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Developing Understanding through Global Case Studies
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The Eyes Don’t See What the Mind Does Not Understand

Beatriz MacDonald, Tedd Judd, Claudia García de la Cadena, and Isis Yahaira Marroquin Jerez de Cifuentes

Los ojos no ven lo que la mente no entiende. (The eyes don’t see what the mind does not understand.)
(Dr. Henry Berrisford Stokes)

The late Guatemalan neurologist, Dr. Stokes, championed neuropsychology in Guatemala for decades. He observed that neurologists and other medical providers often do not appreciate what neuropsychology contributes until they witness it firsthand. Similarly, when we do not see and learn about our client’s culture, we do not appreciate it and apply it to their care. This chapter is dedicated to the memory of our elders and mentors, Dr. Stokes and the great Colombian neuropsychologist, Alfredo Ardila.

Section I: Background Information
Throughout this chapter, we share general information about Guatemala with a focus on the Mam Mayan community to support the case study.

Terminology and Perspective
People from Guatemala are referred to as Guatemalans, Central Americans, Latin-Americans, Hispanics, or Latinos(as)/Latinx/Latine, and, colloquially, Chapines. The preferred terminology is Guatemalan.

This chapter depicts the contributions and knowledge of four authors from different geographical locations. We partnered together to present how neuropsychology has developed in Guatemala and how each one of us has contributed to this process.

I, Dr. Beatriz MacDonald, was raised in Guatemala and moved to the United States to complete college. I left Guatemala with the hope of studying neuropsychology in another country since the field did not exist in my home country. After almost 20 years, I relish the excitement of teaching as invited faculty at the Universidad del Valle de Guatemala (UVG) for the Master’s Program in Clinical Neuropsychology. I am eternally grateful to my dear colleagues and visionaries, Drs. García de la Cadena and Judd, who solidified the field of neuropsychology in Guatemala.

I, Dr. Tedd Judd, was raised in the United States. I began learning Spanish through immersion in Guatemala at age 24 (1977). Since 1986, I have regularly traveled to teach neuropsychology in Latin America, especially Nicaragua, Costa Rica, and Guatemala. I am delighted that we are fulfilling my long-time dream of a Master’s Program in Clinical Neuropsychology for Central America. In the United States, I am the past president of the Hispanic Neuropsychological Society, and I have a multicultural specialty private practice, working with clinical, forensic, immigration, and social issues.

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I, Dra. Claudia García de la Cadena, was born in Mexico City, and my professional training was carried out at the National Autonomous University of Mexico and at the University of La Laguna in Spain. Since 2002, I have worked at the Universidad del Valle de Guatemala as a professor and director. After an unexpected encounter with Dr. Tedd Judd, we began to design a Master’s Program in Neuropsychology in Guatemala. This project took almost seven years to consolidate, and in 2015, we started with the first group of students. Now, we are enrolling the fifth cohort with students from Central American countries.

I, Lcda. Isis Yahaira Marroquin Jerez de Cifuentes, am a graduate student completing my last semester of the Master Program in Clinical Neuropsychology at UVG. My title of Lcda means licenciada or “licensed” (psychologist). I was born in Puerto Barrios, Izabal, on the Caribbean coast of Guatemala, and belong to the Afro-descendant community. I trained with a pioneer of neurosciences and neuropsychology, Dr. Henry Stokes, who opened the doors to the field. He instilled in me continuous learning and love for the most important organ of our body, “the brain,” which led me to become interested in the Master’s Program in Clinical Neuropsychology.

All four authors have different degrees of language fluency and proficiency in English. Much of this paper is translated from Spanish, intentionally preserving the nuances of the Spanish language and writing style and illustrating the richness of the Guatemalan culture. This undertaking has been particularly broad in its cultural diversity: an Afrodescendent Guatemalan, a Mexican-Guatemalan, a Guatemalan-American, and a gringo working with Mayans. Multiculturalism is typical of Guatemalan neuropsychological encounters.

Geography

The Republic of Guatemala is home to 17 million and located in Central America, the isthmus that connects North and South America. Guatemala borders with Mexico, Belize, El Salvador, Honduras, and the Pacific and Atlantic oceans. While divided into twenty departments (departamentos in Spanish; equivalent to states), Guatemala contains mountains, beach, tropical rainforest, desert, and valleys. We have 37 volcanoes, three of which are active.

History and People

The indigenous community in Guatemala is the direct descendant of the ancient Mayan civilization. They erected pyramids for polytheistic ceremonial rituals, wrote hieroglyphics, developed an advanced calendar system, and traded goods (e.g., cacao). Major lowland regions and cities (e.g., Tikal) were abandoned around 1,100 years ago, possibly due to drought, deforestation, and climate change. All major features of the civilization continued in the highlands until the Spanish conquest.

The Spanish conquistadores (conquerors) arrived in 1524, bringing diseases and military conquest that decimated the Mayan civilization and population. Guatemala was part of the Spanish Captaincy General of Guatemala (colonial government) for nearly 330 years. The Spanish established feudal patterns of land ownership. European elites ruled with the assistance of ladinos(as), a label identifying non-indigenous Guatemalans. Mestizos or biracial Indigenous-European people were next in the social hierarchy and the bottom rank belonged to the Mayan community, who were stripped of their community life. Such demarcation of status marked a divide that continues to drive the economy and social life in Guatemala.

The current distribution by ethnic self-identification is as follows: 56% Ladino, 41.7% Maya, 1.8% Xinka, 0.1% Garifuna, 0.2% Afro-descendant/Creole/Afromestizo and 0.2% foreigners. Ethnic self-identification is complex and influenced by half a millennium of repression and racism that persist to the present. Based on the census in 2017, 33.4% of the population were between
1 and 14 years of age, 61.0% were between 15 and 64 years of age, and only 5.6% were older than 65 years of age.3

Guatemala became independent of Spain in 1821 and a fully independent nation in 1841. A popular uprising in 1944 led to a ten-year revolution and a US-backed coup in 1954 with an installed military dictatorship. From 1960 to 1996, we lived a civil war with human rights violations and a genocide of the indigenous Maya. Many Mayans sought asylum in Mexico; for example, the Mam used to be one of the larger groups but were forced to migrate and spread to different areas in Guatemala and the United States. The 1996 Peace Treaty reestablished a representative democracy and established indigenous rights, which are poorly enforced due to high crime and government corruption.4

The Mayan diaspora during the civil war from 1960 to 1996 initiated major relocation struggles for the Mayan population, who sought asylum in Mexico and the United States and moved to different parts of the country to avoid persecution and genocide. Prior to this, each Mayan community mainly interacted within their respective members and had unique typical handwoven clothing language and territory. However, displacement prompted Mayan communities to interact with each other, learn how to communicate with each other, and exchange goods and, clothing with profound impact on Mayan community identities. In addition, as of 2017, there were 1,444,000 Guatemalans in the United States, with the largest populations in California, Florida, and Texas. Diaspora communities tend to cluster, for example, there are Mam communities in East Oakland, CA, Forks, WA, and Lynn, MA.5

Language

Twenty-four languages are spoken in Guatemala. The majority (93%) of citizens speak Spanish as either their first or second language. Twenty-one Mayan languages (completely unrelated to Spanish) are heard and used throughout the country as a musical melody. The most used are K'iche' (1 million speakers), Q'eqchi', Kaqchikel, and Mam, while some are endangered.6 Most of these have multiple dialects that may not be fully mutually intelligible, important in selecting interpreters. Mam has 686,000 speakers in southeastern Guatemala. The order of the sentence is usually verb, subject, and object. There are no independent pronouns. Numbers above 20 are rarely known or used.7 Communities in three departments speak two additional non-Mayan languages, Garífuna (an Afro-Caribbean creole) and Xincan.

Communication

Forms of address are more complex in Spanish than in English. When speaking English, we use either first names (e.g., Mary) for informal close relationships or titles for formal relationships (Ms., Dr., or Rev). In-groups will sometimes use “brother” and “sister” metaphorically, but these would rarely be used in a mainstream clinical context or cross-culturally. Spanish has these options and, additionally, has Don (male) and Doña (female) titles for respected elders. In addition, “tío” (uncle), “tía” (aunt), “abuelo” (grandfather), and “abuela” (grandmother) may be used in the same metaphorical ways. Guatemalan clinical relationships with a psychologist can progress to being more informal and could include such terms. In the United States, we typically use “señora” or “señor” as a sign of deference with Guatemalan families and clients. However, in Guatemala, it may be considered a sign of poor rapport to address a client overly formally.

Personal disclosure helps to build an alliance. Guatemalans value personalismo—personal relationship—and psychologists are expected to disclose about themselves, for example, sharing where one is from and one’s knowledge about Guatemala. Guatemalans have a deep respect for

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the medical community and as a sign of deference, they typically do not question physicians or psychologists. Therefore, we have to be mindful to ensure that clients and families understand the purpose, results, impressions, and recommendations of an assessment.

Professional interpreter training for Mayan languages is not well developed in Guatemala, the United States, or elsewhere and few trained interpreters are available. Briefing and debriefing the interpreter and explaining the use of an interpreter during an assessment are instrumental. In diaspora communities, the language community may be small, and interpreters may have dual-relationships with the clients. Therefore, providers need to navigate these considerations carefully. Many Mayans are bilingual in their Mayan language and Spanish. Even when Spanish is not their better language, it is sometimes the most pragmatic language for portions of the evaluation.

Translation of words is a nuanced process and providers need to be aware of the subtle differences. For example, _demencia_, in Spanish, is understood as “crazy,” with much more stigma than “dementia” in English. Additionally, the Spanish second person has three forms—informal “tu,” colloquial informal “vos” (similar to English “thou”), and formal “usted.” These also have cultural and political implications beyond the scope of this chapter. When an English speaker says “you,” the interpreter has to choose which form to use. This introduces the potential for misunderstanding the English speaker’s intentions about the nature of the relationship.

**Education**

The educational system in Guatemala perpetuates vast disparities based on socioeconomic access. There is an abyss between public and private education that perpetuates differences in educational experience and quality. Public education rarely offers English or other foreign languages. Special education in Guatemala started in 1940 for vision impairment. Disability accommodations and special education laws and policies were enacted in the 1990s and early 2000s, but implementation is lagging due to lack of resources and funding. Mayan language preservation and education was a promise of the 1996 peace accords, still only partially fulfilled. Recently, UNICEF and the Ministry of Intercultural Bilingual Education have constructed curricula by towns, codified Intercultural Bilingual schools (Spanish and the local Mayan language), and promulgated educational policies to strengthen the National Education System. The program has also contributed to the evaluation of language, culture, the participation of parents, and the generation of community education experiences. Mayan community colleges are emerging.

**Literacy**

The Guatemalan literacy rate had steadily increased from 64.2% in 1994 to 81.3% in 2014. Of the literate population, only 5% of women report more than seven years of schooling. Literacy over age 65 was 46.8% in 2015. Indigenous populations register higher percentages of illiteracy. Mayan languages are mostly oral, but a written literature is developing, especially in K’iche’, Q’eqchi’, Kaqchikel, and Mam.

**Socioeconomic Status**

Living conditions in rural and urban areas are impoverished. A small percentage of the population holds most of the wealth. About 59% of households have running water, 56% have indoor toilets, 88% have electricity, 54% cook with firewood, and 44% buy propane gas. In rural communities, many homes are made of metal roof panels with dirt floors.
Values and Customs

The folklore of Guatemala is rooted in colorful clothing, delicious food, strong beliefs, and rich traditions. Guatemalans value a collective community, with customs and traditions centered on family.

Gender and Sexuality

*Machismo* (strong or aggressive masculine pride and family responsibility) and *marianismo*, (female submissiveness, self-sacrifice for family, chastity, religiosity) continue to be part of relationships that permeate all social spaces, including social policy, employment, educational choices, and family life.9,10

Homosexual activity became legal in 1871, but sexual orientation and the LGBTQIA+ community are still largely taboo topics.11 In January 2018, the Inter-American Court of Human Rights (IACHR) ruled that the American Convention on Human Rights requires the recognition of same-sex marriage, but this is not recognized in Guatemala. Guatemalan laws do not safeguard the LGBTQIA+ community and there is no prohibition against discrimination in housing, education, healthcare, employment, banking, etc.

Spirituality and Religion

Mayan religious practices are syncretic or blended. Preconquest Mayans practiced polytheism. Spaniards imposed Catholicism. Mayan communities blended both, often blending specific Catholic saints with Mayan gods and blending rituals. Some traditions endure, such as patron saints/Gods and festival days for each village or pueblo. In recent decades, there has been a shift toward evangelical Christianity.1

Acculturation and Systemic Barriers

Guatemala has entrenched systemic barriers to access to power, wealth, justice, health care, etc., due to governmental corruption and socioeconomic class divides dating back to the conquest. Rural-urban acculturation is a major change for rural Mayans who move to Guatemala City to work as housekeepers, construction workers, etc. They confront entirely different languages, beliefs, institutions, technologies, clothing, and food.

Health and Mental Health Views

When speaking with families and clients, information gathering is often difficult because of different conceptualizations of medical conditions and medications. Our strategies for gathering information include asking for pictures of medication bottles, calling more knowledgeable family members, asking in several different ways, and familiarity with idioms of symptoms. The coordination of medical records and medications among providers is poor. Additionally, medication adherence is impacted by an understanding of how to take the medication. For example, “I was feeling depressed yesterday, so I took one of my antidepressants.”

Malnutrition is a fundamental health problem among Mayan communities, affecting all other neurological risks. The majority of Mayan children show growth stunting due to malnutrition, which impairs cognitive development, and increases susceptibility to diseases including infections, hypertension, diabetes, and stroke.12,13 Vascular disease is prevalent and medical treatment and prevention are poorly understood and followed by the public. Neurologically important
infectious diseases include cysticercosis, HIV, Zika, COVID-19, dengue, and malaria. Pesticide toxicity and drug and alcohol abuse are widespread.

Many Mam believe that diseases have supernatural causes or are due to moral transgressions. Traditional healers are very important in the community, with political and religious functions. They attend to illnesses of the spirit, such as strong emotions, anger, sadness, and shame. Anger is seen as an emotion that upsets the body’s balance and leads to headaches, stomachaches, fatigue, and chronic illness. *Nervios* (nerves) is a disease due to experiencing strong emotions, particularly anxiety, pain, and sadness. Other examples of Mayan conceptualization of emotional/physical/social disorders with their K’iche names are listed in Table 32.1.

### Table 32.1 Mayan conceptualization of emotional/physical/social disorders with their K’iche names

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Q’ij Alaxik</em></td>
<td>The discomfort of not knowing oneself. If one does not know or ignores the vocation that is destined to follow from birth, an imbalance arises in the health and life circles of the person.</td>
</tr>
<tr>
<td><em>X’ibiliril</em></td>
<td>Loss of spirit (jaleb’) arises due to a violent or traumatic event affecting the normal balance of the human body.</td>
</tr>
<tr>
<td><em>Pak’ab Chuch Tat</em></td>
<td>Health effects due to traditional ethical transgressions, especially from a level of authority.</td>
</tr>
<tr>
<td><em>Moxrik</em></td>
<td>Physical and mental discomfort due to assimilation to a foreign culture, especially for personal reasons.</td>
</tr>
<tr>
<td><em>Molem Yab’il</em></td>
<td>Psychosomatic consequences from the dissatisfaction of basic needs of food, land, housing, health, and education.</td>
</tr>
</tbody>
</table>

The most frequent diseases in the Mam community are parasites and respiratory infections. Diseases are generally cured by herbalists, who are often also midwives. Health depends on the blood as it is perceived as “the seat of physical strength and sensory perceptions.” Traditional medicine has over a thousand treatments derived from local flora and fauna.

### Approach to Neuropsychological or Psychological Evaluations

The development of neuropsychology in Central America has a long history. The Master’s Program in Clinical Neuropsychology was born from collaborative work among Dr. Judd, Dr. García de la Cadena, and Guatemalan psychologists. The program began in 2015 with a student cohort of psychologists, neurologists, a psychiatrist, and a criminologist. The subsequent four cohorts have been psychologists. The program offers two years of training with 21 courses, 500 hours of practical experience, a portfolio of 20 cases, and a final project. The design of monthly, three-day intensive courses in Guatemala City has drawn students from rural parts of Guatemala and from Honduras, El Salvador, and Costa Rica, as well as professors from Colombia, Mexico, Spain, Brazil, and the United States. These courses became virtual during the COVID-19 pandemic, which improved geographic and disability access and broader teaching and clinical experiences. While this training is modest compared to North America, Europe, and other Latin American neuropsychology master’s programs, it has established recognition of the profession and field. The Master’s Program has a truly Guatemalan and Central American identity, with instruction entirely in Spanish, and a strong focus on local cultures, languages, needs, and conditions.

Supervised practice is adapted to available instruments, limited resources, illiteracy, low formal education, and single session assessments. The Department of Neuropsychology at UVG has researched the adaptation of neuropsychological tests in adult and pediatric Guatemalan populations.

The program has been able to address some of the country’s greatest needs through practice sites in the two main public health national hospitals, the Roosevelt Hospital and the San Juan de
Dios Hospital. Other programs include the Military Hospital, the Social Security health system, and the university clinic CIPA (Centro Integral de Psicología Aplicada) at UVG, which offers care at low cost for low-income populations.

The case study we selected is a portfolio case for Lcda. Marroquin Jerez de Cifuentes under the supervision of Dr. García de la Cadena. Presenting this case highlights not only neuropsychology in Guatemala but also the training achieved through the Master's Program in Clinical Neuropsychology.

Section II: Case Study — “The Eyes Don’t See What the Mind Does Not Understand”

Note: Possible identifying information and several aspects of history and presentation have been changed to protect client identity and privacy.

The client is a 72-year-old female from the Mam community who speaks Mam and Spanish. Per the request of a provider in the rural areas of Guatemala, the Chief for External Consults coordinated the referral for an evaluation due to concerns with memory and changes in behavior. She was seen at the San Juan de Dios Public Health Hospital in the Department of Neuropsychology. The hospital is in Guatemala City, a 4-hour bus ride from her home village. The information below was reported by Sra. Milagro, her granddaughter, and daughter.

The examiner contacted multiple providers in the hospital for access to Sra. Milagro’s medical records. However, since these are not electronic, access is limited, and she was unable to obtain imaging records. In general, access to medical care in rural regions in Guatemala is extremely limited, and urban medical healthcare has systemic barriers in place.

Presenting Concerns

Sra. Milagro reported distress because her eldest son decreased the frequency of visits and calls. This change in the relationship, according to Sra. Milagro, was because she told her son that his wife (Sra. Milagro’s daughter-in-law) was cheating on him with a man, who reportedly was also in love with Sra. Milagro. Sra. Milagro’s daughter and granddaughter shared that the existence of this man and infidelity was not true, and part of Sra. Milagro’s imagination. The family also indicated that Sra. Milagro’s eldest son was upset because Sra. Milagro shared the supposed infidelity with the whole family causing problems in his marriage. Also, she had been saying sexually disinhibited statements to men in the street and hugging everyone, so that her family no longer let her go out alone.

The family’s greatest concern was that Sra. Milagro’s independence had declined. Several times she left home and got lost. Once she got off a bus and did not recognize where she was, even though it was a place she frequented. She had decreased motivation to clean the house. In the past, Sra. Milagro was a highly active woman, who took care of her home and family.

Daily Functioning

Sra. Milagro indicated that she started working as a child with her father in agriculture. From a very young age, she worked at home doing domestic work. After moving in with her partner and father of her children, Sra. Milagro started working in her village’s market selling meat and vegetables. She continued selling produce until her family recently asked her to stop because she was giving away the merchandise without payment. According to her daughter, Sra. Milagro started struggling with business transactions, such as charging another amount
or giving the wrong change back to clients. Sra. Milagro also started accusing others of stealing because she misplaced the money or had lost it. Consequently, Sra. Milagro’s daughter and other family members were managing Sra. Milagro’s finances because she was giving away money. Her daughter added that “[Sra. Milagro] is a person who likes to share, but now she gives everything away.”

Sra. Milagro reported feeling sad because of the changes in her daily life. She no longer interacted with the people who worked in the market and whom she had known for many years and had a lot of affection for them. Consequently, at home, she was unmotivated to complete housework. Most recently, she helped in the kitchen when her daughter asked her. She described feeling bored, as well as getting upset with the noise of her grandchildren playing, the chickens, and of people passing the house at night. She expressed frustration because her family did not allow her to take the bus or go outside alone. Sra. Milagro shared that she used her daughter’s cell phone to communicate with her children. Her children were aware of changes in personal hygiene and the cleanliness of her clothes.

**Health History**

Sra. Milagro described visual alterations in both eyes. She was diagnosed with hyperthyroidism six years ago that was managed with medication. Her family noted that three years previously she had been admitted to a hospital in Retalhuleu (a nearby town) for a cerebrovascular event producing memory and language difficulties. She recovered leaving sequelae in her memory. Since that time, she had taken medication for hypertension. She reported frequent headaches that made her irritable, which she treated with over-the-counter medication. Her daughter reported that Sra. Milagro may have tremors, but they were not often, and she struggled to describe them. Because her father died of alcoholism, Sra. Milagro learned that alcohol is not good, so she did not have a history of alcohol or cigarette use. At home, she and her family ate tortillas, herbs, and vegetables, with very little animal protein. She reported that her sleep time had decreased, she woke up very early and it was difficult for her to fall asleep. On two occasions at the beginning of a dream, she woke up screaming because, according to Sra. Milagro, her grandson, let a person enter the house to have sex with her. This bothered her and she was angry with her grandson. According to her daughter, this was part of her imagination because when they got up and did not find the man either inside or outside the house. From what the family described, both Sra. Milagro’s mother and uncle passed away from vascular events. She had also told her sister that she saw a man in the marketplace who was of normal size, but as he came toward her, he shrank until he disappeared.

**Educational History**

Sra. Milagro’s parents did not enroll her in school when she was a child because she was a girl and had to take care of her younger siblings. She did not read, but she learned to count on her own and through her work, it became increasingly easier for her. However, she now had difficulty performing basic mathematical operations.

**Language Proficiency**

Sra. Milagro’s mother tongue was Mam. She reported speaking and understanding Mam very well compared to Spanish. She noted that in Spanish, she struggled with pronouncing certain words. She learned most of her Spanish vocabulary while working in the village. Sra. Milagro
Beatriz MacDonald et al. spoke Mam with her siblings, children, family, and acquaintances in her village, and used Spanish to communicate with her grandchildren and acquaintances. According to her family, there had been no changes in language functioning at the time of the assessment.

Sra. Milagro’s dominant language was clearly Mam. Given limitations in available measures, her Spanish skills were determined to be adequate to evaluate her in Spanish and administer neuropsychological tests. However, this significantly limited the evaluation.

**Cultural History**

Sra. Milagro was the first daughter of two boys and two girls. She was born and continued to reside in a small village in the *departamento* of Retalhuleu in southwestern Guatemala. Guatemalans navigating rural and urban spaces, as well as crossing ethnic and Mayan communities, engage in identity processes. Sra. Milagro rarely visited urban spaces.

Sra. Milagro’s family worked in agriculture, growing corn and vegetables for the home and for sale. Her mother was a homemaker. Sra. Milagro recalled that as a child, she helped her mother at home to take care of her younger siblings and in the afternoons, she played with the children in the community. When Sra. Milagro was eight years old, her mother died of a cerebral vascular event. From eight years of age, Sra. Milagro worked the fields, tended the home, and took care of her younger siblings, a burden made harder by her father’s alcoholism. She knew that in her community, young women were offered to older men and in return they received financial help for the bride’s family. She said that when her father wanted to give her to a man, she ran away from home, which led her to look for work in a home where she was subjected to sexual abuse. She became pregnant with her first child at the age of 12, and a year later, she became pregnant with her second child. At age 16, she was together as a couple with the man with whom she lived for 34 years until he died. With her partner, they procreated eight children—she was the mother of seven living children and one died in an accident.

**Emotional Functioning**

Sra. Milagro communicated her sadness by describing the activities that changed due to being sad versus stating she felt sad. She reported that she could not go out alone and could not work or see her friends in the market or her relatives. Consequently, she was not motivated to do housework and was bored. Her grandchildren’s noise irritated her, and she did not like her children telling her what to do.

**Behavioral Observations**

Sra. Milagro came to the neuropsychology clinic for the first time accompanied by her granddaughter who was the only relative who could accompany her that day. They left at dawn for the 4-hour, 140-km interurban bus ride to be at the hospital early. She started the session by expressing relief and saying, “it’s good that it’s early because I have to go home.” Sra. Milagro was alert. Sra. Milagro appeared disoriented but was smiling, polite, and greeted the examiner with a hug, as if she knew her. She was wearing the traditional Mayan clothing of her region with purple guipil (handwoven blouse) with a colorful handwoven skirt. She appeared to have taken little interest in her hygiene.

During the interview, Sra. Milagro spoke in Spanish with some grammatical errors and her Spanish was coherent but somewhat disorganized. She consented for the evaluation to be in
Spanish. Her facial expression was generally consistent with what she was sharing. She constantly called on her granddaughter to answer for her when she did not remember some general information. It also became evident that Sra. Milagro wanted to express herself alone. Her granddaughter was asked to wait outside, allowing Sra. Milagro to describe the event that most concerned her at that time, building a relationship of trust with the examiner. As the interview progressed, Sra. Milagro appeared worried, so the evaluator asked her why. She explained that she was hungry and wanted to return home early. Therefore, the first portion of the evaluation was completed, with the recommendation to return to the next appointment accompanied by a person she lived with to provide the necessary data for the history. Instructions also included to sleep well and eat before the next appointment. Sra. Milagro said goodbye with several hugs, smiling, and gratitude.

After the information and data gathered during the first session, the examiner was extremely concerned about Sra. Milagro’s neurological well-being and requested a consult with neurology. Consequently, Sra. Milagro’s neurologist started her on Fulcrum (https://www.eurofarma.com.gt/produtos/fulcrum), which is the combination of the benzodiazepine, chlordiazepoxide, together with the tricyclic antidepressant, amitriptyline. She started taking this medication before the second session.

For the second session, seven weeks later, Sra. Milagro greeted the examiner with a loving hug. She maintained a sense of good humor for a long period of time, as well as told several stories of her life. Sometimes Sra. Milagro had to be asked the same question several times and in different ways to ensure her understanding. In this session, her daughter corroborated and elaborated on previous information.

Sra. Milagro was not comfortable with testing and constantly tried to tell stories to avoid it. She did not like to wear glasses and did not bring them to the sessions, making visual tests impractical. Additionally, she refused reading and writing activities, justifying her illiteracy by saying that in their culture, women “should take care of others and do things around the house.”

**Test and Norm Selection**

Tests were selected considering age, no schooling and illiteracy, visual limitations, commute to the evaluation, socioeconomic conditions, and relevant data that were obtained in the interview.

**Session 1:** Montreal Cognitive Assessment (MoCA)—Basic in Spanish.

**Session 2:** Evaluación Neuropsicológica Estandarizada—Adulto (ENE-A; Standard Neuropsychological Evaluation for Hospitalized Adults)\(^{16}\): orientation, attention and concentration (digits forward and successive series), working memory (digits backward), processing speed (coding), verbal memory, executive functioning, praxias, visual-verbal name memory, verbal fluency, and verbal abstract reasoning (similarities). The Depresión Geriátrica Escala abreviada de Yesavage (Abbreviated Geriatric Depression Scale; GDS)\(^{17}\) in Spanish, which was read to her. The Actividades Básicas del Indice Barthel de Vida Diaria (Barthel Index of Basic activities Daily Life).\(^{18}\)

**Test Results**

Sra. Milagro did not know her age, the name of her departamento, or the day, month, or year. She could not distinguish left from right. These limitations in her conventional orientation to space were all potentially culturally congruent. However, she also had difficulty remembering the names of her children and other family members, which is atypical.

On the MoCA Sra. Milagro scored in the moderate impairment range. On the ENE-A, she evidenced abilities within normal limits (average or low average) in verbal memory recall and recognition, motor functioning, working memory, understanding of directions, confrontational
naming, semantic fluency, sentence repetition, and tactile perception. She demonstrated mild
deficits in verbal auditory attention, learning rote-verbal information, and phonemic fluency.
Her conversational language in Spanish was notable for reduced fluency, repeating the same
phrases, not conjugating verbs correctly, semantic paraphasias, and disorganized sentences,
which is often observed in individuals who Spanish is their second language. Due to the limita-
tion of not using an interpreter, language data need to be broadly examined. In making compro-
mises, the ethical standard of do no harm is central. On the questionnaires (orally administered),
Sra. Milagro scored in the mildly depressed range. Her family rated her as independent in basic
activities of daily living.

**Impressions and Case Conceptualization**

Overall, there were marked changes in Sra. Milagro’s behavior, including disinhibition, as well as
forgetfulness and reduced independence in the completion of activities of daily living. Table 32.2
documents the delusions that Sra. Milagro and her family described. These fit within Nomura
and colleagues’ cross-cultural dementia delusion classification system. It balances the relativism
(cultural variations) and universality of the construct of dementia, highlighting the universality
of delusions, such as phantom boarder, infidelity, and theft. Applying this approach allowed the
family to understand Sra. Milagro’s symptoms and provide reassurance that the delusions were
due to her illness. This helped mend the rupture in the relationship between Sra. Milagro and her
son and daughter-in-law.

When working with individuals from culturally and linguistically diverse backgrounds, the tri-
angulation of clinical observation, family data, and testing results is critical. Testing data carry
less weight in case conceptualization. For this case, clinical information and observations indi-
cated memory decline impacting functioning and emotional well-being, as well as delusions and
prior history of a vascular event. During the evaluation, Sra. Milagro’s disinhibited behaviors
were concerning. Although Guatemalans are warm by nature, greeting a medical provider with a

### Table 32.2 Applied classification of delusions

<table>
<thead>
<tr>
<th>Classification of delusions</th>
<th>Sra. Milagro’s symptomatology</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 1</strong></td>
<td></td>
</tr>
<tr>
<td>• Belief that her house is not her house</td>
<td>Sra. Milagro reports that her grandson lets a man come into the house at night (phantom boarder).</td>
</tr>
<tr>
<td>• Phantom boarder</td>
<td></td>
</tr>
<tr>
<td>• Delusion of abandonment</td>
<td></td>
</tr>
<tr>
<td>• Belief that others are no who they claim to be</td>
<td></td>
</tr>
<tr>
<td><strong>Factor 2</strong></td>
<td>None</td>
</tr>
<tr>
<td>• Delusion relating to the TV</td>
<td></td>
</tr>
<tr>
<td>• Delusion of persecution</td>
<td></td>
</tr>
<tr>
<td><strong>Factor 3</strong></td>
<td>Sra. Milagro reports that her daughter-in-law cheated on her son with Sra. Milagro’s imaginary boyfriend.</td>
</tr>
<tr>
<td>• Delusion of abandonment</td>
<td></td>
</tr>
<tr>
<td>• Delusional jealousy</td>
<td></td>
</tr>
<tr>
<td><strong>Other symptoms</strong></td>
<td>Sra. Milagro hides her belongings and believes others have stolen them when she cannot find them.</td>
</tr>
<tr>
<td>• Delusion of theft</td>
<td></td>
</tr>
</tbody>
</table>

Source: Material taken and adapted from Nomura.19
hug at the first meeting is not customary, and this fits her family’s description of her changed and atypical behavior in her village.

When considering what type of neurological event, dementia, or neurocognitive disorder to diagnose, there are limitations to consider. First, the neuropsychological battery was administered in Spanish and not Mam, and the normative data were based on the Mexican population. However, testing results were average for verbal comprehension, memory recognition, and semantic fluency, allowing us to interpret these results and rule out the possibility of an Alzheimer’s dementia diagnosis. Without brain imaging, it was difficult with certainty to rule out frontal dementia or vascular dementia, so we hypothesized that it was mixed given her history. Since neuroimaging was not readily available, the focus then shifted from a specific diagnosis to symptomatology and treatment planning. The importance to differentiate between these two dementias would be the medication to be prescribed. Additionally, Sra. Milagro presented with depressive symptoms and the prescribed medication (Fulcrum) needed to be taken daily. Yet, medication adherence is a cultural aspect to integrate. If the client does not feel well or has side effects, the client may stop taking the medication without consulting the doctor. Therefore, emphasizing the importance of medication adherence to family was necessary.

Feedback Session and Follow-Up

Feedback to Sra. Milagro and her family was impacted by the COVID-19 pandemic and follow-up was provided over the phone over the course of two sessions. Technological limitations prevented videoconferencing.

The examiner explained validation therapy (https://vfvalidation.org/get-started/what-is-validation/) to Sra. Milagro’s daughter as a strategy to accept Sra. Milagro’s reality and not argue with her. The examiner emphasized the importance of understanding, respecting, and valuing Sra. Milagro’s experience by recognizing that her behavior was due to an illness. The feedback included mutual problem solving regarding safely managing Sra. Milagro’s problematic behavior while increasing her access to friends and household participation. Additionally, medication adherence and increased behavioral activities were emphasized to support Sra. Milagro’s emotional well-being. As part of follow-up, the examiner recommended speaking with each family member and sharing the results to support their acceptance.

We recognize that this was an extremely limited neuropsychological service. Challenges of language, culture, access, transportation, tests, and other resources greatly limited conventional testing and diagnosis. Nevertheless, a respectful and caring attitude and a neuropsychological perspective allowed our student to provide this family with a better understanding of their loved elder and mitigated family conflicts.

Section III: Lessons Learned

The lessons learned from this case study are unique because of where the authors live, practice, and supervise. In the United States, the first and second authors deliver clinical services to Guatemalans, who may or may not be Mayan, and remotely supervise trainees who are enrolled in the graduate program in Guatemala. In Guatemala, the third author teaches and supervises, and the fourth author is completing her graduate training. Our diverse experiences coupled with our deep commitment to the emerging field of neuropsychology in Guatemala creates a multifaceted approach on how to practice. Therefore, we hope that the lessons learned we share can be applied when assessing individuals living not only in Guatemala but also in other countries. As a result of writing this book chapter, we also reflected on possible next steps in the
development of Mayan Neuropsychology (see Section below on “How Can We Develop Mayan Neuropsychology?”).

What to consider and learn when delivering neuropsychological care to Guatemalans?

- **Diversity**—Guatemala is comprised of a multitude of diverse languages and cultures. Neuropsychologists can thoughtfully research the cultural background of potential clients to be proactively prepared and practice socially responsible neuropsychology. Unless providers take the time to learn about the richness of Guatemala's diversity, we will not know what to ask—"the eyes don't see what the mind does not understand."

- **Culture**—Acculturation, assimilation, and enculturation occur not only for immigrants leaving Guatemala but also for individuals living in Guatemala, especially Mayan rural-to-urban migration.

- **Epidemiology**—Guatemalans may be exposed to malnutrition, infectious diseases, and toxins uncommon in the United States.

- **Access**—Guatemalans often face significant barriers to access healthcare in Guatemala and the United States. It is the provider’s responsibility to understand these barriers as systemic health disparities and not attribute them to the client’s character. One step further is, as providers, to tackle these barriers, drive social justice change, and increase access to services.

- **Collective Community**—As members of a collective, family-based community, individuals with dementia rarely seek help because families compensate for behaviors and offer protections and supports. Families may finally seek help once symptoms are fairly advanced. This can also happen with developmental and other progressive diseases/disorders (e.g., autism spectrum disorder and multiple sclerosis), as well as intermittent ones, such as epilepsy.

- **Collateral Information**—As part of the assessment, providers often cannot access all the necessary medical records and clinical history to inform case conceptualization. For example, we may receive a diagnosis of intellectual disability on a prescription pad or not have neurodiagnostic information for a client with a history of a stroke. This happens in Guatemala, the United States, and other countries. Barriers that perpetuate these limitations are resources, beliefs about medical care, and geographic access. Additionally, clients and their family members are often not knowledgeable to provide such information. One can say that oftentimes, providers are both clinicians and detectives in trying to acquire all of the necessary data.

- **Language**—It is of great importance to inquire about language usage, bilingualism, and level of language skills in each language. Having this knowledge prior to the assessment is ideal, but often we do not know it until the appointment. An advance phone call may help determine languages of interview, interpreter needs, and test selection. A detailed language use interview and testing may be needed to determine whether language difficulties reflect impairment or fluency, as well as provide documentation and resources in the appropriate language. This is most often best done with an informed clinical interview.

- **Interpreters**—Ideally, we ethically strive to use professionally trained interpreters and complete assessments in the client’s dominant language. However, Mayan language interpreter training and resources are limited, so we make necessary compromises, on a case-by-case basis, to serve the best needs of the client.

- **Communication**—Guatemalans and Mayan communities may describe symptomatology differently (e.g., physical pain instead of sadness) and define diseases differently. Forms of address and of physical contact in greeting are culturally complex in Guatemala. Practitioners need to be aware of the range of responses and follow the client’s lead. It is safest to start with usted with adults and to switch to tu or vos if they do, and to be aware of this when working with...
interpreters. Acceptable greetings may range from no physical contact and little eye contact to handshakes, single “air kisses,” or hugs.

- **Family Involvement**—For effective continuation of care, it is best for the client’s family to be involved from the outset to understand the client’s context, roles, resources, barriers, aspirations, etc.
- **Alliance**—Establishing rapport to facilitate disclosure and trust to conduct an assessment are the cornerstones for non-Mayan providers working with Mayan communities. Families will not share information if they do not trust the provider. Practitioners may need to share about themselves more and take time to connect with the client and family before starting an interview. Guatemalans love to joke and have a great sense of humor, so sharing a laugh is a safe icebreaker.
- **Cultural Practices**—When conceptualizing a case, we thoughtfully determine if the behavioral presentation and changes of a client may be a cultural practice or an atypical presentation; this is especially important cross-culturally. For example, this case study highlighted mental health stigma, social isolation, and family dynamics.
- **Cultural Healing Practices**—Mayan cultural healing practices are particularly important in mobilizing community in support of those in need. It is prudent for neuropsychologists to be aware of such practices and to view them as complementary when possible, so that conceptualizations and interventions support one another rather than compete.
- **Medications**—Medications vary around the globe in their type, names, and availability. Internet searches may be needed to determine what someone is or was taking.
- **Measurements and Normative Data**—There are many neuropsychological measures in Spanish, but quality and norms are very varied. Dr. García de la Cadena and colleagues have developed normative data in Guatemala for specific adult and pediatric measures.22,23
- **Feedback and Recommendations**—Collaborative follow-up with other professionals, creates an emerging network of consultation. Sharing our findings with professionals, family, and the community is especially important and harder to put in a cultural context since neuropsychology is barely known, even by professionals in Guatemala. We can add more value in doing psychoeducation in a cultural context and address the need to increase disability rights and access, practice inclusion, reducing overprotection, and fostering independence. As a growing field in Guatemala, neuropsychology has the responsibility to educate the community about mental and behavioral health. Explaining relationships between quality of life and well-being, and its connection to the brain could foster preventative care. We can increase awareness of the value of taking care of the brain and how it relates to the quality of life.
- **Impressions**—Evaluating is a dance concerning how it will be received by the client and family—not only to find out what they see but how they will process the resource.
- **Training Challenges**—Clinical cases in public hospitals are of great educational value in neuropsychology for trainees. For supervisors, the perspective shifts when providing supervision for clinical cases in Guatemalan public hospitals. These cases are significantly more challenging for trainees and supervisors due to the limited armamentarium of appropriate neuropsychological measures and norms. Often trainees have only pieces of information to determine the level of functionality of the client and to make a diagnosis. Supervisors need to model a modified conceptualization process that mainly focuses on symptomatology and clinical history so the trainees can develop a refined, culturally informed neuropsychological approach.
- **Improvements**—As we reflect on this case, there are certain things we could have done differently. We would have tested odor identification as a dementia marker. Teleneuropsychology may have allowed us to deal with the distance, interview more family members who were more
knowledgeable about the patient, and have follow-up over time. We might have attempted more advocacy with local primary care and other community resources.

- **COVID-19 Pandemic**—Our case study and the completion of the assessment were impacted by the COVID-19 pandemic. In Guatemala, public hospitals have closed outpatient services, so the evaluation could not be completed. However, telephone was used to provide feedback to the family for the continuation of care.

- **Mayan Neuropsychology**—As per this case, it seems to us that neuropsychology currently is only marginally able to contribute to the well-being of Mayans. Cases such as this one give us direction on how to continue to develop as a field in Guatemala.

### How Can We Develop Mayan Neuropsychology?

This case is an illustration of what we regard as the current state of Mayan neuropsychology within Guatemala. Developing a viable service of neuropsychology is a long social process and we believe that we are barely at the point of being able to offer something of value to Mayans. Among the needs for and barriers to such services, as seen in this case, are:

- Mayan community knowledge about neuropsychological problems
- Mayan community access to professionals who would refer them to our services
- Confidence in and willingness to seek professional help for such problems
- Confidence in and willingness to complain to professionals about neuropsychological problems when they have them
- Understanding that such problems can be treated
- Asking for an evaluation and treatment for these problems
- Professionals who know about and have confidence in our services
- Professionals who will make the referral
- Timely referrals with adequate information
- Follow-through to make sure it happens
- Adequate payment system
- Neuropsychologists available
- Adequate transportation and communication
- Availability of informed family members
- Neuropsychologists with cultural knowledge and skill
- Availability of interpreters
- Adequate tests and norms
- A clinical process that is satisfactory to the family
- Recommendations that are viable in the context of the community resources and belief systems
- Follow-through on recommendations

Many of these considerations are involved in the development of neuropsychology services more generally in Guatemala. Many concern issues of poverty and infrastructure development that are well beyond the direct reach of the neuropsychologist and neuropsychology community. But an important component also involves neuropsychological public health. The World Health Organization's Community Based Rehabilitation program was developed as a community economic development strategy. When neuropsychology can contribute to vocational rehabilitation for those affected by brain disabilities and to reducing caregiver burden, then this is also a contribution to community economic development.
Certainly, it is possible to look at each of the barriers mentioned above and propose a solution to it. For example, conducting public health education in Mayan languages and communities about neurodisabilities and available services, education of referral sources, improving health and transportation infrastructure, training culturally competent neuropsychologists, developing and researching tests, and the list goes on. Perhaps, many of these solutions are appropriate. However, framing them up that way maybe externally imposed, paternalistic solutions that may fail. If we are to approach this process with cultural humility not only at the level of the client but also at the level of the system, then, we will want to engage Mayan communities in the process of deciding if we, as neuropsychologists, have anything of value to offer them, to prioritize what we offer, and to shape how it is offered. We cannot even be certain how to approach such engagement since we will want to do so in a way that establishes trust and is congruent with Mayan community decision-making systems. We can hope for future indications from models of community-based health care, mental health care, rehabilitation, and research.24

Acknowledgments

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