FACULTY GUIDE

Core Module 7:

Management of Common Medical Conditions Observed During Middle and Late Stages of Dementia

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Slide 1:

• This module focuses on developing a primary care plan to evaluate and manage common medical issues pertinent to persons with middle- and late-stage dementia.

Slide 3:

• These are the topics we will be addressing in this module. We begin with a review of the similarities and differences between the different types of dementia during the middle and late stages, including information on mixed dementias. We will focus on common medical management issues in dementia. All links were last confirmed to be active on April 20, 2017.

Slide 4:

- Our goal, by the time we finish with this module, is for you to learn four sets of items. You will be able to:
 - Identify common components of an individualized primary care plan for persons with either middle- or late-stage dementia.
 - Enumerate common medical issues related to either middle- and late-stage dementia.
 - Discuss evaluation and management of incontinence in persons living either middle-and late-stage dementia.
 - Identify manifestations of pain in persons living with either middle- and late-stage dementia.

Slide 5:

- The more advanced the stage of dementia, the greater the number of comorbid conditions likely to be present.
- Worsening of comorbid diseases and conditions such as pain, infection, incontinence, and eating dysfunctions can occur with dementia.
- Incontinence is often a primary cause of moving persons living with dementia to institutional care.

Slide 6:

• We begin with an examination of middle- and late-stage dementias.

Slide 7:

- There is no set time period for how long each stage persists. The rate of progression can be gradual and depends on individual patient factors, the underlying cause of dementia, the presence or absence of comorbid medical problems, psychiatric illness, and other factors.
- Manifestations depend on the underlying cause of dementia.
 - There are no clear means—no markers or diagnostic tests—that determine when a person transitions out of early-stage dementia.
- Most persons with middle-stage dementia experience progressive deterioration of cognitive abilities, increasing memory impairment, and increasing difficulty attending to personal activities of daily living (ADL).
- Behavioral and psychological symptoms of dementia (BPSD) emerge and progress, if they have not already done so.

- Primary care providers (PCPs) may wish to refer to specialists—such as neurologists, neuropsychiatrists, neuropsychologists, geriatric psychiatrists—if the patient has):
 - Unusual or atypical presentation.
 - Onset of dementia before age 60. Because early-onset dementia is uncommon, it is important to confirm the diagnosis and rule out other potentially reversible causes of the symptoms.
 - Overwhelming psychological or behavioral issues that are difficult to manage.
 - Depression with violence or suicidal behaviors.

Slide 8:

- The person in late-stage dementia is no longer able to care for him or herself and requires fulltime, around-the-clock assistance with daily personal care.
- By late-stage dementia, the person may manifest with:
 - o Profound memory impairments, such as significant memory deficits
 - o Increasing difficulty communicating, with minimal verbal abilities
 - Inability to ambulate independently
 - o Inability to perform any ADL
 - Urinary and fecal incontinence
- Common concerns of persons with end-stage dementia include eating problems and nutritional concerns, infections, and inappropriate medication use.

Slide 9:

• Management of persons living with dementia is addressed on an individualized basis and must consider many different medical concerns: particularly comorbid diseases and conditions that co-occur with dementia, such as pain, infection, incontinence, and eating dysfunctions.

Slide 10:

- It is necessary to continually reevaluate the individualized plan and make appropriate alterations:
 - For example, the patient should be routinely assessed for medical complications, pain, psychotic manifestations, and safety. Changes or adjustments made to medications, the introduction of over-the-counter (OTC) agents, acute illness, or changes in medications for other comorbid conditions must be noted and reviewed. This review also requires open and frequent communication with the care partner and all primary care physicians and health care providers (HCPs) involved in the treatment team.
 - It may be necessary to carefully and cautiously prescribe medications to treat aggression, anxiety, sleep disorders, and the like, if nonpharmacologic strategies are not successful.
 - However, the value of specific types of medications, such as statins or antibiotics, may need to be carefully evaluated in light of the stage of the persons living with dementia. This situation will be addressed in more detail in Module 8.
 - The care plan must address all of the medical comorbidities and conditions that frequently co-occur with dementia.

• There is a need to monitor the mental and physical well-being of the care partner to ensure he or she continues to be able to care for the persons living with dementia.

Slide 12:

• We start with looking at specific considerations concerning medications—not just those pertaining to dementia, but also those associated with any comorbid or co-occurring conditions.

Slide 13:

- Persons living with dementia likely will receive medications for other comorbid illnesses and vascular diseases, as well as antidepressants, antipsychotics, anxiolytics for BPSD, and medications to treat Parkinsonian symptoms. Comorbid illnesses can occur with dementia either preceding dementia, beginning concurrently with dementia, or associated with dementia.
- It is imperative that primary care providers (PCPs) are aware of all medications their patients are taking for these conditions—both prescribed and OTC agents, as well as any vitamins or herbal agents.
- There needs to be careful and continual review of all of the medications a patient is receiving, as well as continual reevaluation whether the patient is able to continue taking those medications as they are prescribed.
- It is also important, particularly during late-stage dementia, to determine whether these medications continue to have value and benefit—or whether they can be eliminated.
- All clinicians should reference the 2015 updated <u>Beer's Criteria for potentially inappropriate</u> medications for the elderly.

Slide 14:

- Normal aging can be associated with an increase in medical concerns—failing vision, osteoarthritis, hearing loss, cardiovascular concerns, to name a few.
- Research indicates that specific medical concerns are prevalent and/or have substantial consequences in an older persons living with dementia. It is important for primary care providers to be cognizant of the increased risk of the following medical concerns in their older adults with dementia, to perform appropriate evaluations, and initiate treatment as needed.
- Looking at the outline, we now begin examining specific areas of concern to be addressed in the primary care plan of action, beginning with comorbid conditions.

Slide 15:

• A study of nearly 2,200 cognitively normal adults found 87 percent had multimorbidity. The risk of mild cognitive impairment (MCI) or dementia was much higher in persons with multimorbidity compared with persons with zero or one comorbidity. Having four or more comorbidities was associated with the greatest magnitude risk of dementia or MCI, and risk was even higher among men than among women with multiple comorbidities. The authors concluded that preventing chronic diseases may have a role in delaying or preventing dementia or MCI.

- Persons living with dementia and high comorbidity report the most compromised health status compared with older adults with no dementia. This is especially true if the persons living with dementia have visual, oral, and genitourinary problems.
- A recent study reported that persons with early-onset Alzheimer's disease (AD) (younger than age 60) had significantly fewer overall comorbidities compared with persons with late-onset Alzheimer's disease. Persons with early-onset Alzheimer's disease had lower prevalence rates of diabetes, obesity, and circulatory disease, but they also had higher prevalence rates of diseases of nervous system. Of note is that endocrine, nutritional and metabolic diseases, and diseases of the circulatory system were present in just slightly more than one in three older adults with early-onset Alzheimer's disease. (We have already discussed this in Module 1.)
- On the other hand, among persons living with dementia, as the severity of dementia increases, so does the rate of comorbid conditions. Many guidelines emphasize promoting independence for persons living with dementia for as long as possible, so there is a need for comprehensive assessments of their needs, as well as for possible comorbid symptoms. Timely identification of symptoms decreases the risk of hospitalization, reduces health care costs, and maintains physical comfort and quality of life (QoL). Unplanned acute emergency admissions are common among persons living with dementia and are associated with high 6-month mortality. These findings highlight the need for consistent evaluation and management of the numerous medical comorbidities associated with dementia.
- A person's having dementia may affect or complicate management of other comorbidities. Persons living with dementia may not receive optimal care or have comparable access to care for each comorbid condition (Bunn, Burn, Goodman, Rait, Norton, Robinson, ... Brayne, 2014).
- For example, pneumonia, urinary tract infection (UTI), and congestive cardiac failure accounted for two-thirds of admissions in persons living with dementia. (Fox, Smith, Maidment, Hebding, Madzima, Cheater, ... Young, 2014).
- Another study showed that more comorbid conditions contribute to the onset of walking and eating problems (Slaughter & Hayduk, 2012).

Slide 16:

- Multi-morbidity is common as we age. A large study identified 15 comorbidity complexes more common in persons living with dementia: Parkinson's disease, stroke, diabetes, atherosclerosis (or fluids and electrolyte disorders), insomnia, incontinence, pneumonia, fractures, and injuries. The researchers found no difference based on where the persons living with dementia were living (at home versus long-term facility) (Bauer, Schwarzkopf, Graessel, & Holle, 2014).
- Those comorbidities most frequently cited in the literature as commonly observed in persons living with dementia are diabetes, hypertension, and cardiovascular diseases.
- Other syndromes that occur more often in persons living with dementia than with other older people are falls, delirium, epilepsy, weight loss and nutritional disorders, incontinence, sleep disturbance, visual dysfunction, oral disease, and frailty (Kurrle, Brodaty & Hogarth, 2012).
- Persons living with dementia are also likely to have other neurologic disorders, musculoskeletal disorders, chronic obstructive pulmonary disease, vascular disorders, cancer, sleep apnea, osteoporosis, hypercholesterolemia, ischemic cerebrovascular disease, depression, and psychosis (Duthie, Chew, & Soiza, 2011; Smith, Maidment, Hebding, Madzima, Cheater, Cross, ... Fox, 2014).

A recent cross-sectional study reported the two most common comorbidities with dementia were hypertension and diabetes—but they also found Parkinson's disease, congestive heart failure, cerebrovascular disease, anemia, cardiac arrhythmia, chronic skin ulcers, osteoporosis, thyroid disease, retinal disorders, prostatic hypertrophy, insomnia, anxiety, and neurosis.
 (Poblador-Plou, Calderón-Larrańaga, Marta-Moreno, Hancco-Saavedra, Sicras-Mainar, Soljak, & Prados-Torres, 2014).

Slide 17:

• We will now examine issues concerning pain in persons living with dementia.

Slide 18:

- Worldwide, an estimated 50 percent of persons living with dementia experience regular pain (Achtenberg, Pieper, van Dalen-Kok, de Waal, Husebo, Lautenbacher, ... Corbett, 2013).
- Pain prevalence—and especially chronic pain—is strongly associated with aging, such that an estimated 72 percent of persons living with dementia older than age 85 have regular pain.
- Results from the (most recent) 2011 wave of the National Health and Aging Trends Study reported that nearly 64 percent of the 802 participating persons living with dementia experienced bothersome pain, and 43.3 percent had pain that limited their activities during the prior month. These are persons living in private residences or non-nursing home residential care settings. Their rates of pain were significantly higher than those in the cohort without dementia. Bothersome pain was associated with arthritis, heart and lung disease, disability in ADL, symptoms of depression or anxiety, and low energy. Of note, 30.3 percent of persons with disability reporting pain stated they rarely or never took any medications for pain.

Slide 19:

- Common causes of pain among older adults with dementia include musculoskeletal, gastrointestinal, and cardiac conditions, genitourinary infections, pressure ulcers, and orofacial pain:
 - Approximately 35 percent of stroke patients suffer from post-stroke central neuropathic pain (Siniscalchi, Gallelli, De Sarro, Malferrari, & Santagnelo, 2012).
- Evidence indicates dementia, and primarily Alzheimer's disease, changes the way persons living with dementia process pain (Kunz, Mylius, Schepelmann, & Lautenbacher, 2015). Specifically, greater cognitive decline is associated with enhanced pain responses.
- A recent study reported that pain behaviors were increased in Alzheimer's disease (compared with healthy controls), across almost all levels of pain severity—except for the lowest pressure intensity (Beach, Huck, Miranda, & Bozoki, 2015). These findings were based not only on subjective pain responses, but also on autonomic evaluation of heart rate and behavioral changes in vocalizations, facial, and body behaviors. Persons with severe Alzheimer's disease were not able to provide reliable subjective reports, but persons with moderate dementia were, and they significantly rated low-level pressures as more painful than did the healthy cohort.
- It is not yet known whether greater pain sensitivity results from a general decline in cognitive functioning or whether there are specific domains of cognitive functioning that influence the perception of pain. Recent research suggests neurodegeneration in prefrontal areas may not

only impair executive functioning but may also diminish inhibition of pain perception (Kunz, Mylius, Schepelmann, & Lautenbacher, 2015).

• Evidence highlights an elevated risk of severe pain in persons with late-stage mixed Alzheimer's and vascular dementias, related to the limited use of pain medications (Husebo, Strand, Moe-Nilssen, Borgehusebo, Aarsland, & Ljunggren, 2008).

Slide 20:

- Pain is thought to be one of the primary causes of behavioral and psychological symptoms of dementia (BPSD), particularly agitation or aggression.
 - Primary care providers (PCPs) should evaluate for possible pain if an older adult suddenly demonstrates aggression or agitation or other behavioral changes.
- The American Geriatrics Society identified six common manifestations of pain in older adult with cognitive impairments: facial expressions, verbalizations/vocalizations, body movements, changes in interpersonal interactions, changes in patterns or routines, and mental status changes (AGS Panel on Persistent Pain, 2002).
 - According to AGS, signs of pain can include grimacing, rapid blinking, noisy breathing, verbally abusive behaviors, tense body posture, aggressiveness, withdrawing, changes in appetite, alterations to common routines, and emotional changes—crying, irritability, and distress. (AGS Panel on Persistent Pain, 2002).
 - Pain is often associated with BPSD—including agitation, aggression, mood changes, and sleep disorders (Flo, Gulla, & Husebo, 2014).

Slide 22:

- Clinicians who work with persons living with dementia should perform regular assessments for pain.
- It can be very difficult to assess pain in persons with moderate to severe dementia. They may not be able to communicate (1) that they have pain, (2) where they have pain, (3) what type of pain they have, and (4) its severity. Consequently, pain is underdetected and undertreated in persons living with dementia.
 - Pain assessment is challenging and can involve patient self-report, proxy reports, pain assessment tools, and clinical observations—of the person's body language, facial expressions, and behaviors.
 - A study of persons living with dementia in nursing homes found that only approximately half were able to provide a reliable answer regarding their pain (Malara, De Biase, Bettarini, Ceravolo, Di Cello, Garo, ... Rispoli, 2016).
 - Investigators recommend combining self-report/assessment with observational tools to obtain a more accurate assessment.
- There are many different scales available (Neville & Ostini, 2014)—for example, the Abbey Pain Scale, DOLOPLUS-2 Scale, Checklist of Nonverbal Pain Indicators Scale; each has strengths and weaknesses. The Numeric Rating Scale (NRS) can be used for persons with minimal cognitive impairment, and the Pain Assessment in Advanced Dementia Scale (PAINAD) for those in later stages of dementia (Malara, De Biase, Bettarini, Ceravolo, Di Cello, Garo, ... Rispoli, 2016). However, there is limited evidence supporting their reliability, validity, and clinical utility in this population (Lichtner, Dowding, Esterhuizen, Closs, Long, Corbett, & Briggs, 2014).

- There are questions regarding the value of numerical pain scores. One option is to compare pain scores over time, integrating professional notes and observations. (Lichtner, Dowding, D., & Closs, 2015).
- Prevention of pain is always preferable to having to treat pain. Clinicians can recommend that the care partner frequently assess for potential sources of pain—skin ulcers, bruises, mouth problems, infections, and illness.
- There are challenges in assessing different types of pain; acute pain is often easier to recognize than chronic pain, which more likely manifests with avoidance versus observable behavioral changes (Achterberg, Pieper, van Dalen-Kok, de Waal, Husebo, Lautenbacher, ... Corbett, 2013).
- It is very difficult to assess central neuropathic pain in persons with vascular dementia because it requires approaches that are different from those used for other types of pain (Achterberg, Pieper, van Dalen-Kok, de Waal, Husebo, Lautenbacher, ... Corbett, 2013). Neuropathic pain is pain emanating from injury or damage affecting the nerves, such as shingles, phantom limb syndrome, or diabetic nerve pain. Diagnosis can involve a medical history, physical exam, blood work, and possibly neurologic evaluation.
- There are older guidelines, published in 2004 and revised in 2009 by the European Federation of Neurological Societies (EFNS) Panel on Neuropathic Pain, that may provide guidance for an assessment of neuropathic pain (Cruccu, Sommer, Anand, Attal, Baron, Garcia-Larrea, ... Treede, 2010), although there are no such guidelines for persons living with dementia.

Slide 23:

- Untreated (or undertreated) pain has been associated with depression, agitation, and aggression in persons living with dementia.
- Routine clinical monitoring for potential causes of pain can facilitate prevention and initiate early treatment of acute pain.
- Nonpharmacologic interventions are preferred when possible.
 - Options can include relaxation, distraction, superficial heating/cooling (heating pads or ice packs), massage, music therapy, and the use of assistive devices.
- Evidence suggests that behavioral interventions to reduce pain are effective in reducing both pain and behavioral symptoms (Achterberg, Pieper, van Dalen-Kok, de Waal, Husebo, Lautenbacher, ... Corbett, 2013). In addition, pain management appears to lessen behavioral symptoms, including agitation, complaining, and constant need for attention.
- Although persons living with dementia have been shown to be more sensitive to pain, they also have been shown to have less access to pain relief as their healthy cohorts.
- Pain management may require medications (which will be covered in Module 8).
- It is important for PCPs to work with the care partner and the pharmacist to identify appropriate medications—based on the apparent or perceived severity and chronicity of the pain, the older adult's prior experience with pain medications, and the potential for adverse effects (such as constipation or sedation).

Slide 25:

• Persons in late-stage dementia are particularly vulnerable to infections—especially urinary tract infections (UTIs) and respiratory tract infections (RTIs), including pneumonia.

- Cardiovascular diseases and neoplasms are more frequent causes of death in the general population; in comparison, persons living with dementia are more likely to die from infections, including pneumonia (Foley, Affoo, & Martin, 2015).
- Pneumonia is the most common cause of death in persons with Alzheimer's disease (Foley et al., 2015). Among persons living with dementia, respiratory diseases have been cited as the cause of death in 55 percent of persons with Alzheimer's disease and 33 percent of persons with vascular dementia (Higashijima, 2014).
- A recent meta-analysis reported the odds of pneumonia-associated mortality were increased more than twofold for persons with versus without dementia (Foley, Affoo, & Martin, 2015).
- A retrospective analysis found pneumonia complications were particularly common among persons with Lewy body dementia (LBD) and somewhat less so for persons with Alzheimer's disease or vascular dementia. (Manabe, Mizukami, Akatsu, Teramoto, Yamaoka, Nakamura, ... Hizawa, 2015). In all three groups, pneumonia complications shortened survival time.
- An important consideration focuses on the use of antibiotics to treat these infections, particularly among persons with advanced stages of dementia. Many studies suggest that antimicrobial treatment is not associated with survival, and in fact, treatment may prolong the dying process. These issues are covered in detail in Modules 11 and 12, which cover ethical concerns and palliative care, respectively.
- Also of concern, especially in persons residing in nursing homes, is the risk of promoting multidrug-resistant organisms with inappropriate use of antimicrobials.
- Another consideration is whether to vaccinate older adults with dementia against respiratory infections—influenza, pneumococcal disease, or pertussis. Vaccinations can be of benefit, although current data suggest possibly lower immunogenicity among this population.

Slide 27:

- Urinary incontinence is a common concern affecting a large proportion of persons living with dementia with potentially significant consequences, particularly if it is unmanaged or untreated.
- Persons living with dementia can become incontinent during early stages, although more typically incontinence manifests in moderate- to late-stage dementia.
- Incontinence is a substantial burden to the care partner. It can be very distressing and difficult and costly to manage.
- It is often a primary driver behind the decision to move persons living with dementia to institutional care.
- There have been many studies trying to quantify the prevalence of incontinence in the older population with dementia; however, the studies have included different populations, different criteria, and a variety of assessment tools. Consequently, prevalence rates have ranged from 1.1 percent in a general community population to 38 percent and higher in persons receiving home care services (Drennan, Rait, Cole, Grant, & Iliffe, 2013).
- Data involving nearly 55,000 persons ages 60 to 89 with dementia and 205,795 without dementia found a substantially greater rate of urinary incontinence in men and women with dementia versus those without dementia; having dementia nearly doubled the rate of bladder incontinence (Grant, Drennan, Rait, Petersen, & Iliffe, 2013).
- The prevalence of incontinence rises with advancing age (Drennan, 2014).

Slide 29:

- Urinary incontinence can stem from the dementia, be secondary to the development of dementia, or co-occur with dementia.
- For example, autonomic dysfunction associated with Lewy body dementia and Parkinson's disease dementia can lead to urinary incontinence, as well as constipation and orthostatic hypotension. Autonomic dysfunction is less likely the cause of incontinence associated with Alzheimer's disease or frontotemporal degeneration. (Idiaquez & Roman, 2011).
- Initial assessment for urinary incontinence must consider a wide range of possible causes for incontinence:
 - Is the incontinence caused by an inability to find, get to, or use the toilet?
 - Or Is there an underlying medical concern associated with incontinence?
- Clinical assessment involves an older adult's medical history (which may need to be provided by proxy), history of urinary symptoms, physical exam, and urine tests to rule out infection or other urinary problems.
- A well-known list of transient causes of incontinence is DIAPPERS: Delirium, Infection, Atrophic vaginitis, Pharmacologic, Psychological (depression), Excessive urine production (from medical conditions), Restricted mobility, Stool impaction.
- Medications are frequent causes of incontinence. Common culprits include antihistamines, antipsychotics, sedative hypnotics (including alcohol and long-acting benzodiazepines), diuretics, and alpha-antagonists.
- Anticholinergic agents are of particular concern in older persons living with dementia. Side effects of medications with anticholinergic properties can include urinary retention, frequency, and overflow incontinence.
- Elevated rates of urinary incontinence are observed in older adults treated with cholinesterase inhibitors (ChEIs). A study investigated the effects of treatment with cholinesterase inhibitors and found that increasing severity of dementia may cause an increase in the incidence of urinary incontinence (Kröger, van Marum, Souverein, Carmichael, & Egberts, 2011).
- Lower urinary tract symptoms (LUTS), including increased frequency, urgency and/or pain with urination, and/or increased obstructive or voiding urinary symptoms (poor stream or incomplete voiding), often precede severe cognitive impairment in Lewy body dementia and vascular dementia, whereas urinary incontinence correlates with late-stage Alzheimer's disease. There is a need to match treatment with an older adult's needs and disease status (Averbeck, Altaweel, Manu Marin, & Madersbacher, 2015).

Slide 30:

- Incontinence is one of the most difficult issues for the care partner to deal with and is often a primary cause of moving persons living with dementia to institutional care.
- Conservative nonpharmacological, nonsurgical interventions are the first-line treatments for incontinence, whether the person has dementia or not.
- The majority of strategies for managing urinary incontinence involve common lifestyle interventions (Gormley, Lightner, Burgio, Chai, Clemens, Culkin, ... Vasavada, 2012).
- In the case of persons living with dementia, the strategies are likely to be discussed with and provided by the care partner, particularly in the later stages of dementia.

- One challenge is to preserve the dignity of the persons living with dementia, despite instances where they are not aware of the incontinence, are not bothered by the incontinence, and do not understand why there is need to institute the recommended strategies.
- Interventions often begin with education on the role of fluid intake on urinary frequency and the benefits of eliminating bladder irritants—such as carbonated beverages, tea/caffeine, alcohol, nicotine, and spicy foods. Weight loss, which may be challenging to facilitate during the middle and later stages of dementia, has been shown to be beneficial also.
- Toileting education and bladder training, such as scheduled or prompted voiding, are often more challenging for the care partner to implement. In fact, a recent study reported that care partners attempted fewer than half of the suggestions made by occupational therapists regarding toileting interventions to help manage urinary incontinence in their partner with dementia (Drennan, 2014).
- Often, the care partner is reluctant to seek help for incontinence for the persons living with dementia and delays until it is an acute or emergency issue. Encourage care partners to be open about this issue and not to be ashamed. Ask questions designed to place the care partner at ease.
- Other strategies that might afford some benefit include relaxation exercises, distraction strategies, and deep breathing exercises. These were discussed in Modules 5 and 6.
- Many prescription treatments for urinary incontinence are not appropriate or are contraindicated for use in older persons or persons with cognitive impairment (Drennan, 2014). However, research suggests that medications and indwelling catheters are offered much earlier to persons living with dementia, and at much higher rates, compared with healthy counterparts of the same age (Grant, Drennan, Rait, Petersen, & Iliffe, 2013):
 - Although this subject will be discussed in Module 8, there is limited information regarding the use of many current medications for incontinence in persons living with dementia—such as trospium, solifenacin, darifenacin, and fesoterodine, and no data for mirabegron. Oxybutynin has significant adverse cognitive effects and should be avoided (Chancellor & Boone, 2012).
 - It is of critical importance to consider the total anticholinergic load of all medications persons living with dementia are receiving before prescribing an anticholinergic for incontinence (Orme, Morris, Gibson, & Wagg, 2015). Consult with the person's pharmacist when determining a treatment plan.
 - Catheters are associated with an increased risk of infection, and, with long-term use, pain, damage, and risk of bladder stones (Grant, Drennan, Rait, Petersen, & Iliffe, 2013).

Slide 31:

- It is challenging to maintain the skin's integrity among healthy older individuals. The consequence of this loss becomes more problematic in persons living with dementia who are incontinent.
- Incontinence-associated dermatitis (IAD) is common in urinary and/or fecal incontinence. IAD
 has been defined as erythema and edema of skin surface "possibly with bullae with serous
 exudate, erosion, or secondary infection" (Beeckman, Van Lancker, Van Hecke, & Verhaeghe,
 2014).

- There are many neurourologic and structural causes of incontinence, and substantial evidence of the effects of incontinence on wound healing and in the development of pressure ulcers. Neurological deterioration associated with dementia can also impair bladder function.
- Exposure to urine (and/or fecal) matter leads to hyperhydration of the skin, causing a rise in skin pH that then reduces tissue tolerance, resulting in dermatitis and, potentially, ulcerations. Moisture from urine weakens the skin, leaving it more vulnerable to the effects of pressure and shear—and increasing the risk of pressure ulcers. Exposure to feces can be especially damaging to the skin owing to the combination of fecal enzymes, intestinal flora, and moisture (Beeckman, Van Lancker, Van Hecke, & Verhaeghe, 2014).
- Ideally, it is preferable to prevent the consequences of incontinence. Care partners will need to gently cleanse the perineal area with a product with a balanced pH, using a skin protectant following each major incontinence episode. Recommended products include creams or ointments containing zinc oxide, lanolin, or petrolatum, as well as some towelette products that form a protective film over the area (Doughty, Junkin, Kurz, Selekof, Gray, Fader, ... Logan, 2012; Gray, Beekman, Bliss, Fader, Logan, Junkin, ... Kurz, 2012). Some skin protectants are available that do not need constant reapplications and thus may be preferred (Beeckman, Van Lancker, Van Hecke, & Verhaeghe, 2014; Holroyd & Graham, 2014).
- Evidence suggests that bowel incontinence and pressure ulcers are among a host of variables that are most predictive of 6-month mortality.

Slide 32:

- Fecal or bowel incontinence is an under-recognized problem in both community-dwelling and institutionalized persons living with dementia. However, it is a common gastrointestinal complaint of persons living with dementia over age 65. Fecal incontinence can be associated with either diarrhea or constipation and is frequently misidentified by persons living with dementia and their care partners as diarrhea.
- As with urinary incontinence, the prevalence is substantially higher in men and women with dementia compared with persons of the same age group without dementia.
- Studies have reported prevalence rates ranging from 1 percent in a community population to 36 percent of ambulatory older adults identified in an insurance database. Most studies suggest rates of 10 percent to around 30 percent for persons living with dementia, compared with 3 percent to 4 percent in persons without dementia.
- The prevalence appears to increase as dementia progresses:
 - It is a prevalent condition among persons residing in nursing homes and has been associated with dementia and frailty (Saga, VInsnes, Møkved, Norton, & Seim, 2013).
- As with urinary incontinence, fecal incontinence may result from anatomical changes, muscular weakness associated with normal aging, or neurologic impairments including stroke and dementia (Shah, Chokhavatia, & Rose, 2012).
- Any cognitive or sensory deficit that interferes with awareness of the need to defecate—or that
 impedes a person's ability to communicate the need for help with defecation—can result in or
 exacerbate fecal incontinence. Consequently, clinicians should inquire about continence for
 persons with vision, speech, and/or gait impairments associated with dementia (Shah,
 Chokhavatia, & Rose, 2012).

- Management involves educating the care partner about potential food changes and reviewing the current medications to rule out an adverse effect.
- Persons living with dementia and/or their care partner are instructed to keep the perineal area dry and clean, using barrier creams and wipes in order to minimize the risk of developing pressure sores.
- A recent study of community-dwelling individuals with fecal incontinence reported that more than half had incontinence-associated dermatitis, predominantly around the anal and rectal area (Rohwer, Bliss, & Savik, 2013).

Slide 33:

• We now will examine the eating dysfunctions associated with progressive dementia.

Slide 34:

- Eating and drinking difficulties are common in persons living with dementia. Evidence suggests that one in three older persons living with dementia have problematic eating behaviors.
- During the later stages of dementia and particularly in frontotemporal degeneration (FTD), persons living with dementia can develop apraxia (inability to perform purposeful movements) and agnosia (impaired recognition or comprehension of sensory stimuli). These impairments can interfere with the ability to use utensils or to recognize food and comprehend what should be done with the food. At the same time, visual impairments and loss of fine motor skills can minimize the physical abilities involved in eating, and smell and taste impairments can reduce appetite and thus food intake. Vascular changes can cause loss in the ability to control and coordinate chewing and swallowing. There can be concurrent dental problems, combined with poor oral hygiene, that cause pain and chewing difficulties that can exacerbate dysphagia and has been linked to gagging, coughing, and aspiration. All of this can lead to malnutrition. Comorbid depression can manifest with reduced appetite. Lastly, some medications (including those used to treat psychological or psychiatric disorders) may cause agitation or somnolence that can interfere with eating behaviors. See Module 16 for more on oral health care and the role of the dentist.
- Dysphagia, or impairment in the ability to swallow, can result in malnutrition, dehydration, and weight loss (Alagiakrishnan, Bhanju, & Kurian, 2013). Of greatest concern is the increased risk of aspiration pneumonia and mortality (Cereda, Cilia, Klersy, Canesi, Zecchinelli, Mariani, ... & Pezzoli, 2014). Persons with dysphagia have a threefold increase in pneumonia, which is further increased by aspiration (Altman, Richards, Goldberg, Frucht, & McCabe, 2013). Dysphagia can also cause functional decline and a fear of eating or drinking, which ultimately decreases the person's quality of life (Alagiakrishnan, Bhanji, & Kurian, 2013).

Slide 36:

- Dysphagia is prevalent in persons living with dementia, with estimates ranging from 13 percent to 57 percent.
- Dysphagia can first occur during early-stage Alzheimer's disease, but usually becomes more severe in later stages, and manifests much later in persons with frontotemporal degeneration.
- However, it is an often under-recognized complication of acute stroke, even though it is believed to affect up to 78 percent of persons after stroke (Altman, Richards, Goldberg, Frucht,

& McCabe, 2013). Dysphagia increases morbidity, length of hospitalization, and mortality, particularly within the first week after stroke. Rates and severity of dysphagia are influenced by the degree of damage to the dominant hemisphere. In fact, aspiration pneumonia is the most common cause of death in persons with Parkinson's disease.

- A recent retrospective study of nearly 6,500 persons with Parkinson's disease reported a prevalence of symptomatic dysphagia of 11.7 percent, with increasing prevalence associated with longer disease duration, increasing age, and male gender (Cereda, Cilia, Klersy, Canesi, Zecchinelli, Mariani, & Pezzoli, 2014).
- Eating abnormalities are a core criterion for diagnosing behavioral variant frontotemporal degeneration. Recent research suggests that eating abnormalities are also prominent in persons with semantic FTD. Eating abnormalities were reported in increased appetite and food preferences (specifically for higher intake of sugar and carbohydrates). Of note, these abnormalities were substantially more common among persons with any FTD variant compared with persons with Alzheimer's disease or matched healthy controls (Ahmed, Irish, Kam, van Keizerswaard, Bartley, Samaras, & Piguet, 2014).

Slide 37:

- EDWINA (Eating and Drinking Well IN DementiA), a systematic review of small, short-term studies, found no definitive evidence on effectiveness (or lack thereof) of any specific eating interventions. The review looked at oral nutrition supplementation, food modification, dysphagia management, eating assistance, and supporting the social element of eating and drinking. There is limited evidence to support diagnostic tests, effect of postural changes, fluid or diet changes, behavioral management, or use of medications. (Alagiakrishnan, Bhanji, & Kurian, 2013).
- As will be discussed in Module 12, the use of percutaneous endoscopic gastrostomy (PEG) tubes is of minimal benefit with regard to survival, improved quality of life, or reduction in aspiration pneumonia, and most health care professionals recommend that they should not be used in persons with advanced dementia (Alagiakrishnan, Bhanji, & Kurian, 2013; Altman, Richards, Goldberg, Frucht, & McCabe 2013). However, numerous other ethical and legal factors—including the wishes of the persons living with dementia and the care partner—need to be considered in any PEG use decisions.

Slide 38:

• We conclude by examining other medical concerns associated with progressive dementia.

Slide 39:

- Sensory impairments associated with "normal" aging must not be overlooked in persons living with dementia.
- Vision impairments—glaucoma, cataracts, changing visual acuity—may need to be evaluated by an optometrist or ophthalmologist, possibly necessitating additional treatment, surgery, or corrections to current eye wear.
- Similarly, normal aging is associated with gradual hearing loss, and older persons living with dementia may require a hearing aid.

- Oral hygiene is often poor in persons living with dementia, which can lead to pain as well as medical consequences such as systemic infection. It is important to stress the need for attention to oral hygiene, and it may be necessary to refer persons living with dementia to dentists or other dental specialists for additional evaluation and treatment. This will be covered in depth in Module 16.
- Appropriate specialists and therapists may be needed to evaluate the persons living with dementia for additional assistive devices—canes, walkers, wheelchairs, as well as household items such as electric can openers.
- For persons with substantial pain, a referral to a pain specialist may be appropriate. Similarly, a person with recurrent urinary problems may need to be evaluated by a urologist. A referral to a neurologist, psychiatrist, or neuropsychiatrist might be beneficial for a person exhibiting particularly severe behavioral and psychological symptoms of dementia. Eating disorders may require specialty management that will depend on where the person resides and the stage of dementia. Additional information about specialists and other members of the interprofessional team are addressed in Module 9 and Modules 13 to 16.

Slide 40:

- Psychosis is common in patients with Parkinson's disease dementia (PDD), and visual hallucinations are particularly common.
- Persons with PDD may report "minor" symptoms, such as visual illusions, a sense of presence, misidentification syndromes, or passage.
- Hallucinations are the most common psychosis, present in up to almost 50 percent of persons with PDD, with a lifetime prevalence up to 60 percent:
 - They may appear as well-formed visual images.
 - Early visual hallucinations are a risk factor for early dementia.
 - Persons with PDD also may have hallucinations involving other sensory modalities (auditory, tactile, olfactory, somatic, or gustatory).
- Paranoid delusions (especially concerning spousal infidelity and abuse) tend to be less common than visual hallucinations, occurring in about 5 percent of older adults.
- Psychotic symptoms can be extremely disruptive and frightening to the older adult and any care partners, substantially affecting the quality of life—of patients, their families, and care partners. The continued presence of psychosis is frequently associated with a need for institutionalization.
- Risk factors of psychosis include age over 65 years, older age at disease onset, disease duration of more than 6 years, more advanced disease, rapid eye movement sleep behavior disorder, impaired visual acuity, higher doses of dopamine agonists, axial Parkinsonism, cognitive impairment or dementia, or a family history of dementia.
- Impulsive and compulsive behaviors have been recognized as serious and relatively common adverse effects in PD older adults taking dopamine agonist medications.

Slide 41:

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. Medication management
- 2. d. All of the above

Slide 42:

Answers:

- 3. d. Scheduled toileting and lifestyle changes
- 4. c. Sudden changes of behavior