

Cultural Considerations across the Lifespan

How culture affects caregiving

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Introduction to Cultural Considerations, Dementia, and ID

- Adults with IDD come from many different backgrounds and cultures
- When an adult with IDD exhibits signs and symptoms of dementia, seeking help, assessment, and treatment will be directly impacted by the culture of the adult and the adult's caregivers
- Ethnically diverse communities define IDD and dementia differently depending on the culture and the cultural belief systems definition of disability and disease

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Cultural beliefs

- Signs, symptoms, and behavioral changes may be seen as normal aging in some cultural groups
 - Significant changes have been made in attitudes about aging and dementia but there are still myths about aging in some cultures
 - Some beliefs may delay or prevent diagnosis and treatment
 - Health care providers and formal paid caregivers may also have similar beliefs based on cultural backgrounds

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Dementia as Mental Illness

- Signs and symptoms of dementia in some communities may be seen as a mental illness
 - This perception may prevent or delay assessment and treatment
 - May be associated with the stigma of mental illness and reluctance to acknowledge the symptoms
 - Very few still believe dementia is a curse or punishment for past behavior

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Family Dynamics and Dementia

- Belief systems regarding family impact assessment and interventions
 - The caregiver who most identifies as the primary caregiver may have no legal or blood relationship but still take on the primary responsibility
 - Legal and ethical challenges may occur when the primary caregiver not legally related or held responsible
 - Some may perceive dementia as a “European White Man’s Disease”
 - May result in ignoring or blaming signs and symptoms on mental illness or other underlying causes, not dementia

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Caregiving and Family Beliefs

- Respect for elder may result in tendency not to mention the functioning loss or to bring it to the health care providers attention
 - Tendency by Japanese families want to maintain harmony, avoid conflict, and show respect to the elder
- “We take care of our own” resulting in reluctance to seek outside help from community agencies
 - Can result in distrust of the agency especially if the staff do not reflect the ethnic background of the family
- Decision maker and caregiver may be different people

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Caregiving and Family Belief Systems

- Help seeking behaviors will vary among ethnic communities
 - Who is expected to seek out help within the family
- Signs and symptoms of dementia may be perceived as signs of "craziness in the family"
 - The stigma can result in refusal or reluctance to seek help

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Culture and Language Challenges

- May be no exact term for the type of dementia that can be translated directly to and from English
- The pre-existing disability may not be recognized by the specific culture or have a term to refer to the specific disability
- In some languages the terms used to describe dementia translate into "crazy" or "catatonic"
 - For example – Japanese characters have been developed in recent years to more accurately describe Alzheimer's type dementia

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Culture and Supportive Services

- For some ethnic groups the concept of supportive services is not understood or used
- Often difficulty finding supportive services that speak the caregiver's preferred language
- Supportive services often do not have familiarity with the specific ethnicity or culture and may not have staff representative of the specific culture
- Individuals with less formal education or education in another country are less likely to seek services or even educational workshops on dementia

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“Acculturation” Levels

- Even if the family or caregivers are seen as acculturated into the regional mainstream culture the cultural norms often exist for many generations.
- The more isolated from the regional mainstream culture the increased likelihood ethnic communities will maintain long term held beliefs and practices.

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Summary

- Adults with ID come from many different backgrounds and cultures.
- Signs, symptoms, and behavioral changes may be seen as normal aging in some cultural groups.
- Cultural beliefs may affect access to services.

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