

FACULTY GUIDE

Core Module 3:

Recognizing the Role of Diversity in Dementia Care

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Slide 1:

- Module 3 examines issues of racial and ethnic diversity as they pertain to dementia.
- It examines how sex, ethnicity, or race may influence the risk, incidence, and prevalence of dementia; how dementia is perceived by persons living with dementia and their care partners across different groups; and how assessment and treatment may be affected within diverse populations.

Slide 3:

- As you can see in this outline, we plan to cover a wide range of “diverse” populations—by considering sex, race, ethnicity, sexual orientation, and geographic location.

Slide 4:

Our goal, by the time we finish with this module, is for you to learn about the following topics:

- How sex, ethnicity, and race may influence the risk of dementia.
- Factors to consider when diagnosing and treating dementia in diverse populations.
- Cultural, personal, and professional barriers to optimal care among different groups.
- Communication strategies to use when interacting with diverse populations.

Slide 6:

- “One size does not fit all.”
- An attitude of cultural humility plus cultural competence is helpful when working with diverse elders.
- Numerous avenues are available for providers to sharpen their skills for providing care to the increasingly diverse U.S. population of older adults.
- Attendance at continuing education webinars, workshops, and online courses and willingness to consult with colleagues with appropriate expertise are excellent ways to sharpen your skills to work effectively with the increasingly diverse U.S. population of older adults.

Slide 7:

- We begin by exploring why health care professionals need to be sensitive to the needs of a diverse patient population—especially, the particular ways in which dementia affects specific populations.
- Before we begin, we need to acknowledge that very little information has been published about dementia in diverse populations. The literature that has been published has overwhelmingly focused on Alzheimer’s disease, with a dearth of information about other forms of dementia, such as Lewy body dementia, frontotemporal degeneration (also known as frontotemporal disorder, frontotemporal dementia, and frontotemporal lobar degeneration), or vascular dementia in diverse populations.
- There is a great and immediate need for research on issues regarding care for persons living with dementia from diverse ethnoracial and marginalized backgrounds.

- We also need to clarify the terminology that this module uses. When referring to “White” Americans, we use the terminology operationalized in the research study. Some studies specify Caucasians, others specify non-Hispanic Whites, but many studies use the term “White.” We are limited to using the language of the study.
- A final goal of the module is to help health care providers engender cultural humility, at a minimum, and become culturally competent. The Agency for Healthcare Research and Quality notes that “*culturally competent care respects diversity as well as the cultural factors that can affect health and health care, such as language, communication styles, beliefs, attitudes, and behaviors*” (Agency for Healthcare Research and Quality, 2016; n.d.). Cultural humility engenders respect for different cultures, without the depth of knowledge regarding the various cultures required for competence. Furthermore, the Office of Minority Health of the U.S. Department of Health and Human Services has developed the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (Office of Minority Health, n.d.).

Slide 8:

- There is very little concrete guidance in the literature to help the providers to deliver care to persons living with dementia from diverse groups.
 - Whenever possible, we have included published (often anecdotal) recommendations.
 - In general, it is recommended for health care providers whose care populations encompass diverse populations to first familiarize themselves with the general cultural beliefs and family dynamics of those groups.
- Oftentimes, providers will rely on family members as interpreters or as the culturally identified resource person. Provider/interpreter conversations must be done within the 1996 Health Insurance Portability and Accountability Act—or HIPAA—policies.
 - HIPAA notes that the person living with dementia may request that the clinician not share the diagnosis with care partners or family members.
 - “Where the individual is incapacitated...covered entities generally may make such uses and disclosures, if in the exercise of their professional judgment, the use or disclosure is determined to be in the best interest of the individual” (U.S. Department of Health and Human Services, 2003)
 - Capacity is decision specific and is discussed in more detail in Module 11.
 - Dementia does not prove incapacity. However, persons who lack the ability to understand the diagnosis and make decisions about treatment likely require that the diagnosis be shared with a care partner, family member, or other identified proxy. Providers may disclose against the person’s request if it is determined the person lacks capacity or the benefits of disclosure to the person outweigh the risks of nondisclosure.
 - Any capacity evaluation and determination should be documented.

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- Why is it important to address diversity in the context of dementia? Because of the “ethnogeriatric imperative”.
 - “Ethnogeriatric imperative” refers to the expanding population of older individuals from diverse ethnic backgrounds living in the United States who will require health care.

- By 2050, approximately 39 percent of older Americans are projected to be from one of the four populations designated as “minority” (or “non-White”) by the U.S. Census Bureau, up from 21 percent in 2012. These are Black/African American, Asian American, American Indian/Alaska Native, and Native Hawaiian/Other Pacific Islander.
 - Hispanics (or Latinos, as they are more often referred to in the Western United States) can be of any race; the term “Hispanic” or “Latino” refers to one’s ethnic identification.
- Today, the term “Caucasian” or “White” is being replaced by the more accurate terms of “non-Hispanic White” or “Hispanic White,” recognizing that most Hispanics and Latinos are of the Caucasian race (U.S. Census Bureau, 2014).
- Besides racial and ethnic identification, the term “diversity” encompasses other domains of difference including:
 - Groups based on comorbid medical, cognitive, or psychiatric conditions.
 - Groups formed on the basis of sexual orientation.
 - Those formed on the basis of sex or age of dementia onset.
 - Groups formed on the basis of their location—rural versus urban or suburban.

Slide 11:

- In the context of dementia, there are several key points to know.
- Rates of dementia differ by race and ethnicity, as well as other aspects of diversity—although racial and ethnic differences have been studied the most.
- This is most likely due to lifestyle and socioeconomic risk factors, as well as certain medically comorbid conditions (such as hypertension, cardiovascular disease, and diabetes) with higher prevalence rates of these vascular conditions found in many minority groups.
- There are also differences in longevity, as well as in the presence of “protective factors” such as higher levels of education and employment and greater financial resources to purchase care (Chin et al., 2011).
- There are other significant sociocultural factors affecting how minorities use the health care system for dementia (Smedley, Stith, & Nelson, Eds. 2003).
- Much has been written on the topics of “disparities” in access to health care and “low health literacy” as factors that reduce the number of minorities who seek diagnosis or assistance for dementia and its related disorders. These are typically related to language ability, degree of acculturation, knowledge of how the health care system “works” and how to access and use available resources, and lack of acceptance of culturally rooted attitudes and beliefs by health care providers (Yeo, 2009).
- The Institute of Medicine (2003) points out that these factors are very real and society has an obligation to recognize and address them.

Slide 12:

- There is considerable variability in attitudes, beliefs, and values regarding dementia and dementia care in the diverse subgroups described in this module. These unique attitudes, values, and beliefs influence how dementia is understood, when and from whom help is sought, and how caregiving is understood and implemented.
 - For example, one common thread across many minorities is the belief that early signs and symptoms of dementia represent “normal aging.” This belief delays help-seeking—

often until dementia has progressed to the point that currently available treatments (for example, medications and nonpharmacological interventions) are likely to be of less benefit.

- Delayed help-seeking, in turn, is associated with higher health care costs when care is finally sought and higher burdens of care for the primary (often family) care partners.
- Ethnoracial disparities—namely, genetics and differences in biological risk factors—can influence incidence and prevalence, whereas race-specific cultural factors may influence diagnosis and treatment (Chin et al., 2011).
- Persons from “minority” ethnic groups may be less able to access dementia services and are underrepresented in U.S. dementia drug. Evidence indicates that persons with dementia from “minority” ethnicities access diagnostic services later in their illness and, after receiving a dementia diagnosis, are less likely to access medical treatment, research trials, and 24-hour care.
- There may be differences in informant ratings of Black/African American versus non-Hispanic White persons with dementia, which can contribute to disparities in detection and treatment of dementia.
- For these reasons, it is imperative that health care providers learn about how diversity affects all aspects of dementia care—from recognition of the problem, to diagnosis and treatment planning for both patients and care partners, and on to addressing long-term care needs, settings, and costs, finally resulting in end-of-life decision-making, which, again, varies greatly by race, ethnicity, culture, self-identification, and other related factors.

Slide 13:

- By 2050, approximately 39 percent of older Americans are projected to be from one of the four populations designated as “minority” (or “non-White”).
- **Race** refers to a person’s physical characteristics, such as bone structure and skin, hair, or eye color.
 - The U.S. Census Bureau recognizes five races and an “Other” category (note: these categories are current at the time of publication but may change over time):
 - Black or African American
 - White (European American; often includes Hispanics and Latinos)
 - Asian
 - Native Hawaiian or Other Pacific Islander
 - American Indian or Alaska Native
 - Other
- These racial categories are in flux, and definitions change over time and across regulating agencies.
- **Ethnicity**, however, refers to cultural factors, including nationality, regional culture, ancestry, and language.
 - Examples include German, Spanish, Mexican, or Latino ancestry.
- Racial and ethnic beliefs influence diagnosis and treatment of dementia.
- Persons from marginalized groups may be less able to access dementia services.
- Religious diversity will not be examined in depth in this module.

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- Incidence:
 - Identifies change in status from non-disease to disease.
 - Is limited to newly diagnosed cases within a specific period.
 - Measures:
 - How fast disease occurs.
 - Proportion of population developing new cases of disease.
 - Is important for tracking how quickly a new disease is occurring in a population.
- Incidence of dementia declines with changes in educational attainment and reduction of vascular risk factors
 - A study occurring over 3 decades, primarily of Americans of European descent, found a 44 percent decline during fourth decade compared with baseline among persons with at least a high school diploma.
 - A lower prevalence of most vascular factors except obesity and diabetes was observed among those with higher levels of education, including a HS diploma.
- Lower incidence of vascular dementia was associated with earlier diagnosis of heart disease, early treatment of stroke, and at least the attainment of a high school diploma.
- Prevalence:
 - Includes both new cases and those still living with the disease.
 - Measures the proportion of population with the disease.
 - Is important if focus is on overall number of cases in population.
- Challenges in measuring prevalence in ethnic groups include:
 - Lack of assessments in non-English languages.
 - Reluctance of population to trust medical providers.
 - Unwillingness to participate in medical research.
 - Higher occurrences within ethnic groups of known risks such as those who were poorly educated or who have cardiovascular or cerebrovascular diseases.

Slide 15:

- According to definitions adapted by the American Psychological Association:
 - Sex refers to a person's biological status (generally male, female, or intersex).
 - Gender refers to the attitudes, feelings, and behaviors culturally associated with biological sex.
 - Gender identity refers to one's "sense of self as male, female, or transgender."
 - Sexual orientation refers to the "sex of those to whom one is sexually and romantically attracted."

Slide 16:

- Numerous studies have demonstrated that there are disparities in access to, and type of, health care provided based on a set of variables that interrelate with one another. For example,:
 - There are significant differences in rates of illnesses (such as, cancer, heart disease, and diabetes) in different racial or ethnic groups.

- There are a host of known barriers to accessing health care (such as lack of understanding of written or spoken English or reliance on one's native language, lack of knowledge about diseases and remedies, mistrust of the health care system, lack of insurance, belief in the power of indigenous healing methods, just to name a few).
- There are great differences in patient perceptions of care, global satisfaction ratings, and other indices of quality of care.
- Access to care and perception of the quality of care are improved when the physician or health care provider and the patient are of the same race or ethnicity and speak the same language.

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- General barriers applicable to minority patients and families include:
- Selection of appropriate assessment tools:
 - Most cognitive tests were normed on White middle-class participants and generally are not considered by most clinicians who work with diverse populations to be appropriate for an elder whose native language is not English.
- Inappropriate use of interpreter and translating services.
 - An interpreter translates spoken words and must be fluent in both languages without relying on outside source materials. A translator translates written words and can use outside sources. Ideally, both should be familiar with dementia assessment.
 - Why NOT use family members? They bring their own issues and may not be able to be objective.
 - Your community may have professional medical interpreters whose services are free.
 - Engagement of the family should be determined by the patient's functional capacity because usual cognitive tests may not be reliable or valid.
- Explaining the diagnosis includes giving feedback using culturally appropriate methods.
- Treatment planning should be conducted within culturally appropriate methods.

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- In 2016, the American Geriatrics Society's—or AGS—Ethnogeriatrics Committee developed and published a set of culturally sensitive indicators to help health care providers deliver the best possible care to ethnically diverse older adult populations.
- The AGS recommends that practitioners ask all older adults five questions and document answers in their medical records.
 - What is your ethnicity?
 - What is your preferred language?
 - Do you know that interpreter services are available free of charge?
 - Do you want to choose one of the available interpreter services (online, telephone, or in person)?
 - How much education did you complete (none, less than 7th grade, or 7th grade or higher)?
- Because the language a patient speaks is closely linked to his or her culture, assessing the patient's preferred language and effectively using interpreter services are essential for enhancing communications. Practitioners should seek qualified trained medical interpreters—not family members—for these services.

- Aside from language, other factors may come into play for practitioners who treat minority or marginalized older adults. For example, many people of various ethnicities use complementary or alternative health practices, including home-healing therapies and techniques.
- The AGS recommends that health care professionals be self-aware of their own biases and perceptions by considering how personal cultural groups influence values. What's more, health care professionals should consider how their perceptions are different from those of people from other cultural backgrounds.

Slide 19:

- Before we look at dementia in a variety of diverse populations, we will explore major conditions and factors that influence rates of dementia—particularly genetic factors and medical illnesses.

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- Genetic factors (APOE-ε4) play a role.
- Medical conditions, particularly hypertension (Murray et al., 2018), type 2 diabetes mellitus (Hendrie et al., 2017, 2018), and HIV, are also important factors.
- The Atherosclerosis Risk in Communities program studied racial disparities related to stroke, subclinical brain infarction, leukoaraiosis, and cognitive change and dementia (Gottesman, Fornage, Knopman, & Mosley, 2015).
 - Disproportionate rates of vascular risk factors explain some disparities in cognitive impairments. The program found that particular risk factors, including diabetes, may differentially affect the brain in Black/African American versus White participants.
 - There is a greater burden of clinical and subclinical brain disease in Black/African Americans compared with Whites. Black/African Americans have higher rates of stroke, subclinical microvascular disease, and hospitalized dementia than do Whites.
 - Cardiovascular risk factors appear to explain much of the excess burden in Black/African Americans.
 - On the basis of the program's data, the researchers concluded that risk factors for dementia may be more prevalent and more severe in Black/African Americans than they are in Whites (Gottesman et al., 2015).
- The Nun and the Honolulu-Asia Aging studies also researched factors in dementia.
 - Both studies included repeated cognitive assessments during life and comprehensive brain autopsies (Mortimer, 2012; White, Edland, Hemmy, Montine, Zarow, Sonnen, ... Montine, 2016).
- No one single lesion type accounted for the majority of identified cognitive impairment.

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- A large study was conducted involving 1,079 Medicare beneficiaries without Alzheimer's disease and related dementias at baseline (Tang, Stern, Marder, Bell, Gurland, Lantigua, ... Mayeux, 1998).
- The study found that the presence of an APOE-ε4 allele was a determinant of Alzheimer's disease risk in Whites (RR 2.5) but that Black/African Americans (RR 1.0) and Hispanics (RR 1.1) have an increased frequency of Alzheimer's disease regardless of their APOE status.

- In the absence of APOE-ε4 allele, cumulative risks of Alzheimer's disease to age 90 (adjusted for education and sex) were four times higher for Black/African Americans (RR 4.4) and two times higher for Hispanic/Latinos (RR 2.3) compared with Whites. In the presence of APOE-ε4 allele, similar cumulative risk of the disease to age 90 is evident across all three groups.
- Results suggest that other genes or risk factors may contribute to the increased risk of Alzheimer's disease in Black/African Americans and Hispanic/Latinos.

Slide 23:

- Statistics from the American Heart Association and American Stroke Association show:
- Nearly half of all Black/African American adults have some form of cardiovascular disease, 48 percent of women and 46 percent of men.
- Black/African Americans have nearly twice the risk for a first-ever stroke than do Whites and a much higher death rate from stroke.
- About 43 percent of Americans have total cholesterol of 200 mg/dL or higher—including 41 percent of Black/African American women and 37 percent of Black/African American men.
- Rates of hypertension among Black/African Americans are among the highest of any population in the world.
- In the United States:
 - Approximately 46 percent of Black/African American women and 45 percent of Black/African American men have high blood pressure versus 33 percent of White men and 30 percent of White women (Mozaffarian et al., 2016; Centers for Disease Control and Prevention, 2018).
 - Black/African Americans develop high blood pressure more often, and at an earlier age, than do non-Hispanic and Hispanic Whites.
 - More Black/African American women (46 percent) than men (43 percent) have high blood pressure.
- Both Black/African Americans and Hispanic/Latino Americans have higher rates of hypertension and stroke than do Whites and, therefore, higher rates of vascular and mixed dementia.
- Risk of dementia is nearly eight times higher if a person has type 2 diabetes mellitus—or T2DM—and experiences a stroke; 43 percent of dementia cases is attributable to T2DM, stroke, or a combination of the two (Haan, Mungas, Gonzalez, Ortiz, Acharya, & Jagust, 2003).
 - Data from the Chicago Health and Aging Program (from 1993 to 2008) indicate that the racial differences in blood pressure control in older adults are not explained by socioeconomic factors. The study found Black/African Americans had a statistically significantly higher prevalence of hypertension compared with Whites, along with a higher awareness of hypertension, but poorer blood pressure control compared with non-Hispanic Whites, even after controlling for socioeconomic factors, medical conditions, obesity, and the use of antihypertensive medications (Delgado, Jacobs, Lackland, Evans, & de Leon, 2012).
- Proactive identification and management of cardiovascular risk factors may be the best current dementia prevention strategy.

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- Diabetes is an independent risk factor for cognitive decline in both Black/African Americans and Hispanic/Latino Americans.
- Many studies have found that people with diabetes, especially T2DM, have lower levels of cognitive function and have higher risk for dementia.
 - Twenty-six percent of people ages 65 and older in the United States have diabetes.
 - American Indians and Alaskan Natives have the highest rate (at 15.9 percent), followed by non-Hispanic Blacks (13.2 percent) and Hispanics (12.8 percent), compared with 7.6 percent of non-Hispanic Whites and 4.4 of Chinese Americans.
 - A recent study found a similar rate of cognitive change in older persons with or without T2DM over a mean follow-up of 6 years but reported poorer cognitive performance in persons with diabetes, regardless of their ethnicity.
- A large-scale multiethnic study identified nearly 22,200 patients with diabetes ages 60 and older who did not have preexisting dementia and followed them over a 10-year period. During this time, 17 percent of study participants were diagnosed with dementia.
 - The highest age-adjusted rates of dementia were among Native Americans (34/1,000 person-years) and Black/African Americans (27/1,000 person-years).
 - The lowest rates were found among Asians (19/1,000 person-years).
 - Black/African Americans and Native Americans had a 40 to 60 percent greater risk of dementia compared with Asians, non-Hispanic Whites, and Latinos who had an intermediate risk. However, as we discuss shortly, the risk of dementia is higher for Latinos when the comorbid condition of diabetes is present.

Slide 25:

- We are now going to focus on how sex, race, and ethnicity may specifically influence dementia in America.

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- Ethnicity may influence dementia through age of onset, comorbidities, family history, APOE gene status, and cognitive changes over time.
- Variations in health, socioeconomic risk factors, education levels, and lifestyles may have greater influence than genetics.
- Older Black/African Americans and Hispanic/Latinos are more likely than older Whites to have Alzheimer's disease and related dementias.
- Hispanic/Latinos are 1.5 times more likely to have Alzheimer's disease and related dementias than are older non-Hispanic Whites (Gurland et al., 1999; Haan, Mungas, Gonzalez, Ortiz, Acharya, & Jagust, 2003).
- Largest and longest study to date examined 274,283 health care members ages 64 and older over a 14-year period; all participants were from northern California and members of large private health care system (Mayeda et al., 2016).
 - Dementia incidence (59,555) was highest for Black/African Americans (26.6/1,000 person-years) and American Indians/Alaska Natives (22.2/1,000 person-years). It was intermediate for Hispanics and Latinos (19.6/1,000 person-years), Pacific Islanders

(19.6/1,000 person-years), and Whites (19.3/1,000 person-years) and lowest among Asian Americans (15.2/1,000 person-years).

- Risk was 65 percent greater for Black/African Americans than it was for Asian Americans.
- Cumulative 25-year risk at age 65 was 38 percent for Black/African Americans, 35 percent for American Indians/Alaska Natives, 32 percent for Hispanics and Latinos, 30 percent for Whites, 28 percent for Asian Americans, and 25 percent for Pacific Islanders.
- The study documents these differences but does not explain the mechanisms underlying them.
- Racial and ethnic differences were observed for both sexes, but they were stronger for men. Dementia rates were 93 percent higher for Black/African American men compared with those **for Asian American men and 60 percent higher for African American women than they were for Asian American women.**

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- First let's examine differences in dementia by sex.

Slide 29:

- More women than men have Alzheimer's disease and other dementias; almost two-thirds of Americans with AD are women.
 - Of 5.1 million Americans ages 65 and older with Alzheimer's disease, 3.2 million are women and 1.9 million are men.
 - Estimates from the Aging, Demographics, and Memory Study of people ages 71 and older reveal that 16 percent of women have Alzheimer's disease and other dementias compared with 11 percent of men.
- One explanation is that women live longer on average than do men, and older age is the greatest risk factor for Alzheimer's disease.
- Data from the Framingham Study report that men have a higher death rate from cardiovascular disease compared with women in middle age, so men who live longer may have healthier cardiovascular risk profile.
- However, studies on incidence (which indicates risk of developing disease) do not show any significant difference between men and women in the proportion who develop Alzheimer's disease and related dementias at any age, but biological or genetic variations or even different life experiences might account for sex difference.
- The APOE-ε4 genotype, which is the best known genetic risk factor for AD, may have stronger association with Alzheimer's disease in women than it does in men, possibly associated with estrogen.

Slide 31:

- We begin our examination of racial and ethnic differences with the African American population.
- The overwhelming majority of research regarding dementia across different races and ethnicities focuses specifically on Alzheimer's disease, and there is an almost total absence of information regarding ethnoracial disparities as they influence other etiologies of dementia.

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- There are several risk factors for dementia among Black/African Americans.
 - The prevalence of APOE e4 allele is higher among Black/African Americans than it is among non-Hispanic Whites.
 - APOE e4 allele along with ATP-binding cassette transporter-7(ABCA7) gene is related to increased risk Alzheimer's disease among Black/African Americans.
 - The risk and rates of diabetes are higher among older Black/African Americans than they are among other groups.
- There are also cultural and social differences in risk.
 - Black/African Americans are less likely to seek medical attention, and they present later in the disease course.
 - They may mistrust medical providers.
 - They have often experienced discrimination in health care settings.
- Black/African Americans have a higher prevalence of vascular dementia than do Caucasians (Froehlich, Bogardus, & Inouye, 2001).
 - They have an increased prevalence of risk factors for vascular disease.
 - The incidence of vascular dementia in Black/African Americans is 7.4 per 1,000 for those younger than age 75, increasing to 21/1,000 for ages 75 to 79, then to 33.7/1,000 for ages 80 to 84, and 55.9/1,000 for ages 85 and older. Incidence rates for each age group is higher among Black/African Americans than they are for Caucasians.
- The prevalence of Parkinson's disease for Black/African Americans appears to be lower than or equal to that for Caucasians (Froehlich et al., 2001; McInerney-Leo, Gwinn-Hardy, & Nussbaum, 2004; Rajput, Rajput, & Rajput, 2003). However, community-based studies suggest that Parkinson's disease is under diagnosed in the Black/African American population, which may leads to delay in diagnosis because doctors may not consider it (McInerney-Leo et al., 2004)

Slide 34:

- Black/African Americans appear to have greater likelihood of a missed diagnosis of Alzheimer's disease compared with non-Hispanic Whites.
 - Black/African Americans who are evaluated have a much higher rate of false-positive results. However, at the same time, there is substantial evidence of underreporting of dementia among African Americans.
 - Black/African Americans tend to be diagnosed at a later stage of the disease limiting the effectiveness of treatments and interventions that are more effective with early intervention.
 - Black/African Americans are seriously underrepresented in current clinical trials of potential treatments for Alzheimer's disease even though evidence of genetic differences and response to drugs varies significantly by race and ethnicity.
 - Clinicians need to be respectful of Black/African Americans' mistrust and distrust of the research community because the history of research in this country has not been sensitive to and respectful of Black/African Americans and their culture.
 - Delayed or missed diagnoses or misdiagnoses lead to delays in treatment.

- Black/African Americans have higher rates of medical conditions associated with dementia such as hypertension, diabetes, and HIV infection compared with White counterparts.

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- Barriers to discussing cognitive impairment with health providers among Black/African Americans include fear of deleterious effects of a diagnosis and lack of awareness of potential benefits of early diagnosis.
- When using the Mini Mental State Exam—or MMSE—it is important to use age- and education-corrected norms because:
 - There is a risk of false-positive results associated with limited education.
 - Higher education levels may show false-negative results.
 - MMSE scores are not significantly associated with functional difficulties in community-dwelling older adults regardless of their ethnicity.
- To improve accuracy of cognitive screening in multiethnic sample, a recent study recommended combining MMSE and the Mini-Cog and Functional Activities Questionnaire. The study also found Black/African Americans had significantly fewer depressive symptoms on the Geriatric Depression Scale compared with older participants of Hispanic/Latino and European descent.
- As discussed in Module 2, there are copyright limitations, costs, and efficacy concerns with using the MMSE and other tools. Please see Module 2 for more information on appropriate screening assessments.

Slide 36:

- As shown in the previous slides, it is important to treat confounding comorbidities.
- Professional considerations include:
 - Facilitating compliance in light of mistrust of the health care system.
 - Recognizing strong reliance on faith and spirituality.
 - Providing reassurance, empathy, and encouragement, even if this requires additional time; providers should present options and solutions and emphasize that help is available.
- Treatment of Alzheimer's disease is based almost exclusively on studies of non-Hispanic Whites. Evidence suggests that Black/African Americans with Alzheimer's disease decline more slowly and have longer survival rates compared with non-Hispanic Whites with the disease. However, there are no differences in rates of change over time between ethnicities (Barnes & Bennett, 2014).
- Centers for Medicare and Medicaid Services data show that in four states there were significant disparities in pharmacotherapy exposure based on race and ethnicity among persons diagnosed with Alzheimer's disease—not just among non-Hispanic Whites versus minorities, but also among different minorities and different geographic locations (Gilligan, Malone, Warholak, & Armstrong, 2012).
 - Notably, the study found Black/African Americans are less likely to receive Alzheimer disease pharmacologic treatments.

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- Care partners for Black/African Americans are more likely to be adult children, extended family members, or friends, whereas spouses are most likely to be the care partner among non-Hispanic Whites.
- Black/African American care partners are often younger and less educated and have fewer financial resources and more unmet needs with regard to support and access to services.
- Black/African American care partners are less likely to put persons with dementia into nursing home setting (compared with non-Hispanic White care partners) and appear to be less distressed by behavioral and psychological symptoms of dementia than do non-Hispanic White care partners.
- A study reported lower anxiety, better well-being, and less use of psychotropic medications for African Americans with dementia than for other groups. There were no differences among the groups in self-rated health, but Black/African American care partners engaged in unhealthier behaviors than did non-Hispanic White care partners.
- Black/African American care partners may find caregiving more rewarding than do non-Hispanic White care partners; it is considered to be a normative experience with spiritual purpose and pride, which brings partners closer to the person with dementia.
- Evidence suggests care partners require information, referrals for services, and assistance in recognizing disease progression. Health care providers need to give greater attention to help care partners address the needs, stressors, and expectations of Black/African Americans with Alzheimer's disease. They also need to communicate more than they currently do with these care partners (Lampl-Dallas, Mold, & Flori, 2005).
- There are many benefits for providing training and care to the care partner, as demonstrated in the findings from the Resources for Enhancing Alzheimer's Caregiver Health—or REACH—programs.

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- We now examine dementia in Hispanic/Latino Americans.

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- Hispanics and Latinos come from diverse countries, cultures, and backgrounds. For example, they come from Mexico, Cuba, Puerto Rico, and Central and South America.
 - The majority of Latinos are Catholic, but a growing proportion affiliate with Protestant denominations.
 - These very diverse groups have different educational levels and immigration patterns.
 - Each subpopulation has its own traditions and holidays.
 - Each subpopulation speaks its own Spanish dialect.
- Hispanics and Latinos have the fastest growing elderly population in the United States.
 - Their population increased from 35.3 million (12.5 percent of the U.S. population) to 50.48 million (16.3 percent of population) from 2000 to 2010—an increase of more than 15 million or 43 percent.
 - Members of this group have longer life expectancy than those in the general U.S. population.

- U.S. Hispanics and Latinos living in Southwestern United States are, on average, younger by 4 years at the time of their diagnosis of dementia compared with non-Hispanic Whites, but the only difference appears to be ethnicity.

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- Hispanics and Latinos have lower frequency of APOE $\epsilon 4$ allele. Dementia in this group may be related to modifiable (vascular) causes more so than it is with Americans of European descent.
 - Socioeconomic factors play a role.
 - Hispanics and Latinos have the lowest educational levels of any group in the United States.
 - Low health literacy affects their ability to understand directions and instructions about taking their medications.
 - Hispanics and Latinos do not use health care services as often as non-Hispanic Whites, delaying their possible diagnosis.

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- Approximately 25 percent of Hispanic and Latino elders live below the poverty line—more than twice the rate of non-Hispanic adults.
- They are less likely to see health professionals because of financial and language barriers.
- Memory loss is seen as a normal part of aging or as mental illness (stigma).
- Clinicians need to be sensitive to culture and language (Arguelles & Arguelles, 2006; Montoro-Rodriguez et al., 2006).
- There is a lack of culturally appropriate diagnostic tools and of bilingual health professionals (Talamantes et al., 2006).
- Older Hispanic and Latinos rely on families for assistance; they underuse nursing home and home health care services.
- Spanish and English Neuropsychological Assessment Scales (SENAS) is a validated Spanish and English neuropsychological test battery.

Slide 43:

- Some medical comorbidities are particularly relevant to Hispanics and Latinos.
 - Vascular risk factors increase the likelihood of dementia (Haan, Mungas, Gonzalez, Ortiz, Acharya, & Jagust, 2003).
 - A study found the presence of each cardiovascular risk factor (or CVRF), smoking, stroke, heart disease, diabetes, hypertension, and central obesity) to be associated with a 0.1 standard deviation (SD) lower score in general cognitive processing, memory, and executive function in Black and Hispanic participants compared with non-Hispanic Whites using a composite score that included smoking, stroke, heart disease, diabetes, hypertension, and central obesity. CVRF was associated with poorer cognitive functioning but not with cognitive decline among minority older adults (Schneider, Gross, Bangen, Skinner, Benitez, Glymour, ... Luchsinger, 2015).
 - A study of 1,351 Mexicans in California found that abdominal fat in late life (older than 60) increased the risk of cognitive impairment without dementia (CIND) but overall obesity appears to be protective. However, prevalence of central and general obesity is

disproportionately higher among Mexican Americans than it is among non-Hispanic Whites and other Hispanic groups (West & Haan, 2009).

- A group of Mexican Americans followed for 10 years with type 2 diabetes and a history of stroke was found to be eight times more likely to develop dementia over the course of the study compared with those without either comorbid condition (Haan et al., 2003).
- An association between type 2 diabetes mellitus and dementia and cognitive impairment with no dementia (CIND) remains strong in Mexican Americans. Persons with treated or untreated diabetes had an increased risk of dementia compared with those without diabetes (Mayeda, Haan, Kanaya, Yaffe, & Neuhaus, 2013).
- Forty-six percent of Hispanic men and 43 percent of Hispanic women have total cholesterol of 200 mg/dL or higher; this is higher than the general U.S. population (Mozaffarian, Benjamin, Go, Arnett, Blaha, Cushman, Turner, 2016).
- Thirty percent of Hispanic men and 30 percent of Hispanic women have high blood pressure (Mozaffarian et al., 2016).

Slide 44:

- Recommendations for health care interventions with Hispanic and Latino family care partners include:
 - Addressing the elder patient by his or her last name.
 - Communicating indirectly through the son or oldest child.
 - Having limited or indirect eye contact.
 - Reserving closer contact until familiarity is established.
 - Teaching the care partner adaptive coping skills.

Slide 45:

- We now switch gears to look at the many groups of Asian Americans living in the United States.
- There are many similarities between the different Asian American subpopulations with regard to their cultural values. Providers face similar challenges in assessing and managing dementia across these groups based on linguistic and cultural barriers.
- Despite an abundance of information about the role and needs of care partners in these communities, less is known regarding the unique issues faced by health providers in the United States when diagnosing and managing dementia in Asian American communities. In addition, as mentioned earlier, research has predominantly and almost exclusively focused only on Alzheimer's disease, with no guidance or information regarding other etiologies of dementia.
- We begin with the Chinese American population, because it is the largest and most well studied of the Asian American populations.
- South Asian Indians, including persons from Thailand, India, Pakistan, Afghanistan, the Hmong, and others, comprise the second largest Asian population in the United States—more than 2.8 million alone or nearly 3.2 million in combination with other Asian Americans (U.S. Census Bureau, 2010). Despite their size, there is an absence of any studies on dementia among these populations living in the United States.

Slide 46:

- Chinese Americans are the largest Asian group in the United States, making up approximately 25 percent of Asian Americans. Their proportion grew 39 percent from 2000 to 2010.
- According to the 2010 U.S. Census, more than 3.3 million Chinese Americans are in the United States. More than 4.0 million persons self-identify as Chinese alone or in combination with other groups.
- The Chinese American population older than 65 represents about 10 percent of all Chinese Americans.
- Ethnicity is a key factor in helping Chinese American older adults and their families make caregiving decisions, regardless of social or economic status.

Slide 48:

- Misconceptions about dementia are common.
- There is no word for “dementia” in the Chinese languages; other words such as “crazy,” “stupid,” and “slow” are used instead to describe cognitive impairment.
 - In the Chinese language, the character used to designate dementia is translated as “crazy.”
 - It does not reflect Western understanding that dementia is a brain disease and not a mental illness.
- Many Chinese believe that memory problems are a normal part of aging, so diagnosis and treatment are not sought until the later stages of the disease, when behavioral problems are more apparent.
- More education is needed to reduce negative attitudes associated with dementia so that families seek treatment earlier in the process.
- Reframing psychological treatment as psychoeducation increases willingness to participate in research and treatment programs.

Slide 49:

- Linguistic and cultural barriers make it difficult to interpret cognitive test scores for Chinese American older adults.
- Recommended adjustments include:
 - Using screening tools that have been validated for Chinese American older adults, such as the Cognitive Abilities Screening Instrument—or CASI—Chinese Version 2.0 (Lin, Wang, Liu, & Teng 2012). (See resources.)
 - Considering the person’s first language (different dialects); it is optimal to conduct the assessment in the person’s first language with a bilingual and bicultural examiner, if possible.
 - Being aware that some words used or required in cognitive tests do not exist in the Chinese language.
 - Using a paint brush rather than a pencil; this may yield more culturally fair results (Dick, Dick-Muehlke, & Teng, 2006).
 - Using more than one instrument for cross-validity (Wang, Tong, Liu, Long, Leung, Yau, & Gallagher-Thompson, 2006).

Slide 50:

- The cultural belief that “family disgrace should not be made public” is deeply rooted among Chinese American families and may become an issue during diagnosis and treatment.
- “Face” is a unique abstract concept in Chinese culture and does not relate to the anatomic face. Rather it is a combination of social status, reputation, honor, dignity, and influence. Dementia is often perceived as an embarrassment, a disgrace, and something to be denied or hidden to “save face”.
- Filial piety, or the virtue of love and respect for one’s parents and ancestors, is deeply rooted in three of China’s major philosophies: Confucianism, Buddhism, and Daoism. Parents raise children into adulthood, and children provide for their parents as parents age in return as an expression of gratitude.
- Caring for one’s elders is considered a moral and social responsibility. In a traditional Chinese family, the son provides economic support for his parents and the daughter-in-law is responsible for providing personal care. If the son’s parents are ill, the daughter-in-law becomes the primary care partner, but the son makes major decisions about caregiving. Chinese American families caring for family members with dementia tend to rely on extended family for support and do not seek external help until all resources in the family system have been exhausted.

Slide 51:

- Approximately 2.65 million Filipino Americans lived in the United States in 2010.
- Filipino Americans are the second fastest growing Asian American group in the United States, increasing by 44 percent from 2000 to 2010.
- The prevalence of dementia in the Philippines increases from 11.5 percent in persons ages 60 to 69 to more than 15.6 percent in those older than 70.
- Dementia is not listed as a top 10 cause of mortality in Filipinos by the World Health Organization (WHO, 2002), but dementia risk factors are listed including ischemic heart disease, hypertension, cerebrovascular disease, and diabetes mellitus (WHO, 2002).
- Filipino Americans may have unique characteristics associated with their risk of dementia.
 - They have a high prevalence of low HDL. Low HDL level is associated with vascular dementia.
 - Other risk factors include older age, family history, few years of education, and lack of access to and utilization of health care.
- Cultural values influence diagnosis and treatment and include:
 - Cognitive decline is expected with aging.
 - Dementia is perceived as punishment or evil spirit and associated with stigma and shame; “crazy” people need psychiatric care.
 - They use “Alzheimer’s disease” as general term for dementia.
 - A home-based model of care (Eastern versus Western) is more culturally accepted. The family is very involved in caregiving but may also reach out to spiritual leaders (McBride 2006a, 2006b).
 - Providers should demonstrate concern and respect and identify and communicate with the family decision-maker.

Slide 52:

- Just under 1.55 million persons self-identify as Vietnamese American alone or as part of another group.
 - An estimated 150,000 Vietnamese Americans were older than 65 in the United States in 2012.
 - The majority of older Vietnamese Americans speak little or no English.
- Most identify as either Buddhist or Catholic/Christian.
- Symptoms are considered part of “normal aging”.
- Shame of diagnosis is felt by all family members.
- Dementia is considered a mental illness.
- The family of the person with dementia self-isolates and feels stigmatized.
- Diagnosis:
 - Formal testing is not a cultural norm.
 - Diagnosis usually stems from a workup for other chronic illnesses.
 - The Montreal Cognitive Assessment—or MoCA—has been used with this population but should be adjusted for level of acculturation and assimilation.
- Little is known or available regarding culturally tailored programs.
- Providers should be courteous not friendly and should understand the family hierarchy (young defer to old).

Slide 54:

- More than 1.4 million Koreans are in the United States.
- In Korea, the dementia prevalence rate is between 7.4 and 13.0 percent.
- Research in the United States on dementia prevalence among Korean Americans is limited and exact rates are unknown.
- Awareness of the term “Alzheimer’s disease” is low, whereas there is greater awareness of the term “dementia.”
- Dementia is a cultural stigma and shame; the belief is that memory loss is a normal part of the aging process. This, combined with the cultural influence of saving face, leads to barriers for seeking evaluation and service).
- Awareness of available treatments and caregiving resources is low among the Korean community.
- Providers need to emphasize that these services can complement family caregiving.
- Other barriers to use of the U.S. health care system include language difficulties, low health literacy, lack of trust in Western medical care, and lack of health insurance.
- Various assessment tools are available for use by Korean populations. These tools address some of needs specific to Korean persons in the United States.
- Family is the primary source of caregiving. Family members may be reluctant to accept formal support.

Slide 56:

- According to the 2010 U.S. Census Bureau, there are more than 760,000 Japanese Americans living in the United States (U.S. Census Bureau, 2014) and more than 1.3 million persons who

self-identify as Japanese American in combination with another ethnicity. However, with fewer persons immigrating from Japan and more persons marrying other ethnicities, the number of older Japanese Americans continues to decline.

- Compared with the substantial body of literature on Chinese Americans, very little research has been done on Japanese Americans.
- Japanese American older adults and their families are reluctant to report symptoms of cognitive decline; they may think that these symptoms result from a genetic defect or are punishment for previous actions (Braun & Brown, 1998).
- Japanese American families often wait for a crisis to seek help for an older family member.
- Dementia is seen as either a normal part of aging or a reflection of bad behavior.
- Many Japanese American older adults maintain cultural customs, beliefs, and values—specifically filial piety, fatalism, and refusal of assistance from others.
- There is a belief among many that problems in a family should be solved by the family.
- Taking these factors into account when providing appropriate care for Japanese American older adults with dementia improves quality of life for care partners and their loved ones.

Slide 58:

- Next, we are going to examine American Indian/Alaska Native populations. Despite being fast-growing populations, they are not well researched with regard to dementia.

Slide 59:

- American Indians and Alaska Natives may be one of fastest growing populations. According to 2010 Census, 5.2 million people identified as American Indian or Alaska Native, an increase of 39 percent from the 2000 Census. And the numbers are expected to swell by 2050.
- Prevalence and incidence data differ by tribe and group.
 - Only a few tribes have been studied.
 - Urban American Indians/Alaska Natives not yet been studied
- In addition, urban American Indians often assimilate and do not identify as American Indians; consequently, it is difficult to study this subpopulation.
- The lack of research makes it difficult to estimate prevalence and incidence, but current numbers, which are now low, are expected to swell by 2050 (Garrett et al., 2015). This is related to the expected increase in life expectancy as their risk factors (such as alcoholism and comorbid medical conditions) are reduced.
- They are often considered an “invisible minority”.
- Research shows American Indians/Alaska Natives have a 40 to 60 percent greater risk of dementia compared with Asian Americans among persons with diabetes.
- However, dementia statistics are lacking, and American Indians/Alaska Natives are not well represented in clinical trials.
- Risk factors include:
 - The association between APOE $\epsilon 4$ is not as strong as that among non-White groups.
 - Diabetes among older American Indians/Alaska Natives is projected to increase fivefold, so incidence of dementia should also increase substantially.

- Barriers to seeking help for dementia include:
 - They do not conceptualize dementia as illness but rather as a normal consequence of aging.
 - They assign spiritual or psychological causes to it.
 - They believe caring for a person with dementia is a personal and family responsibility.
- Caregiving issues include:
 - Evidence shows they enter nursing homes at earlier stages of need.
 - There is no well-developed continuum of care for older adults in these communities.
 - Younger persons are moving out of the communities, resulting in fewer people to provide care and therefore to institutionalization of the person living with dementia at an earlier stage.

Slide 61:

- Lastly, we are going to examine Native Hawaiian/Other Pacific Islander.

Slide 62:

- Native Hawaiians/Other Pacific Islanders include Native Hawaiians, Samoans, Chamorros, and Micronesians.
 - They are often grouped with Asian Americans as Asian Americans and Pacific Islanders.
 - As an aggregate, Asian Americans have longer life expectancy, higher educational achievement, lower poverty rates, and better health indicators than the general U.S. population.
 - However, Native Hawaiians/Other Pacific Islanders have significant health disparities compared with other ethnicities.
- Native Hawaiians/Other Pacific Islanders make up only 0.4 percent of the total U.S. population, and only 5.6 percent of them in the United States are ages 65 and older compared with 13 percent of the general U.S. population.
- Native Hawaiians/Other Pacific Island elders have lower per capita incomes, the highest poverty rates of all American ethnic groups, and the shortest life expectancies among Hawaii's seven major ethnic groups.
- The median age of Native Hawaiians/Other Pacific Islanders is 10 years younger than U.S. population as a whole.
- Native Hawaiians/Other Pacific Island adults have a much higher age-adjusted percentage of diabetes—nearly 24 percent compared with 7.6 percent non-Hispanic Whites. They have higher rates of obesity as well. There seems to be a high prevalence of amyotrophic lateral sclerosis and Parkinson disease (PD)-complex in Chamorro residents.
- Families are expected to care for elders. The cultural values support the belief that illness and dementia are caused by island spirits and reflect disharmony or imbalance of family, faith, the physical environment, and the spiritual world.
- An ideal means of reaching out to this community is through values related to family and faith. Providers should connect first on the individual level before they try to provide medical and other care. Also, language barriers should be addressed.

Slide 63:

- In this last segment, we are going to examine three distinct communities: lesbian, gay, bisexual, and transgender—or LGBT—communities; rural communities; and the growing population of persons with intellectual disabilities such as Down syndrome.
- Each subpopulation has unique issues with regard to dementia diagnosis and treatment. Although people from diverse ethnicities live in rural areas, rural communities have unique medical and dementia care needs, and we discuss those here.
- We begin with LGBT communities.

Slide 65:

- It is difficult to identify prevalence among these communities because so many LGBT individuals do not disclose orientation or gender identity, even to their physicians.
- The lack of epidemiologic data on dementia for older LGBT adults requires information to be extrapolated to determine prevalence.
 - Using 2013 National Health Interview Survey data, 96.6 percent of adults identified as straight, 1.6 percent identified as gay or lesbian, 0.7 percent identified as bisexual, and 1.1 percent identified as “something else” or “I don’t know” or refused to provide an answer (Ward, Dahlamer, Galinsky & Joestl, 2014).
 - LGBT adults are estimated to make up between 3 and 4 percent of the general U.S. population (Gates & Newport, 2012) and up to 11 percent when considering both sexual behavior and attraction (Gates, 2011).
- The number of older LGBT adults ages 64 and older is currently estimated to be 3 million and projected to double by 2050.

Slide 66:

- There is a general lack of dementia awareness in LGBT communities and among clinicians treating LGBT persons leading to serious risk of unmet needs, social isolation, and premature morbidity.
- Homophobia and stigma are also important factors for these communities.
- There is a lack of access to high-quality health care among older LGBT persons. A recent New York state study found that nearly 40 percent of LGBT individuals feared that their health care providers would not be trained and prepared to care for them.
- Lack of disclosure or awareness of sexual or gender identity can result in incomplete assessment.
 - Bisexual and transgender (if they have not begun to transition) persons are less likely to disclose than are gay and lesbian persons.
 - Physicians and other health care professionals fail to ask about or recognize sexual orientation and gender identity and may lack appropriate communication skills.
- Services and programs fail to account for unique difficulties that LGBT older adults face, including discrimination, violence, and lack of legal protections.
- Same-sex partners may not have equal access to financial or legal benefits as do heterosexual partners. Few regulatory safeguards are in place to protect older LGBT individuals in long-term care settings (Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders, 2010).

- Whether the care partner is heterosexual or LGBT, he or she may face barriers as a result of LGBT discriminatory policies (Mazey, 2015).

Slide 68:

- An Institute of Medicine report on LGBT health noted higher rates of depression, suicidal thoughts and attempts, substance use (including alcohol and tobacco) and abuse, and experiences of harassment, discrimination, and stigma in LGBT communities compared with heterosexual peers.
- The landmark *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults* found that, among older LGBT adults:
 - 91 percent engaged in wellness activities.
 - 13 percent have been denied health care or received inferior care.
 - Approximately 50 percent have a disability.
 - 33 percent report depression, a risk factor for dementia.
 - More than 20 percent do not disclose their sexual or gender identity to their doctor.
- Older lesbian, gay, and bisexual adults may have a higher risk of disability, poor mental health, smoking, and excessive drinking than their heterosexual counterparts.
- The impact of HIV/AIDS on the gay male community is evident. Both age and HIV are important risk factors related to later life cognitive impairment, making HIV-positive older adults more susceptible to cognitive impairment and dementia (Tozzi, Balestra, Galgani, Murri, Bellagamba, Narciso, ... Wu, 2003). As HIV-positive older adults age, HIV-related dementia or cognitive impairment is expected to rise where the severity of the impairment is correlated with poor quality of life (Cahill & Valadez, 2013).
- Diagnosis and treatment considerations include HIV-Associated Neurocognitive Disorder, side effects of chemotherapy (chemo-brain) and other anti-viral medications, and hormone therapy for transgender people (Marra, Deutsch, Collier, Morgello, Letendre, Clifford, ... Grant, 2013).
- Transgender people have strong tendency to nondisclosure. Male-to-female transgenders are at high risk for HIV and other sexually transmitted infections.
 - About 28 percent of male-to-female transgender persons in the United States are HIV positive.
 - Other high-risk behaviors that can influence cognitive impairment include smoking, drug and alcohol use, and higher rates of depression than the general population.

Slide 69:

- Barriers to diagnosis in rural America include:
 - Underreporting of persons living with dementia.
 - Underdiagnosis.
 - Provider lack of knowledge.
 - Stigma surrounding diagnosis of disease.
 - Lack of support systems after a diagnosis (Stark, Innes, Szymczynska, Forrest, & Proctor, 2013).
- There are also several barriers to care:

- Geographical isolation often results in difficulties coordinating patient care with other specialists (Dal Bello-Haas, O'Connell, & Morgan, 2014a; Dal Bello-Hass, Cammer, Morgan, Stewart & Kosteniuk, 2014b; Kosteniuk et al., 2014).
- Local communities lack care facilities.
- Programs may be far away, and residents may have transportation difficulties getting to them.
- The cost of care is high.
- Physicians noted that the stigma surrounding a diagnosis of dementia has resulted in hesitation to give a diagnosis if they believed the illness to be untreatable (Kosteniuk et al., 2014).
- Access to specialists (Orpin, Stirling, Hetherington, & Robinson, 2014), services (Forbes, Finkelstein, Blake, Gibson, Morgan, Markle-Reid, ... Thiessen, 2012), and important members of the treatment team (for example, social workers and therapists) may be limited.
- Informal care partners prioritize caregiving over attending to their own needs. They may not trust others to help with caregiving and may lack knowledge and access to community-based services.

Slides 71-72:

- About 70% of persons with Down syndrome will develop Alzheimer's disease.
 - It has been suggested that almost all persons with Down syndrome are at significant risk of developing Alzheimer's disease as they age (Hartley et al., 2015).
 - It is not yet understood what attributes to this high comorbidity (Strydom, Chan, King, Hassiotis, & Livingston, 2013).
- Current estimates of 250,000 to 400,000 persons with Down syndrome live in the United States. The majority is expected to develop Alzheimer's disease pathology beginning in their 30s.
- There are many barriers to early and appropriate diagnosis and management.
 - Dementia often remains undetected because of a lack of knowledge about how it manifests in persons with Down syndrome (Beaumont & Carey, 2011).
 - There are few effective tools (Hutchinson & Oakes, 2011).
 - Assessing for dementia may be appropriate in this population (Strydom et al., 2013).
 - Psychiatric symptoms are common among this group (Urv, Zigman, & Silverman, 2010).

Slide 73:

- 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. d. Geographic location within the United States
2. c. Parkinson's disease dementia

Slide 74:

Answer:

3. b. The belief that dementia is a psychiatric illness that is an embarrassment to the family

Slide 75:

Answer:

4. c. Try to understand the family hierarchy before addressing the elder person living with dementia