FACULTY GUIDE

Core Module 6:

Understanding Middle Stage Dementia for an Interprofessional Team

November 2018

This module was developed under a contract from the U.S. Department of Health and Human Services, Health Resources and Services Administration. Some of the views expressed in this presentation module are solely the opinions of the author(s) and do not necessarily reflect the official policies of the U.S. Department of Health and Human Services or the Health Resources and Services Administration, nor does mention of the department or agency names imply endorsement by the U.S. Government.

Slide 1:

- These next two modules—Modules 6 and 7—both deal with the middle stage of Alzheimer's disease and related dementias, or ADRD. In this module, we focus attention on cognitive, behavioral, and functional manifestations and provide suggestions for nonpharmacologic interventions that manage these symptoms. We also spend time focusing on the many safety concerns that frequently emerge during middle-stage dementia.

Slide 3:

- These are the topics we will be addressing in this module. We begin with an overview of middle-stage dementia, including a review of cognitive impairments and behavioral/psychological symptoms of dementia, or BPSD for short, before getting into the similarities and differences between the various types of dementia.
- We then focus on issues that are most likely addressed by health care professionals—nonpharmacologic strategies and assessment of the older adult for a variety of safety considerations. Finally, we introduce the topic of transitioning to the different levels of care currently available, from in-home paid/professional care to institutional care.

Slide 4:

- The goal is for you to have learned the following items by the time we finish this module. You will be able to:
    - List clinical manifestations of middle-stage dementia.
    - Describe behavioral and psychological manifestations commonly observed during middle-stage dementia.
    - Describe and be able to apply the Describe, Investigate, Create, and Evaluate Model (DICE) model for managing behavioral and psychological manifestations of dementia (BPSD).
    - List safety concerns for persons living with a middle-stage dementia diagnosis.

Slide 6:

- Persons with middle-stage dementia have progressive deterioration of cognitive abilities, executive function, and functional abilities.
- Behavioral and psychological symptoms of dementia (BPSD) are common, and include mood disorders, sleep disorders, psychotic symptoms, and agitation.
- Persons living with dementia have increasing problems with memory and overt changes in personality.
- Persons with middle-stage dementia need help with personal care, such as choosing clothes, but generally retain the ability to perform other basic ADLs (Ortigara & Scher McLean, 2013). In addition to the escalating cognitive impairments, behavioral and personality changes become more apparent and bothersome to both the person living with Alzheimer's disease and the care partner.

Slide 7:

- We are beginning with the clinical manifestations of middle-stage dementias across the most common types. We will be covering issues pertaining to end-stage dementia and palliative care in Module 12.

Slide 8:

- There is no set time period for how long each stage of dementia persists. The rate of progression depends on individual factors, the underlying cause of dementia, and the presence or absence of comorbid medical or psychiatric illness.
- Manifestations depend on the underlying cause of dementia:
    - There are no clear means—no biomarkers or diagnostic tests—that determine when a person transitions out of early-stage dementia.
    - PLwD will demonstrate progressively greater difficulty with memory and executive functioning and increasing difficulties in engaging in social and avocational activities. They will have increasing difficulty performing instrumental activities of daily living, or IADLs, although they generally retain the ability to perform basic ADLs, such as bathing, dressing, transferring, toileting, and eating, and they will need more assistance on a daily basis (NIA, 2017a).
    - Manifestations in the older adult with vascular dementia will depend on the portion of the brain affected—for example, subcortical versus stroke-related varieties of vascular dementia. Manifestations generally become more like those of AD as the brain damage progresses, although there are more plateaus and fluctuations with stroke-related vascular dementia (NIA, 2017b).
    - Similarly, persons diagnosed with LBD will show symptoms similar to Alzheimer's disease along with Parkinson's disease type symptoms, such as tremors, difficulty walking, rigidity, and other motor function impairments. Language skills also continue to decline (NIA, 2015).
    - Frontotemporal degeneration, which is also known as frontotemporal disorders, frontotemporal dementia, or frontotemporal lobar degeneration (FTLD), manifests with increasingly severe language and movement problems, as well as behavior and personality changes, and fewer memory-related issues (NIA, 2017c).
- This is the stage in which behavioral and psychological symptoms of dementia, BPSD, typically emerge and grow worse. In fact, these symptoms can become exceedingly challenging for the care partner to manage, more so than the deterioration of cognitive abilities.

Slide 10:

- Progressive deterioration of cognitive abilities, executive function, and functional abilities, along with emergence of BPSD, is often increasingly challenging for care partners to manage.
- Persons living with dementia:
    - May lack orientation to time or place
    - Still retains awareness of spouse's/children's names in middle stages
    - May not remember relevant information about own life (name of high school or college; names/ages of grandchildren)

    - May have trouble problem-solving
    - May have difficulties completing routine tasks
    - May have difficulty concentrating or focusing
    - May have difficulty following logic
    - May have difficulties making choices
- A PLwD may have increasing difficulty attending to personal IADL:
    - For example, the person may require assistance choosing appropriate clothing.

Slide 11:

- In addition to cognitive and functional impairments, almost all persons living with dementia (98 percent) will exhibit behavioral and psychological symptoms of dementia (BPSD.
- Some of these symptoms are caused by neurodegeneration; other symptoms, such as obstructive sleep apnea, coexist or are commonly observed in persons living with dementia.
- In general, behavioral and psychological symptoms of dementia encompass four groups of symptoms/concerns (Aarsland, Taylor, & Weintraub, 2014; Desai, Schwartz, & Grossberg, 2012; Dodd et al., 2017; Kales, Gitlin, & Lyketsos, 2015):
- Mood disorders:
    - Apathy, depression, dysphoria, and (rarely) euphoria
- Sleep disorders:
    - Insomnia, hypersomnia, and circadian rhythm disorders
    - Obstructive sleep apnea
- Psychotic symptoms:
    - Delusions and hallucinations
- Agitation:
    - Pacing, wandering, sexual disinhibition, aggression, and anxiety

Slide 12:

- Returning to the outline, we are now going to begin addressing the specific manifestations of and issues pertinent to middle-stage manifestations of Alzheimer's disease and related dementias (ADRD). We begin with Alzheimer's disease.

Slide 13:

- The moderate or middle stage of AD can be prolonged in comparison with early- and late-stage phases.
- There is notable cognitive decline that is now apparent to people who do not regularly see the person with dementia.
- Persons living with dementia have increasing problems with memory and overt changes in personality, including:
    - More consistent loss of recent memory and some long-term memory
    - Inability to recall address, phone number, and name of high school or college attended
    - Tendency to get lost in familiar places
    - Need for reminders and cues about ADL and IADL
- Increasing neurologic damage interferes with the ability to:

  - Express thoughts
  - Perform routine tasks
  - Accomplish ADLs
- Cues the persons living with dementia have transitioned to middle-stage include:
  - Confusion of words
  - Inability to recall one's own phone number
  - Increasing moodiness
  - Social withdrawal
  - Inability to recall information or events from one's past
  - Alterations in sleep patterns
- The person with middle-stage AD has increasing difficulties with IADLs (Ortigara & Scher McLean, 2013):
  - The person may be confused about location or the day or date; for example, thinking that he or she is somewhere else or a younger version of self.
  - Persons living with dementia may have difficulties completing sentences and understanding other people.
  - The person may need cues and assistance initiating and following through with tasks; for example, after taking orange juice out of the refrigerator and a glass from the cupboard, he or she does not know what to do next.
  - He or she may have difficulties with mathematical calculations, such as making change.
- People with middle-stage AD also require increasing levels of daily care and attention and may require some help with basic ADLs:
  - Persons with middle-stage dementia need help with personal care, such as choosing clothes, but generally retain the ability to perform other basic ADLs. In addition to the escalating cognitive impairments, behavioral and personality changes become more apparent and bothersome to both the person living with Alzheimer's disease and the care partner.
  - These personality and behavioral changes can include rage, suspiciousness, delusions, compulsive/repetitive behaviors, and increasing moodiness and social withdrawal.
  - These changes may make it challenging for the person living with Alzheimer's disease to continue to engage in regular social outings. There may need to be changes or accommodations in the timing, place, and support structure of these outings:
  - For example, Friday dinners out with the same group of friends may need to be changed to lunches, or limited to only one other couple to minimize sensory overload.
  - Persons living with dementia are likely to repeat questions and engage in repetitive actions and are at risk of getting lost in the community.
  - Psychiatric manifestations, such as delusions, may begin, or may worsen if they had already emerged (Horning, Melrose, & Sultzer, 2014).
- Safety considerations now include:
  - Driving
  - Home safety
  - Medication management
  - Getting lost

Slide 15:

- Manifestations of vascular dementia become increasingly similar to those of Alzheimer's disease as the vascular disease progresses.
- Symptoms are determined by the location and extent of brain damage:
  - Subcortical dementia has a more gradual, slower progression, like Alzheimer's, whereas symptom onset with stroke-related vascular dementia can be sudden, quickly worsening with each subsequent stroke, but staying somewhat stable between attacks. This is generally referred to as the step-wise progression, similar to walking down a flight of stairs.
  - Progressive memory impairments manifest during later stages.
- As mentioned in Modules 1 and 5, persons with vascular dementia have a shortened life expectancy, typically only 5 years after symptom onset.

Slide 16:

- Lewy body dementia (LBD) encompasses both dementia with Lewy bodies (or DLB) and Parkinson disease dementia (PDD).
- The rate and progression of cognitive deterioration is less consistent compared with Alzheimer's disease; there is no clear consensus in the literature identifying a faster or slower rate of decline.
- Persons with Lewy body dementias (LBD) manifest increasing impairments in executive function, including the ability to plan and process information; memory; and the ability to understand visual information. There is an eventual global loss of memory. These persons also have increasing problems with movement. The Parkinsonian symptoms include tremors, rigidity or stiffness, slowness, and difficulty walking (LBDA, n.d.; Mayo Clinic, 2017).
- Visual hallucinations are common in middle stage. Persons with DLB or Parkinson's disease dementia (PDD) may see things that are not present, such as shapes, people, or animals. These visual hallucinations may be one of the first symptoms of LBD. Less frequently, people may have auditory, olfactory, or tactile hallucinations. Evidence indicates that delusions and hallucinations in PDD are associated with poor outcomes.
- Sleep disorders, especially rapid eye movement (REM) sleep behavior disorder, or RBD for short, are also common. To the care partner, sleep behavior disorder (RBD) looks as if the person is acting out dreams while asleep.
- Language skills decline; the person has difficulties speaking, understanding, and reading and/or writing.
- Behavioral and mood symptoms persist and may escalate. These symptoms include depression, apathy, anxiety, agitation, delusions, and paranoia.
- Medical complications can stem from changes in autonomic body functions, such as deteriorations in blood pressure control; pulse and temperature regulation, including the ability to sweat; and bladder and bowel function. Consequently, there may be episodes of dizziness, an increased risk of falling, and incontinence.

Slide 17:

- Impairments progress over time: symptoms and rate of deterioration depend on the type of frontotemporal degeneration, or FTD for short, and on the individual.

- Characteristic manifestations are as follows:
    - Behavioral variant FTD manifests with psychiatric symptoms, including increasing apathy, inappropriate and impulsive behaviors, emotional lability or excessive emotionality, and lack of initiative—but memory generally remains intact.
    - As bvFTD progresses, there are increasing language and movement impairments. BvFTD was originally known as Pick's disease; however, this term now refers to abnormal collections in the brain of the protein tau, called "Pick bodies." Not all older adults with bvFTD have Pick bodies in the brain.
    - Among the most common manifestations of middle-stage FTD are problems with executive functioning, including skills such as planning, prioritizing, organizing, and multi-tasking; repetitive behaviors; social disinhibition; compulsive behaviors, particularly eating; and an inability to resist touching objects or using objects for no apparent reason.
- The two language subtypes included under primary progressive aphasia are (1) semantic dementia (sFTD) and (2) progressive nonfluent aphasia (PNFA) (Mioshi, Hsieh, Savage, Hornberger, & Hodges, 2010; Piguet, Hornberger, Mioshi, & Hodges, 2011). Each is characterized by progressive language decline including impairments in the ability to speak, understand, read, and write.
- Progressive motor decline is characterized by progressive muscle weakness, lack of coordination, and inability to ambulate.
- Eventually, muscular deterioration from FTD results in difficulties swallowing and chewing.

Slide 18:

- We are now going to examine how to manage the common behavioral and psychological symptoms of dementia, or BPSD, which typically arise or are exacerbated during the middle-stage of dementia.
- The neuropsychiatric symptoms, or NPS, of dementia include depression, hallucinations/delusions, and apathy (Aarsland, Taylor, & Weintraub, 2014).
- Numerous terms and acronyms are used to describe the noncognitive symptoms of dementia. We are using behavioral **and** psychological symptoms of dementia because they encompass both neuropsychiatric and behavioral symptoms.
- After explaining the symptoms, we will introduce the DICE approach as a model to help address these issues (Kales, Gitlin, & Lyketsos, 2014), and we will apply this model to some of the most common BPSD manifestations.
- We will conclude this segment with a look at the sexuality issues that may arise during middle-stage dementia.

Slide 19:

- BPSD include mood disorders such as apathy, depression, and dysphoria; sleep disturbances, including insomnia, hypersomnia, circadian rhythm disorders, and obstructive sleep apnea; psychotic symptoms, such as delusions and hallucinations; and agitation, which can manifest as pacing, wandering, sexual disinhibition, aggression, and anxiety.
- Behavioral/psychological symptoms of dementia, or BPSD, are primarily caused by progressive damage to the brain, but may be caused by many other factors:

  - Medication side effects and interactions (especially benzodiazepines, opiates, and anticholinergic medications)
  - Infections (particularly urinary tract infections, pneumonia)
  - Pain
  - Unmet needs (loneliness, boredom, inactivity)
  - Other common comorbid conditions (constipation, delirium, dehydration, sleep problems)
  - Environmental changes, transitions (excessive noise, temperature changes)
- Nonpharmacologic interventions are generally preferred as first-line treatment strategies over medications, which can cause adverse effects or other problems, including mortality.

Slide 21:

- Persons living with dementia are typically not screened for behavioral and psychological symptoms in primary care.
- BPSD are generally considered to be more common in middle- and late-stage dementia but may first appear during early-stage dementia. It is important and helpful for clinicians and care partners to be cognizant that these kinds of symptoms are common during dementia and that sometimes they may indicate transition to a later stage.
- Identifying the underlying cause of behavioral and psychological symptoms can inform treatment. Among the many causes are:
  - Medications (especially benzodiazepines, opioids, and anticholinergics)
  - Medical conditions (delirium, pain, urinary tract infection, constipation, and dehydration)
  - Environmental factors (temperature, ambience, and home versus institution)
  - Prior psychological or psychiatric illness
  - Unmet needs (Kales, Gitlin, & Lyketsos, 2015):
    - Psychosocial factors, such as loneliness or boredom
    - Physical factors (need for touch)
- BPSD can also stem from problems with the care partner. For example, persons living with dementia might be responding to the care partner’s depression, stress, general anxiety, or feelings of being overwhelmed (Kales, Gitlin, & Lyketsos, 2014).
- A comprehensive and systematic assessment strategy is needed for addressing BPSD.
- Ongoing screening should be part of standard comprehensive care for persons living with dementia.
- There are many screening and assessment tools available for BPSD (Cerejeira, Lagarto, Mukaetova-Iadinska, 2013). In addition to interviewing persons living with dementia and care partners and noting identified concerns, you might want to use a tool such as the *Neuropsychiatric Inventory* or the earlier *BEHAVE-AD*. The *Neuropsychiatric Inventory* is a well-established semi-structured interview that assesses 12 symptoms based care partner information.

Slide 22:

- Management is on an individualized basis with care partner serving as a member of the team.
- There are few well-proven strategies or treatments currently available for managing BPSD.

- Nonpharmacologic approaches serve as first-line treatment. However, no one intervention is ideal:
    - They have only low or modest effectiveness in real-world settings (Kales, Gitlin, & Lyketsos, 2014; Azermai, 2015).
    - There is a lack of agreement in guidelines regarding which interventions to use (Azermai, 2015).
- Medication may be necessary for emergencies or when behavioral disturbances are severe and persistent:
    - Psychotropic medications (e.g., antipsychotics) are often prescribed to manage symptoms.
    - No drugs are approved by the US Food and Drug Administration (FDA) for the management of behavioral disturbances in PLwD.
    - Drugs have modest efficacy. They can worsen dementia and are associated with significant risks, including mortality (Kales, Valenstein, Kim, McCarthy, Ganoczy, Cunningham, & Blow, 2007).
- If clinically significant BPSD remain untreated, they can lead to a faster progression of the dementia.
- The goals of nonpharmacologic interventions include prevention of symptoms, symptom relief, and reduction of care partner distress.

Slide 23:

- We now introduce a model that can be used to help manage BPSD – the DICE approach.

Slide 24:

- The DICE approach is a model that can be used to manage BPSD. It has four levels and requires input from both care partner and provider (Kales et al., 2014): Describe, Investigate, Create, and Evaluate.
- The approach assumes that a problem has been identified and mentioned to the provider.
- DESCRIBE – Care partner **describes** behavior and its context:
    - Describe the behavior as clearly and objectively as possible: what specifically is happening, when does it occur, who is involved, and where does it occur?
    - Identify what is most distressing/problematic about the behavior.
    - Whenever possible, elicit input from persons living with dementia.
    - Identify a treatment goal—what would the care partner like to see happen/change?
- INVESTIGATE – Provider thoroughly **investigates** possible underlying causes of problem behavior:
    - Health (medical/psychological concerns)
        - Undiagnosed medical condition (pain, illness, infection)
        - Medication side effects
        - Dementia symptoms
        - Comorbid conditions (medical or psychiatric)
        - Psychological concerns (boredom, helplessness, etc.)
        - Sleep problems
- Role of care partner in BPSD:

    - Lack of understanding of dementia
    - Feeling overwhelmed, tired
- Cultural factors
- Environmental factors:
    - Over- or under-stimulating environment?
    - Sensory concerns (too hot, too loud, too dark/light)
- CREATE – Together, the care partner and provider collaborate to develop, **create,** and implement a treatment plan that includes the following:
    - Addresses medical etiology appropriately (pain management, antibiotics, etc.).
    - Optimizes sleep hygiene
    - Addresses sensory impairments (poor vision, hearing)
    - Uses generalized or targeted behavioral strategies:
        - Generalized strategies are not behavior specific:
            - Include care partner education
            - Enhance effective communication between persons living with dementia and care partners
            - Create meaningful activities
            - Simplify tasks/establish structured routines
        - Targeted strategies are behavior specific.
- EVALUATE – Provider **evaluates** safety and efficacy of intervention:
    - Were measures implemented? If not, why not?
    - Were measures successful?
    - Any unintended consequences?

Slide 25:

- As discussed in Module 5, a care partner can use many general, nonbehavior-specific strategies to help manage BPSD.
- No one strategy will work for all persons living with dementia, or for every BPSD. There is no way to know which approach will work for a given individual or on a given day.
    - Physical activity: Engage persons living with dementia into activities based on their prior interests or capabilities; recommend activities that involve repetitive motions (folding towels).
    - Communication: Allow more time for persons living with dementia to process the communication, provide cues, remain calm and reassuring, break down instructions into small steps.
    - Environmental changes: Adjust the temperature, the lighting, the noise level; remove clutter.
    - Task simplification: Break down tasks into small steps, and provide only one or two steps at a time.
- Nonpharmacologic interventions are preferable to medication. It should be noted up front, however, that most studies of nonpharmacologic strategies focus on short-term rather than long-term benefits or effects (Cohen-Mansfield, Marx, Dakheel-Ali, & Thein, 2015), and many of the studies have methodological limitations. Not all of the strategies will be appropriate or

effective for any given person, and the care partner will need to carefully select which approaches best fit the person and the specific situation.

Slide 26:

- There are different types of sleep disturbances in dementia, although each cause of dementia may be associated with a different type of sleep disorder.
- The primary sleep disturbances include:
    - Insomnia
    - Increased daytime sleepiness
    - Altered circadian rhythm
    - Obstructive sleep apnea
    - Rapid eye movement, or REM, sleep behavior disorder (RBD)

Slide 27:

- Sleep problems are common in many older adults, affecting approximately 40 percent of people older than 65, but most elderly people do not have a true sleep disorder.
- Similarly, disturbed sleep is a major clinical problem in dementia, but not all persons living with dementia develop sleep problems.
- Disordered sleep is a common reason for institutionalization.
- Recent studies suggest a bidirectional relationship between sleep and Alzheimer's disease/dementia pathology:
    - Persons living with dementia have poor sleep patterns.
    - Poor sleep patterns and insomnia have been associated with (causing) dementia.
- How and when sleep problems manifest in dementia depend on the type and stage of dementia, but there is greater variation in frequency and types of sleep disorders during early- and middle- versus late-stage dementia.
- The highest frequency of disordered sleep problems is found in persons with Lewy body dementia, affecting up to 90 percent of persons.
- Alzheimer's disease and FTD have a similar frequency of insomnia; however, insomnia frequency is 2.5 times higher in vascular dementia and 1.5 times more common in LBD.
- Despite the high incidence of sleep disorders, physicians and other health care professionals have a low recognition of the disorder and underdiagnose disordered sleep in persons living with dementia. Health care professionals would benefit from education on the tools, incidence, and treatments (nonpharmacologic and pharmacologic) for persons living with dementia living at home and in institutions.

Slide 28:

- The term "sundown" is frequently used, despite the lack of a consistent definition:
    - It is generally considered a clinical phenomenon that refers to a worsening of disruptive behavioral and psychological symptoms of middle-stage dementia.
    - It typically occurs in late afternoon or early evening or at night.

- Manifestations of sundowning include agitation, confusion, anxiety, screaming/moaning, hallucinations, mood swings, suspiciousness, aggressiveness, and abnormally demanding attitude (Ferrazzoli, Sica, & Sancesario, 2013; Raggi, Neri, & Ferri, 2015).
- Prevalence:
  - Sundowning may affect up to 25 percent of persons with Alzheimer's disease.
  - It is the second most common cause of disruptive behavior in institutionalized older adults (Raggi, Neri, & Ferri, 2015).
- Consequences:
  - Sundowning appears to foreshadow a faster cognitive decline in Alzheimer's disease (Ferrazzoli, Sica, & Sancesario, 2013).
  - It may represent a marker of frailty (Ferrazzoli, Sica, & Sancesario, 2013).
- No pharmacologic treatment has been approved for sundowning; nonpharmacologic approaches are preferred.

Slide 29:

- Nocturnal and daytime sleep disturbances are common in persons with Alzheimer's disease and affect up to 45 percent of persons in clinic and community-based samples.
  - Common problems include:
  - Obstructive sleep apnea, or OSA, associated with night awakenings
  - Circadian rhythm changes ("sundowning")
  - Sleep disturbances in Alzheimer's disease have multifactorial causes:
  - Factors associated with night awakenings include male gender, greater memory problems, and decreased functional status (Cipriani, Yammine, Bestuji, & Crisile, 2015).
  - Results from the prospective Women's Health Initiative Memory Study (1995–2008) on women between ages 65 and 80 found statistically significant higher risks of mild cognitive impairment and dementia in women who had either short (fewer than 6 hours per night) or long (more than 8 hours per night) sleep durations compared with women who slept the standard 7 hours per night, independent of vascular risk factors (Chen et al., 2016).
- Sleep disturbances may appear at an early stage, but they are more often correlated with more severe cognitive decline.

Slide 30:

- Obstructive sleep apnea shares common risk factors with Alzheimer's disease. OSA may be part of a pathological process.
- OSA induces neurodegenerative changes resulting from intermittent hypoxia and sleep fragmentation. The pathological impact of hypoxia leads to upregulation of amyloid beta generation and tau phosphorylation. This facilitates memory/cognitive impairment and progression in Alzheimer's disease.
- However, several pathophysiologic mechanisms in OSA are reversible. Therefore, treating OSA before treating mild cognitive impairment (MCI) may be a possible strategy to reduce risk for decline and Alzheimer's disease in older people.
- Studies suggest the benefits of using continuous positive airway pressure, or CPAP.

Slide 32:

- Sleep disturbances affect up to 90 percent of persons with Lewy body dementia.
- Rapid eye movement sleep behavior disorder, or RBD, is most often seen in people with LBD.
- REM sleep behavior disorder is suggestive of LBD and predictive for neurodegeneration in people with Parkinson's disease (Bombois, Derambure, Pasquier, & Monaco, 2010).
- RBD may be an early marker of neurodegeneration; it may precede dementia and worsen the prognosis.
- Excessive daytime sleepiness in people with Parkinson's disease may be related to the role of monoaminergic system disruption and disruption of clock genes expression.
- Persons with Parkinson's disease–MCI have poorer sleep efficiency compared with those without Parkinson's disease–MCI and had significantly more nontremor features of Parkinson's disease.

Slide 33:

- There are few published studies regarding sleep disorders in the behavioral variant of frontotemporal degeneration.
- Studies generally compare sleep disturbances in those with bvFTD with those in persons with Alzheimer's disease:
    - Sleep disruption in bvFTD appears at an earlier stage than it does in Alzheimer's disease.
    - Disturbances may be apparent in the early stage of the disease.
    - Sleep appears more disrupted in people with bvFTD than in those with Alzheimer's disease.
    - Sleep duration is shorter among those with bvFTD than it is among those with Alzheimer's disease.

Slide 34:

- Little is written about sleep disorders in vascular dementia.
- Persons with vascular dementia have a substantially higher frequency of insomnia (2.5 times greater) than persons with either Alzheimer's disease or bvFTD.

Slide 35:

- Nonpharmacologic interventions are preferred in the management of sleep disorders in dementia:
    - Use bed for sleep and sex only.
    - Minimize noise, light, and extreme temperatures in bedroom.
    - Don't drink fluids after 8 p.m. to minimize nighttime awakenings.
    - Don't nap.
    - Participate in moderate physical exercise during the daytime.
    - Minimize bright light in bedroom.
    - Avoid nicotine, caffeine, and alcohol at least a few hours before bedtime.
    - Avoid heavy meals that interfere with sleep (especially proteins); light snacks are okay.
    - Sleep restriction therapy:
- Set sleep time and wake time and stay in bed only during that stretch.

        - Cognitive behavioral therapy
    - Bright light therapy
    - Continuous positive airway pressure for obstructive sleep apnea
    - Melatonin/melatonin agonists are sometimes used for insomnia, but there is minimal evidence of any benefit.
- Some persons may require medications (such as sedative-hypnotics or antipsychotics), but they can have significant adverse effects, particularly in elderly persons living with dementia or persons who are already taking other medications:
- Donepezil may worsen symptoms, whereas galantamine and rivastigmine do not.
    - Memantine has no apparent benefit.
    - Antipsychotics are often used for other behavioral symptoms; however, their sedative effects may be of benefit in the evening (Ferrazzoli, Sica, & Sancesario, 2013).
- Nonpharmacologic approaches mentioned above are preferred, especially light therapy.
- Activities can be structured to prevent sundowning and to create a relaxing environment (Ferrazzoli, Sica, & Sancesario, 2013).

Slide 36:

- Let's use the DICE model to help the care partner address Circadian rhythm disruptions, such as nighttime wakefulness and sundowning:
- The care partner **describes** when persons living with dementia are awake at night or have disrupted sleep.
- The health provider **investigates** possible causes:
- Evaluate current sleep habits: sleep routine, sleep hygiene:
    - Optimize sleep routine and hygiene.
- Assess environmental contributions to sleep disorder (temperature, noise, light, shadows, for example).
- Together, they **create** possible strategies:
- Eliminate caffeine.
- Create daily structure/routine that includes activity during daytime and quiet bedtime routine.
- Limit daytime napping.
- Use a nightlight.
- Arrange for nighttime respite for care partner.
- They **evaluate** which strategies provided beneficial change.

Slide 38:

- Psychotic symptoms are prevalent in persons living with dementia:
    - Early-stage manifestations of Lewy body dementia
    - Middle- and late-stage manifestations of Alzheimer's disease or other dementias
    - Uncommon in Frontotemporal degeneration
- Psychotic symptoms typically include delusions and hallucinations:
    - Delusions are false beliefs that persist despite consistent evidence to the contrary; they are generally simple and nonbizarre.

  - Hallucinations are sensory experiences that cannot be verified by anyone except the person experiencing them. They are most commonly visual or auditory in dementia.
  - The majority of persons with Lewy body dementia have visual hallucinations.
- Delusions, hallucinations, and aggression are more episodic than consistent (Kales et al., 2015).

Slide 39:

- The care partner needs to be able to describe the hallucination or delusion and determine whether the behavior represents a potential safety concern to either the persons living with dementia or to others. If there is no apparent harm, there may not be a need for intervention. Not all delusions or hallucinations will require an intervention on the part of the care partner or care provider.
- The provider needs to determine whether the delusion or hallucination is directly related to the progressive damage from the dementia or to another possible cause. When appropriate, the clinician can treat infection, delirium, or pain or address medication adverse effects. Regular vision and hearing assessments, along with examination of sensory aids (glasses or hearing aids), are important. Diminished hearing, for example, may lead persons living with dementia to hear and react to “unintelligible noises”—which is then misinterpreted by the care partner to be a hallucination or delusion:
  - Falls, particularly leading to injury to the head, should be considered with sudden appearance of psychotic-like behavior.
- Developing a treatment plan can begin with reiterating to the care partner to not take the accusations personally, that it is the dementia and not the persons living with dementia who is making accusations.
- Common strategies can include distraction, activity, or engagement. It is (almost) never effective to argue or directly disagree when persons living with dementia are reporting a delusion or hallucination. If the delusions occur at the same time of day, or in a specific environment, alterations can be made so as to try to prevent them.

Slide 41:

- Agitation is the second most common behavioral disturbance, after apathy (depression is the second most common mood disorder.
- Agitation is typically seen in moderate-to-severe dementia. It increases in prevalence with increasing impairment.
- Agitation involves feeling restless or worried and can manifest in many different ways. Persons can be physically nonaggressive—wandering, pacing, other anxiety-related behaviors. They can have sleeplessness or become verbally nonaggressive—such as with repetitive vocalizations.
- Perhaps the most concerning manifestation of agitation for care partners involves verbal or physically aggressive behaviors.
- People with Frontotemporal degeneration often exhibit behaviors typical of executive control loss, such as disinhibition, wandering, and social inappropriateness.
- Aggression occurs in up to half of persons living with dementia.

Slide 42:

- Unlike with some other BPSD, it usually is important to address agitation in persons living with dementia quickly. First and foremost, it is important to evaluate the safety of self and others, including the persons living with dementia.

Slide 43:

The care partner DESCRIBES how persons living with dementia demonstrate agitation, if there is any pattern or warning clues, and whether there are any safety issues to be considered.

INVESTIGATE:

- Agitation in middle-stage and advanced dementia often reflects unmet needs.
- Causes of agitation and aggression can include pain, depression, or stress; lack of sleep; environmental concerns (too much or too little noise, temperature, people, etc). Loneliness, medications, constipation, and urinary or bowel incontinence can also all lead to agitation.

CREATE:

- Strategies suggest remaining calm, communicating in a calm and reassuring manner. Listening to persons living with dementia to determine what is causing the agitation is important. Use routine, structured activities; minimize all types of environmental clutter, and use distraction.
- Carefully select nonpharmacologic intervention based on specific factors.
- Suggested interventions include:
- Modifying the environment to elicit calm by changing lighting or temperature or by introducing music, white noise, or touch
- Engaging the person in an activity, such as art therapy
- Scheduling therapy dog visits or other animal-assisted therapy
- Engaging the older adult with real people or with simulated social contacts such as videos or lifelike dolls
- Additional options include hand or full-body massage and distraction activities such as folding towels, tossing a ball, arranging flowers, or taking a (supervised) walk outside (Cohen-Mansfield, Marx, Dakheel Ali, & Thein, 2015).

Slide 44:

- Before we move on to safety considerations, we are going to look at sexuality and intimacy issues that can arise in middle-stage dementia.

Slide 45:

- Remember that older adults with dementia are NOT asexual beings. In middle stages of dementia, they continue to need love, touch, and companionship, and many remain interested in sexual activities:
    - Although there is a natural decrease in the percentage of older adults engaging in sexual intercourse, this may reflect the lack of a partner or the presence of comorbid health issues rather than a lack of desire.

    - Not all persons living with dementia are heterosexual—be sensitive to and supportive of LGBT persons.
- Persons living with dementias and particularly care partners may be hesitant to raise the issue of sexuality. Nearly one in five persons with middle-stage dementia exhibits sexually inappropriate behaviors, including public masturbation, exposing oneself, inappropriate touching or comments, and attempts to have sex with others. Sometimes the cause of the behaviors can be traced to medications, such as benzodiazepines, taken with or without alcohol. Antiparkinson medications like pramipexole can act as dopamine agonists and increase sexual desire and trigger compulsive masturbation.

Slide 47:

- Persons living with dementia can exhibit sexually inappropriate behaviors that are embarrassing or that can have legal consequences.
- These behaviors can reflect unmet needs or be a result of the dementia, as we have discussed with bvFTD.
- Health professionals can advise the care partners about many strategies:
    - Remain calm and try not to react with shock, disgust, embarrassment, or anger.
    - Remember that the persons living with dementia may lack awareness that this behavior is inappropriate.
    - Use distraction.
    - Demonstrate more socially acceptable behaviors.
    - Try to involve the person in another activity, change the topic of conversation, or move to a different room or a private area.
- The use of massage or touch, or a physical activity, may appease the person's desire for sexual touch. This can lead to inappropriate sexual advances as demented persons may misinterpret physical contacts.
- If the persons living with dementia are indecently exposing himself, or, less likely, herself, recommend to the care partner that the person wear clothing that is difficult to remove, such as pants with a belt or with numerous buttons.
- Tell the care partner to let the persons living with dementia know that the behavior is not acceptable and makes the care partner uncomfortable.
- Some sexuality concerns may necessitate additional intervention, such as a psychosexual assessment or history to distinguish between normal pattern and new-onset behaviors. The primary care provider can rule out delirium and medications.
- Recommend psychotherapy or counseling for family members, if appropriate.
- If the persons living with dementia make advances or act inappropriately with professional staff, it is important to document the behavior, noting the intervention and its effect.
- It is optimal for all care partners and providers to use the same response and intervention, if possible, and to identify which interventions are effective and which are ineffective.
- It is important to note that you, as the health provider, might feel uncomfortable and even threatened or frightened by these inappropriate behaviors. You too might need to discuss your own feelings with appropriate colleagues or professional staff.

Slide 48:

- We are changing gears now to focus on safety considerations.
- Some of these issues first manifest during early-stage dementia.
- Likely all care partners will need to deal with each of these issues at some point during the course of the dementia.

Slide 49:

- Safety concerns assume increasing importance as dementia progresses. These critical concerns typically become more relevant and can have more serious consequences during middle-stage dementia.
- As the persons living with dementia progress into and through middle-stage dementia, there is greater likelihood of risk or harm associated with taking or misusing medications, of leaving the person alone at home, of the person driving, and of the person's getting lost in the community. Progressive impairments in cognition and executive function limit the person's ability to reason, minimize understanding of how to use or answer the telephone, and cause greater confusion about simple tasks.
- It often falls to the care partner to assume increasing oversight to ensure the safety of the persons living with dementia and others.
- We are going to focus on the following predominant concerns:
    - Medications
    - Driving
    - General home safety
    - Wandering or getting lost in the community

Slide 50:

- Persons living with dementia are likely to be on numerous medications for a variety of conditions. This situation requires an enhanced level of oversight of all medications.
- Both primary care and health care providers (PCPs and HCPs, respectively) are likely to be involved in managing medications for persons living with dementia whether the medications are specifically prescribed for dementia, its consequences, or other comorbid conditions (Poland, Mapes, Pinnock, Katona, Sorensen, Fox, & Maidment, 2014).
- The entire interdisciplinary team needs to coordinate oversight and responsibility for the following:
    - Maintaining medication records
    - Identifying adverse effects
    - Ensuring ability to correctly take medications
    - Minimizing risk of overdose (See Module 15 for a discussion of pharmacist roles and responsibilities.)
- The importance of maintaining up-to-date records that are shared among ALL health care and primary care team members cannot be underestimated. Module 9 provides a more in-depth look at the roles and responsibilities of the interdisciplinary team:
    - Maintaining records involves keeping a list of medications in an easily accessible location. Providers can recommend that care partners look into resources such as the

    Vial of Life or File of Life (see Resource List). Providers should list each medication, prescribing clinician, dosage, and frequency—and if possible, why the medication is prescribed.
  - Maintaining up-to-date records also involves noting whether the persons living with dementia are using herbal supplements, vitamins, dietary supplements, or other over-the-counter agents, because they can interfere with the action of prescribed medications.
- Providers should inquire frequently about appropriate medication use, such as whether the persons living with dementia are taking the medication at the correct dose and time, as well as the presence of any adverse effects, such as confusion, falls, rashes, and gastrointestinal concerns:
  - Identify any adverse effects.
  - Ensure that the care partner is able to administer the medication correctly, and provide support for the difficulties they may face in administering medications. For example, can the care partner administer insulin injections? Correctly mix laxative preparations? Administer eye drops?
  - Does the care provider understand the instructions for each of the medications used by the persons living with dementia?
- Ensure that the persons living with dementia are capable of taking the medication as prescribed. Is he or she able to swallow pills? Can he or she remember to take the pills at the correct time and in the correct amount?
  - If not, discuss with the primary care provider or local pharmacist for additional guidance [Note: Information related to medications will be in Modules 8 and 15, which have pharmacist-specific information].
- Ensure that medications are properly secured to prevent accidental overdose:
  - Identify who dispenses the medication and keep the rest of the medication secure.
  - Check to make sure that the persons living with dementia have not inadvertently taken medication in an inappropriate manner.

Slide 52:

- All persons living with dementia will need to stop driving. Deciding when is one of the most difficult decisions to make for all involved because it affects the persons living with dementia, all care partners, and other family members and friends:
  - Use a simple explanation for the loss of driving ability.
  - Work with the care partner to develop alternative transportation strategies.
- Driving capabilities depend on the cause of dementia and other factors.
- Driving cessation has many consequences for both the older adult and family:
  - Recognize grief.
  - Facilitate healthy adjustment.
  - Be sensitive to significant loss of independence.
  - Be ready to suggest transportation options.
- ALL PCPs and HCPs need to know their state-specific rules and regulations for driving cessations and reporting driving concerns. In those states that have mandatory reporting laws for persons diagnosed with dementia, physicians are responsible.

- Sometimes, an effective technique is to write a prescription for persons living with dementia to "Stop Driving" if he or she is likely to follow doctor's orders.
- PCPs and HCPs can recommend a driving evaluation. However, there is no identified person or profession responsible for performing driving assessments for dementia. In addition, there is no consensus on which types of assessments apply to older drivers with cognitive impairment or on how to determine the relationship between dementia severity and ability to drive (Carr & O'Neill, 2015). There is simply no gold standard for determining driving fitness.
- One recent study found that adult children were more accurate at rating the driving ability of persons living with dementia than the spouse; it noted that clinician predictions of driving ability were not associated with naturalistic driving errors or driving performance (Bixby, Davis, & Ott, 2015).
- Another recent study highlighted the challenges physicians face when evaluating older persons for driving fitness, and noted the importance of both clinician assessment as well as on-road driving assessments (Meuser, Berg-Weger, Carr, Shi, & Stewart, 2016)

Slide 55-56:

- At some point, the care partner or HCPs will need to assess whether the persons living with dementia are able to continue living at home, and whether the persons are able to be left alone. If the answer to either question is NO, the options are to make adaptations or to consider alternative living arrangements, through either in-home care or transition to a long-term care facility.
- Are the persons living with dementia able to continue living at home?
    - This requires a room-by-room assessment of the home environment with an eye to preventing problems and identifying necessary adaptations to ensure safety.
- Are the persons living with dementia able to be left alone, particularly after the dementia has progressed into middle stage? Are the persons at risk of getting lost at home or in the community?
- In the next three slides we will look at what needs to be assessed, along with recommendations to improve safety.

Slide 57:

- With neurologic impairments progressing as the persons living with dementia move through middle- and late-stage dementia, there are likely to be increasing problems with physical coordination, sensory abilities, and cognition. The person may also be increasingly vulnerable and sensitive to environmental changes, such as temperature and lighting changes.
- The primary care provider may recommend a home assessment. This would encompass assessing for fall prevention, bathing and toileting safety, and kitchen and laundry room safety.
- A survey of nurses found that the most frequent risk factors for falling include confusion, gait problems, dementia, disorientation, and an inability to follow safety instructions (Tzeng & Yin, 2013). The study identified a number of potentially effective interventions that can be recommended to the care partner: keeping floor surfaces dry and clean; making sure that the persons living with dementia wear appropriate footwear and clothing—for example, no flip-flops and pants that are an appropriate length; and removing sharp-edged furniture and tripping hazards like small toys for children and pets. If the person is using a hospital bed, the care

partner should ensure that the brakes are locked. A bedside monitor should be easily accessible and turned on (Tzeng & Yin, 2013).
- All dementia care team members should be aware of any state regulations regarding reporting risk of harm from persons living with dementia with access to firearms. Also, they should be aware that people ages 65 years and older have the highest rate of suicide by a firearm.
- The care partner should also be advised to:
  - Put childproof locks on appliances.
  - Remove or lock up all cleaning supplies, detergents, and hazardous materials.
  - Keep doors locked and windows closed and locked, if possible.
  - Put alarm bells on appliance doors.
  - Ensure that smoke detector and carbon monoxide detectors work.
  - Consider installing flood and temperature monitors and alarms that register when doors open and close.
  - Secure guns and ammunition.

Slide 57:

- Dementia affects all five senses. Both age and progression of dementia can impair any of the senses: persons living with dementia can experience a decreased sense of smell, vision impairments, loss of sensation to temperature and touch, hearing impairments, and loss of taste sensitivity.
- They may also have vision conditions, along with the vision impairments from dementia. Care partners should adjust lighting accordingly, minimize shadows, and provide adequate lighting throughout the day.
- Olfactory deficits are associated with Alzheimer's disease pathology preferentially in the central olfactory structures and are prevalent in persons with Alzheimer's disease. This can impair taste, and more importantly it can minimize awareness of dangerous smells, such as smoke or gas.
- People with AD and other dementias may experience a loss of sensation or may not be able to interpret feelings of heat, cold, or discomfort. They should have the thermostat settings adjusted for heat and air conditioning as necessary and the water temperature of baths and the like should not be too hot or cold.
- Although many persons living with dementia retain "normal" hearing, they may lose the ability to interpret what they hear. Using white noise and calming sounds, minimizing extraneous sounds, and alerting the persons living with dementia before operating an appliance that will make a loud noise are helpful. Care partners should be aware of age-related hearing loss as a complicating factor.
- If the persons living with dementia have lost taste sensitivity, he or she may use too much salt or other seasoning or eat food that has gone bad.

Slide 58:

- It becomes increasingly less likely that the person living with middle-stage dementia will be able to be left alone for any period of time.
- The NIA recommends asking the following questions to determine whether the persons living with dementia can be left alone (NIA, 2017a)—and a "yes" answer to ANY of the first group of questions indicates that additional supervision or action is needed:

    - Do the persons living with dementia:
        - Become confused or unpredictable under stress?
        - Recognize a dangerous situation, such as a fire?
        - Wander and become disoriented?
        - Show signs of agitation, depression, or withdrawal when left alone for any period of time?
        - Attempt to pursue former interests or hobbies that might now warrant supervision, such as cooking, appliance repair, or woodworking?
- Likewise, a "no" answer to the following questions indicates a need for additional supervision:
    - Do the persons living with dementia:
        - Know how to use the telephone in an emergency?
        - Know how to get help?
        - Stay content within the home?
- Home safety protocols to prevent unattended exits that you can share with the care partner include positioning door locks higher or lower than eye level and installing novel locking mechanisms for doors and windows—keeping in mind the need for safe exit of all family members in emergency situations. There are unobtrusive wireless systems with door and window sensors, remote alarms, and information panels at the care partner's bedside that do not require the persons living with dementia to wear any type of sensor or tag while in the home. In one study, the use of such a system reduced nighttime injuries and unattended home exits by 85 percent. In another study, use of such a system improved care partners' peace of mind, quality of sleep, and energy level (Rowe, Greenblum, & D'Aoust, 2012).
- Other strategies include sewing tags in all the person's clothes with "in case of emergency" or ICE, information; alerting neighbors and police about the person in advance; and having a current photograph with current personal information, including height, weight, hair and eye color, and identifying marks (Jenkins & McKay, 2013).

Slide 59:

- A primary care provider reported very contentious discussions with Mr. Smith, who was a WW2 Veteran. Despite several minor accidents, becoming so lost he had to be brought home by the police, and losing his car in a parking lot, Mr. Smith would not even entertain the possibility of not driving. His family could not even broach the subject with him without significant agitation including yelling and throwing objects. The family asked the PCP for help but, after several frustrating meetings, no progress was made.
- The PCP finally decided to ask Mr. Smith to keep a daily log of where he drove. He was willing to do this task and what emerged was that there was one place he went to nearly every day: the American Legion Post that was only a few miles from his home, but too far to walk. Other uses of the car were sporadic. The PCP discussed a plan with him for getting him to the American Legion Post on a daily bias, and his resistance to quitting driving disappeared. This showed Mr. Smith that he was in a loving environment where people cared for him, respected his needs and would do what was necessary to meet these needs.

Discussion Points:

- Would you have thought of this solution?

- What other strategies might you have considered?
- Might this strategy work for some of the persons you currently care for?

Slide 60:

- Because of impairments in memory, judgment, spatial disorientation, and abstract thinking, persons living with dementia may find themselves in an unfamiliar environment, unable to remember why they are there or how they got there, or to understand what is happening. (Nakaoka, Suto, Makimoto, Yamakawa, Shigenobu, & Tabushi, 2010).
- The terminology is confusing. There is no clear definition of wandering, missing, or elopement, which has also been called critical wandering. It is not clear whether these are distinct phenomena or parts of a continuum. We do not even know whether they have different etiologies.
- Here is one description of how these three different phenomena are perceived:
    - Missing: Occurs when persons living with dementia are unattended and unable to navigate a safe return to the care partner. It is unpredictable and is often precipitated by agitation or confusion. The person often travels by foot (Rowe, Greenblum, & D’Aoust, 2012).
    - Wandering: May be more predictable, occurring during specific times of day and may be precipitated by an unmet need, such as hunger or the need to use the toilet. Wandering often involves repetitive locomotion with lapping or pacing patterns (Rowe, Greenblum, & D’Aoust, 2012).
    - Elopement: Occurs when the person leaves a safe area, such as home or a residential facility (Rowe, Greenblum, & D’Aoust, 2012).
- Any PLwD is at risk of becoming lost in the community once he or she begins to “wander” or get lost (Rowe, Greenblum, & D’Aoust, 2012):
    - Such incidents may occur even in mild dementia (Ali et al., 2016).
    - Men are more likely to go missing (Petonito, Muschert, Carr, Kinney, Robbins, & Brown, 2013; Rowe, Vandeveer, Greenblum, List, Fernandez, Mixson, & Ahn, 2013).
- In one study, the reported distance from the place last seen to the place where found for missing persons living with dementia who drove away ranged from 0.03 to 1,745 miles, with a median of 41.3 miles (Rowe, Vandeveer, Greenblum, List, Fernandez, Mixson, & Ahn, 2011).
- Any time persons living with dementia wander away, he or she is at increased risk of injury, falls, and death (Ali et al., 2016; Kropelin, Neyens, Halfens, Kempen, & Hamers, 2013).
- The increased risk of morbidity or mortality highlights the need for rapid mobilization of people to search, because there is often no rhyme or reason to where the person might be (Rowe, Greenblum, & D’Aoust, 2012). There is a substantially increased risk of morbidity and mortality after the persons living with dementia have been missing for 24 hours (Rowe, Greenblum, & D’Aoust, 2012).
- If possible, before an incident happens, someone should help the care partner develop a protocol to mobilize a response.
- Programs to locate missing or wandering older persons include Safe Return, Project Lifesaver, and Silver Alert (Petonito, Muschert, Carr, Kinney, Robbins, & Brown, 2013; Rowe, Vandeveer, Greenblum, List, Fernandez, Mixson, & Ahn, 2013).

Slide 61:

- We conclude this module by mentioning the wide range of residential and nonresidential care options for persons living with dementia who can no longer be alone in their home.

Slide 62:

- The slide delineates the wide range of options available to persons living with dementia who can no longer remain alone in the home. We will be covering all of these options in detail in Module 10.
- This decision is very challenging for the care partner or partners to make, and the interdisciplinary team can assist in the discussion.
- Many factors must be considered, including the type and severity of dementia, finances, other medical conditions, and the needs of the individual persons living with dementia.
- Ideally, these issues can be addressed during early- or middle-stage dementia, well before the decision must be made.

Slide 64:

- These items are provided to allow faculty to evaluate what students have learned. The items can be used in several ways including given at the end of the lecture to assess knowledge or as a pre-post test to assess knowledge gain. These items have face validity. Psychometric testing was not conducted on these items.

Answers:

1. a. Difficulties performing instrumental activities of daily living

2. d. Hyposexuality

Slide 65:

Answer:

3.b. Identifying the possible underlying cause(s) of the distressing symptoms

Slide 66:

Answer:

4. c. Rapid eye movement (REM) sleep behavior disorder (RBD)