Perspectives on Dementia in Culturally and Linguistically Diverse Populations

By: TSHA CLD Committee

The CLD Corner was created in an effort to provide information and respond to questions on cultural and linguistic diversity. Questions are answered by members of the TSHA Committee on Cultural and Linguistic Diversity. Members for the 2015-2016 year include **Brittney Goodman**, *MS, CCC-SLP (co-chair);* **Raúl Prezas**, *PhD, CCC-SLP (co-chair);* **Amanda Ahmed**, *MA, CCC-SLP;* **Mary Bauman**, *MS, CCC-SLP;* **Phuong Lien Palafox**, *MS, CCC-SLP;* **Alisa Baron**, *MA, CCC-SLP;* **Raúl Rojas**, *PhD, CCC-SLP;* **Judy Martinez Villarreal**, *MS, CCC-SLP; and* **Ryann Akolkar**, *BA, (student representative). Submit your questions to tshcld@gmail.com, and look for responses from the CLD Committee on TSHA's website and in the* Communicologist.

Speech-language pathologists (SLPs) play an important role in the screening, assessment, diagnosis, and treatment of individuals with dementia. The American Speech-Language-Hearing Association (ASHA; ASHA, n.d.) defines dementia as "a group of symptoms related to memory loss and cognitive impairment." The most common (and perhaps visible) cause of dementia is Alzheimer's disease, which encompasses roughly 70 percent of individuals diagnosed with dementia. Other categories of dementia include multiple small strokes, Parkinson's disease, Huntington's disease, Lewy body dementia, Frontotemporal degeneration, and Creutzfeldt-Jakob disease (ASHA, n.d.).

Like most conditions, dementia affects people from all cultures and backgrounds. Researchers have found that the incidence and prevalence of dementia varies across racial and ethnic groups (Manly & Mayeux, 2004). In some cases, ethnic groups may be more likely to develop dementia. For example, African Americans and Hispanics are more likely to have Alzheimer's disease and other dementias (Dilworth-Anderson, Hendrie, Manly, Khachaturian, & Fazio, 2008). Of those groups, bilinguals may have an interesting advantage; speaking two languages has been found to delay onset of Alzheimer's disease by as much as four years (Bialystok, Craik, & Freedman, 2007). However, once the disease does emerge, it may be challenging to accurately diagnose, due to sociocultural barriers that exist among individuals and their families. In fact, dementia-related symptoms are often construed as a normal part of the aging process in some cultures (Hinton, Guo, Hillygus, & Levkoff, 2000). For many, Alzheimer's carries a "social stigma," and diagnosis is often "shunned" and considered to be an "intrusion" on family. African Americans, Hispanics, and Asian Americans (along with some Native American tribes) are less likely to report a memory-related illness (Alzheimer's Association, 2010).

This article explores perspectives from professionals with knowledge and expertise in the area of dementia and who have worked with individuals from various backgrounds. The TSHA

Cultural and Linguistic Diversity Committee, in an effort to provide more information in the area of dementia, reached out to SLPs at the most recent TSHA Convention in San Antonio. From those interactions, **Melissa Collier**, **Nancy Shadowens**, and **Peggy Watson** responded and answered questions related to the assessment and treatment of dementia in culturally and linguistically diverse populations. It is our hope that their contributions provide additional insight and perspective in this area.

Melissa Collier

Melissa Collier, MS, CCC-SLP, CAEd

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What should an SLP consider when completing an assessment on a patient from a CLD background who may have Alzheimer's/dementia?

Alzheimer's disease and other related dementias do not discriminate among ethnic and racial groups. It's a disease that affects all culturally diverse populations. When providing an assessment to a patient from a CLD background diagnosed with dementia, an SLP should first obtain a thorough social history from the patient, family, staff, and/or peers to gain a better understanding of the context and dynamic of the patient's circumstances as well as their values and belief system.*

When evaluating a CLD patient, an SLP should utilize a variety of assessment tools, including standardized cognitive linguistic assessments, informal assessment, patient and family interviews, and observation. One should not over-rely on a single assessment but rather utilize a variety of tools that focus on more than just the language and literacy abilities of the patient.

How do you modify evaluations to consider the patient's cultural background?

In order to provide a culturally sensitive evaluation, it's always best to provide the evaluation in the patient's native language. If the SLP does not speak the patient's native language, an interpreter may need to be utilized. One should be cautious when using a family member as an interpreter. Family members may not want their loved one to perform poorly and, as a result, may not be as objective as needed.

SLPs must understand that a literal translation of an English standardized assessment may not be equivalent across cultural populations when directly translated into the patient's native language. A literal translation may cause a varying level of difficulty and/or clarity, which may negatively affect the results of an assessment. Therefore, SLPs should use caution when adapting assessment measures into another language. It's not just a linguistic issue; set items must be culturally equivalent as well.

Utilizing a variety of tools will give the most comprehensive information about a CLD patient. Utilizing a tool such as the Allen Diagnostic Module or Allen Cognitive Level Screen, which do not solely rely on language and literacy abilities, combined with a standardized cognitive linguistic assessment, such as the Ross Information Processing Assessment–Geriatric, Mini-Mental State Examination, or Montreal Cognitive Assessment, may provide more accurate results when interpreted in conjunction with patient and family interviews and informal observation.

What should an SLP consider when conducting speech therapy/providing treatment for a patient from a CLD background diagnosed with Alzheimer's/dementia?

An SLP should remember that each patient with dementia is unique. Seeking to provide person-centered treatment that facilitates the patient's physical and cognitive linguistic independence should be the ultimate goal of an SLP's plan of care. However, an SLP should learn as much as they are able about the patient's culture and belief systems, including the culture's perception of dementia, the level of awareness the culture has to dementia care-related services, and the cultural influences that may affect a person with dementia. Cultural values may include beliefs that cognitive changes related to the dementia disease progression are a part of normal aging; therefore, it is important for an SLP to know when the primary focus of the plan of treatment should begin with patient and family education. However, it is also critical to understand the limits of these belief systems and not place a great amount of significance on them, assuming that one approach is appropriate for everyone in a particular culture/ethnic group.

When creating a person-centered plan of care, an SLP should also take into consideration the patient's communication style, expressive and receptive language abilities, interests and hobbies, religious beliefs and practices, socioeconomic variables, such as level of education, occupation, and family dynamic, and the patient's cultural, racial, or ethnic identity. It is important to note that, above all, an SLP should be open-minded, nonjudgmental, and respectful.

**Melissa discusses the idea of gaining a better understanding of a patient's values and belief system, which is in line with establishing cultural competence. For more information related to cultural competence and resources, consider the following links:*

ASHA Resources on Cultural Competence:

http://www.asha.org/practice/multicultural/self/

• ASHA Self Assessment for Cultural Competence

• Cultural Competence Checklists (heighten awareness for working with CLD populations)

• Cultural Competence Awareness Tool

National Center for Cultural Competence:

http://nccc.georgetown.edu/

• Toolkit for Community Health Providers

• *Promoting Cultural Diversity and Cultural and Linguistic Competency Checklist*

• *Information in Spanish, including Spanish resources*

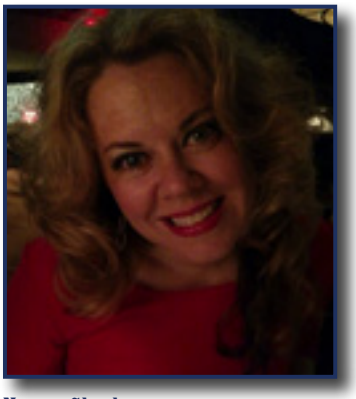
Melissa brings up important points regarding cultural considerations and dementia. ASHA provides a list of resources for working with dementia, including assessment and treatment considerations for CLD populations online (ASHA, n.d.). Additionally, guidelines are in place that include the scope of practice in speech-language pathology (2007) for working with culturally and linguistically diverse populations. Some considerations specific to dementia include the following:

• Identifying risk factors for dementia, taking into account variability among individuals from different racial and ethnic backgrounds and culturally and linguistically diverse populations;

• Conducting a culturally and linguistically appropriate comprehensive evaluation across the SLP scope of practice, including assessment of cognitive-communication functioning and swallowing;

• Selecting culturally and linguistically appropriate techniques for interventions;

• Providing indirect intervention through the individual's caregivers and environmental modification.



Nancy Shadowens

Peggy Watson

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What should an SLP consider when completing an assessment on a patient from a CLD background who may have Alzheimer's/dementia?

When a patient has a diagnosis of dementia, having the appropriate expectation of that person, regardless of co-morbidities or background, is the most important factor to address. To gain insight into the cognitive abilities of any patient with dementia, a standardized evaluation* for dementia should be administered. This assessment is key in determining the level of cognitive impairment. "A dementia diagnosis must minimally meet the following criteria: impairment of memory and at least one other cognitive domain (language, personality, executive function), and represent a decline from previous level of functioning" (Watson & Shadowens, 2011, pg. 5). One of the most important pieces of information the standardized assessment will provide is the stage of dementia. Knowing and understanding the stages of dementia will give the SLP valuable insight into spared vs. impaired capabilities. An excellent resource for staging is the Global Deterioration Scale for Dementia (GDS; Reisberg, Ferris, Leon, & Crook, 1982).

How do you modify evaluations to consider the patient's cultural background?

A person's cultural and ethnic background should always be considered during SLP assessments. A successful model that responds to cultural diversity for a person with dementia is the Global Deterioration Scale (GDS) for Dementia. The GDS is a subjective measure. It is based on characteristics rather than questioning, and family members can be utilized to assist the SLP in gathering information regarding the person's behaviors, personality, language, and memory (Reisberg et al., 1982). Often people with dementia will experience retrogenesis (i.e., going back in time) and revert back to childhood language (or revert back to native language in the case of a bilingual/multilingual speaker) and behaviors based on indigenous culture. Family members should be instructed to consider the person's cultural background when responding.

What should an SLP consider when conducting speech therapy/providing treatment for a patient from a CLD background diagnosed with Alzheimer's/dementia?

The stage at which the person is showing characteristics of dementia is the most valuable consideration in planning therapy. Determining the stage allows the SLP to better understand the behaviors observed in the patient. This knowledge enables knowledgeable choices of evidence-based interventions and specific strategies for multiple areas, including communication, socialization, mobility, and behaviors. There is a great deal of information from the literature regarding evidence-based interventions designed to help the patient achieve or maintain their highest level of function (Watson & Shadowens, 2014). Among the most popular are Montessori-Based Dementia Programming® (Camp, 1999), spaced retrieval (Day, 1997), reminisce (Woods, 2005), validation (Feil, 1993), and sensory (Burns, 2002). Choosing among them can be a daunting task.

**The TSHA Cultural and Linguistic Diversity Committee want to add that all standardized tests should be interpreted with caution when working with CLD populations. Nancy and Peggy make a good point that the stage of dementia is critical. Additionally, we want to recommend that practitioners consider dynamic assessment when working with CLD populations. A full list of assessment procedures for dementia has been provided by ASHA and can be found here: http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935289&section=Assessment*

Conclusion

As highlighted in the responses to the interviews above, there are clearly multiple facets to consider when working with culturally and linguistically diverse clients diagnosed with dementia. Understanding the individual's background will assist in making the appropriate diagnosis and creating an individualized treatment plan. SLPs should learn as much as they can about the patient's culture and belief systems, including the culture's perception of dementia, the level of awareness the culture has to dementia care-related services, and the cultural influences that may affect a person with dementia. These values and belief systems may deeply impact the patient's functional outcomes. SLPs serve as advocates for their patients and help team members, caregivers, and families understand and navigate through barriers regarding cognition, communication, and swallowing for patients in culturally and linguistically diverse populations diagnosed with dementia.

It is the hope of the TSHA CLD Committee that the perspectives and expertise presented above will provide additional insight regarding the roles and responsibilities of the SLPs serving individuals of the CLD community diagnosed with dementia. We would like to thank Melissa Collier, Nancy Shadowens, and Peggy Watson for contributing and providing their knowledge and experiences.

Finally, we would love to hear how clinicians across Texas make a difference for individuals of culturally and linguistically diverse backgrounds in their settings. If you are interested in sharing your experience or have a question, please send us an email at tshacld@gmail.com. ★

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