16 Neuropsychological Considerations with Bhutanese Refugees of Nepali Ethnicities Residing in the United States

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Section I: Background Information

Terminology and Perspective

The term Nepali refers to the people/language/food of Nepal. The term Lhotsampa translates as “people from the south” and is often used to refer to the Bhutanese people of Nepali ethnicities who predominantly resided in the southern-most part of Bhutan. Most of them are now refugees of Bhutan residing in the United States. For the purposes of this chapter, I will use the terms “Bhutanese-Nepali”, “Bhutanese people of Nepali ethnicities,” and “refugees of Bhutan.”

I (KB) am a white woman, bilingual in English and Spanish, living in Dallas, Texas, and I often evaluate non-English speakers and people with limited to no formal education. When I was asked to evaluate an elderly man for a medical waiver for his US citizenship application in 2015, I had no prior interactions or awareness of the Bhutanese-Nepali languages or culture. I quickly learned that the Bhutanese-Nepali community was very new to the United States, the literature concerning them was sparse, and the only interpreters were Nepali and not from Bhutan. Fortunately, I was able to work closely with a Nepali law intern, originally from Kathmandu, and together we learned about the community and evaluated about 100 adult Bhutanese refugees of Nepali ethnicities.

This chapter is based on the training I have received in multicultural assessment, reading of the literature, advice from mentors, and personal interactions with Bhutanese refugees and their families in Texas. It is my hope that this chapter will lead to a discussion that fosters the inclusion of the Bhutanese perspective. I additionally aim to provide an example of one way to approach novel populations with regard to neuropsychological assessment.

Geography

Bhutan is a landlocked country, about one-half the size of Indiana, that lies at the base of the Eastern Himalayas between China and India. At its north lies the highest unclimbed mountain in the world, the Gangkhar Puensum (7,570 m), and only 150 km south are subtropical broadleaf forests. The weather in the north is like the arctic, and the weather in the south is tropical. Most of the population of Bhutan resides in the north, east, and west. The low-lying foothills of the southern border are home to the Bhutanese people of Nepali ethnicities.

People

There are about 156,000 Bhutanese people of Nepali ethnicities. They are a linguistically and ethnically diverse group with ancestral roots in Nepal and the Nepali-speaking part of Darjeeling in
West Bengal. They have close ethnic and cultural ties to parts of India and predominantly follow the Hindu religion, with some belonging to the highest castes. Most are descendants of peasant farmers.

**History**

The Bhutanese nation has a diverse past of multi-ethnic, multicultural, and multi-religious identity, and the issue of “who arrived in Bhutan when” is important to refugees of Bhutan. Some claim Nepali presence in Bhutan as far back as the seventeenth century. Most of the migration occurred after the Anglo-Bhutanese wars of 1864–1865 and lasted through the 1930s. Nepali workers settled in southern Bhutan, cleared the land, established agrarian communities, and became valuable contributors to agriculture and commerce.

The modern concept of citizenship was introduced for the first time in Bhutan with the Citizenship Act of 1958, which granted Nepali inhabitants' equal rights as citizens. Some citizens of Nepali ethnicity rose to influential positions in society, and the king and ruling elite feared the group could overrun the majority. In the late 1970s and beginning of the 1980s, the Bhutanese government initiated a movement toward a homogenous Bhutanese cultural identity: the One Nation One People policy.

Laws were enacted that systematically disenfranchised Bhutanese people of Nepali ethnicities. The Marriage Act placed penalties on Bhutanese citizens who married ethnically non-Bhutanese individuals including disqualification from receiving state benefits such as land, medical care, and education. A new Citizenship Act in 1985 nullified the Citizenship Act of 1958. Households were required to provide proof of legal Bhutanese residence by way of a 1958 Land Tax Receipt. The Bhutanese of Nepali ethnicities were mostly farmers with limited education and did not keep documents. When they did, Bhutanese authorities usually refused them.

On January 6, 1989, the king issued a royal decree requiring all inhabitants of Bhutan to follow the elite Drukpa religion and language. The policy enforced national standards for dress, etiquette, and cultural practice. Schools and seminaries in southern Bhutan were closed, and the Nepali language was removed from the curriculum. People were fined, imprisoned, forced into labor, and refused state services if they did not wear the traditional Drukpa dress, which was expensive and incompatible with the tropical climate of southern Bhutan.

In 1990, there were widespread demonstrations against the government, which responded with brutal retaliatory measures including mass arrests and violence. There are over 2,000 documented instances of physical torture, consistent with the World Medical Association's definition. Homes, lands, and belongings were destroyed or redistributed to people of other communities and many cities were re-named.

The exiled Bhutanese of Nepali ethnicities first sought refugee status in West Bengal, India, but they were turned away. Bengali authorities deported them to Nepal, where the local government constructed refugee camps with the help of the United Nations High Commissioner for Refugees (UNHCR). By 1992 up to 500 individuals arrived in the refugee camps daily. In all, over 100,000 refugees were expelled from Bhutan, an estimated sixth of the total population.

Between 2008 and 2016, the United States accepted the largest number of refugees of Bhutan among all nations that received them—a total of about 90,000. The first large group accepted was sent to Dallas, Texas, in 2009, followed by waves in Pennsylvania and Ohio. New York and Georgia also received smaller groups of refugees. Due to internal secondary and tertiary migration, Central Ohio now has the highest population, estimated at around 30,000. Australia, Canada, New Zealand, the Netherlands, and Denmark received about 15,000 refugees all together. As of December 1999, only around 7,000 people remained in the refugee camps located in Nepal.
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The UNHCR drastically cut funding to the camps in 2021, and the refugees who remain there are being referred to Nepali public services.9

Knowledge of the history and context just described can contribute considerably to a clinician’s ability to establish rapport and provide accurate diagnoses and treatment recommendations. For example, an individual who emigrated from Bhutan earlier may have experienced years without permanent residence or social services. Alternatively, an individual who emigrated later may have been exposed to more severe trauma. In particular, children born between 1988 and 1993 are likely to have been exposed to high levels of maternal stress and disease and to have received poor pre- and post-natal care. An evaluator must also consider the condition of the camp to which the examinee was assigned, as there is considerable variability in this experience as related to education, medical care, nutrition, and trauma history.

Immigration and Relocation

Understanding the circumstances surrounding Bhutanese refugees’ relocation is important, as those who moved to the United States earlier may have had little support upon arrival, and those who left camps later may have had uncontrolled medical conditions or may have spent time in camps alone without the support of extended family. Intergenerational disagreements likely complicated the decision for many families to leave Nepal as well. Although younger generations who had spent most of their lives in the camps were generally excited at the prospect of new opportunities, older generations were intimidated by the relocation process and hoped for a return to the home they once knew.2,5

Language

Most refugees of Bhutan speak Nepali and many speak multiple other languages including Hindi, Tamang, and Dzongkha.2,5 Younger generations who grew up in refugee camps in Nepal were regularly exposed to English as well.10 However, although the UNHCR estimates that about 35% of Bhutanese refugees have some functional English abilities, 90% require interpreters for medical screening examinations,11 which has important implications for clinicians. Additionally, a clinician should consider that some refugees are deaf or hard-of-hearing; although special support was available in some camps to teach lip reading and sign language, the quality of this training varied substantially among camps. After arrival to the United States many have begun to learn American and Nepali Sign Language.

Communication

Younger refugees of Bhutan were born in refugee camps and educated in English. As such, they are typically much more comfortable communicating with it than older individuals, who require an interpreter. A clinician should be aware that older individuals generally prefer to rely on family members in this role. Familiarity with the traditional greeting, Namaste (I greet the god within you), may help with rapport building. This salutation may be used for both hello and goodbye. Typically, Bhutanese refugees press their palms together in the prayer position when offering a greeting. Refugees of Bhutan make eye contact during all types of communication, including greetings. As it is in many cultures, pointing directly at people is considered impolite. The right hand is used when handing things to people and eating since the use of the left hand is considered impolite.9

From my experience, I have observed that adult children typically speak on their parent’s behalf. Older individuals are often hesitant to speak with me directly during evaluations and
usually require encouragement from family. This may also be partially attributable to distrust of authority figures and, more broadly, White, English-speaking individuals. Elderly parents expect that their adult children will communicate on their behalf and may become angry if they do not; as such, a clinician should be flexible about allowing family members to participate in the evaluation process more extensively than is typical.

**Education**

Bhutanese citizens of Nepali ethnicities who grew up in Bhutan generally had little to no formal education. Ironically, despite limited access to academic resources, Bhutanese people of Nepali ethnicities had higher levels of literacy compared to their nativist Drukpa counterparts due to their close proximity to India, where their children sometimes attended school.

After their expulsion from Bhutan and subsequent resettlement in refugee camps, Bhutanese refugee school-aged children received formal education through the Bhutanese Refugee Education Program (BREP) administered by the international Catholic charity organization CARITAS, who also sponsored the Child Play Centre for younger refugee children and the Youth Friendly Centre for 18- to 21-year-learners. The teachers themselves were also refugees living in the camps. Although the quality may have varied in the camps, in general, the standard of English education was higher than that in the rest of Nepal. All subjects were conducted in English except the Nepali and Dzongkha language classes. After completion of the 10th year of study, students could sit for a Nepali national exam required to earn the School Leaving Certificate (SLC), the Nepali equivalent of a high school diploma. There were very few educational opportunities beyond this for residents of the refugee camps.

**Literacy**

The literacy rate among Bhutanese refugees of Nepali ethnicities was estimated between 65% and 85% in 2000. However, these statistics apply to younger individuals who received education in the refugee camps. Most of the older refugees that I have evaluated grew up in Bhutan, did not participate in any sort of formal education, and had no ability to read or write.

**Socio-Economic Status**

After resettling in the United States, the Bhutanese refugee community primarily obtained employment in the service industry or by working in factories. Young members of the community appear to have quickly acclimated to the United States and are rapidly advancing to higher socio-economic levels; many are completing university degrees and are obtaining professional careers. When living in Bhutan, people of Nepali ethnicities lived an agrarian lifestyle. As refugees, they had limited food rations and experienced nutritional deficiencies. Housing generally consisted of bamboo huts with thatched roofs and lacked electricity, indoor plumbing, and running water.

**Values and Customs**

When evaluating and treating Bhutanese refugees of Nepali ethnicities, there are many cultural factors and customs of which a well-informed clinician should be aware in regards to religion, social organization and hierarchy, disability and illness, marriage customs, and privacy. Bhutanese people of Nepali ethnicities have traditionally followed a formal caste system, with status often denoted by family name. Today, however, although some older individuals still maintain an awareness of such a system, younger individuals are far less observant of caste status.
general, the clinician should also be aware that those who still adhere to the social and behavioral mores of a caste system are unlikely to discuss them with outsiders.14

The average household is multigenerational and includes elderly individuals as well as the spouses and children of younger members. In general, household members remain close throughout life events. As discussed earlier, the social structure of Bhutanese refugee families and communities may be considered interdependent with a patriarchal social hierarchy. Younger generations assume the responsibility of caring for aging relatives, who are, in turn, considered to bring good fortune to the home. Sons are expected to care for their parents, and daughters-in-law are obligated to care for their mothers-in-law.9

I have observed this dynamic during my evaluations of Bhutanese refugees of Nepali ethnicities. Adult children often report providing 24-hour care to a parent and sharing supervisory responsibilities with other adult peers in the community. Adult children nearly always attend their parents' doctor's appointments, manage their medications, and assist with their parents' personal needs. There appeared to be no family pressure for these designated care partners to maintain employment in the community.

Another important cultural factor for clinicians to keep in mind is that Bhutanese refugees consider deafness and disability to be a karmic form of punishment for the family. As such, caring for a family member with a disability is a spiritual endeavor that serves to purge the household of karmic burden, and Bhutanese refugees are hesitant to delegate this responsibility to individuals outside their immediate household. Because of this, teasing apart the details of an individual's true functional capacity within the context of cultural expectations is difficult. Additionally, older Bhutanese people of Nepali ethnicities often consider sickness to be related to an imbalance of mind, body, and spirit (perhaps caused by engaging in behavior discordant with their traditional values) or the result of evil spirits. Traditional healers called dhami-jhakri focus on re-establishing balance through methods such as reading rice, recommending special diets, and performing blessing rituals.14 The use of home remedies is also common.

Refugees of Bhutan have several other cultural factors bearing mention including household customs, marriage practices, attitudes toward authority and privacy, and the conceptualization of time. Like many Eastern and Northern European cultures, Bhutanese refugees typically remove their shoes when entering or visiting homes. I have observed in my practice that many elderly refugees of Bhutan experiencing cognitive decline have removed their shoes upon entering my office while their families did not, suggesting reduced awareness or confusion. In general, refugees of Bhutan are vegetarian, and staple foods include rice and dal. Also, prayer rooms and kitchens are considered sacred spaces and should not be entered without permission. Traditionally, marriages were arranged when a boy reached the age of 7 or 8, and polygamy was an occasional practice.14 Another practice within this context was the custom of encouraging a young man to marry his wife's close relatives of similar age if one of them experienced a chronic illness or disability.4,14 This is relevant to clinical practice, as Bhutanese refugees often use late marriage as a proxy for intellectual impairment or disability. For example, I have observed that collateral interviewees use the age of marriage as a gauge of premorbid capacity, with higher age signifying lower levels of functioning.

Bhutanese refugees are hesitant to trust people in positions of authority. Many are leery of the police and are afraid to call them for assistance due to their traumatic experience with authority figures in Bhutan (the police, the military, and government officials).14 In my experience, patients who are refugees of Bhutan have often shown distrust for evaluative and immigration processes, and some have verbalized distrust of non-Bhutanese Nepali interpreters. Taking the time to explain the evaluation process and answer all questions is an important part of building rapport, not just with the identified client but also with their family. Efforts should always be made to obtain a Bhutanese-Nepali interpreter. When not available, communicating your understanding of the challenges and being open to alternatives, including family participation, is helpful.
Additionally, I provide a comfortable and safe place for larger groups to collect if necessary, as patients are often accompanied by large groups of extended family and community members several hours prior to their scheduled appointment time. I also stream a live Nepali language radio station in the waiting room, which helps with comfort and rapport building.

A final, very important consideration when working with refugees of Bhutan is that one should prepare office mates, staff, and security personnel ahead of time to receive these individuals, as cultural differences regarding hygiene, time, and family involvement may be disruptive.

**Gender and Sexuality**

Gender roles are clearly defined within the culture of refugees from Bhutan—women are expected to take responsibility for household chores and parenting, and both genders are equally expected to participate in work outside the home. Men traditionally hold decision-making authority in the family and community.

Traditionally, sexuality is a taboo subject among Bhutanese people of Nepali ethnicities, and most older individuals are hesitant to discuss sex-related topics. A clinician should be aware that women will consciously avoid discussing the experience of sexual violence due to fear that they will be ostracized by their family and peers. In Bhutanese-Nepali cultural practice, the experience of rape is attributed to sins committed in a past life and considered karmic retribution. Although many Bhutanese refugee women experienced sexual violence during their expulsion, they are frightened of reporting incidence of trauma, torture, and rape in fear that they will be further punished by family and peers. A clinician should be sensitive to these factors when probing for a history of trauma; I have noticed that sometimes older women euphemistically refer to sexual violence as “ill-treatment,” “mistreatment,” and “misbehavior.” As younger Bhutanese Nepali women are more open to discussing sex-related topics among themselves and with providers, collecting collateral information is vital to the assessment process. However, the clinician should also keep in mind that even young Bhutanese refugee women remain hesitant to discuss sex and related topics with elders, men, or family members.14

**Spirituality and Religion**

There is religious diversity within the Bhutanese refugee community; around 60% of refugees are Hindu, 27% are Buddhists, 10% are Kirat, and some are Christians.11,15 Brahmins—or Hindu priests—provide prayer leadership and officiate ceremonies puja, among other responsibilities. Worship takes place at Hindu temples and prayer is regularly carried out in the home. Formal transition to adulthood occurs at seven for girls and eight or nine for boys. Girls are given their first sari before puberty and boys receive a jennoi (a holy thread worn throughout life) from the Brahmin in their community.14 Birthdays and festivals are celebrated according to the Hindu calendar, and a clinician may find it useful to have a Hindu calendar on hand for evaluating orientation.

**Acculturation and Systemic Barriers**

Prior to relocating to the United States, the International Organization for Migration (IOM) provided classes to dispel stereotypes and orient refugees to US culture. Educational topics included how to use a seatbelt, maintain proper personal hygiene, manage a misbehaving child, and use a Western-style toilet.7,10

Limited access to medical care was another systemic barrier that Bhutanese refugees of Nepali ethnicities faced after they arrived in the United States; federal resettlement benefits only provided eight months of financial assistance to pay for medical services following relocation. As
a result, many older adults often lacked medical insurance and received limited medical care until they obtained citizenship and access to Medicare. With regard to mental health services, MacDowell et al. found that over one-third of refugees reported having problems accessing care. Individuals over the age of 55 had the most difficulty accessing services due to limitations in their ability to read, speak, and write English.

Refugees faced many additional systemic and cultural barriers to acculturation in the United States. For example, many had never been formally employed and were not accustomed to associated responsibilities such as punctuality, time management, and autonomous work. Additionally, prior to relocation, refugees had never rented or owned their own homes and were unaccustomed to maintaining them and paying rent in a timely manner. These factors combined with family separation and limited social and governmental support made the transition to life in the US challenging.

Despite these barriers, refugees of Bhutan display many resilience factors including a strong sense of connection to their families, community, and spirituality. Bhutanese refugees have also initiated annual events to bring the community together and have recently formed formal social organizations including the Bhutanese American Sports Council (BASC), the United Bhutanese Community of Texas, and the Bhutanese Community Association of Akron.

**Mental Health Views**

As in many Asian cultures, refugees of Bhutan associate mental illness and its treatment with social stigma, particularly older individuals. Because there are high rates of psychiatric illness and suicide among the Bhutanese refugee community both within camps in Nepal and in the United States, the clinician should be aware of stigma-related barriers, cultural tendencies to conceal emotions, and idioms of distress including *aatmahatya* and *jhundera maryo*. Familiarity with common spiritual and cultural beliefs, in addition to related idioms of distress, may reduce obstacles and facilitate improved treatment. *Idioms of distress* refer to colloquial methods by which individuals of a certain culture communicate the experience of negative emotions. For example, in English speaking cultures expressions such as “feeling down” or “feeling blue” are idioms of distress.

Most Bhutanese refugees follow the Hindu faith system in which the self is understood as the interaction of *man* (heart-mind), *dimaag* (brain-mind), *jiu/saarir* (physical body), *saato* (spirit/soul), and *ijjat* (honor). Knowledge of these concepts allows one to be sensitive to idioms of distress that can guide corresponding treatment options.

For example, a Bhutanese refugee expressing problems related to *ijjat* may be concerned about social shame and stigma; corresponding treatment modalities can include social inclusion activities and relationship counseling. Likewise, when patients and families disclose *dimaag*/brain-mind-related problems, this may suggest symptoms of psychosis, anger, and substance abuse. The *man*/heart mind is considered the center of desire, emotion, and memory, and related problems include suffering, sadness, despair, worry, and memory symptoms such as flashbacks. In such cases, a clinician can encourage support from friends and family, participation in talk therapy, and participation in traditional healing rituals. Speaking from my personal experience, when I first interviewed a refugee from Bhutan, I asked whether he felt sad. The interpreter laughed, explained that the patient would never admit to that, and appeared uncomfortable himself at the suggestion. I would likely have been able to receive an honest answer by asking about problems with *man*/heart-mind, a Bhutanese-Nepali idiom of distress. Another important source of information is collateral interviews with patients’ younger care partners, who generally manage their older relatives’ medical appointments. These individuals are much less averse to discussing and seeking mental health services.

Nepali refugees of Bhutan do not hesitate to endorse problems related to physical health (*jiu/saarir*). However, the clinician should be aware that persistent somatoform disorders and medically...
unexplained pain are common among Bhutanese refugees.\textsuperscript{11,24} Notwithstanding, physical health problems should be taken seriously and warrant referral to appropriate medical providers.

\section*{Approaches to Testing}

Because younger and older generations have had distinctly different cultural, language, and educational experiences, the clinician will need to tailor the testing approach based on individual needs. In general, refugees under 30 years of age were born inside refugee camps and received more consistent education including instruction in English. Conversely, older individuals born prior to the \textit{One Nation, One People} movement are far less acculturated and, as such, require flexibility in regards to the testing approach.

As always, when conducting a neuropsychological examination, the clinician should include a thorough interview with the family, a behavioral exam, functional testing, and corroborating information such as academic and medical records. In particular, collateral interviews with younger individuals, who generally care for their elders, are likely the clinician’s best resource in case conceptualization. Young men are most typically the individuals arranging medical appointments and completing medical paperwork for their parents and also other senior members of the community. In general, seniors never complete these tasks unassisted. Even with input from younger care partners, uncovering the onset and course of symptoms in older individuals can be a challenge. Younger persons are often unaware of their parents’ developmental, educational, and trauma histories. Although they may be able to recall their elders’ level of functioning in the refugee camps, life there involved few of the functional demands that are required for the transition to the United States. For example, they seldom used money in the camps to purchase goods, which were rationed. Additionally, purchases were made with Indian Rupee bills, for which a larger physical size denotes higher value. As a result, older individuals did not need to acquire number sense (the magnitude of numbers and their relation to each other). As such, the clinician should determine whether the examinee grasps this concept, which is necessary to make purchases using the US Dollar. This can also give the clinician an idea about the examinee’s ability to learn new and abstract information. Speaking from personal experience, I have observed many older Bhutanese-Nepali display significant limitations in numbers sense and who cannot count above the number 5. Likewise, tasks involving reading or using writing instruments may be unfamiliar for older examinees and even perceived as threatening. The clinician should be familiar with alternative methods of examination such as the match stick test, which requires the examinee to copy a simple figure by using matches as opposed to drawing with a pen or pencil.\textsuperscript{25}

Orientation is another important aspect of cognition, as some older Nepali-Bhutanese individuals may use the Hindu calendar but not the Gregorian calendar. The Hindu calendar has a cycle of 60 years and the New Year usually begins at the end of April according to the Gregorian calendar. As such, one should be aware of the Hindu date and related alternate responses to support recognition cuing for orientation. Likewise, the clinician is encouraged to be familiar with recent and upcoming holidays and festivals to guide inquiry into orientation to time and the functional aspects of episodic memory, as measured, for example, by the CDR\textsuperscript{®} Dementia Staging Instrument (CDR\textsuperscript{\textcopyright}).

Motivation and effort is another factor to keep in mind when providing evaluations for refugees of Bhutan. In my experience, I have observed that some Bhutanese Nepali individuals feel pressure to perform poorly so they can secure citizenship, and with it, access to medical services. Suboptimal test performance can be an indication of distrust. To assuage patient and family concerns, the clinician should enlist the support from trusted leaders within the Bhutanese refugee community (who are generally younger, educated, and familiar with the US medical system) to help explain the process to examinees. One more thing to keep in mind is that although Nepali
interpreters are available, refugees of Bhutan are culturally distinct from them, and differences in language use and terminology can not only introduce error but also erode trust. As such, one is encouraged to use a Bhutanese-Nepali interpreter.

Section II: Case Study — “She Speaks a Strange Language”

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

Reason for Evaluation

In October 2020, I evaluated Ms. Rai, a 65-year-old refugee of Bhutan, who was seeking US Citizenship. In my experience, all of the Bhutanese individuals of Nepali ethnicities that I have evaluated were seeking accommodations for the US Citizenship Evaluation, and my role was to determine eligibility for such accommodations. Her son arranged the appointment and completed all of the intake paperwork in English. He told me that although Ms. Rai’s best language is Nepali, she sometimes “speaks in a strange language that nobody knows.” With this knowledge, I wanted to ensure I had access to an interpreter who could potentially identify and understand other languages spoken in Bhutan (e.g., Hindi, Tamang, and Dzongkha), and this was only available telephonically. Prior to the evaluation, I met with the interpreter and discussed the evaluation procedures, including the importance of interpreting with a more concrete approach that might reveal expressive communications deficits including aphasia. I also emailed the interpreter validated Nepali versions of the standard measures (i.e., PHQ-9, RUDAS, etc.) that I typically use for these types of evaluation.

Background and Behavioral Observations

Ms. Rai arrived at her appointment one and a half hours early, accompanied by several members of her family including her younger brother, 27-year-old son, and daughter-in-law. Although her family conversed casually in both Nepali and English in the waiting room, she did not participate in any social interaction and instead stared at the floor. Ms. Rai did not respond when I initially greeted her and invited her into my office; her daughter-in-law prompted her to return my greeting and also guided her by hand during ambulation, which was characterized by a slow and antalgic gait. After her brother and extended family crowded into my office together, I asked her if she wanted their company. She appeared confused and was unable to confirm her preference until the interpreter and I tried a variety of wordings, and she continued to appear alternately overwhelmed and apathetic throughout the interview process. She frequently looked to her son and daughter-in-law for reassurance; her son generally spoke for her and her daughter-in-law provided emotional support. After a simplified explanation of my role and the purpose of the assessment, she provided consent. The details were reviewed more thoroughly with her family and each member verbalized consent and understanding.

Based on her family’s report, Ms. Rai was born in Bhutan and experienced no developmental delays or problems with adaptive functioning during childhood. Her first language was Nepali, and she received no formal education. She married at about age 13, had four children, and occupied her time following marriage with domestic and agrarian activities. Her husband was arrested for political reasons during her fourth pregnancy, and she was forced to leave Bhutan as a condition of her husband’s release. She subsequently emigrated together with her family to Nepal, where she was eventually reunited with her brother in a refugee camp. Her husband was fatally injured after a fall about five years after they arrived in Nepal.
In terms of psychiatric history, Ms. Rai’s son reported that she had experienced “mental problems” on occasion before leaving Bhutan. However, he explained that they did not interfere with culturally relevant instrumental activities of daily living (IADLs) including agrarian and domestic activities. Her brother denied having observed Ms. Rai present with psychiatric problems prior to marriage, though he had little interaction with her following that time.

When asked to explain Ms. Rai’s “mental problems,” her son reported that she experienced “attacks,” characterized by seizure-like symptoms, that occurred about once a month. These episodes included falls followed by full-body spasms lasting several minutes, subsequent confusion, and states of alternating agitation and hypersonmolence that lasted from hours to days afterward. He also reported that she retained no memory of the falls or spasms themselves. These episodes interfered with domestic-related IADLs, for which she received support from her sister-in-law and older children. She also neglected hygienic activities for days following these episodes and seemed unaware of any problem. Her family reported that although she was prescribed medication in Nepal, they were unclear as to the purpose. They were also unaware whether she visited a traditional healer during this time. She did not bring medical paperwork with her when she relocated to the United States in 2015.

Ms. Rai’s family reported that she experienced a severe seizure-like episode six months following her arrival to the United States. During this episode she fell, displayed disorganized speech and combative/aggressive behavior. Briefly thereafter, she lost consciousness and could not be roused. Her son took her to the emergency room, and she was hospitalized for three days. After staff could not identify the cause of her episode, she was referred to a physician who prescribed her risperidone and quetiapine; although these appeared to reduce the severity of subsequent attacks as well as associated behavioral symptoms, they did not eliminate the seizure-like episodes themselves.

At the time of assessment, Ms. Rai’s family reported that she did not recognize familiar people or remember their names. She displayed considerable regression for IADLs including her ability to make simple purchases, prepare meals, and contribute to maintaining the home. She also displayed considerably reduced initiative. Formerly social with neighbors and friends in the community, she became uncharacteristically withdrawn, spending most of her time sitting in her room and staring out a window. Her reduced level of motivation and initiative also markedly impacted basic ADLs. For example, she no longer requested food and only ate when meals were placed in front of her, and she also did not initiate other self-care skills including dressing and hygienic activities.

**Appearance and Behavior**

Ms. Rai appeared undernourished and disheveled; she was hastily dressed in a mismatched combination of traditional and Western attire (she wore a sari, tikka, and bangles, with a dirty sweatshirt and wool-hat despite temperate weather). Her voice was hoarse and raspy, and she spoke with low volume. Language content was limited in Nepali; she spoke in single words and short phrases. As detailed above, Ms. Rai had difficulty understanding the purpose of her evaluation; notwithstanding she appeared to understand that the evaluator was a medical professional, as she pointed to places on the right side of her body where she experienced pain. She required significant encouragement, demonstration, and prompting throughout her evaluation. Her daughter-in-law was included in the testing session and provided emotional support and encouragement after agreeing not to offer answers or direct help. Ms. Rai displayed a tendency to give up quickly, which may have suggested suboptimal effort. This was considered during case conceptualization. Her family carried all her personal effects including her identification card.
Test and Norm Selection

All measures were reviewed with a Nepali-Bhutanese interpreter prior to the appointment and administered together with the interpreter. The battery included the following tests:

- CDR® Dementia Staging Instrument (CDR26)
- Informant Questionnaire on Cognitive Decline in the Elderly IQ-CODE—Short27
- Common Objects Memory Test (COMT28)
- Rowland Universal Dementia Assessment Scale, Nepali version (Nepali-RUDAS29)
- Patient Health Questionnaire, Nepali adaptation (PHQ-930)

Test Results

Ms. Rai was completely disoriented to time when administered the CDR, and she remained disoriented to time with the provision of a Hindu calendar. She was also disoriented to place, and she was unable to recall her address or city of residence despite having lived there for the past five years. Notwithstanding, she was able to recognize her state of residence from among three options.

When administered the Nepali-RUDAS, Ms. Rai struggled with a basic praxis examination, she was unable to return a demonstration of basic hand movements, and she could not differentiate between right and left. She required five attempts to repeat a list of four items and could not recall them after a brief distraction. She could repeat simple three-word sentences and follow simple one-step commands. She was only able to follow the final step of two and three-step commands, suggesting a recency effect. On a measure of list generation, she was able to name 3 animals in 60 seconds. She was able to successfully duplicate a simple geometric pattern with match sticks.

Confrontational naming and short-term memory were measured using the COMT. On the confrontational naming portion of the examination, she was only able to name two out of ten everyday objects when presented with them initially. Although she was able to repeat the names of the remaining objects with demonstration, she was unable to name them spontaneously on second and third trials of confrontational naming. When asked to recall these items from memory after a delay, she could remember none of them. Notwithstanding, she accurately identified nine of the ten objects and had only one false positive error when offered recognition cues, which suggested good effort and some level of functional carryover of new information.

Ms. Rai was unable to understand the concepts presented on the PHQ-9 despite the provision of considerable non-standardized assistance from her daughter-in-law and the interpreter. Ms. Rai's son endorsed marked decline from prior levels of functioning in episodic memory, orientation, problem-solving, basic financial skills, decision making, and receptive and expressive communication on a questionnaire addressing cognitive abilities and IADLs (IQ-CODE).

Impressions

Ms. Rai's clinical course and symptoms as reported by her family included seizure-like episodes beginning with falls, evolving into full-body spasms that last a minute or two, and resolving into protracted episodes of confusion, amnesia, disorganized speech, and agitation or hypsomnolence. These clinical symptoms strongly suggested an epileptic syndrome. I requested a release of information so that I could obtain her medical records from the hospital, her primary care physician, and her psychiatrist. The hospital records indicated a diagnosis of seizure disorder and status epilepticus, but there was no documentation of follow up with EEG or brain imaging. Her family and primary care physician appeared completely unaware of her hospital diagnosis. According to records, her primary care physician referred her to psychiatry after her son reported
concern regarding “mental problems” as he did with neuropsychology. Psychiatry diagnosed Ms. Rai with Major Depressive Disorder with psychosis. Although Ms. Rai was provided with a Nepali interpreter, her family was barred from participation in the interview process with psychiatry, likely due to a naive attempt to protect her privacy and confidentiality. Like with primary care, psychiatry appeared to have had no knowledge of her seizure diagnosis from the hospital.

Ms. Rai’s overall neurobehavioral profile suggested global cognitive decline, highlighted by marked problems in both receptive and expressive communication, memory loss, and general functional impairment. Her progressive deterioration of language and other cognitive skills in the context of her clinical history strongly suggests an epilepsy syndrome, which would clearly interfere with her ability to learn the information and demonstrate the language skills necessary to pass the US citizenship test. Ms. Rai’s level of difficulty on direct testing was such that she could complete very few standardized formal measures, and implementation of non-standardized procedures provided better clinical utility by testing limits. Using non-standardized techniques helped garner important information that would assist Ms. Rai to receive an appropriate diagnosis, medical treatment, and her citizenship.

Feedback and Follow-Up

I provided feedback to Ms. Rai and her family with the same telephonic interpreter that assisted with the evaluation. Given her neurobehavioral profile and the information I obtained from medical records, I provided basic education regarding seizures and a referral to a Nepali-speaking seizure specialist in the area. In March, 2021 Ms. Rai’s family called to inform me that she had been diagnosed with symptomatic epilepsy due to underlying neurocysticercosis, was granted citizenship, and with it, Medicare. She was receiving treatment with anticonvulsant medication and had not had any seizures for several months. Neurocysticercosis is a parasitic infection caused by the tapeworm Taenia solium and is contracted through the consumption of undercooked pork, water contaminated with the tapeworm egg, or through poor hygienic practices, and is the most common underlying pathology for epilepsy in Nepal.30,31

This example illustrates the number of barriers Bhutanese refugees face in receiving treatment for medical and psychiatric problems, including poor understanding of medical terminology, social stigma related to neurobehavioral symptoms, suspicion of authority figures, and problems communicating with providers. As such, sensitivity to cultural beliefs including idioms of distress is important in establishing rapport so that a clinician can obtain an accurate history of symptoms and be enabled to provide effective feedback and education that will help refugees of Bhutan become stronger self-advocates in the US healthcare system.

Section III: Lessons Learned

• Culturally adapted tests (in other words, tests that are not simply translated) are essential for questionnaires regarding health, mood, and beliefs about health. For example, the PHQ-9 has not only been translated into Nepali but also includes idioms of distress. Also, clinicians should stay up to date with new adaptations, translations, and research for diverse populations in order to use the most valid and reliable instruments possible.
• Clinicians must be flexible and adapt their approach to best serve people for whom our traditional measures of neuropsychological functioning are of limited utility. This means liberal use of non-standardized procedures—qualitative data is likely of much greater value than normative data.
• There are many sources of relevant data beyond traditional neuropsychological test scores, especially medical records and behavioral observations. Likely the most valuable assessment
technique is a thorough interview with collateral sources combined with sensitivity to cultural factors. In the present case, good communication with the family, detailed collateral interview, and the obtaining of medical records allowed for the client to obtain the correct diagnosis, and with it, effective treatment.

- In general, the meaning ascribed to physical and psychiatric problems is culturally bound, and it is important to know cultural idioms of distress. For example, for the Bhutanese refugee population, a clinician should understand that stigma and implied guilt may be associated with certain medical and psychiatric conditions. Older Bhutanese refugees may view trauma as the result of bad karma, and, as such, they may be less likely to endorse these types of symptoms. Again, building a strong rapport with both the client and family combined with detailed collateral interviews is crucial to arriving at an accurate diagnosis.

- Although cultural beliefs may present barriers to accessing mental health services, these can be protective factors as well. For example, among refugees of Bhutan, participation in purification rituals may help survivors of trauma to let go of negative memories and move past the experience. This may be an excellent adjunct to treatment.

- Among refugees of Bhutan and similar groups, community and peer counselors can be very effective in facilitating the acquisition of mental health support. For example, in the case sample above, the participation of younger individuals who were fluent in English and were viewed as community leaders was crucial in both rapport building and obtaining client history.

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Glossary

Aatmahatya. The Hindi word for suicide.
Dal. A soup prepared from lentils, peas, or beans (pulses) considered a staple food in South Asian countries.
Dhami-jhakri. Traditional healer or shaman.
Dimaag. The brain-mind; the seat of thoughts, the pragmatic mind that acts according to social norms and is responsible for controlling behavior and thinking. Includes many symptoms of mental illness including psychosis and alcoholism.
Drukpa. The term collectively refers to the Buddhist peoples of Bhutan with Mahayana Buddhism as the religion and Dzongkha as the language.
Dzongkha. The national language of the Kingdom of Bhutan.
Ijjat. Honor or reputation, is the link between the person and the social world and is indicated by social status and respect. Behaving in a manner consistent with the caste hierarchy and social norms is essential to maintaining ijjat.
Jhundera maryo. The term used to describe suicide and suicidal behavior among Bhutanese refugees. Literally meaning “to hang oneself.”
Jennoi. A holy thread given to a young man by the Brahmin in their community that is worn throughout life.
Jiu/saarir. The physical body and site of physical pain. Related to diseases and injuries.
Karma. A term used in Hinduism and Buddhism that refers to the sum of a person’s actions in this and previous lives and is viewed as deciding their fate in future lives.
Kirat. A religion practiced by some Bhutanese individuals of Nepali ethnicities. People who practice Kirat worship ancestors and nature, such as trees, rivers, animals, and stones.

Man. The heart-mind; the seat of desires, referring to opinions, intentions, and personal feelings.22

Puja. A cleansing ritual performed by a Hindu priest.

Saato. The spirit or soul, presence of mind, and consciousness. The soul helps protect the body from supernatural forces. Symptoms of psychological distress may include frightening easily, lack of energy, and fatigability.22

Sari. A brightly colored garment worn by women made of several yards of lightweight cloth draped so that one end forms a skirt and the other a head or shoulder covering.

Tikka. A Hindu traditional blessing made of red powder that is placed on the forehead between the crown of the nose and the hairline.

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