of prosocial stimulating activities.
- The staff began to engage Mrs. Jones in more group activities and to use music in her room during her personal time, thus filling her days with more positive and meaningful activities.
- See also Module 16 to learn more about PLwD and Dentistry.

Slide 22:

- When a person's memory begins to fail beyond the usual signs of aging or other changes in cognition and behavior occur and dementia is suspected, symptoms can manifest themselves in ways that draw concern and attention.
- Family, friends, or neighbors may notice someone repeating themselves, getting lost in familiar places or wandering in the neighborhood and unable to find their way home.
- Care partners can assist in getting an evaluation by a physician or a clinical psychologist to provide testing and/or medical attention for a correct diagnosis of dementia vs. another etiology.
- Let's examine how clinical social workers and clinical psychologists practice with persons suspected of/assessed as having dementia and their care partners across the illness continuum.

Slide 23:

- Clinical social workers and clinical psychologists can play a significant role in the assessment, evaluation and treatment of dementia and MCI. They can provide information to persons affected by dementia about what are normal vs. what are not normal signs of aging; provide counseling to concerned care partners on how and when to seek medication attention or further diagnostic evaluations and they can assist in coordination of this care.
- They are active in assessing for dementia or MCI in persons suspected of having dementia.
- Family conflicts and dynamics may occur as the family comes to terms with a dementia diagnosis and the care needed for the PLwD. Clinical social workers and clinical psychologists can assist individuals and their care partners work through conflicts and find a degree of acceptance.

Slide 25:

- Both clinical social workers and clinical psychologists can train and provide testing to assess for cognitive impairment. **Each discipline is aware that full evaluation of possible dementia is an interdisciplinary, holistic process involving other health care providers.** F**ull evaluation of possible dementia is an interprofessional, holistic process involving other health care providers.** Over the next few slides, we will be identifying and reviewing various assessment resources and tools.
- Many dementis screening tools, guidelines, and resources exist and include:
- Mini cog
- 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

Slide 26:

- Clinical social workers and clinical psychologists conduct and/or coordinate a comprehensive, biopsychosocial-spiritual assessment which forms the basis for their practice and interventions (such as counseling, behavioral management, long term care planning) with persons affected by dementia. The assessment is updated on an ongoing basis.
- In order to conduct this comprehensive assessment, clinical social workers and clinical psychologists need to understand and be able to articulate the neurobiology, as well as cognitive and behavioral manifestations of dementia across all stages of the disease's progression, while considering that each person living with dementia experiences different symptoms of the disease.

Slide 27:

- These examples of assessments that can be used by clinical social workers and clinical psychologists emphasize a person centered approach and inclusion of all biopsychosocial factors that affect a PLwD and their care partner (s).

Slide 28:

- A person is asked two questions during the mini-cog.
    - Remember and a few minutes later repeat the names of three common objects
    - Draw a face of a clock showing all 12 numbers in the right places and a time specified by the examiner
    - The Mini-cog is copyrighted and permission must be granted for its use

Slide 29:

- The American Psychological Association (APA) provides information for clinical psychologists to evaluate persons for dementia and age-related cognitive change. The APA's *Guidelines for the Evaluation of Dementia and Age-Related Cognitive Change* were developed to help promote

psychologists' proficiency and expertise in assessing for dementia and age-related cognitive decline.

Slide 30:

- This publication 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. This resource was developed in response to the increasing necessity for a workforce to address the mental health and substance abuse needs of older adults.

Slide 31:

- The Advanced Practice in Mental Health Settings module is focused on teaching students the distinctions among three mental health disorders that often accompany the aging process: dementia, depression, and delirium.
- It also includes a dyad class activity demonstrating administration of the Folstein Mini-Mental Status Exam and the Yesavage Geriatric Depression Scale, the latter used to assess for depression in older adults with signs of depression.

Slide 32:

- When a person or care partner is interested in participating in clinical trials, or is seeking guidance on complicated cases, memory clinics and centers can offer supportive resources. Memory clinics and centers, including Alzheimer's Disease Research Centers, offer teams of specialists who work together to diagnose the problem. Tests are often done at the clinic or center which can speed up diagnosis. There are 31 ADCs across the country.

Slide 33:

- In 2011, the National Institute on Aging and the Alzheimer's Association charged a workgroup with the task of revising the 1984 criteria for dementia and these guidelines help practitioners assess for dementia.

Slide 34:

- Clinical psychologists complete a geriatric assessment and evaluate older adults with regard to:
    - Depression
    - Anxiety
    - Cognitive impairment
    - Sleep disturbance
    - Suicide risk factors
    - Psychotic symptoms
    - Decision making capacity
    - Management of behavior problems associated with these and other conditions.

Slide 35:

- Persons living in the early stages of dementia can benefit from various interventions to cope with short term and long term implications of the disease.

- A dementia diagnosis can bring emotional reactions of sadness and anger (see Module 2 on diagnosis).
- Some individuals may not have insight into their memory loss or other cognitive changes they are experiencing and as a result be unwilling to obtain needed assistance.
- Clinical social workers and clinical psychologists can help translate information that PLwD and care partners receive in terms that are more natural for a non-medical professional to understand. These professionals can provide education, emotional support and guidance, advance care planning and decision-making and resource navigation to persons in the early stages of dementia.

Slide 36:

- 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.

Slide 37:

Read case vignette.

- 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, 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.
- In the next slide, we will discuss how psychologists can support Mr. Connors and his wife.

Slide 38:

- Specific interventions by the psychologist in this case might include:
    - Providing the wife with behavior management education and helping her to plan strategies to better manage the changes in her husband's behavior and function.
    - Facilitating a family meeting to educate the couples' children about dementia and provide them with guidance on how to offer emotional support to their father and assist their mother in the caregiver role.
    - Collaborating with the family physician around medical treatment for the depression and dementia.
    - Linking the family with community resources such as the Alzheimer's Association, caregiver support groups and respite programs for the caregiver.

- In a case very similar to this, the comprehensive involvement of the psychologist was effective in reducing the challenging behaviors and depressive symptoms, reducing the caregiving stress experienced by the wife and delaying placement of the husband in a long term care setting.

Slide 39:

- Geropsychologists/neuropsychologists perform comprehensive cognitive assessments to obtain evidence of dementia and to determine the individual's competency and capacity.
- Clinical psychologists may also explain the findings of the assessment, and provide education to the older adult and care partner about dementia. See Modules 2 and 4 for more information.

Slide 40:

- The Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists References and The APA Family Caregiver Briefcase are resources that include both assessment information for diminished capacity and competency and evidence based interventions for PLwD and their caregivers.
- The APA Caregiver Briefcase is an online resource for health and social service professionals assisting family caregivers through individual and organizational practice, research, teaching and community service. Provides useful information for family caregivers under resource section.

Slide 41:

- 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. Clinical social workers and clinical psychologists are mandated reporters of suspected abuse/neglect and/or exploitation.

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    - 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.

Slide 43:

- Clinical social workers and clinical psychologists, as well as health care professionals, can utilize the National Center on Elder Abuse, a national resource for policy makers, social work and health care practitioners, the justice system, researchers, advocates and care partners, or their local Adult Protective Service unit to staff or obtain guidance on concerns related to abuse, neglect or exploitation of older adults, including persons affected by dementia.
- The Alzheimer's Association operates a 24-hour helpline available to persons affected by dementia to address any questions and concerns.
- The American Bar Association and the American Psychological Association provide guidance for psychologists to assess diminished capacity in older adults in their publication, Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists.

Slide 45:

- Social workers and psychologists often work together to address the psychosocial needs of persons affected by dementia. In the case vignette about Jose and Lydia, a social worker responded to the allegations of neglect and abuse by gathering an assessment and working with Jose and Lydia on suggestions of caregiver respite and education with Jose about communicating and caring for someone with dementia. She also referred him to take Lydia to her physician to assess her agitation and paranoid behaviors and see if he had any recommendations.
- The Adult Protective Service social worker alerted emergency services to Lydia's suicidal behavior and helped get Lydia to treatment and safety by ensuring she had an emergency psychiatric assessment and psychological intervention. Jose received help from the psychologist and social workers by receiving education and counseling about living and caring for Lydia and her illness, also providing information on respite care and adult day health services for Lydia.

Slide 46:

- Clinical social workers and clinical psychologists serve a role in helping care partners learn how to address issues when driving becomes too dangerous for a person with dementia.
- Driving is a powerful symbol of competence and independence, besides being a routine part of adult life. Provide counseling regarding change in identity that can accompany giving up driving.
- The focused concentration and quick reaction time needed for safe driving tends to decline with age
- Addressing this need and safety concerns
- Clinical social workers and clinical psychologists can help care partners address their concerns about PLwD's driving and safety. They often work with persons affected by dementia and their physicians to address driving assessments and levels of cognitive function regarding whether

they have the ability to drive safely. They also provide counseling to address the change in identity that can result from giving up driving.

Slide 47:

- Clinical social workers and psychologists can also provide support by assisting with problem-solving for transportation needs and providing referrals for driver assessments programs and tests. They may also suggest physician interventions or, in some cases, clinical psychologists may conduct driving assessments to determine the PLwD's level of cognitive functioning.
- It's important to bear in mind that state mandatory reporting laws vary.

Slide 49:

- Let's look at support and counseling as primary interventions provided by clinical social workers and clinical psychologists to persons affected by dementia.

Slide 50:

- Psychosocial (psychological and social) therapy is an intervention that is intended to enhance self-esteem, well-being, social and communication skills, and to decrease behavioral disturbances.
- These are counseling strategies used to help persons with early to moderate stages of dementia and care partners:
- Grief and bereavement counseling
- Communication strategies and counseling
- Reminiscence work-this approach is based on recall and discussion between the PLwD and trusted individuals to think about and revisit past events, experiences, and activities. It often involves the use of objects and supports (i.e., photos, personal belongings, music) to help trigger specific memories.

Slide 51:

- Reminiscence therapy is an approach based on recall and discussion between the PLwD and trusted individuals to think about and revisit past events, experiences, and activities. It often involves the use of objects and supports (i.e., photos, personal belongings, music) to help trigger specific memories. The goal of validation therapy is to promote and stimulate communication skills in the dementia patient, and to provide the individual with insight into their external reality.

Slide 52:

- Anxiety and depression are common among persons living with dementia and mild cognitive impairment. 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.
- These conditions can be treated by clinical social workers and clinical psychologists.

Slide 53:

- 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.
- Behavioral therapy interventions focused on teaching care partners specialized skills to identify and increase pleasant events for the person with dementia, to develop strategies to increase involvement in meaningful activities, and to prevent or reduce depressive behaviors in the person with dementia can improve depression.

Slide 54:

- Behavioral and psychiatric symptoms are common in PLwD. Clinical social workers and clinical psychologists often respond to care partners living with, and professionals working with persons living with dementias to address behavioral disturbances with non-pharmacologic modalities.
- The primary treatable behavioral and psychiatric symptoms in dementia include psychosis, agitation, depression, anxiety, and insomnia.
- Behavioral disturbances in persons living with dementias cause significant caregiver distress, especially apathy. In the early and later stages of dementia, features related to apathy may appear, but are often confused with depression, particularly by care partners.
- Care partners often bring PLwD who are experiencing behavioral disturbances to health care providers due to the challenge in caring for them.
- Social workers and psychologists provide support, education and referrals to physicians to help with recommendations and management of these challenges.

Slide 56:

- Carter works with Lucy to address her long term role as primary caregiver 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 power of attorney for her father (advising to use an elder care lawyer) and weighing the decision of keeping her father at home or placing him in assisted living. 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 and Eve a few times to proceed placing her father in a small assisted living home that caters to persons with dementia and offers habilitation services to enhance functioning and support therapies 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 try placement to see how each of them adjust and if placement is indeed the right fit at this time.

- Summary: In this case, the social worker and psychologist work in tandem to address Lucy's concerns as primary caregiver to her father and provide counseling, support and care options and planning for what is the best option of care for George and for Lucy as his primary caregiver.

Slide 57:

- Clinical social workers and clinical psychologists can provide training to care partners of PLwD to provide helpful versus negative responses to PLwD when they have dementia symptoms.
- The Progressively Lowered Stress Threshold (PLST) model teaches family care partners problem-solving strategies to identify and provide activities that are appropriate for the individual's current level of functioning and to implement environmental modifications that support dementia function.
- The importance of maintaining *mobility and physical activity* in dementia has been recognized in clinical and long-term care settings and randomized trials have demonstrated that individualized exercise programs are both feasible and beneficial for increasing strength and maintaining mobility for cognitively impaired nursing home residents. Clinical social workers and clinical psychologists can educate care partners on the importance of continuing physical exercise and mobility for PLwD, to the extent it is safely tolerated.
- Additionally, they can promote the importance of providing activities that help cognitive stimulation, socialization and engagement opportunities that help maximize the PLwD's functioning and well-being.
- Informing care partners how to address concerns about the PLwD no longer driving

Slide 58:

- Diagnosis of early dementia can have negative psychological and social consequences for the diagnosed person. Yet there are potential benefits to early dementia diagnosis.
- Early diagnosis creates an opportunity for healthcare professionals to help individuals and their families cope with the impact of the diagnosis on quality of life (QOL) while the patient is still able to participate in decision making on his/her own behalf.
- Many Alzheimer's Association chapters and other groups provide early stage support groups (ESSGs) to address early diagnosis support for the individual with dementia and their care partners. These early stage support groups have many benefits for PLwD in the early stages of dementia.
- The ESSGs may focus on providing medical information about dementia, discussing strategies for coping with changes in mood and activities, and encouraging discussion among group participants and their family members about their personal experiences with memory loss and associated problems.
- Studies have shown that outcomes from ESSGs include less decline in quality for life (QOL) participants with dementia compared to controls, significantly decreased family conflict for participants living with dementia and significantly improved QOL for family care partners.

Slide 59:

- Clinical social workers and clinical psychologists who practice with persons affected by dementia can offer counseling with care partners to address coping with the diagnosis, family conflict, provision of care and caregiver support.
- Care partners of PLwD witness changes-including cognitive, behavioral, physical, emotional, financial and social- in the PLwD, often over the course of years.
- As PLwD decline in their cognitive and functional capacity, care partners are challenged to adjust and incorporate the losses and role changes into their lives.
- The burden of care becomes increasingly greater over the course of the illness; caregivers can benefit from support, counseling and education to cope and manage.
- Clinical social workers and clinical psychologists often provide guidance to care partners on strategies to minimize and manage the occurrence of behavioral and psychological symptoms of dementia.
- For additional information on Care for the CarePartner, please see the HRSA-created Caregiving specific modules

Slide 60:

- These are excellent resources to guide social workers in their practice with care partners of older adults, including PLwD.

Slide 61:

- Social media can be a significant resource for education, information and support for professionals and persons affected by dementia. Clinical social workers and clinical psychologists can utilize internet based videos and resources to educate themselves, persons affected by dementia, and other professionals about dementia and how to live with and care for someone across the disease continuum. The resources can be easily accessed online by care partners seeking helpful information on practical tasks of caregiving for a PLwD or for learning more about the illness and available treatments.
- There are multiple purposes of using well developed social media resources, including:
- Practical tasks such as how to help someone safely ambulate and transfer
- Understanding the biological and emotional aspects of dementia
- Caregiving and support for persons affected by dementia
- Learning about dementia treatments and how to access these resources
- Education of social work and psychology students and professionals
- The YouTube channels provided are just some of the online resources available for consumer or professional training about dementia. National Institute on Aging YouTube Channel can be retrieved online.
- UCSF Memory and Aging Center YouTube Channel can be retrieved online.

Slide 62:

- Clinical social workers and clinical psychologists working with persons affected by dementia may be presented with complicated situations that may need intensive assessment, treatment planning and/or counseling.

- Review slide text list.
- For more information on dementia and Racial/Ethnic Diversity, please see Module 3

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Slide 65:

- Both the social worker and psychologist responded to Charlie, the person who had just lost his wife, and took into their assessment and consideration his dementia diagnosis, but both disciplines provided person centered care and provided transition of care planning and case management to work toward a safe discharge plan for Charlie since he no longer had a caregiver.

Slide 66:

- With its strengths-based, person-in-environment perspective, individuals in the social work and psychology professions are well trained to develop and improve support systems (including service delivery systems, resources, opportunities, and naturally occurring social supports) that advance the well-being of individuals, families, and communities.
- Social workers and psychologists provide case management practices which engage clients in the collaborative process of identifying, planning, accessing, advocating for, coordinating, monitoring, and evaluating resources, supports, and services.
- Through case management skills, social workers and psychologists inform and guide persons affected by dementia and their families by helping them consider the various types of care that may be needed along the care continuum. The therapeutic relationship between the client/client system and social worker and/or clinical psychologist is an integral part of the case management process.

Slide 67:

- Clinical social workers and clinical psychologists can assist PLwD and their caregivers with short and long term planning. This includes:
    - Developing current and future care plans
    - Identifying patient preferences for all stages of the disease
    - Assisting with addressing financial and legal matters (Power of Attorney, Estate Planning)
    - Addressing potential safety issues
    - Learning about living arrangements/housing options
    - Identifying community resources for caregiver support and financial assistance
    - Navigating systems of care and assistance
    - Developing support networks

- Investigating clinical trials and research studies that are testing possible new treatments for dementia.

Slide 68:

- Clinical social workers and clinical psychologists across many practice settings (long term care, community and home, geriatric case management, hospitals, primary care, mental health clinics, hospice) can advise persons affected by dementia regarding care options and can help address difficult topics and decisions along the continuum of care, often in collaboration with professionals from Area Agencies on Aging and local Alzheimer's Association chapters.
- Most persons when asked where they want to live the remainder of their life answer—**home**. Aging in place and understanding long term care options and costs are discussions that social workers and psychologists often have with PLwD and care partners.

Slide 69:

- Long-term care is the range of services and supports a PLwD may need to meet their personal care needs. PLwD need more assistance and supervision with their daily tasks as their disease progresses. Most long-term care is provided at home. Other kinds of long-term care services and supports are provided by community service organizations and in long-term care facilities. Most long-term care is not medical care, but rather assistance with the basic personal tasks of everyday life, sometimes called Activities of Daily Living (ADLs). ADLs include bathing dressing, using the toilet, transferring to and from the bed or chair, incontinence care, and eating.

Slide 70:

- Other tasks may include housework, money and medication management, meal preparation and clean up, food and clothing shopping, pet care, use of phone and communication devices and responding to emergency alerts such as fire alarms.

Slide 71:

- Clinical social workers and clinical psychologists practicing with persons living with dementia are well versed in the options of care and how care planning may change along the illness trajectory. They advise persons affected by dementia with care options to best meet their needs and wishes, including the **importance of maintaining socialization, engagement, physical exercise (as tolerated) and cognitive stimulation and emotional attachment.**
- Types of care and programs include: personal care and assistance services, community rehabilitation service, skilled home health care, senior centers and adult day health centers and services, PACE programs, residential care, veterans' benefits and care options and palliative or hospice care.

Slide 72:

- Personal care and assistance services for persons living with dementia can include nursing, companions, transportation to appointments or services, and respite care for caregivers.
- How this care is paid for may come from someone's personal savings or public or private resources.

Slide 73:

- Habilitation and rehabilitation services are designed to assist individuals in acquiring, retaining, and improving the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings.
- Clinical social workers and clinical psychologists can recommend habilitation services for PLwD and caregiver education to maximize the functioning of and focus on the **Person** and not just the disease.
- These services may include physical and occupational therapy, speech-language pathology, nursing, nutrition and other services. The services enable PLwD to acquire, retain, and improve the self-help, socialization, and adaptive skills necessary to reside successfully in home and community-based settings. These services can be used by individuals using in-home care and those in more formal residential care facilities.

Slide 74:

- Home health care includes the wide range of health care services that can be provided in a person's home for an illness or injury. The goal of home health care is to treat the illness or injury and may involve multiple disciplines in the care.
- Home health care helps the individual get better, regain his/her independence, and become as self-sufficient as possible. It also teaches care partners how to care for PLwD.
- For more information, review module 9 which discusses the interprofessional team

Slide 75:

- In 2012, adult day centers provided over 8 million hours of care for dependent adults in a supervised, protective group setting during some portion of a 24 hour day. The goals of adult day center programs are to enhance self-esteem, encourage socialization and delay or prevent institutionalization by providing alternative care.
- There are two types of adult day services: senior centers, and adult day health and service centers. Senior centers coordinate and integrate services for older adults such as social activities, congregate meals, community education, health screening, exercise/health promotion programs and transportation.
- Adult day health care offers more intensive health, therapeutic and social services for individuals with severe medical problems and those at risk of requiring nursing home care. They provide care and companionship for seniors who need assistance or supervision during the day. This program offers relief to family members or care partners and allows them the freedom to go to work, handle personal business or just relax while knowing their loved one is well cared for and safe.

Slide 76:

- PACE (the Programs of All-Inclusive Care for the Elderly) provides comprehensive medical and social services to certain frail, community-dwelling elderly individuals, most of whom are dually eligible for Medicare and Medicaid benefits. An interprofessional team of health professionals provides PACE participants with coordinated care. For most PACE participants, the

comprehensive service package enables them to remain in the community rather than receive care in a nursing home.

- While PACE is a Medicare program, states can elect to provide PACE services to Medicaid beneficiaries as an optional Medicaid benefit. Financing for the program is capped, which allows providers to deliver all services the participants need rather than only those reimbursable under Medicare and Medicaid fee-for-service plans.

Slide 77:

- 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 services for Medicare and Medicaid eligible enrollees. Individuals can leave the program at any time.

Slide 78:

- Older adults may need a long-term care facility for extensive care or supervision if their needs can no longer be met at home. There are a number of options.
- **Continuing Care Retirement Communities** (CCRC) offer a range of services and levels of care. Residents may move first into an independent living unit, a private apartment, or a house on the campus. The CCRC provides social and housing-related services and often also has an assisted living unit and an on-site or affiliated nursing home. If and when residents can no longer live independently in their apartment or home, they move into assisted living or the CCRC's nursing home.

Slide 79:

- The Centers for Medicare and Medicaid (CMS) and its partners are committed to finding new ways to implement practices that enhance the quality of life for persons living with dementia, protect them from substandard care, and promote goal-directed, person-centered care for every nursing home resident.
- CMS aims to create individualized and person centered care to nursing home residents, many of whom have a cognitive impairment. The CMS National Partnership to Improve Dementia Care in Nursing Homes emphasizes nonpharmacological, person-centered, evidence-based practice approaches for residents, such as stronger family involvement, consistent staff assignments, increased exercise or time outdoors, monitoring and managing acute and chronic pain, and planning individualized activities. Use of a consistent process to address the behaviors associated with dementia and that focuses on the resident's individual needs, will help to reduce the percentage of antipsychotic medications that are prescribed.
- Social workers and psychologists are at the forefront of providing mental health services in nursing homes.

Slide 80:

- The Veterans Administration offers a number of care options for veterans with dementia and their caregivers, including health care services, home based and facility based care and caregiver support. It is important for veterans and their caregivers to contact the VA. to see if they are eligible for services.

Slide 81:

- 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 at-home care 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.

Slide 82:

- The VA has two additional programs that help veterans stay in their homes:
- **The Housebound Aid and Attendance Allowance Program.** This program provides cash to eligible veterans with disabilities and their surviving spouses to purchase home and community-based long-term care services such as personal care assistance and homemaker services. The cash is a supplement to the eligible veteran's pension benefits **A Veteran Directed Home and Community Based Services program (VD-HCBS).** This program was developed in 2008 for eligible veterans of any age. The program provides veterans with a flexible budget to purchase services. Counseling and other supports for veterans are provided by the Aging Network in partnership with the VA

Slide 83:

- Hospice care focuses on pain management and emotional, physical, and spiritual support for the patient and family. It can be provided at home or in a hospital, nursing home, or hospice facility. Medicare typically pays for hospice care. Hospice care is not usually considered long-term care.
- The goal of palliative care is to help patients with serious illnesses feel better. It prevents or treats symptoms and side effects of disease and treatment. Palliative care also treats emotional, social, practical, and spiritual problems that illnesses can bring up. When patients feel better in these areas, they have an improved quality of life.
- Palliative care can be given at the same time as treatments meant to cure or treat the disease. You may get palliative care when the illness is diagnosed, throughout treatment, during follow-up, and at the end of life.
- For more information on hospice and palliative care, review module 12

Slide 84:

- Dementia care costs Americans billions of dollars in paid and informal care — and that number is growing.

- Clinical social workers and clinical psychologists are instrumental in working with PLwD and their care partners both navigate and understand their care options and guide care partners to determine what options are best across the disease continuum.

Slide 85:

- It is imperative that clinical social workers, clinical psychologists, and other healthcare professionals understand the enormity of long term care costs, in order to educate and empathize with PLwD and their care partners who face these challenges.
    - Some average costs for long-term care in the United States (in 2010) were:
    - $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

Slide 86:

- Social workers are familiar with the financial considerations and resources for PLwD and their care partners when looking at decisions and planning that needs to occur across the disease continuum.
    - Spousal or adult disabled child asset protection
    - Medicare and Medicaid
    - Long term care insurance
    - 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

Slide 87:

- A number of public programs, including Medicare and Medicaid, may help pay for some long-term care services under certain circumstances. However, each program has specific rules about what services are covered, how long a person can receive benefits, whether or not someone qualifies for benefits, and how much someone has to pay in out-of-pocket costs.
- Community programs can provide these services through state and local agency networks known as the Aging Network and include:
    - Nutrition programs such as home-delivered meals for homebound elderly or meals served in community settings
    - Transportation services
- Health promotion services to help prevent disease or manage chronic illnesses
- Personal care assistance and help with household chores and shopping
- Legal assistance and services that protect the rights of older persons such as the long-term care ombudsman program

- Family caregiving services and supports including time off from their responsibility, called respite care
- While the financial eligibility criteria for these programs differ by state and by program, they are generally targeted for low-income, frail seniors over age 60, minority older adults, and seniors living in rural areas. Specific funds are often set aside for Native American older adults.
- Local agencies, called Area Agencies on Aging (AAAs), work with State Units on Aging (SUAs) to plan and develop service and support programs based on the needs of older adults and families.

Slide 88:

- A short video (under 2 minutes) explaining what health insurance does and does not cover for long term care, visit the Administration on Community Living YouTube online.

Slide 89:

- 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 person living with dementia 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
    - Clinical social workers and clinical psychologists each provide important roles in these areas but an elder care lawyer is one of the best resources for PLwD and their care partners for financial and legal planning.

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Slide 91:

- Show this brief online video on Advance Directives available at NIH Senior Health YouTube channel online.

Slide 92:

- It is very important for clinical social workers and psychologists to understand end of life care planning and be able to explain these terms to PLwD and care partners. Social workers and psychologists working with PLwD often have this experience and training.

Slide 93:

- This module has provided an in-depth look at the role of clinical social workers and clinical psychologists working with persons affected by dementia. The information and resources provided are designed to equip clinical social workers and clinical psychologists with current knowledge, evidence based practices and research to provide successful practice in their work with PLwD and care partners. The module aims to help clinical social workers and clinical psychologists to:
- Understand best practices in dementia detection and assessment by clinical psychologists and cognitive testing performed by both disciplines
- Educate and counsel persons affected by dementia to manage and respond to the cognitive, psychosocial, and behavioral changes in many PLwD
- Identify multiple interventions, tools, practice standards and resources utilized by clinical social workers and clinical psychologists who practice with persons affected by dementia
- Identify resources available to assist and support persons affected by dementia to best meet their care and support needs during the disease continuum

Slide 94:

Answer:

1. d. Supporting community health and mental health programs

Slide 95:

Answer:

2. d. Solicit assistance from someone who can translate information into natural non-medical terms