

Alzheimer's Disease in Bilingual Latinos: Clinical Decisions for Diagnosis and Treatment Planning

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Abstract

Early and accurate identification of cognitive and functional decline in bilingual Latino/a older adults with Alzheimer's disease and related dementias continues to be a substantial public health concern. This paper highlights the heterogeneity in the clinical expression of Alzheimer's disease among bilingual Latino/as, the clinical decisions leading to a culturally and linguistically congruent neuropsychological assessment, and the interdisciplinary, multi-setting partnerships needed to ensure a healthy longevity post-diagnosis for the patient, the caregiver, and the family. Psychologists play an important role in advocating for the best standard of care, as the patients and families endure the long journey of care with dignity and respect.

Keywords Alzheimer's Disease · Latino/Hispanic · diagnosis · treatment · healthy longevity

Clinical Vignette

El Señor Del Pueblo is a bilingual White Latino¹ in his sixties who acquired Spanish language first and then sequentially acquired English language capabilities (a sequential bilingual). He is a right-handed, married, cis-gendered man, with 16 years of education who presents with a history of progressive memory and language decline in the context of complex medical comorbidities (diabetes, hypertension, cancer in remission). Señor Del Pueblo previously received a mild cognitive impairment (MCI) diagnosis from a neuropsychologist in private practice.

Notably, his clinical interview and assessment were carried solely in English, including the cognitive screeners and comprehensive neuropsychological assessment. He reportedly demonstrated "good enough" conversational capacities in English to engage in the assessment in his second language. The provider initially conceptualized Señor Del Pueblo's memory impairment as secondary to his "English as a second language." However, his performance in higher-order executive functioning tasks (Wisconsin Card Sorting Test and Trail Making Test – B) was suggestive of a remarkable decline from his premorbid intellectual functioning.

Señor Del Pueblo had worked in high-executive positions. The neuropsychologist who assessed him wrote the following in his report: "Based on the above information, including the records provided, there are concerns regarding his cognitive functions. At this time, this should be considered

a cognitive impairment. Other medical and neurological events should be considered as well." The post-assessment treatment recommendations were general in nature.

Señor Del Pueblo wanted a second opinion and requested a language congruent follow-up neuropsychological assessment given his marked cognitive decline, directly impacting his activities of daily life including driving and difficulties with higher-order tasks, that led him to contemplate early retirement. Upon conversation during our clinical interview, he stated, "I think I am being selective of what I remember" to denote his awareness of the notable discrepancy between recalling remote information about his childhood compared to his difficulties recalling recent events.

He presented as an excellent storyteller who was able to recall several stories that included details about his immigration journey when he moved from Latin America to the United States in his late teens due to social political unrest. He also recounted his educational and occupational stories, navigating both systems as a Latino man attaining higher-executive positions requiring both excellent verbal and visuospatial skills. He told of his personal story, meeting his wife and raising kids in the United States while always thinking about his native country. He was passionate and detailed in these stories. Nonetheless, his expressive language was notable for the frequent use of fillers in English (e.g., "a thing," "hmm," "whatchamacallit") and in Spanish (e.g., "cómo se dice?", "esa cosa").



As we continued the clinical interview, his wife elaborated on more recent events, including her managing the finances and managing his medications and medical appointments with constant reminders. In order to remain consistent with the previous neuropsychological assessment, we chose the same protocol while adding tools to assess his Spanish and English verbal fluency and proficiency, his confrontation naming in Spanish, and verbal memory in Spanish with neuropsychological tools validated in Latino communities. We routinely assess bilinguals in both languages because bilingual conversationalists can still struggle with the academic and cognitive skills embedded in English assessments.

The resulting neurocognitive pattern, unfortunately, was consistent with his wife's observations. He was a balanced-bilingual Latino in his 60s with progressive and substantial episodic memory decline who nevertheless reportedly remained independent in all instrumental activities of daily living for several years. It was not until his cardiovascular conditions (diabetes, hypertension; confirmed by neuroimaging) impacted brain areas responsible for volitional control, multi-tasking, organizational, and processing speed capabilities to such a degree that he was unable to independently manage his daily activities and regulate his emotions.

As such, by the time of our clinical evaluation, he had already met diagnostic criteria for a Major Neurocognitive Disorder due to Multiple Etiologies (brain neuroimaging and genetic biomarkers were consistent with Alzheimer's disease and vascular pathologies) with behavioral disturbances due to a significant decline in emotional regulation. By this time, Señor Del Pueblo and his wife were both thankful for the time we all spent explaining, in Spanish, his cognitive, behavioral, and emotional changes yet devastated to learn about the Alzheimer's disease diagnosis. Their reaction was that of many patients who receive the news of an Alzheimer's diagnosis in that they thought it means a "death sentence" with no hope for a meaningful life. Navigating the healthcare systems was overwhelming.

¹A Brief Background on the U.S. Designated Ethnic Categories of Hispanic and Latino/a

The term Hispanic was utilized by the U.S. government in the 1970s to collect data on U.S. Spanish-speaking residents from Puerto Rico, Cuba, Central and South America (Noe-Bustamante & Flores, 2020). However, resistance grew about the term Hispanic as it was strongly associated with Spain, which had historically colonized several countries in Central and South America, as well as in the Caribbean. As a result, the Latino/a term emerged. However, the term Latino ascribes to the more traditional gendered (feminine/masculine) connotations. More recently, the term Latinx has been widely used with the intention of being more gender

inclusive. Pew Research Center, however, reported that most Latinos and Hispanics in the U.S. have not heard of the term Latinx, and only 3% actually use the term (Noe-Bustamante et al., 2020). Clinically, we have seen that older adults continue to use the terms Latino and Latina, denoting potential generational intersectionalities. That is, younger generations are more inclined to use the term Latinx, whereas older generations continue to use the term Latino/a. As such, we use the terms Latino and Latina (or Latino/a) throughout the paper.

Timely and Accurate Alzheimer's Disease Diagnosis in Bilingual Latinos/as

Latino/a older adults are one and a half times more likely to develop Alzheimer's disease than non-Hispanic Whites (Alzheimer's Association, 2021). Yet, under-representation of Latino/a ethnic groups in U.S. federally funded Alzheimer's disease neuroimaging-neurocognitive studies continue to obscure the neuropsychological markers pathognomonic of the disease specific to this population. Cognitive phenotypes are known to be impacted by socio-cultural and linguistic factors (i.e., acculturation, immigration, quality of education in country of origin, occupation, bilingualism; reviewed by Bialystok, 2017) not typically quantified in research designs. Consequently, clinical neuropsychologists working with Latino/a adults with suspected progressive cognitive and functional decline (e.g., UCLA's Cultural Neuropsychology Program) are often challenged in providing accurate diagnoses and targeted behavioral treatment recommendations.

Latino/a adults continue to be misdiagnosed exclusively with other often comorbid conditions (i.e., depression, stroke; reviewed by Vega et al., 2017), thus delaying early behavioral interventions focused on sustaining functional independence and reducing caregiving socioenvironmental barriers to enhance a healthy longevity while going through the Alzheimer's disease stages. Multiple clinical cases seen within UCLA's Cultural Neuropsychology Program catalogue this pattern of later diagnoses where functional barriers and family/caregiver experiences are significantly impacting their quality of life. Moreover, non-specific recommendations attempting to ameliorate the chronicity of symptoms are the only viable options for the patient and family at the time of the late diagnosis. One example is our usual nutrition recommendation where, following scientific evidence, we recommend the Mediterranean diet. With a late diagnosis, we often cannot adequately engage patients and their families in discussions around how these diets match, or not, the patient's culture and traditional values maintained through food. In later stages, it is also more challenging to consider their finances or other social determinants of health, such as living in food swamps (that is, an area where



an abundance of fast food, junk food outlets, convenience stores, and liquor stores outnumbers healthy food options).

Timely and accurate diagnosis of Alzheimer's disease increases the effectiveness of the early linguistically and culturally congruent behavioral interventions that focus on minimizing the potential, yet predictable, impact of other social factors (e.g., isolation, loneliness) and medical conditions (e.g., diabetes, hypertension) on the brain and body. By more closely assessing the cognitive and functional phenotypes associated with the Alzheimer's disease neuropathology and its progression, providers have the opportunity to tailor behavioral interventions to the specific needs of the patient and their families. This tailoring of needs is critical as they progress through the Alzheimer's disease stages and suffer the progressive and visible loss of the loved ones with the illness. When patients are diagnosed later in the disease after the cognitive and functional presentation is no longer pathognomonic of a particular etiology (e.g., hallucinations, episodes of anger, combativeness, wandering episodes), treatment options are often limited, non-specific, and more palliative in nature. Therefore, a timely and accurate diagnosis of Alzheimer's disease is clinically necessary to ensure a healthy longevity post-diagnosis for the patient, the caregiver, and the family.

Multiple factors have been linked to untimely and inaccurate Alzheimer's disease diagnosis (Mansfield et al., 2019). Many older adults and their families continue to believe that memory problems are an inevitable part of the aging process. A precipitating event 12 to 24 months after the onset of symptoms (i.e., wandering episodes, disorientation while driving, anger outbursts), unfortunately, is the antecedent triggering awareness that the symptoms are beyond normal aging. After the precipitant event, nonetheless, family members might still show reluctance to seek medical consultation due to systemic barriers, including stigma associated with "being demented," mistrust toward medical institutions, the time required to obtain a diagnosis, the cost of procedures, language proficiency, economic status (i.e., financial access), the lack of access to physicians trained to diagnose dementia, the limited number of linguistically and culturally congruent physicians, and not receiving a specialist referral (i.e., neurology) from a primary care physician. Upon the medical examination, however, Latino/a patients continue to be misdiagnosed with other often comorbid conditions also impacting memory functions, including pseudo-dementia secondary to depression/anxiety, delirium secondary to metabolic dysregulations in major organ systems, polymedication, or undiagnosed obstructive sleep apnea. A new confounding condition is the long-term sequelae of COVID-19, as new findings suggest that COVID-19 accelerates Alzheimer's pathology (tau and amyloid) and potentially impacts hippocampi mediated episodic memory functions due to low oxygen saturation levels (Heneka et al., 2020).

Primary care physicians have recognized their contribution to untimely and inaccurate diagnosis of Alzheimer's disease. They have reported the following personal and healthcare system barriers to timely recognition of possible dementia in general: difficulties recognizing symptoms, perceiving a lack of need to determine a specific diagnosis at the time of consult ("all dementias are the same" narrative), limited time during the clinical consult, negative attitudes toward the importance of assessment and diagnosis, insufficient knowledge of appropriate and validated cognitive screeners/tools, and reluctance to refer patient/family to a comprehensive neuropsychological evaluation (Alzheimer's Association, 2021).

Untimely and inaccurate Alzheimer's disease diagnoses in Latino/a older patients have also been attributed to the lack of sensitive neuropsychological tools and equitably representative normative samples accounting for language- and culture-related factors, such as the acquisition and maintenance of a second language during the acculturation process (Rivera Mindt et al., 2008). Recent findings suggest that bilingualism delays the onset of Alzheimer's disease by approximately four years, despite the presence of greater neuropathology and white matter integrity deterioration (Mendez et al., 2019; Weissberger et al., 2019). Bilingualism, therefore, has been claimed to favor cognitive reserve in Alzheimer's disease (Perani et al., 2017), especially if high proficiency levels are attained (Gollan et al., 2011). Please note that this effect of bilingualism is seen in people with lower levels of education such that learning a second language appears to represent a source of cognitive reserve. This same effect of bilingualism was not replicated in individuals with higher levels of education suggesting that cognitive reserve gets "maxed out" with education and, at that threshold, bilingualism does not confer an additive protective effect (Gollan et al., 2011).

Another factor rarely discussed is the potential alterations in the clinical expression (i.e., phenotype of onset and progression of symptoms) of Alzheimer's disease at the mild stages (including mild cognitive impairment as seen with Señor Del Pueblo) secondary to bilingualism. The presence of constant dual-language activation, consequently, implies that bilingualism is subserved by volition and cognitive control. Consistent with this claim, the experience of bilingualism appears to subserve an advantage in executive function throughout the life span (Bialystok, 2017). Therefore, rather than arguing that bilingualism delays the onset of Alzheimer's disease, we argue in favor of a different pattern of cognitive decline at the early stages of Alzheimer's disease among bilingual Latino/a older adults. Specifically, bilingual Alzheimer's disease will more likely resemble non-amnestic cognitive presentations early in the disease course. For bilingual Alzheimer's disease, we continue to see clinical presentations with language changes where family members



express an insidious and progressive decline in the secondly acquired language (L2) alongside a regression to the first acquired language (L1). We also see executive deficiencies (seen in Señor Del Pueblo's first neuropsychological evaluation) masking the typically known amnestic profile.

Clinical and Ethical Challenges

The most intrinsic quality of the Latino/a population living in the United States is the richness and complexity of their cultural and linguistic diversity driven by their history in their native countries, their racial identities (Indigenous, Black, White, Asian, Bi/Multiracial Latinos/as), their immigration journey, and their acculturation process to the mainland's culture and traditions. According to the U.S. Census Bureau (2020), the Latino/a population went from 52 million in 2010 to 62.1 million in 2020, growing 23% since 2010. Mexicans and Mexican Americans represent the majority of the Latino/a population (62%). Other Latino/as are from Puerto Rico (10%), Cuba (4%), and other parts of South America, Central America, and Caribbean islands (Noe-Bustamante & Flores, 2020). This cultural diversity obviously provides linguistic diversity of the Latino/a population in the United States, as Spanish-speaking Latinos/as residing in the U.S. have increased 133.4% since 1990. In fact, 57.5% Latinos/as self-reported speaking English "very well" (U.S. Census Bureau, 2020). These national statistics highlight that a substantial proportion of Latino/a individuals in the U.S. have varying degrees of fluency and proficiency in both their native Spanish language and English.

Individuals might be balanced bilinguals or dominant in one particular language depending on the acquisition and maintenance of L1 (first acquired language) and L2 (second acquired language) based on their social, academic, and occupational practices. These individuals can be described as simultaneous or sequential/successive bilinguals. Simultaneous bilinguals are individuals who learned two languages at the same time, whereas sequential/successive bilinguals acquired one language first followed by the second one. Neurolinguistics' research suggests divergent brain development depending on the age of acquisition and maintenance of both languages (Połczyńska & Bookheimer, 2021). In the Latino/a population, we often encounter individuals whose native language is Spanish but has acquired/maintained English fluency at a "superficial level." These individuals are categorized as circumstantial bilinguals; those who maintain a certain level of conversational fluency in their second language to help them navigate social and, perhaps, occupational interpersonal dynamics without fully attaining cognitive-academic language proficiency. Basic Interpersonal Communicative Skills (BICS) capture conversational language necessary for day-to-day social interactions while Cognitive-Academic Language Proficiency (CALP) assesses the formal academic learning skills necessary to fully understand cognitive test instructions and produce valid/reliable verbal and written academic work (Cummins, 2000). As such, an individual can develop conversational English that appears fluent (i.e., "good enough") for daily life conversations. As such, assessing bilingual individuals exclusively in their second language might not accurately assess the underlying brain-behavior relations gold standard neuropsychological tools (i.e., developed, standardized, and normed on monolingual individuals) are meant to capture, thus obscuring the specificity of identifying the underlying syndrome.

Experts in the field of cultural neuropsychology have provided detailed directives on assessing language fluency and proficiency, and on determining the best language(s) to use for the evaluation. Practical directives were put forward by several pioneers, and we will summarize their main points to facilitate the information to the reader. Please refer to the original papers for more detail. Pontón and León-Carrión (2001) highlighted that the first step should focus on determining the best language for testing via a two-pronged approach. That is, the first approach is the use of subjective information obtained during the clinical interview (i.e., covering the number of years in the current country; the language typically used at home, work, and social situations; when and how English language was learned; how often and in which context each language is used and with whom). The second approach is the use of more objective measures assessing: (1) the linguistic preferences in which the client rates their own fluency, and (2) factors related to acculturation. Judd et al. (2009) further recommended a cost-benefit analysis between language preferences and the goal of the neuropsychological evaluation to determine the language of the evaluation while acknowledging the limitations in the availability and/or appropriateness of tests and norms for that particular preferred language and cultural background. For example, the authors recommended (1) the use of both Spanish and English for the evaluation of language disorders, (2) the use of English language when the referral question is to determine the patient's ability to function in a treatment or rehabilitation program in English, and (3) to implement the evaluation in both languages when the patient's preference and abilities vary across domains or during an academic evaluation.

Rivera Mindt et al. (2008) recommended the following: for English-dominant bilinguals, the authors urged neuropsychology trainees and professionals to become familiar with the literature that illustrates how bilingual clients are often at a disadvantage relative to monolinguals on a variety of tests of language (i.e., vocabulary production, including reduced lexical/phonological retrieval and semantic fluency due to competing names for one semantic representation), even when such



bilinguals are tested exclusively in their more dominant language. When the patient is a more balanced bilingual, Rivera Mindt et al. (2008) urged evaluators to examine the patient in both languages in order to more accurately capture information that is more readily available in either language. For Spanish-dominant adults, the authors recommended evaluating the patients in their native Spanish language with appropriate tools and norms. All in all, it is recommended to obtain a detailed history of someone's development with regard to language acquisition, frequency of use throughout the lifetime, academic skills in each language, and context of usage in the past and present. This lifelong approach to language development and usage will aid the clinician in contextualizing objective measures of proficiency and fluency in each language and ultimately decide how bilingualism might be impacting cognitive functioning at the time of diagnosis.

These directives are not new, and many advances have been made in the field from understanding that culture and language have an impact on verbal and non-verbal measures. The clinical challenge, to date, remains on why we keep encountering bilingual individuals across the bilingualism spectrum who have been tested only in English. We believe the answer to this question is not a simple one and it is likely related to scarcity of resources at the normative, armamentarium, and provider levels. Moreover, at the organizational and institutional levels, bilingual individuals are disproportionately impacted by lack of neuropsychological services for similar reasons that they lack access to services in other areas of physical and mental health.

Now, you might wonder, "But isn't it better to test the patient than to not test them at all?" The answer to this question is absolutely driven by our ethics code (American Psychological Association, 2017): "of course we need to test them as denial of services is unethical" (1.08). Yet, other clinical and ethical challenges arise regarding the best practices of care. Specifically, "Am I qualified to provide these services?" (2.01), and "How should I incorporate this linguistic information in the brain-behavior inferences driving diagnostic formulations and adjacent treatment planning from a science that lacks equal representation of racial and ethnic minorities?" (2.04).

Evidence-Based Assessment or Practical Considerations

We have been providing neuropsychological services to the Latino/a community in Southern California for the past eight years and we continue to encounter numerous cases where bilinguals were referred to a linguistically and culturally congruent neuropsychological evaluation for a second opinion after being examined in only English by a previous provider, similar to our case vignette. El Señor Del Pueblo demonstrated lower than expected performance on the Trails B test during his first evaluation, but at the time there would have been no reason to suspect that such a score (percentile) represented a decline for him. But even at the time, the research, as stated previously in this paper, would have already suggested that lower than expected scores on a test of controlled-switching (Wisconsin Card Sorting Test and Trail Making Test – B) for a bilingual individual with high estimated premorbid abilities more likely than not represented a decline in functioning. As you can see from this one specific aspect of El Señor Del Pueblo's testing results, "evidence-based assessments" in individuals not typically represented in neuropsychological samples (study samples are mostly educated, Caucasian, monolingual English-speaking individuals) rely heavily on the neuropsychologist's individual responsibility to provide standard of care. This is particularly problematic when assessing bilingual patients considering the large body of literature that now documents bilingual differences at the functional and structural levels with little or no translation into how to interpret such differences on tests commonly used to diagnose brain dysfunction.

In an attempt to bridge the gap between cognitive and imaging research with bilinguals and clinically useful tools, a recent study examined whether or not norms developed for monolingual Spanish-speakers from the Southwest borderland of the United States with various degrees of English fluency were appropriate for use with bilingual individuals (Suarez et al., 2021). As expected, this study found that higher Spanish-English bilingualism was associated with higher education and higher socioeconomic status, and also found that higher degree of bilingualism was associated with all raw scores across a battery of 15 tests. When demographically corrected norms were derived, however, bilinguals had significantly higher T-Scores (approximately 5 T-Scores) than their monolingual counterparts on the WAIS-III Digit Symbol, Symbol Search, Letter-Number Sequencing and Trail Making Test - B. Altogether, research with this specific population of native Spanish-speakers with various degrees of English fluency suggests that bilingualism confers an advantage on tasks requiring rapid set-shifting. Thus, clinicians should interpret scores on tests measuring these abilities in the context of these findings suggesting that bilingualism has measurable effects in specific tests or ability level. More importantly, clinicians should consider, as was likely the case with El Señor Del Pueblo, that patterns of cognitive changes among bilingual individuals might not follow the same pattern as a monolingual patient and can obscure a timely and accurate diagnosis.

By Pew Research estimates, approximately 70% of Latinos/as (referring to Spanish-speaking countries of origin) in the United States speak English "very well" (Noe-Bustamante & Flores, 2020). Another way of putting this



is that 30% of Latinos/as do not speak English proficiently and possibly have various degrees of English fluency. Altogether, these numbers indicate that approximately 40 million Latinos/as in the United States might be Spanish-speaking and possess some degree of bilingualism (Spanish-English). Yet, while the number of bilingual providers in the United States cannot be estimated, a survey conducted by Rabin et al. (2017) estimated that only 3% of neuropsychologists identified as Latino/Hispanic with no indication that these providers are bilingual themselves. Add this lack of providers to the lack of language concordant assessments to bilingual patients and to the lack of representation and/or characterization of bilingual individuals in research studies examining brain functioning and it quickly becomes evident that much work needs to be done in order to provide equitable care to patients like Señor Del Pueblo.

Ideally, a bilingual (Spanish/English) provider should be able to engage the patient in both languages as needed, test the person in both languages, and objectively determine testing language and/or test most domains in both languages when indicated. To add to the previous suggestions about acquiring information from the patient and family, specific recommendations for interviewing a bilingual patient who is suspected of developing a neurodegenerative process should include questions regarding differences in rate of decline across the first acquired language (L1) and the second acquired language (L2). Anecdotally, we have found that most of the patients with a suspected neurodegenerative process report a reversal to speaking only their L1 even when they have used both languages for the majority of their lives. Another question to consider is whether or not the patient is experiencing difficulties in sustaining the appropriate language (L2) when speaking in an English-only setting, as this might be an indication of difficulties with executive functioning (language control). It is just as important for the clinician to understand, during the interview process, that previous research in bilingualism and emotional processing suggests that bilingual patients might process emotions differently depending on the language they are speaking. More specifically, Dylman and Bjärtå (2019) found that emotions of distress might be experienced more harshly when engaging a person in their L1 as opposed to L2. With this in mind, bilingual providers might want to consider engaging patients in L2 when discussing traumatic experiences during a clinical interview for a neuropsychological assessment given the limitations in providing therapeutic interventions in this context. Conversely, clinicians might want to be attuned to patients who initially speak in their L1 and abruptly switch to their L2 as a way to distance themselves from traumatic experiences. Again anecdotally, this scenario has been observed in many of the cases re-assessed by our program where Alzheimer's disease was confounded with memory changes related to longstanding histories of trauma (Alzheimer's disease vs. undiagnosed lifelong posttraumatic stress disorder).

Please note that currently no gold standard exists to aid clinicians in determining the best language of testing for balanced bilinguals. Based on research mentioned in a prior section of this paper, however, we have opted to systematically assess language fluency by using the letters F-A-S in English and P-M-R in Spanish and proficiency in both languages to determine language testing by using the Bilingual Verbal Abilities Test (BVAT; Muñoz-Sandoval et al., 2005). A patient is considered bilingual when the ratio of total words produced in English (language fluency test) to the total words produced in both languages falls between the .34 and .66 when tested in both languages. As was the case with Señor Del Pueblo, his fluency ratio was .46 and he underwent testing of verbal working memory, controlled inhibition, and verbal memory in both Spanish and English. Performance across tests of language and other domains where bilingualism has been found to impact clinical measures, such as the Golden Stroop and Trail Making Test - B, and some processing speed measures, will be interpreted with this in mind (Suarez et al., 2021). The same is true for measures where bilingualism is thought to hinder performance as with the case of confrontation naming and semantic fluency where one semantic representation (animals) has two competing words ("horse, vs. caballo;" Bialystok, 2017).

At this juncture, it might be overwhelming to think about how to systematically incorporate the aforementioned directives into the evaluation of a bilingual individual, especially with all the intertwined complexities and the limitations of our neuropsychological tools/norms. At best, given the limited knowledge, providers should make every attempt possible to stay updated on the research regarding bilingualism and how it might impact a neuropsychological profile to render a diagnosis. In the least, by reading the case of Señor Del Pueblo, clinicians will engage in a process of critical thinking whereby basic assumptions of brain-behavior relationships will be challenged when addressing a patient who is not typically represented in the clinical population they usually serve. To this end, some practical considerations include asking questions: Is this patient represented in the normative sample with respect to early life experiences, language development, educational attainment, quality of education? Is the volumetric analysis for the patient based on comparing them with subjects who might not have formal education in the instance where a patient has no formal education? Monolingual providers might reflect on whether they are the proper persons to get a full picture of the cognitive profile of their bilingual patient. Should the patient be tested in English or Spanish, or both? Once testing is completed, which norms are applied-English norms derived from monolingual English-speakers or Spanish norms? Do both and compare? These are the clinical decision-making



dilemmas that providers constantly face when serving a bilingual population, as exemplified by the case of Señor Del Pueblo.

Conclusions and Lessons Learned Relating to the Vignette

Señor Del Pueblo is the most common story in our clinical practice rather than the exception. Latino/a older adults continue to be diagnosed with Alzheimer's disease disproportionately later in the disease course for many reasons. One reason is that many bilingual Latino/a older adults continue to be assessed only in English with our current gold standard cognitive toolkit of largely monocultural-monolingual neuropsychological measures. The reduced diagnostic specificity and sensitivity of these neuropsychological tools for Latino/a older adults continue to obscure the neuropsychological markers of subtle cognitive decline necessary for timely and accurate diagnosis and treatment planning. Furthermore, clinicians continue to struggle with establishing accurate brain-behavior diagnostic predictions, given that neurocognitive phenotypes are impacted by language-related factors (bilingualism) that are not readily quantified in the available neuropsychological tools and normative sample. Heterogeneity in the clinical expression of Alzheimer's disease among older Latino/a adults, alongside the limitations of our evidence-based assessments can confound early detection of symptoms leading to inaccurate and untimely clinical diagnoses. It can also delay the application of culturally and linguistically cognitive and behavioral treatments that are tailored to the specific needs of the patient and their families.

As we reflect on Señor Del Pueblo and many other similar stories, the themes of interdisciplinary, multi-medical, and community setting collaborations emerge. Neuropsychologists are trained in understanding the brain, brain-behavior relationships, and clinical syndromes. Cultural (non-Eurocentric) neuropsychologists are trained to conceptualize the individual within a linguistic, socio-cultural, political, and historical-multi-generational context that impacts the same brain-behavior systems that are constantly changing depending on life experiences in a particular historical epoch. While we exceed in diagnostics with the exceptions mentioned above, our recommended treatment planning is, oftentimes, lagging in applicability. Similar to the recommendations given to el Señor Del Pueblo, our treatment recommendations are generic in nature. However, we can do better by working alongside providers from other disciplines (e.g., geropsychology, rehabilitation psychology, health psychology, occupational and speech therapy, nursing). After spending several hours with patients and their families, understanding their stories, and observing them while performing the neuropsychological and psychiatric assessments, we have a particular expertise in seeing how the observable pattern of cognitive, behavioral, and emotional strengths and weaknesses impacts their daily lives. Indeed, this professional insight was lacking when working with Señor Del Pueblo and his family. We wished we knew more about linguistically and culturally tailored behavioral interventions offered in medical and community settings, as these behavioral interventions are widely available.

To enhance Latino/a Alzheimer's disease care, Montoro-Rodriguez and Gallagher-Thompson (2020) suggested to take into account the caregivers' and the family's level of acculturation while examining and addressing caregiver distress, as well as to account for structural and social determinants of health directly impacting the specific Latino/a patient, caregiver, and family in your clinical practice. Remember, Latinos/as are a diverse community with unique stories (including language diversity beyond the Spanish-English spectrum; Latinos/as also speak indigenous languages) leading to a particular region in the United States. For instance, in a qualitative study by Rodriguez and Padilla-Martínez (2020) they emphasized the importance of including emic (meaning-centered) techniques in the tailored interventions making the underlying therapeutic construct accessible to the individual (e.g., peanut butter sandwich vs. a Colombian arepa vs. a Mexican Chilaquiles when referencing food). The authors also highlighted the need of cultural humility and sensitivity, as well as awareness of family values and its intergenerational complexities (i.e., mixed status families) during the development of interventions within Latino/a families who cared for a family member with dementia. Gelman et al. (2020) also suggested engaging in early intervention efforts by increasing access to culturally sensitive psychoeducation regarding Alzheimer's disease diagnosis and treatment. For instance, in a study by Gallagher-Thompson et al. (2015), psychoeducational interventions such as fotonovelas (referred to as photo novels) have been shown to decrease depression symptoms and increase engagement in health education in Latino/a Alzheimer's disease caregivers. In this study, the authors created a 16-page picture book called "Together We Can! Facing memory loss as a family." The picture book included a storyline with pictures of Latino/a actors navigating difficult scenarios, including managing behavioral symptoms related to dementia (BSD), managing stress, and actively engaging in coping skills.

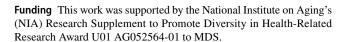
Psychologists and neuropsychologists can enhance Alzheimer's disease diagnosis and treatment planning for Latino/as by utilizing our expertise in brain and behavior relationships to educate healthcare providers on cultural, societal, environmental factors (e.g., exposure to pollutants, occupational hazards, etc.), systemic barriers/inequities that can impact the expression of symptomatology, and



linguistic factors that impact brain functioning. It is also imperative for psychologists to provide psychoeducation to Latino/a patients and their families, including early identification of Alzheimer's disease behavioral symptoms. This support could also include how to navigate the healthcare system, how to engage in a dialogue with their medical providers to discuss the observed symptoms, and how to build community post-diagnosis. Psychologists can provide assistance with culturally and linguistically tailored behavioral interventions to ensure healthy longevity with respect and dignity. Señor Del Pueblo and his family would have benefitted greatly from this comprehensive, timely, and tailored behavioral interventions.

Key Clinical Considerations

- Timely and accurate diagnosis of Alzheimer's disease
 is impacted by multiple structural and individual factors, including cultural and linguistic lived experiences
 not readily quantified by research studies, thus leaving it
 up to individual providers to integrate this information
 into their clinical practice with bilingual Latino/a older
 adults experiencing early stages of cognitive decline.
- 2. While it is the case that most brain-behavior relationships are similar across cultures and languages (e.g., a dominant inferior temporal lesion will likely cause naming problems), there are many differences across cultural practices that impact this relationship in ways that are less salient to the untrained eye (neuropsychologist) and which can greatly impact diagnostic accuracy and treatment planning.
- Practically, it is recommended to obtain a detailed history of someone's development with regard to language acquisition, frequency of use throughout the lifetime, academic skills in each language, and context of usage in the past and present.
- 4. The lifelong approach to language development and usage will aid the clinician in contextualizing objective measures of proficiency and fluency in each language and ultimately decide how bilingualism might be impacting cognitive functioning at the time of diagnosis.
- 5. To enhance Latino/a Alzheimer's disease care, interventions are to be specifically tailored to account for the current socio-economic, political, and linguistic realities of the patient, the family, and the caregivers, who often times are family members living in the same household.
- Partnering with language and cultural congruent community organizations, and community hospitals are a crucial step to ensure a post-diagnosis journey of care with dignity and respect for the patient, caregiver, and family.



Declarations

Conflict of Interest We have no conflict of interest to disclose.

References

- Alzheimer's Association (2021). Alzheimer's disease facts and figures. Alzheimer's & Dementia, 17(3), 1-106. https://www.alz.org/ media/documents/alzheimers-facts-and-figures.pdf
- American Psychological Association. (2017). *Ethical principles of psychologists and code of conduct*. Washington, DC: Author.
- Bialystok E. (2017). The bilingual adaptation: How minds accommodate experience. *Psychological Bulletin*, 143(3), 233–262. https://doi.org/10.1037/bul0000099
- Cummins, J. (2000) Putting language proficiency in its place: Responding to critiques of the conversational/academic language distinction, in J. Cenoz and U. Jessner (eds.) *English in Europe: The acquisition of a third language*. Clevedon: Multilingual Matters.
- Dylman, A.S. & Bjärtå, A. (2019) When your heart is in your mouth: the effect of second language use on negative emotions. *Cognition and Emotion*, *33*:6, 1284-1290. https://doi.org/10.1080/02699931. 2018.1540403
- Gallagher-Thompson, D., Tzuang, M., Hinton, L., Alvarez, P., Rengifo, J., Valverde, I., Chen, N., Emrani, T., & Thompson, L. W. (2015). Effectiveness of a fotonovela for reducing depression and stress in Latino dementia family caregivers. *Alzheimer Disease and Associated Disorders*, 29(2), 146–153. https://doi.org/10.1097/WAD. 0000000000000000077
- Gelman, C. R., Umpierre, M., & Steinberg, K. (2020). Education, diagnostic, and supportive psychosocial interventions for Latinos with dementia. In H.Y. Adames & Y. N. Tazeau (Eds.), Caring for Latinxs with dementia in a globalized world (1st ed., pp. 155-167). New York, NY: Springer
- Gollan, T. H., Salmon, D. P., Montoya, R. I., & Galasko, D. R. (2011). Degree of bilingualism predicts age of diagnosis of Alzheimer's disease in low-education but not in highly educated Hispanics. *Neuropsychologia*, 49(14), 3826–3830. https://doi.org/10.1016/j. neuropsychologia.2011.09.041
- Heneka, M.T., Golenbock, D., Latz, E. *et al.* Immediate and long-term consequences of COVID-19 infections for the development of neurological disease (2020). *Alzheimer Research and Therapy*, 12, 69, https://doi.org/10.1186/s13195-020-00640-3
- Judd, T., Capetillo, D., Carrión-Baralt, J., Mármol, L. M., Miguel-Montes, L. S., Navarrete, M. G., Puente, A. E., Romero, H. R., Valdés, J., & NAN Policy and Planning Committee (2009). Professional considerations for improving the neuropsychological evaluation of Hispanics: A National Academy of Neuropsychology education paper. Archives of Clinical Neuropsychology: The Official Journal of the National Academy of Neuropsychologists, 24(2), 127–135. https://doi.org/10.1093/arclin/acp016
- Mansfield, E., Noble, N., Sanson-Fisher, R., Mazza, D., & Bryant, J. (2019). Primary care physicians' perceived barriers to optimal dementia care: a systematic review. *The Gerontologist*, 59, 697– 708. https://doi.org/10.1093/geront/gny067
- Mendez, M. F., Chavez, D., & Akhlaghipour, G. (2019). Bilingualism delays expression of Alzheimer's clinical syndrome. *Dementia and Geriatric Cognitive Disorders*, 48(5-6), 281–289. https://doi.org/10.1159/000505872



- Montoro-Rodriguez, J., & Gallagher-Thompson, D. (2020). Stress and coping: conceptual models for understanding dementia among Latinos. In H.Y. Adames & Y. N. Tazeau (Eds.), *Caring for Latinxs with dementia in a globalized world* (1st ed., pp. 231-246). New York, NY: Springer
- Muñoz-Sandoval, A. F., Cummins, J., Alvarado, C. G., & Ruef, M. L. (2005). *Bilingual verbal ability tests*. Rolling Meadows, IL: Riverside Publishers.
- Noe-Bustamante, L., & and Flores, A. (2020). "Facts on Latinos in America." *Pew Research Center's Hispanic Trends Project*, Pew Research Center, 22 Oct. 2020, www.pewresearch.org/hispanic/fact-sheet/latinos-in-the-u-s-fact-sheet/.
- Noe-Bustamante, L., Mora, L., & Lopez, M. H. (2020). About one-in-four US Hispanics have heard of Latinx, but just 3% use it. *Pew Research Center*. www.pewresearch. org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/
- Perani, D., Farsad, M., Ballarini, T., Lubian, F., Malpetti, M., Fracchetti, A., Magnani, G., March, A., & Abutalebi, J. (2017). The impact of bilingualism on brain reserve and metabolic connectivity in Alzheimer's dementia. *Proceedings of the National Academy of Sciences of the United States of America*, 114(7), 1690–1695. https://doi.org/10.1073/pnas.1610909114
- Połczyńska, M. M., & Bookheimer, S. Y. (2021). General principles governing the amount of neuroanatomical overlap between languages in bilinguals. *Neuroscience and Biobehavioral Reviews*, 130, 1–14. https://doi.org/10.1016/j.neubiorev.2021.08.005
- Pontón, M.O. & León-Carrión, J. (2001). *Neuropsychology and the Hispanic patient*. Mahwah, NJ: Lawrence Erbaum Associates.
- Rabin, L.A., Brodale, D.L., Elbulok-Charcape, M.M., & Barr, W.B. (2017). Diversity issues in neuropsychology: a survey of practicing neuropsychologists. *National Academy of Neuropsychology Bulletin*, Vol 31, 1, 19-21.
- Rivera Mindt, M., Arentoft, A., Kubo Germano, K., D'Aquila, E., Scheiner, D., [...] & Gollan, T.H. (2008). Neuropsychological, cognitive, and theoretical considerations for evaluation of bilingual individuals. *Neuropsychology Review*, 18, 255-268. https:// doi.org/10.1007/s11065-008-9069-7
- Rodriguez, J., & Padilla-Martínez, V. (2020). Latino families living with dementia: behavioral issues and placement considerations. In H.Y. Adames & Y. N. Tazeau (Eds.), Caring for Latinxs with dementia in a globalized world (1st ed., pp. 133-153). New York, NY: Springer.
- Suarez, P. A., Marquine, M. J., Díaz-Santos, M., Gollan, T., Artiola I Fortuny, L., Rivera Mindt, M., Heaton, R., & Cherner, M. (2021). Native Spanish-speaker's test performance and the effects of Spanish-English bilingualism: results from the neuropsychological norms for the U.S.-Mexico border region in Spanish (NP-NUM-BRS) project. *The Clinical Neuropsychologist*, 35(2), 453–465. https://doi.org/10.1080/13854046.2020.1861330

- U.S. Census Bureau (2020). 2020 Census statistics highlight local population changes and Nation's racial and ethnic diversity. https://www.census.gov/newsroom/press-releases/2021/population-changes-nations-diversity.html
- Vega, I. E., Cabrera, L. Y., Wygant, C. M., Velez-Ortiz, D., & Counts, S. E. (2017). Alzheimer's disease in the Latino community: intersection of genetics and social determinants of health. *Journal of Alzheimer's Disease: JAD*, 58(4), 979–992. https://doi.org/10. 3233/JAD-161261
- Weissberger, G. H., Gollan, T. H., Bondi, M. W., Nation, D. A., Hansen, L. A., Galasko, D., & Salmon, D. P. (2019). Neuropsychological deficit profiles, vascular risk factors, and neuropathological findings in Hispanic older adults with autopsy-confirmed Alzheimer's disease. *Journal of Alzheimer's Disease: JAD*, 67(1), 291–302. https://doi.org/10.3233/JAD-180351

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